



Britain Against Cancer 2015:

Transforming outcomes:
How can we deliver
world-class cancer services?

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This report was compiled by Macmillan Cancer Support who provide the Secretariat to the All Party Parliamentary Group on Cancer.

Foreword



Every year the All-Party Parliamentary Group (APPGC) invites the cancer community to gather in Central Hall in Westminster for our annual Britain Against Cancer conference.

Britain Against Cancer 2015 was one of our most important conferences yet. Following the launch of the Independent Cancer Taskforce's report, *"Achieving world class cancer outcomes: a strategy for the NHS 2015–2020"*, the conference was an opportunity to consider the recommendations of that report six months on and for delegates to discuss what the priorities should be for implementation.

The mood of the conference this year was upbeat, with our now traditional vote revealing that the majority of the audience believed that the England Cancer Strategy would achieve its ambitions by 2020. We were pleased to see progress on areas such as the new Cancer Dashboard, which will further encourage Clinical Commissioning Groups to promote earlier diagnosis in order to improve their one year cancer survival rates. We also welcome announcements on the infrastructure to deliver the England Cancer Strategy, including the new Cancer Transformation Board, and National Cancer Advisory Group.

However, whilst these announcements were welcome, the plenary sessions and the workshops revealed the significant amount of work which remains to be done if we are to truly deliver improved outcomes for all cancer patients.

All of the 96 recommendations set out in the England Cancer Strategy are important, but we have used this report to make eight key recommendations on areas we feel should be prioritised over the next year.

Together with my fellow Officers, I would like to thank all delegates who attended Britain Against Cancer and contributed to the day. Whether by organising a workshop, asking a question, providing feedback or simply attending and joining in the discussion, you have helped to shape this report and the recommendations contained within it.

A handwritten signature in black ink, appearing to read 'John Baron'.

John Baron MP
Chairman,
All Party Parliamentary
Group on Cancer

Executive Summary

In December 2015, the APPGC held its 17th annual Britain Against Cancer conference. The conference was an opportunity to hear from senior health policy makers and politicians on their priorities, but more importantly, it was a chance for the cancer community to discuss and debate the issues most important to them.

This report provides an overview of the conference, and sets out the APPGC's position on key areas. Rather than looking at each part of the conference separately, it considers common themes which arose throughout the day, including prevention, early diagnosis, access to treatment and living with and beyond cancer – as well as broader, cross-cutting issues, including new models of care, data, workforce, funding and accountability. In addition, an underlying theme running throughout the day and throughout this report, is the importance of patient involvement throughout the cancer pathway – from research through to service design and evaluation.

In light of the discussions at Britain Against Cancer, the APPGC has set out one priority recommendation from each chapter of the report. We believe that these eight overarching recommendations will be the most important in delivering improved cancer outcomes by 2020.

Recommendations

Prevention

The APPGC calls on NHS England and the JCVI Committee to ensure that the review into extending HPV vaccination to boys reports in 2016.

Early diagnosis

The APPGC calls on all parliamentarians to work with their local health economies to ensure that improvements in one year cancer survival rates are delivered by all Clinical Commissioning Groups (CCGs) across the country.

Access to treatment

The APPGC calls on NHS England and NICE to ensure that an annual review of the efficacy and impact of the new Cancer Drugs Fund process is conducted, including a focus on patient access and outcomes.

Living with and beyond cancer

The APPGC calls on NHS England to set out how it will ensure everyone living with and beyond cancer has access to tailored support that addresses their needs, through a recovery package.

Workforce

The APPGC calls on Health Education England to ensure that, as per recommendation 83 in the Cancer Strategy, a thorough review of the cancer workforce is carried out by the end of 2016 in order to ensure that long term solutions for the cancer workforce can be implemented.

New models of care

The APPGC calls on NHS England to ensure that Cancer Alliances are established in 2016 and have the capacity and capability to carry out functions including leadership, coordination of pathways, patient involvement and data analysis.

Data

The APPGC calls on the government to ensure that a pragmatic approach is taken to the use of patient data which supports the role of Cancer Registries whilst also recognising and addressing concerns around security and consent.

Funding and accountability

The APPGC calls on Department of Health and NHS England to set out its plans for funding and delivering the Cancer Strategy over the next five years, including how it will ensure improvements across the entire cancer pathway.

1 Prevention

With the World Health Organisation estimating that at least one-third of cancer cases are avoidable¹, prevention is a key priority for many people and organisations in the cancer community. The NHS Five Year Forward View published in October 2014 called for “a radical upgrade in prevention and public health”, and this was echoed in the England Cancer Strategy, which highlighted tobacco control and obesity as key areas which should be tackled.²

Prevention, including the importance of education was raised during the expert panel discussion. Dr Pauline Leonard, Consultant Medical Oncologist at Whittington Health noted that education of clinicians was important, as many are not trained in or comfortable talking about prevention. She highlighted in particular that as only 6% of patients referred on a two-week pathway are diagnosed with cancer, there is an opportunity for clinicians to have conversations about prevention with the other 94% who are found not to have cancer.

Prevention was also the theme of one of the workshops held at Britain Against Cancer. Led by the Men’s Health Forum, the workshop looked at some of the most topical issues in cancer prevention today including e-cigarettes, HPV vaccination and processed meat, allowing delegates the chance to vote for the intervention they thought would have the most impact. The outcome of the vote was the HPV vaccination would be the most important intervention to prioritise.



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HPV vaccination

The priority for delegates was implementing Human Papillomavirus (HPV) vaccination for boys. Delegates heard that HPV is estimated to cause around 5% of all cancers, and the numbers of cancers caused by HPV in men is rising. Whilst a vaccination programme for girls aged 12–13 has been in place since 2008, no such programme exists for boys, meaning that they are at greater risk. In November 2015, the Government's Vaccination Advisory Committee (the JCVI) announced that HPV vaccination would be extended to men who have sex with men up to the age of 45 via sexual health clinics.³

The APPGC believes that whilst this is a step forward, the Government needs to go further. The JCVI is currently considering whether the existing vaccination programme should be extended to boys, however the current timescales mean that the inquiry (which began in 2013) will not report until at least 2017.⁴ If a decision is made to extend the programme, this may not happen until 2020, leaving a significant section of the population still unprotected for some time.

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The APPGC recognises the need to assess the evidence base for an extension of the programme, but believes that Government should ensure that the review is conducted as quickly as possible, ideally with a decision in 2016. There was strong support from delegates for the vaccination of boys as well as girls and the APPGC believes that the arguments for this are compelling;

if the JCVI's recommendation is given to vaccinate boys, timely implementation should be a priority.

Recommendation:
The APPGC calls on NHS England and the JCVI Committee to ensure that the review into extending HPV vaccination to boys reports in 2016.



Smoking

Smoking remains the biggest preventable cause of cancer in the UK.⁵ The workshop session at Britain Against Cancer specifically considered the use of e-cigarettes as a way of reducing smoking and the number of tobacco-related cancer cases. The potential use of e-cigarettes to help smokers quit was highlighted in the England Cancer Strategy which stated that "Public Health England and Government should carefully monitor the research programme initiated by Cancer Research UK in conjunction with Public Health England to understand better the use and safety of e-cigarettes in reducing tobacco consumption"⁶.



E-cigarettes are just one part of a wider tobacco control strategy needed if a real reduction in the number of smoking related deaths is to be achieved.

However, whilst this is welcome, e-cigarettes are just one part of a wider tobacco control strategy needed if a real reduction in the number of smoking related deaths is to be achieved. The APPGC fully supports the recommendation in the England Cancer Strategy for a new tobacco control plan within the next 12 months to ensure that progress made over the last few decades does not lose momentum. We look forward to the publication of the Government's tobacco strategy which is due this summer.

Obesity and Alcohol

The session also considered other preventable causes of cancer, including obesity and alcohol, and the recent report from the World Health Organisation which states that red and processed meat are carcinogenic.⁷ However, whilst these findings are important, Dr Rachel Thompson, Head of Research Interpretation at the World Cancer Research Fund who presented at the conference, emphasised the need to place these findings



Around 24,000 people could be saved each year if everyone was a healthy weight, or stopped drinking alcohol.

in context. In particular, she highlighted that whilst around 4,000 cancer related deaths could be avoided if everyone ate very little processed meat, around 24,000 could be saved each year if everyone was a healthy weight, or stopped drinking alcohol. The England Cancer Strategy recommended comprehensive national strategies for alcohol and obesity.⁸ Publication of the Government's planned Childhood Obesity Strategy has now been delayed until the summer.⁹ The APPGC fully supports the Cancer Strategy's recommendations on prevention, and believes that the strategies on both obesity and alcohol should give due attention to the impact initiatives will have on prevention of cancer.

2 Early diagnosis

Early diagnosis of cancer has long been a focus for the APPGC. Since our 2009 Inquiry into cancer inequalities we have focused in particular on how data, such as one year cancer survival rates, can be used to drive improvements at a local level. However, despite significant advances in survival rates over the last few decades, the latest available data shows that England is still lagging behind our European counterparts when it comes to diagnosing cancer at an early stage.¹⁰

One of the key reasons for England's lower survival rate is that many cancers are not diagnosed early enough.¹¹ Following a long campaign by the APPGC during the last Parliament, an indicator on one year cancer survival rates has been included in the new Local Health Improvement and Assessment Framework.¹² This means that Clinical Commissioning Groups are now accountable for improving one year cancer survival rates, and should therefore be encouraged to promote initiatives to improve early diagnosis.

Ways to improve early diagnosis were discussed throughout Britain Against Cancer, and were the focus of a workshop session led by Cancer Research UK and The Rarer Cancers Foundation. We

heard from delegates that two particular areas are important to prioritise: rarer and less common cancers, and recurrent and secondary primary cancers.

Rarer and less common cancers

There is a significant amount of data showing that people with rarer cancers tend to be diagnosed later, and many are diagnosed through an emergency presentation.¹³ Whilst late diagnosis of rarer cancers is likely to impact on survival rates, it can also lead to poor patient experience. This was highlighted during the early diagnosis workshop, and was also recognised by the conference's expert panel member Dr Pauline Leonard, Consultant Medical Oncologist at Whittington Health. She noted that, whilst for some aggressive cancers early diagnosis will not necessarily lead to survival, an early diagnosis "can provide opportunities for better symptom control and if appropriate, early end of life conversations".

During the conference, Professor Sean Duffy, the then National Clinical Director, and Sir Harpal Kumar, Chair of the Independent Cancer Taskforce, discussed the issue of earlier diagnosis for rarer cancers. They highlighted in particular the importance of taking

forward Recommendation 21 of the Cancer Strategy. This states that NHS England should "pilot [...] in conjunction with Wave 2 of the ACE (Accelerate, Coordinate, Evaluate) programme, multi-disciplinary diagnostic centres for vague or unclear symptoms".¹⁴

These centres will enable patients to receive a number of tests in one day which will help to determine a diagnosis for vague symptoms. Sir Harpal Kumar suggested that the focus of these Multi Disciplinary Centres on vague symptoms should mean that they "disproportionately benefit rarer cancers". The APPGC was therefore pleased to see the ACE programme listed as an 'early priority' in the update provided by the National Cancer Director to the NHS England board on 28 January, along with plans for a National Diagnostics Capacity Fund to 'unlock barriers to increasing capacity'.¹⁵

Harpal Kumar suggested that the focus of these Multi Disciplinary Centres on vague symptoms should mean that they "disproportionately benefit rarer cancers".

The role of data

The collection and use of data was also discussed in relation to improving early diagnosis. Karen Fitzgerald, Programme Director for the ACE Programme, spoke at the early diagnosis workshop where she recommended that Government needed to simplify the collection and use of data so that it could be used on a “day-to-day basis” to drive improvement. In the expert panel session, Chris Carrigan, Head of the National Cancer Intelligence Network, also emphasised the importance of not just collecting data, but of using it in the most effective way. Chris spoke about the wealth of data provided by patients that is held by the NHS, and in particular by the National Cancer Registration Service. He also made a particular point that cancer patients expect their data to be used to improve care and outcomes. Chris’s summary point was that he “didn’t think that using data had ever killed anyone, but [that] not using data almost certainly has”.

Chris spoke about the wealth of data provided by patients that is held by the NHS, and in particular by the National Cancer Registration Service.

The APPGC fully recognises the important role data can play in driving improvement in early diagnosis. With one year cancer survival statistics now included in the relevant NHS accountability frameworks, it is vital that the cancer community continues to monitor these, and ensure that they remain a high priority at a local level. The APPGC believes that parliamentarians in particular have an important role to play in holding Clinical Commissioning Groups to account, and will be supporting MPs to take action on this issue.

Recommendation:
The APPGC calls on all parliamentarians to work with their local health economies to ensure that improvements in one year cancer survival rates are delivered by all Clinical Commissioning Groups (CCGs) across the country.

Primary care

The role of primary care, and in particular GPs, was a key theme of the discussion during the expert panel session. Dr Pauline Leonard spoke about the importance of secondary care clinicians supporting colleagues in primary care, through developing models to fast track patients, or simply by being more responsive and making themselves available for phone calls. She also highlighted the importance of creating a learning culture, where primary and secondary care could look together at where a diagnosis had been missed.

This was echoed by Dr Ishani Patel, a GP who joined the panel during the discussion. She spoke about work in Wales where all colorectal, upper GI and ovarian cancer cases were subject to a significant event analysis. She noted that a similar initiative was recommended in the England Cancer Strategy,¹⁶ and emphasised how important this would be in helping to identify areas for improvement in primary care. The APPGC welcomes this recommendation, and would be particularly keen to see patient involvement in these initiatives wherever possible.

Education and awareness

Screening and improved public awareness of the signs and symptoms of cancer were raised frequently by delegates as two ways to improve earlier diagnosis. The early diagnosis workshop heard a case study from Scotland’s Detect Cancer Early programme which used innovative communication techniques and marketing to increase uptake of bowel screening for colorectal cancer. The Programme has also focused heavily on engagement with primary care, including putting contract incentives in place. Contract incentives for increasing uptake of bowel screening is something recommended in the England Cancer Strategy. Scotland has already committed to introducing a new test to its bowel screening programme – the faecal immunochemical test (FIT) rather than guaiac faecal occult blood test (FOBT), making this (as well as other cancer screening programmes) a clear area in which

expertise and learning should be shared between the Nations.¹⁷ The Governments in Westminster, Cardiff and Belfast should also commit to introducing FIT.

Nicole Larkin, a patient representative who sat on the expert panel, also spoke about the work she is involved in with the charity CoppaFeel! about educating young people on the signs and symptoms of cancer, emphasising the importance of making sure that young people are

comfortable talking about health and their bodies. This was highlighted in the England Cancer Strategy which recommended that NHS England and Public Health England explore rolling out cancer education in secondary schools based on the Teenage Cancer Trust's awareness programme model.¹⁸

The use of data to evaluate public health campaigns such as Be Clear on Cancer was also highlighted as important. The

availability of data on these campaigns in a relatively short timeframe means that there are opportunities to monitor the effectiveness and make changes if necessary. In addition, it was suggested that awareness campaigns could be focused not just on specific cancers, but on people who are experiencing a range of vague symptoms as this would be likely to aid awareness and diagnosis of rarer cancers.



3 Access to treatment

Over the last five years, a topic which has been raised every year at Britain Against Cancer is the Cancer Drugs Fund (CDF). The CDF, which was introduced in 2011, aimed to ensure that all cancer patients were able to access the drugs their doctors recommended. Since its inception, the CDF has funded drugs for over 84,000 patients and has become an important part of cancer care and treatment within England, enabling patients to access innovative medicines which would otherwise have been unavailable.¹⁹

The future of the CDF was raised in a question during the plenary session with the Secretary of State for Health, by a patient representative who asked what actions the Government were taking on this issue. The Secretary of State outlined the need to reform the structures of the CDF to ensure that it can fulfil its original purpose – to give patients ‘access to the newest drugs which have a good chance of working at fair rates’.

The issue of accessing cancer drugs was also the subject of a conference workshop led by Breast Cancer Now and Prostate Cancer UK. Rachel Cashman, the then Head of Clinical and Scientific Policy and Strategy at NHS England, outlined the issues with the current system and the proposals for the reforms. She emphasised the need for honest conversations about the price of drugs to ensure that the NHS can provide the best value for taxpayers’ money and best value across the whole pathway.

Rachel Cashman, former Head of Clinical and Scientific Policy and Strategy at NHS England emphasised the need for honest conversations about the price of drugs.



Reforming the Cancer Drugs Fund

The content of the CDF workshop, along with a meeting of the joint cancer APPGs in Parliament in February, informed the APPGC's response to the CDF consultation which closed on February 11th. In our response the APPGC welcomed the proposed reforms which will see the process for approving cancer drugs integrated with NICE appraisal processes. We hope that the new system will ensure that patients are able to access drugs more quickly, as well as enabling better data collection and management of uncertainty where the efficacy of particular drugs is unclear.

However, alongside this, it is vital that lessons from the past five years are learnt and that the new process sees a strong focus on evaluation, data collection and transparency, including an annual review of the efficacy and impact of the CDF. As a first step, the APPGC believes that a draft impact assessment should be published as soon as possible.

The annual review of the efficacy of the CDF needs to include patient access as a key consideration, with the first review after the reforms comparing the old and the new system to be able to analyse carefully the impact this has had on cancer patients. Key questions about patient access have not yet been addressed. For example, the last Q&A document published by NHS England before the close of the CDF consultation seemed to suggest that only patients who would be useful to data collection would have

access to drugs on the new CDF.²⁰ This clearly does not increase earlier access for all patients. The CDF needs to be reformed but the new system needs to be fair and equitable to all cancer patients who could benefit from a particular treatment.

Recommendation:
The APPGC calls on NHS England and NICE to ensure that an annual review of the efficacy and impact of the new CDF process is conducted, including a focus on patient access and outcomes.

Patient involvement

As with many aspects of cancer care, above all, the APPGC believes that it is vital that the views of patients are heard and taken into account both in the development of the new process and in its delivery. A prostate cancer patient expert who spoke at the CDF workshop at the conference, highlighted the challenges in securing meaningful patient involvement without it feeling tokenistic. At the recent joint APPG meeting on the CDF, the APPGC were pleased to hear NICE strongly emphasise the role patients play in their appraisal process. However, as the reforms are introduced, it will be important to review the role played by patients to ensure that the mechanisms in place for this are fit for purpose and that patient engagement is strengthened, not diluted.

A prostate cancer patient expert who spoke at the CDF workshop at the conference highlighted the challenges in securing meaningful patient involvement.

Cancer drugs in the Devolved Nations

Discussions in the workshops touched on the impact of having different systems in the Devolved Nations. NHS England stated that whilst there were no formal conversations with the Devolved Nations as part of the consultation process, informal links existed and that Ministers would be discussing the results of the consultation with their counterparts in the Devolved Nations.

The APPGC believes that discussions with the Devolved Nations should be a priority for Government in order to ensure that inequality is reduced and that best practice from all of the nations is shared. Furthermore, the APPGC believes that in all aspects of cancer treatment it is important to benchmark against counterparts in comparable countries, and calls on the Government to ensure that it fully considers evidence on how we compare to other countries both during the reform process and beyond.

4 Living with and beyond cancer

At Britain Against Cancer, we heard from both delegates and speakers about the important needs of those living with and beyond cancer, and it was also the subject of one of the afternoon workshops. The importance of this issue is reflected in the England Cancer Strategy, which, unlike previous strategies, takes a whole pathway approach with a full chapter on living with and beyond cancer and a number of ambitious recommendations as to how this part of the pathway should be improved.²¹

The APPGC was pleased to hear the Secretary of State for Health reiterate his commitments to everyone surviving cancer in England being entitled to a recovery package by 2020, and a quality of life metric being developed by 2017. These are two important recommendations in the England Cancer Strategy, and we believe they will, if implemented effectively, enhance support for people living with or beyond cancer.

Quality of life

At Britain Against Cancer, delegates heard how survival is only part of the story with cancer; surviving well should be the ambition and many people living with and beyond cancer need support to do so. During her keynote speech, Cally Palmer, National Cancer Director at NHS England, spoke about the importance of capturing data on quality of life. The APPGC hopes that the new quality of life metric will enable better understanding of the issues patients face and make sure that the system is looking at not just how long people are surviving for, but how well they are surviving. The APPGC was pleased to hear the Secretary of State reiterate his commitment to developing a quality of life metric by 2017 during his keynote speech.

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Delegates flagged how quality of life measures will be a helpful mechanism for professionals in having conversations which can sometimes be difficult to start.

In the workshop on measuring quality of life, led by Macmillan Cancer Support and Teenage Cancer Trust, delegates spoke about what they would want a new quality of life measure to deliver for patients and professionals. There was much support for the metric and its potential to meaningfully measure what matters to people on an individual level. Amongst the hopes shared were how it could be a very useful tool for commissioners in quantifying outcomes, and how the information yielded could be a driver for positive change. Delegates also flagged how quality of life measures will be a helpful mechanism for professionals in having conversations which can sometimes be difficult to start, and will enable them to explore support needs within hard to reach groups.

Many delegates, including Professor Sean Duffy, the then National Clinical Director for Cancer at NHS England, highlighted how quality of life should be measured on a long-term basis and should consider key transition points in the care pathway. Dany Bell, Treatment and Recovery Lead at Macmillan Cancer Support, also highlighted the value of an opportunity for people affected by cancer to discuss their concerns and seek reassurance, as is offered presently to those given a holistic needs assessment.

The APPGC believes it is vital that the quality of life metric is multidimensional in measuring a variety of areas which are important to people affected by cancer. It is imperative that the metric is developed to be feasible, relevant and realistic so that implementation is as effective as possible, and that it accounts for transition points, as raised by Sean.

Many delegates highlighted that quality of life should be measured on a long-term basis and should consider key transition points in the care pathway.

Consequences of diagnosis and treatment

Rebecca Nash, Head of Evidence at Macmillan Cancer Support outlined how one in four people living with or beyond cancer face disability or poor health following their treatment. This can include

issues such as pain, depression, severe fatigue and incontinence, and some people face a higher risk of secondary cancer and other health problems. Those living with and beyond cancer are also likely to be living with multiple conditions. Consequences of treatment can last for months or years after treatment and significantly impact on a person's wellbeing and quality of life.

Yet such consequences of cancer and its treatments are not always inevitable. It is possible to significantly reduce the likelihood of long term poor health and wellbeing if people are offered access to the right interventions, treatments and support. This was highlighted by two attendees who spoke about the impact of cancer on their lives, and particularly of the effect on their mental health. They explained that their diagnoses had made them feel negative, depressed and anxious, and how important professional support had been in helping them both regain mental wellbeing. One patient highlighted the unique impact that cancer has on young people who undergo treatment, and the importance of age-appropriate support to manage this.

One in four people living with or beyond cancer face disability or poor health following their treatment.

Consistency of support

Getting the right support at the right time is vital to improve outcomes for people living with and beyond cancer. Delegates

raised concerns about the lack of consistent support throughout the pathway and reported that support must be person-centred, holistic and joined up. A key part of this is joining up primary and secondary care, for example by making sure care plans and treatment summaries are created and then shared with a patient's GP. A holistic needs assessment can help to identify the range of needs patients have across all the different areas of their lives so that they can be signposted to support.

The APPGC was pleased to hear the Secretary of State talk about the opportunity to build upon the work conducted by charities in this area to ensure that there is a 'tailored cancer recovery strategy covering the whole care pathway through and beyond treatment'. The APPGC wants everyone with cancer to be able to access tailored and holistic support during and after treatment, through a recovery package and clear pathways across the whole cancer pathway. To make this a reality by 2020, the Government, commissioners, providers, professionals and charities will all need to work together. The APPGC would like to see NHS England deliver a plan for roll out of a recovery package including upfront funding, and clear guidance for commissioners by July 2016.

Recommendation:
The APPGC calls on NHS England to set out how it will ensure everyone living with and beyond cancer has access to tailored support that addresses their needs, through a recovery package.

5 Workforce

One of the key areas of focus throughout the conference was the cancer workforce. This was an area discussed prior to the conference at a meeting of the five cancer-related APPGs in November 2015 which was addressed by Professor Sean Duffy, the then National Clinical Director for Cancer at NHS England, and Sir Harpal Kumar, Chair of the Independent Cancer Taskforce. Following the meeting, the Chairs of the groups wrote to Health Education England to ask how the organisation was planning to address the issues set out in the Cancer Strategy. The APPGC will be continuing to monitor this area.

Cancer workforce deficits

Deficits in the cancer workforce were identified as a key area to be addressed in the England Cancer Strategy, which stated that investment was required to address “critical workforce deficits” and that “a strategic review of future workforce needs and skills mix for cancer” should be undertaken to report by the end of 2016.²² It identified priority areas as “radiology, radiography and endoscopy for diagnosis; and clinical oncology, medical oncology and clinical nurse specialists for treatment and care”.

At Britain Against Cancer, workforce planning was one of the issues raised by delegates in the event questionnaires, and was also raised during the onstage discussion with Professor Sean Duffy and Sir Harpal Kumar. Both said that this would be one of the most important areas to tackle if the England Cancer Strategy is to achieve its ambitions, with Sir Harpal Kumar stating that it was the area he was most concerned about. He highlighted the need to ensure that the workforce doesn’t “lurch from one crisis to the next” but is planned effectively to meet future needs.

Harpal Kumar and Sean Duffy said that workforce would be one of the most important areas to tackle if the England Cancer Strategy is to achieve its ambitions.

Improving cancer workforce planning

During the discussion, two key points were highlighted – the need to balance national focus with local empowerment, and the need to balance short term fixes with long term solutions. Professor Sean Duffy said that national oversight should lead and drive change, but this needs to be alongside empowerment of local health economies. He said that local planning and development for workforce has the potential to become more independent, and better able to respond flexibly to the needs of the local area.

Sir Harpal Kumar emphasised the need to address the shortage in radiologists and radiographers today in order to ensure that progress can be made in areas

29% of the current consultant workforce plan to retire by 2024

such as early diagnosis over the next five years. The shortage of radiologists has been well known for some time. A census done by the Royal College of Radiologists revealed that 29% of the current consultant workforce plan to retire by 2024, and 46% by 2029. Yet between 2012 and 2014, the number of trainee radiologists has only increased by 2% – much less than the growth in demand for radiology services.²³ In the recent Board Report for NHS England, training of 200 more non-medical endoscopists was identified as a priority.²⁴ Training and development of the non-specialist workforce will be a vital part of achieving a cancer workforce that is fit for purpose. However, whilst training non-medical endoscopists is a welcome first step, this is only one part of a much wider piece of work which needs to be undertaken.

The workforce review to be carried out by Health Education England (HEE) should look at the varied and diverse range of salaried and non-salaried workforce who are part of a cancer patient's care. This should include looking at what roles are needed to ensure swift diagnosis and treatment, coordination at key transition points, as well as the roles needed to ensure that patients are supported to self-manage both in the short and longer term, including a specific focus on Allied Health Professionals.

Recommendation:
The APPGC calls on Health Education England to ensure that, as per recommendation 83 in the Cancer Strategy, a thorough review of the cancer workforce is carried out by the end of 2016 in order to ensure that long term solutions for the cancer workforce can be implemented.

Rarer cancers

When looking at the cancer workforce, it is important to consider how the NHS can best support smaller patient populations such as people with rarer cancers. These cancers need specialist support and expertise and often require professionals to work across organisational boundaries. HEE's review into the cancer workforce should look strategically across organisations and conditions and specifically consider what the workforce requirements are for improving the outcomes of people with rarer cancers. It should consider rarer cancers when looking at the mix of generalists and specialists needed, and how the workforce can best improve co-ordination of care across sectors.

An important consideration for the review will be the workforce requirement for the full roll out of Multi-disciplinary Teams (MDTs) focused on rarer cancers. MDTs are meetings at which the various specialists involved in cancer care come together to share information and expertise. The Cancer Strategy recommended that national or regional MDTs for rarer cancers should be established, as they would particularly benefit from this approach.²⁵ The APPGC strongly agrees with this recommendation, and believes that the mix of specialists required for successful MDTs should be a key consideration in HEE's review of the cancer workforce in order to ensure that we have a workforce which can deliver better outcomes for all cancer patients.



6 New models of care

At the conference, the APPGC asked delegates what they thought NHS England's top three priorities should be for the implementation of the England Cancer Strategy, and many raised variations on the idea of 'better co-ordination of care'.

The impact of poor care co-ordination on patient experience and outcomes is well documented, and was highlighted by a cancer patient who spoke about his care at the new models of care workshop. Whilst he praised the NHS for the care he was given, he noted that throughout the pathway there were several delays, information was not shared and no support was provided after treatment.

Improving care pathways

The need to improve care pathways so that patients can move between different parts of the health care system was also acknowledged by Cally Palmer, National Cancer Director at NHS England in her address. She stated that "current care pathways for cancer are designed around organisations rather than patients", and emphasised the need to work collaboratively across organisational boundaries, noting that "siloed care doesn't do patients justice". In particular, the importance of joining secondary and primary care was highlighted.

Delivering models of care which work for cancer patients will require a step change in many areas of the NHS, as set out in the Five Year Forward View. The importance of building on the work already happening in many areas of the country, rather than creating duplication through implementation of the England Cancer Strategy, was highlighted as particularly important. In response to a question from the audience, Cally Palmer confirmed that an important part of her work would include looking at where best practice already exists and ensuring that any new systems or structures do not undermine that.

Cally Palmer stated that "current care pathways for cancer are designed around organisations rather than patients", and emphasised the need to work collaboratively across organisational boundaries.

The role of charities

During the new models of care workshop, consideration was also given to the role that charities can play in supporting the development and delivery of new models of care. Macmillan Cancer Support and Teenage Cancer Trust outlined how the expertise and networks of charities can be used in a variety of ways to support system change. This could be in an advisory capacity; in representing the patient voice; in investment; in communicating with key stakeholders both locally and nationally; and as neutral facilitators/mutual conveners who can help to overcome barriers in the system. The APPGC commends the work of the charity sector in supporting the development

of the England Cancer Strategy through the Independent Cancer Taskforce, and believes that the third sector is a crucial partner and should continue to play an important role in the delivery of its recommendations.

Cancer Alliances

One of the key recommendations in the England Cancer Strategy which will be crucial to the success of new models of care is the creation of Cancer Alliances. The England Cancer Strategy sets out a clear vision of the function of Cancer Alliances, recommending that they “drive and support improvement and integrate care pathways, using a dashboard of key metrics to understand variation and support service redesign”²⁶ In her address at Britain Against Cancer, Cally Palmer acknowledged the important role Alliances will play in delivering the England Cancer Strategy, highlighting that whilst there was still a decision to be made on what they would look like, they would be central in joining up and co-ordinating pathways.

The APPGC believes that Cancer Alliances are a crucial enabler of improvements in cancer care and should be implemented as a priority in 2016, as set out in the England Cancer Strategy. Whilst they may take different forms in different parts of the country depending on existing structures, it is important that the focus on the role they should play is not lost. In all areas of England, they should have the capacity and capability to drive the delivery of the national Cancer Strategy, support efficiency, provide leadership, and help co-ordinate pathways which cross different organisations.

The APPGC believes that one of the most important roles that Cancer Alliances should play is in ensuring meaningful patient involvement throughout the cancer pathway. Throughout Britain Against Cancer, the importance of patient involvement in the design and delivery of services was emphasised. In the first plenary session, Sir Harpal Kumar said that Cancer Alliances would be the key vehicle for patient involvement, and that patients “would have as important a role [as clinicians], not least so that they can hold local health economies to account”.

Harpal Kumar said that Cancer Alliances would be the key vehicle for patient involvement, and that patients “would have as important a role [as clinicians], not least so that they can hold local health economies to account.”

The APPGC believes that ensuring meaningful patient involvement should be a priority for Cancer Alliances, and that there should be a particular focus on the involvement of under-represented groups such as black and ethnic minority communities. In addition, the National Cancer Advisory Group should hold Cancer Alliances to account on this as part of its annual review of progress.

Recommendation:
The APPGC calls on NHS England to ensure that Cancer Alliances are established in 2016 and have the capacity and capability to carry out functions including leadership, co-ordination of pathways, patient involvement and data analysis.

Devolution and vanguards

At the workshop on new models of care, the topic of devolution was also considered, and in particular health and social care devolution in Greater Manchester which will see the area take control of a £6 billion budget for delivering health care. Against this backdrop, The Christie in Manchester is also part of the National Cancer Vanguard, alongside University College Hospital and the Royal Marsden, tasked with piloting new approaches to service delivery in line with the England Cancer Strategy. Whilst it may be some years before the success of the Vanguards, and the Greater Manchester Devolution Agreement can be assessed, the APPGC believes it will be important to ensure that lessons learnt from these projects are effectively captured throughout the process and used to improve cancer outcomes across the country.

7 Data

The APPGC has long focused on the importance of using data to improve cancer outcomes. We have particularly championed the use of data in driving improvements in early diagnosis. We have also focused on the use of data to improve patients' experience of care and have raised issues within Parliament relating to access to data for research and service improvement. We were delighted to hear the importance of data raised throughout Britain Against Cancer by all of the keynote speakers.

One of the most important recommendations in the Cancer Strategy is the use of data to drive service improvement through a new Cancer Dashboard.²⁷ Cally Palmer, National Cancer Director at NHS England, in her keynote address, emphasised the importance of the Cancer Dashboard being integrated by including metrics and data which can be used by both primary and secondary care, as well as other health bodies within a local area. The APPGC agrees with this view, and was pleased to see a similar approach being taken to the new Local Health Improvement and Assessment Framework (LHIAF).

Cally Palmer emphasised the importance of the Cancer Dashboard being integrated by including metrics and data which can be used by both primary and secondary care, as well as other health bodies within a local area.

Data collection frameworks

The APPGC will continue to monitor the development and progress of both the LHIAF and the Cancer Dashboard. We were pleased to hear commitments from both Cally Palmer, and the Secretary of State for Health, that the new frameworks will focus not just on survival and waiting times, but will also include quarterly staging data, along with new metrics on patient experience and quality of life. However, it will be important to ensure that the new metrics on patient experience and quality of life as recommended in the England Cancer Strategy

are progressed as a priority so that these indicators can start to drive improvement in these areas as soon as possible. We were disappointed to see no reference to the quality of life measure in the recent proposals for the LHIAF and hope that Government will reaffirm its commitment to including a metric on this area.²⁸

The APPGC also believes that patient involvement in the development of these frameworks will be crucial. We were disappointed to see a lack of information in the recent proposals for the LHIAF on how patients had been involved in selecting headline metrics, and we hope that patients will be part of the discussions led by the independent group verifying the ratings and performance on cancer outcomes for each Clinical Commissioning Group.

The use of patient data

Patient involvement in relation to data was also one of the key focuses of Britain Against Cancer. A workshop jointly hosted by Independent Cancer Patient Voices, use MY data and Cancer Research UK looked at data access issues, and particularly public attitudes to this. The workshop presented several

recommendations for action which included:

- All organisations responsible for collecting and sharing patient data should have patient representation in decisions about how that data is used.
- The criteria against which applications to use health records are assessed should be clear, consistent and available to the public.
- Government and NHS should maintain investment in the collection, linking and analysis of cancer data to improve outcomes for patients.
- The APPGC should work with patients, research funders and the NHS to produce a report detailing how patients have benefited from collecting and using health records.

The APPGC agrees with the recommendations set out above, and believes that their implementation would lead to a clearer, fairer system for using patient data. However, whilst having patient representation on decision making panels for organisations collecting/sharing data is hugely important, the APPGC also believes that it is vital that clear evidence is gathered on how the wider cancer population wishes their data to be used.

In the workshop, Martin Sever, Caldicott Guardian and Lead Clinician at the Health and Social Care Information Centre noted that it is important to get the balance right between sharing data and privacy concerns, as even when patients are fully informed, there can be different opinions.

Martin Severs of the Health and Social Care Information Centre noted that it is important to get the balance right between sharing data and privacy concerns.

The issue was also raised in the plenary session with the Secretary of State. In response to a question about ensuring there was a strong patient voice in considering the use of data, he noted that many people with cancer and/or other long term conditions are enthusiastic about their data being used, but that others remained nervous, particularly around whether their data can be kept safe. He pointed to Dame Fiona Caldicott's review which will recommend data security standards to be applied across the NHS (and assessed by the Care Quality Commission as part of their inspections) as one way of improving patient confidence in the use of their data in the NHS.²⁹

The Secretary of State pointed to Dame Fiona Caldicott's review which will recommend data security standards which should be applied across the NHS.

The APPGC believes that, given the important role data will play in the implementation of all aspects of the Cancer Strategy, as well as its role in research, the government should work with partners across the health sector, including patients, to establish a pragmatic approach to the use of patient data. This approach should balance privacy and security concerns with the benefits to both individuals and the wider cancer population. To achieve this balance and unlock the potential benefits, Government should ensure that there is capability in the system to hold and share data safely and securely. There should be adequate capacity for data to be collected and, most importantly, analysed to monitor the quality of care and reveal what can be done to improve it.

Recommendation:
The APPGC calls on the government to ensure that a pragmatic approach is taken to the use of patient data which supports the role of Cancer Registries whilst also recognising and addressing concerns around security and consent.

8 Accountability and funding

Given the APPGC's focus on accountability, particularly through the one year cancer survival indicator, Britain Against Cancer considered how we could ensure that the right accountability mechanisms were in place for the early diagnosis initiatives set out in the Cancer Strategy.

Local Health Improvement and Assessment Framework

The APPGC were pleased to hear reassurances from all of the keynote speakers that the focus on one year survival rates as a means of promoting earlier diagnosis would not be lost, but would be included as a headline indicator in both the new Local Health Improvement and Assessment Framework (LHIAF) and the Cancer Dashboard. The APPGC was also pleased to hear that other complementary measures, such as the new quarterly staging data announced by the Secretary of State for Health are also being included as headline indicators alongside the one year survival indicator, as these can help give Clinical Commissioning Groups (CCGs) and clinicians a much richer understanding of why late diagnoses occur.

The APPGC is pleased to see continued commitment to embedding these indicators in the relevant frameworks, however it is important that they are then used by CCGs and local health leaders to drive improvement. Parliamentarians will have a key role to play in holding CCGs to account, and in addition, NHS England should ensure that it has clear plans to support CCGs who are failing to make improvements.

Sir Harpal Kumar, Chair of the Independent Cancer Taskforce touched on accountability and rarer cancers in his on-stage discussion with the Chairman of the APPGC John Baron MP, noting that it would "not be possible to achieve the ambitions on one year survival or the 28-day referral-to-diagnosis metric if we don't address rarer cancers". The importance of focusing on outcomes rather than activities and putting incentives in place to drive this was also highlighted as an important way to ensure accountability by Professor Sean Duffy, then National Clinical Director for Cancer at NHS England.

Cancer Strategy Accountability

The APPGC was pleased to hear the mechanisms which will be put in place to ensure leadership and accountability for implementation of the Cancer Strategy, including the new Transformation Board headed by National Cancer Director, Cally Palmer, and the National Cancer Advisory Group, headed by Sir Harpal Kumar. The Advisory Group's role in reviewing the assessments for cancer care at a CCG level through the new LHIAF should also provide a strong link which enables accountability at a Clinical Commissioning Group level. The APPGC also believes

that the independent committee reviewing assessments for the LHAIF should have within its scope the delivery of Sustainability and Transformation Plans, as they will be key to understanding how the Cancer Strategy can be implemented at a local level.

In addition to these mechanisms, it will be important to ensure that there is clear parliamentary accountability. Whilst much of the England Cancer Strategy will be led by NHS England, the ambitions set out in the Strategy can only be achieved if all arms-length bodies are committed to its delivery. Parliamentarians have a unique perspective in being able to hold all bodies to account for delivery, and the APPGC will be considering its role in leading parliamentary accountability for the Strategy over the coming months. The APPGC also believes it is important that the whole cancer community plays an active role in scrutinising the progress of the England Cancer Strategy, and in particular, ensuring that the patient voice remains central throughout.

Funding

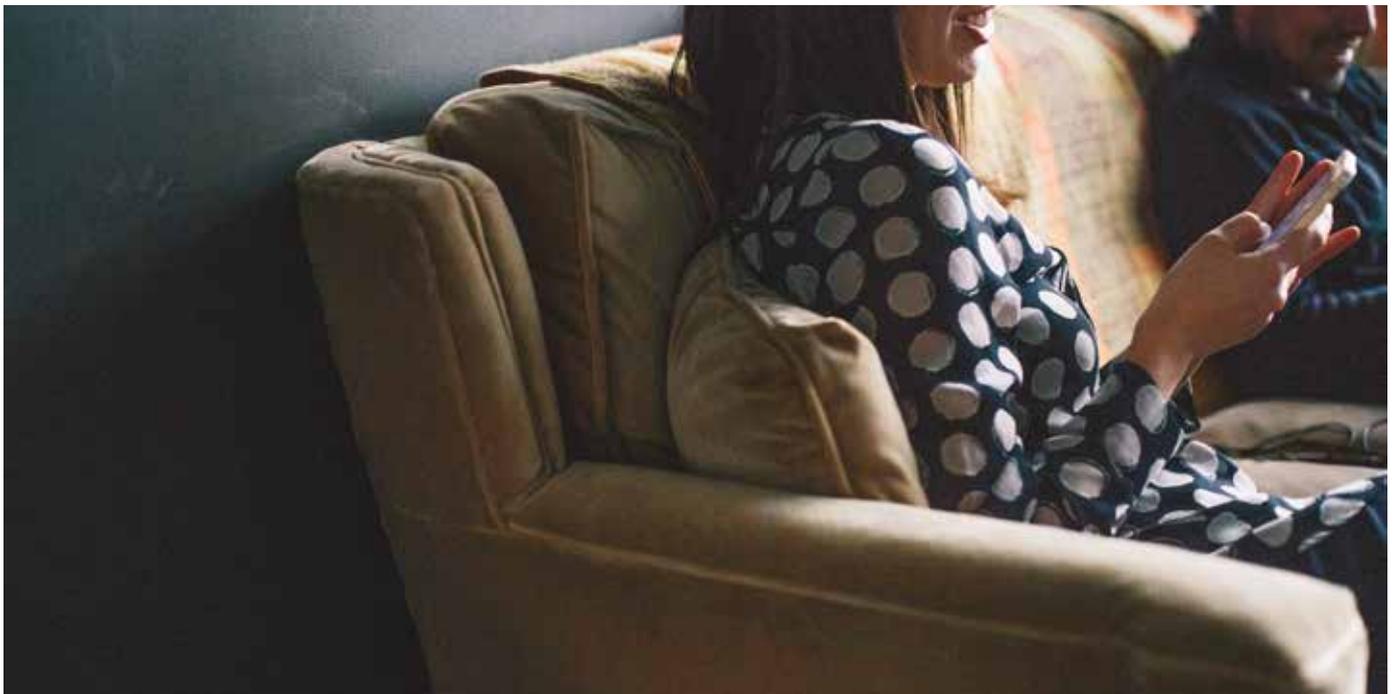
One of the key issues raised at the conference was that of funding. In his opening speech, Chairman of the APPGC John Baron MP, emphasised the efficiencies that could be achieved through implementing the England Cancer Strategy. He cited research from Cancer Research UK and Incisive Health on the costs which could be saved by diagnosing patients earlier; and newly published research from Macmillan Cancer Support revealing that the NHS is currently spending significant amounts of money on emergency care after treatment which could be used more effectively to deliver better care for patients at this stage of the pathway.³⁰

Coming only a week after the Comprehensive Spending Review, the APPGC was pleased that the conference saw the Secretary of State reaffirm his commitment to funding and implementing the Strategy. However, whilst the commitments made so far have been welcome, it will be important that there is continued scrutiny on when and how funds are being made available

In his opening speech, Chairman of the APPGC John Baron MP emphasised the efficiencies that could be achieved through implementing the England Cancer Strategy.

to deliver the ambitions set out in the Cancer Strategy. Whilst some element of prioritisation will be necessary given the large number of recommendations in the Strategy, it is important that the Strategy is implemented as a whole, with a balanced focus across the cancer pathway.

Recommendation:
The APPGC calls on Department for Health and NHS England to set out its plans for funding and delivering the Cancer Strategy over the next five years, including how it will ensure improvements across the entire cancer pathway.



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The All Party Parliamentary Group on Cancer was founded in 1998 to keep cancer at the top of the parliamentary agenda, and to ensure that policy-making remains evidence based and patient centred. The group monitors implementation of government initiatives, provides briefings for parliamentarians, and brings together MPs and Peers from across the political spectrum to debate key issues and campaign together to improve cancer services.

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

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The APPGC is supported by a Stakeholders' Group comprising representatives from: Breast Cancer Now, Cancer Research UK, Independent Cancer Patient Voices, Men's Health Forum, National Cancer Intelligence Network, Prostate Cancer UK, Rarer Cancers Foundation and Teenage Cancer Trust.

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