



# Cancer across the Domains

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## A vision for 2020

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# The All Party Parliamentary Group on Cancer

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

## Currently the Officers of the group are:

<b>John Baron MP</b> – Chairman	<b>Stephen Metcalfe MP</b>	<b>Baroness Morgan of Drefelin</b>
<b>Grahame Morris MP</b>	<b>Baroness Finlay of Llandaff</b>	<b>James Clappison MP</b>
<b>Baroness Masham of Ilton</b>	<b>Paul Burstow MP</b>	<b>Nic Dakin MP</b>

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

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

You can find out more information about the APPGC at [appg-cancer.org.uk](http://appg-cancer.org.uk)  
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# Foreword

**By the end of the next Parliament in 2020, three million people will be living with cancer in the UK – two-thirds of whom will be aged 65 or over.<sup>1</sup> The NHS will not be able to cope with this surge in demand unless it is successful in delivering a dramatic improvement in outcomes.**



**John Baron MP**  
**Chairman, All Party**  
**Parliamentary**  
**Group on Cancer**

Following on from our report last year, *Cancer across the Domains: a vision for 2020* examines the progress of cancer care in the country two years after the health reforms, and sets out our recommendations for the future. We focus on the five domains for which the NHS is held accountable.

Progress has been made across all domains – notably in life expectancy and patient safety. The publication in the Clinical Commissioning Group (CCG) Outcomes Indicator Set (OIS) of one-year cancer survival rates and of stage at diagnosis should help promote early diagnosis if used proactively by decision makers. The future publication of data on diagnosis via emergency routes will also contribute to this aim.

However, despite progress, there is still a huge gap between the present level of care and the best possible care for cancer patients. Our recommendations in this report focus on bridging this gap.

Too many cancer patients continue to be diagnosed too late. It remains a national disgrace that a quarter of all cancers are first diagnosed as late as A&E. If we matched the best survival rates in Europe, the Government estimates that 10,000 lives a year would be saved.<sup>2</sup> We should strive to make this a reality.

To this end, we are dismayed that the recently-introduced tier of accountability which now sits above the OIS – the Delivery Dashboard of the NHS Assurance Framework – contains no specific cancer outcome indicators. This error sends the wrong message and dilutes the efficacy of the OIS' outcome indicators in promoting earlier diagnosis. Correcting this error remains a key objective of the APPGC.

Meanwhile, too many vulnerable patients are still shown a lack of compassion during their care, and others struggle to cope with the long-term effects of treatment with limited support.

The APPGC's vision for 2020 is clear: the NHS must ensure all cancer patients are diagnosed earlier, treated compassionately, provided with the best possible individual treatment, and adequately supported after treatment ceases. Our report aims to provide a constructive platform for decision-makers across Government, the NHS and political parties to ensure these goals become reality.

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

**John Baron MP**  
**Chairman**  
**All Party Parliamentary Group on Cancer**  
**(APPGC)**

1. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/StatisticsFactsheet.pdf>  
2. *Improving Outcomes: A Strategy for Cancer*, Department of Health, January 2011.



## Executive summary

This report presents the All Party Parliamentary Group's (APPGC) analysis of progress in cancer care since the publication of *Cancer across the Domains* in December 2013. It incorporates the key points of NHS England's and the Government's response, as well as the main views of patients and the group of stakeholder charities that support the work of the APPGC.

### Domain 1

#### Preventing people from dying prematurely

Two million people in the UK today have had a cancer diagnosis. If, as predicted, this number continues to rise by over 3% a year, we could see four million people living with cancer by 2030.<sup>3</sup> Meanwhile survival rates in the UK continue to lag behind other European counterparts.

To deliver cancer outcomes that match the best in Europe we need improvements in areas such as early diagnosis, access to treatment, promoting research, and caring for older people. Together these will result in an increase in cancer survival. To achieve this, the APPGC recommends that:

- NHS England delivers the commitments set out in the 'five year forward view' and comprehensively outline how the health service will improve cancer survival rates to match the best in Europe.
- NHS England includes one-year cancer survival rate indicators in the Delivery Dashboard of the 2015/16 Clinical Commissioning Group (CCG) Assurance Framework.
- CCGs use the statistics on one-year cancer survival rates, staging data and emergency presentation to identify areas for improvement and introduce interventions to improve early diagnosis.

- NHS England uses the *Vision for Radiotherapy* to develop a coherent national strategy for radiotherapy with associated investment and resource. A comprehensive strategy to fulfil the duty to promote research across the NHS should also be developed to ensure that research opportunities are presented to patients at every stage of their cancer journey.
- NHS England clarifies the responsibilities of Strategic Clinical Networks, lines of accountability and their relationship with CCGs and other local bodies.
- NHS England works together with the charity sector to develop, support and roll-out tools that support referral and early diagnosis.
- NHS England ensures the importance of early diagnosis is fully recognised when designing financial flows at Primary Care level. This could include an indicator in the Quality Outcomes Framework.
- NHS England introduces a cancer mortality indicator for people over 75 in the NHS Outcomes Framework and the CCG Outcomes Indicator Set.

3. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *Br J Cancer* 2012; 107: 1195–1202.

## Domain 2 Enhancing quality of life for people with long-term conditions

By 2020 almost 1 in 2 people will get cancer however almost 4 in 10 of them will not die from the disease.<sup>4</sup> For many patients there are enduring consequences of their cancer which are physical, emotional and practical.

To improve the quality of life of people with cancer the Living With and Beyond Cancer Programme will play a crucial role.<sup>5</sup> Improvements are needed in the provision of information on the consequences of treatment, personalised care plans, and supporting people with long-term health conditions to stay in or return to work or education. To deliver this, the APPGC recommends that:

- NHS England incentivises CCGs to commission the whole of the Recovery Package within acute contracts.
- Hospital trusts improve the provision of information on the consequences of treatment as part of their action plans on the National Cancer Patient Experience Survey.
- NHS England ensures personalised care plans are embedded in the service specifications and commissioning of cancer services.
- NHS England commissions national vocational rehabilitation services that meet the health and work needs of people affected by cancer.

## Domain 3 Helping people to recover from episodes of ill health

The end of active treatment continues to be challenging for cancer patients, many of whom report feeling abandoned by the health service. Improvements are still needed to rehabilitation programmes and the use of Patient Reported Outcome Measures (PROMs).

To address these challenges, the APPGC recommends that:

- NHS England scales up the PROMs programme, as recommended by the National Cancer Survivorship Initiative.
- Further clarity is provided on where responsibility for cancer rehabilitation lies across the health service.

## Domain 4 Ensuring that people have a positive experience of care

The National Cancer Patient Experience Survey (CPES) 2014 showed improvements on a number of areas, compared with the first survey in 2010. However, this data also suggests areas for further improvement, such as in patients' support from their general practice and care from health and social services post discharge. Thus, more is needed to ensure all patients are treated with the highest levels of dignity and respect. It is also crucial that staff are given the time, training and support they need to deliver this.

More still needs to be done to ensure patient experience is a priority for the health service, carers are effectively identified and patients are able to spend their final weeks and days in the place of their choosing. To make further progress, the APPGC recommends that:

- NHS England improves the accessibility of the results of the CPES and produces an official comparison of the results to help improve patients' choice.
- All hospital trusts publish action plans based on the CPES and report against progress.
- NHS England outlines how it will work with CCGs and Local Authorities to identify carers effectively.
- NHS England and Health Education England support NHS staff to deliver the best possible care. All frontline staff should have time to access training to deliver care with dignity and respect.
- NHS England works with providers to improve access to Clinical Nurse Specialist (CNS) for all cancer patients.

## Domain 5 Treating and caring for people in a safe environment

There has been a drive from the Department of Health and NHS England to capitalise on the seminal moment of progress in addressing failures of patient safety that the series of inquiries and reports and the Government's responses represented at the end of 2013.

To ensure that progress on this area continues, the complaints and peer review mechanisms need to be strengthened further. The APPGC recommends that:

- NHS England ensures the complaints mechanisms across the health service are robust and effective.
- NHS England and Ministers ensure that the Cancer Peer Review Programme is maintained and strengthened in the health service.

4. Macmillan Cancer Support estimate based on; Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Scenario 1 presented here) Forman D, et al. Cancer prevalence in the UK: results from the EUROPREVAL Study. Annals of Oncology. 2003. 14: 648-654; Office for National Statistics; Information Services Division (ISD) Scotland; General Registrar Office Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency

5. <http://www.ncsi.org.uk/news/new-living-with-and-beyond-cancer-programme/>



# Domain 1: Preventing people from dying prematurely

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## 1. Introduction

Two million people in the UK today have had a cancer diagnosis. If this number continues to rise by over 3% a year, this could see four million people living with cancer by 2030.<sup>6</sup> People have a better chance of surviving cancer and having fewer long-term complications if the disease is caught early.

The APPGC welcomes NHS England's 'five year forward view' setting out the changes needed in the NHS, including its ambition for cancer. The focus on better prevention, access to diagnosis and better treatment and care for all those diagnosed with cancer is an important approach which will benefit patients.<sup>7</sup> The NHS has rightfully identified the challenges and gravity of the situation it is facing with the rise in cancer incidence. NHS England now needs to comprehensively outline how it intends to meet the demands that will be placed on cancer services over the coming years. The APPGC is keen to hear in detail how NHS England will ensure England closes the gap in cancer survival on its neighbours in Europe over the next five years to 2020.

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**The APPGC calls on NHS England to deliver the commitments set out in the 'five year forward view' and comprehensively outline how the health service will improve cancer survival rates to match the best in Europe.**

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However, the UK continues to be unprepared to meet the rise in incidence. Our country lags behind its European counterparts with survival rates being labelled 'low' for people with kidney, stomach, ovarian, colon, and lung cancers in the latest EURO CARE comparison.<sup>8</sup> These statistics show that England, with an average survival rate of 68%, lags far behind the best – Sweden, at 81%.<sup>9</sup> Furthermore, far too many cancer patients are diagnosed too late. A quarter of all cancers in England are first diagnosed following an emergency presentation which reduces the chances of people surviving the disease.<sup>10</sup>

*Cancer across the Domains* identified a number of recommendations for NHS England to improve early diagnosis and increase cancer survival. Over the past year, this has informed a large part of the APPGC's work. While significant strides have been made, there is much left to do. By the Government's own estimates, if we matched the best of our neighbours in Europe, we could save 10,000 extra lives a year in England.<sup>11</sup>

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6. Addams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *Br J Cancer* 2012; 107: 1195–1202.

7. NHS England: *Five Year Forward View* p38. (2014)

8. EURO CARE-5: Cancer Registry Based Study on Survival and Care of Cancer Patients, (2013)

9. *Ibid*

10. Elliss-Brookes L et al: *Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets*. *Br J Cancer* (2012); 107: p1220–1226

11. Department of Health: *Improving Outcomes: A Strategy for Cancer* (2011)

## 2. Cancer across the Domains previous recommendations

The APPGC called on NHS England to:

- Define how it will use the Clinical Commissioning Group (CCG) Outcomes Indicator Set to hold CCGs to account and improve early diagnosis.
- Outline how it will ensure that access to the best treatment is available to all cancer patients and how it will honour its statutory duty to promote research.
- Set out how it will work with partners to continue national awareness programmes on the causes and symptoms of cancer and clearly set out the division of responsibility for prevention, symptom awareness and screening.
- Undertake research as to whether financial flow mechanisms could better encourage earlier diagnosis.
- Set out clearly the functions of Strategic Clinical Networks.

## 3. APPGC's assessment of delivery

### a. Measuring survival rates and early diagnosis

The APPGC welcomes the Government's acknowledgement of the importance of good data for 'helping commissioners to improve outcomes'.<sup>12</sup> Measuring cancer survival rates for all cancers is essential to drive improvements in early diagnosis.

Following a campaign led by the APPGC and the cancer community, indicators measuring one-year cancer survival rates for all cancers were embedded by NHS England in the architecture of the health service; nationally in the NHS Outcomes Framework and locally in the CCG Outcomes Indicator Set.

In December 2013, the statistics for one-year cancer survival rates broken down by CCG, were presented for the first time. This data showed several areas in the country performing below the England average (68%) and widespread variation. The APPGC hopes that highlighting this data to CCGs will drive appropriate improvements in earlier diagnosis at a local level to address the needs of populations. For example, by using awareness raising campaigns, improving GP awareness and ensuring timely access to diagnosis through training and innovative diagnostic tools.

The APPGC also welcomes the inclusion of measures on diagnosis via emergency routes, record of stage at diagnosis and other cancer specific indicators in the 2014/15 CCG Outcomes Indicator Set.<sup>13</sup> These statistics are proxy measures that complement and paint a better picture of one-year survival, as recommended in *Cancer across the Domains*.

We commend the work done by the Office for National Statistics, the National Cancer Intelligence Network, the Health and Social Care Information Centre, the London School of Hygiene and Tropical Medicine and others, in the development and publication of this data.

### The APPGC calls on all CCGs to use the statistics on one-year cancer survival rates, staging data and emergency presentation to identify areas for improvement and introduce interventions to improve early diagnosis.

Despite this progress, one-year cancer survival rates only paint part of the picture of people with cancer dying prematurely. It is essential to know how many cancer patients are living to key milestones after diagnosis. For this reason, the APPGC campaigned for the inclusion of five-year survival rates for all cancers in both the NHS Outcomes Framework and the CCG Outcomes Indicator Set.

This indicator was effectively included in both frameworks. However, it was subsequently removed from the 2014/15 CCG Outcomes Indicator Set and the planned data for the previous year was not published. The APPGC is concerned that the indicator was removed without prior consultation with the cancer community and that the discussions with the NICE Advisory Committee do not seem to state the reasons for its exclusion.

In a debate in Parliament on 13 February 2014, the Public Health Minister, Jane Ellison MP, responded to this: 'because of the small number of survivors at five years, disaggregating the data down to individual CCGs would not leave the data statistically robust enough to draw conclusions... [NHS England] are considering how it can be published at a level that is not only meaningful and helpful, but statistically safe.'

The APPGC welcomes efforts to explore the soundest method of publishing five year cancer survival figures, but urges this to be expedited; it is vital that, in order to focus commissioners on delivering improvements on early diagnosis, longer term survival of cancer is also published. The 'forward view' document of NHS England indicates if they were to implement the ambition for cancer set out in the document at sufficient pace and scale by 2020 the NHS could 'deliver a 10% increase in those patients diagnosed early, equivalent to about 8,000 more patients living longer than five years after diagnosis'.<sup>14</sup>

### The APPGC calls on NHS England to develop a robust measurement of five year cancer survival rates for all cancers at a local level.

### b. Holding CCGs and local bodies to account on early diagnosis of cancer

Shortly before the passage of the Health and Social Care Act 2012, the former NHS Commissioning Board (now NHS England) indicated that the scope of the CCG Outcomes Indicator Set would be an 'accountability framework for CCGs'.<sup>15</sup>

However, this is no longer the case as the nature of this framework has changed significantly. In the Government's response to *Cancer across the Domains* it stressed that the CCG Outcomes Indicator Set 'is a tool that supports commissioners to drive improvement and set priorities' and that it will contribute to forming a 'rounded picture of local outcomes'.<sup>16</sup> NHS England would expect, the Government asserted, CCGs to clearly demonstrate the work they are doing to improve both quality and outcomes.

12. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)  
13. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer. (Received 6 May 2014)

14. NHS England: *Five Year Forward View*. (2014)  
15. NHS England: *Commissioning Board: Commissioning Outcomes Framework: Engagement document* (2011)  
16. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

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The APPGC believes that the best CCGs will do this, but that stronger leadership from NHS England is needed to ensure CCGs use this information to drive improvements in their local area. This national leadership and accountability is particularly important for those specialised cancer services which are commissioned directly by NHS England.

Furthermore, NHS England's May 2014 response to our report clarified that it uses the CCG Assurance Framework and its comprehensive Delivery Dashboard to assess CCGs. NHS England's Local Area Teams can use statutory intervention powers if CCGs fall short. Subsequently, recent anecdotal evidence suggests that CCGs are focusing primarily on complying with measures of the Assurance Framework and the Delivery Dashboard only, an assertion that was corroborated in the Government's response to our report.<sup>17</sup>

At the moment, neither the Assurance Framework nor the Delivery Dashboard include cancer survival rate indicators.<sup>18</sup> In practice, this means that there are no adequate incentives for CCGs to improve early diagnosis of cancer locally. The APPGC is concerned with the limited leadership from NHS England to hold CCGs to account on early diagnosis of cancer. Nonetheless, the APPGC is pleased that the Government reported in its response that a review of the 2015/16 CCG Assurance is currently taking place and 'will explore how outcomes, including those in the CCG Outcomes Indicator Set, can be further embedded into assurance'. The APPGC looks forward to seeing the terms of the review and to know more about the Government's plan to engage with the third sector, patients and professionals in this review.

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The APPGC urges NHS England to include one-year cancer survival rate indicators in the Delivery Dashboard of the 2015/16 CCG Assurance Framework. Clarity is also needed on how local CCGs are currently being held to account for improvements of one and five year cancer survival rates.

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### c. Access to the best possible treatment

In the past year, the progress made on improving access to treatment has been mixed. The Government and NHS England's response to *Cancer across the Domains* highlighted some of the key areas in which NHS England is ensuring access to the best treatment:<sup>19</sup>

- Creating national, evidence-based service specifications for a wide range of cancer types. These set out what providers must have in place to offer high quality cancer treatment, care and support.
- Commissioning radiotherapy at a national level, which means that for the first time, cancer patients are considered for the most appropriate, including innovative radiotherapy, regardless of where they live.
- Through the Radiotherapy Innovation Fund, increasing the proportion of radiotherapy treatments delivered with Intensity Modulated Radiotherapy (IMRT) from 13.6% before the fund to a national average of 35% at March 2014.
- Making up to £6m available over the next five years to support trials by Cancer Research UK into the use of stereotactic ablative radiotherapy (SABR). This will allow patients to receive SABR treatment, where clinicians think they could



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17. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

18. The Operational Guidance of the 2013/14 CCG Assurance Guide stated that "in future this section of the Delivery Dashboard will be further developed to include broader data across the CCG OIS in line with changes through planning." However, the most recent Operational Guidance omits this sentence. NHS England: *The CCG Assurance Guide 2013/14: Operational Guidance* (2013) p35; NHS England: *The CCG Assurance Guide 2014/15: Operational Guidance* (2014)

19. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)



benefit, through the trial now. At the same time doctors can fully assess the effectiveness of these treatments so that in future, if it proves to be effective, they will be available for all relevant patients on the NHS.

- In partnership with Cancer Research UK, publishing a ten year vision for radiotherapy which considers the appropriate technology and capacity requirements needed to provide radiotherapy services to cancer patients in England.<sup>20</sup>
- Ensuring consistently high standards of chemotherapy across providers in England through the service specification.
- Supporting the introduction of Proton Beam Therapy at two hospitals in England from 2018.

On the other hand, the Cancer Drugs Fund (CDF) continues to be a cause for concern for the APPGC. The group believes that all cancer patients should be able to access the drugs they need, no matter where they live in the country, their age or the type of cancer they have. We also want to see a system of drug pricing and assessment that makes this possible and understand the challenge that NHS England faces in trying to deliver this.

The CDF was extended until 2016 and the Government recently announced an extra £80 million in each of the two remaining years of the Fund (taking the total to £280 million per year).<sup>22</sup> This increased investment is welcomed by the APPGC; however, it is clear that there is a strain on its budget and so it is evident that it is not a long term solution.

Furthermore, following a public consultation, NHS England announced a revised process for operation of the CDF.<sup>23</sup> The APPGC is concerned about the transparency and robustness of this new process as well as the potential creation of two parallel systems of evaluation of drugs, within the CDF and NICE.

**The APPGC urges NHS England to clarify plans for the Cancer Drugs Fund after 2016. We also call on NHS England to work with NICE, patient groups and the pharmaceutical companies to develop a fair and sustainable system for appraising new cancer drugs.**

#### **d. Honouring the statutory duty to promote research in the NHS**

Progress on this area has been slow. Clinical research is critical to progressing our understanding and is an important means to ensure patients experience high standards of care. The Health and Social Care Act puts a duty on all bodies within the health system to promote research within their organisation.

#### **NHS England should use the Vision for Radiotherapy to develop a coherent national strategy for radiotherapy with associated investment and resource.**

On this area there is currently an urgent need for NHS England to provide clarity on the plans for the specialised commissioning of chemotherapy and radiotherapy, in light of the current specialised commission task force that was established in April 2014 following the overspend in 2013/14.<sup>21</sup>

Services that are commissioned nationally should not be moved to be commissioned by CCGs until a full impact of this has been assessed. This is because there are concerns about the capabilities and capacity of CCGs to take on these additional commissioning responsibilities at this time. In addition, some services for rarer cancers could not be effectively commissioned at a local scale and should therefore be retained as nationally commissioned services by NHS England.

Evidence suggests that 89% of patients would be willing to take part in clinical research and 95% of people said it is important to them that the NHS carries out clinical research.<sup>24</sup> However, according to the National Cancer Patient Experience Survey (CPES), only a third of patients have a discussion about research, a figure that has not changed since 2011.

NHS England consulted on a draft research strategy at the beginning of 2014 which set out a promising overall vision for promoting research in the NHS. While useful, the draft requires more in-depth analysis of some of the areas which need improvement. Following the consultation period, which closed in January, no new research strategy has been produced and there have been indications that it will not be published.

**To fulfil the duty to promote research across the NHS, the APPGC believes that a comprehensive strategy is required to ensure that research opportunities are presented to patients at every stage of their cancer journey.**

The Government also needs to continue to support the National Institute for Health Research (NIHR) as the organisation that provides the infrastructure for most of the UK's clinical research. Because of the work of the NIHR, the UK now recruits around 20% of cancer patients into research studies which is significantly higher than other developed nations. The value of the NIHR should be recognised as critical to continuing progress against cancer.

#### **e. Symptom awareness**

National leadership around symptom awareness continues to be at the centre of the implementation of the Government's *Improving Outcomes: a strategy for cancer*, which is welcomed by the APPGC as it is essential to improving early diagnosis.

On awareness and screening, the Government and NHS England's responses to *Cancer across the Domains* clarified that Public Health England, the Department of Health and NHS England will continue to work together on the development of the *Be Clear on Cancer Campaign for 2014/15*;<sup>25</sup> Public Health England is responsible for piloting and rolling out screening programmes for the delivery of which NHS England then becomes responsible. Furthermore, funding was provided to Public Health England (subject to successful evaluation and reassessment of priorities) over the course of the four years of the spending review to run campaigns to raise awareness of cancer symptoms.<sup>26</sup>

The last twelve months have also seen technological innovation to aid earlier diagnosis such as Macmillan Cancer Support's electronic Cancer Decision Support Tool which draws on cancer risk algorithms developed by Professor Willie Hamilton and Professor Julia Hippisley-Cox. The Tool complements GP records software, helping GPs recognise the symptoms of five cancer types including hard to detect cancers such as ovarian and pancreatic cancer.

**The APPGC urges NHS England to work together with the charity sector to develop, support and roll-out tools that support referral and early diagnosis.**

20. Cancer Research UK: *Vision for Radiotherapy 2014–2024* (2014)

21. <http://www.england.nhs.uk/ourwork/commissioning/spec-services/task-force/>

22. <https://www.gov.uk/government/news/thousands-more-patients-to-benefit-from-additional-160-million-for-cancer-drugs>

23. NHS England. *Standard Operating Procedures: The Cancer Drugs Fund*. (2014) <http://www.england.nhs.uk/wp-content/uploads/2014/11/sop-cdf-1114.pdf>

24. National Institute for Health Research, Clinical Research Network: *What Do People Think About Clinical Research*. (2014)

25. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

26. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)



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#### f. Financial flows

Besides early diagnosis, the APPGC believes that NHS England should ensure the importance of earlier diagnosis is fully recognised locally when designing financial flows at Primary Care level (for example through the Quality and Outcomes Framework).

Encouragingly, NHS England and the Department of Health agree in principle with *Cancer across the Domains'* recommendation that financial flow mechanisms could improve early diagnosis and they have agreed to give further consideration to how this could be implemented.<sup>27</sup>

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**NHS England should ensure the importance of early diagnosis is fully recognised when designing financial flows at Primary Care level. This could include an indicator in the Quality and Outcomes Framework.**

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#### g. Strategic Clinical Networks

*Cancer across the Domains* called on NHS England to clearly set out the functions of Strategic Clinical Networks (SCNs). Four functions, formerly carried out by Cancer Networks, are essential:

- Driving forward the local cancer strategy
- Driving service redesign to ensure integration
- Providing a vital source of expertise on cancer
- Monitoring performance of providers to highlight poor outcomes.

Research in this area suggests that the transition from Cancer Networks to SCNs has created significant gaps.<sup>28</sup> SCNs have a wider remit alongside less resources and responsibility for 'hands on' cancer service change. Cancer Networks had more responsibility to ensure that services were integrated, users and clinicians engaged, and that patient needs across the pathway were sufficiently considered.

In its response to *Cancer across the Domains*, NHS England stated that the role of SCNs is to 'support an integrated, holistic approach to commissioning, engaging with clinicians across the health economy to provide innovative guidance to commissioners.'<sup>29</sup> However, a recent study by Macmillan Cancer Support found 'Many SCNs didn't feel it was within their remit to drive integration, yet no other body is accountable or responsible for doing this. Equally, it is unclear who is able to, and responsible for, facilitating user and clinical engagement groups in the absence of the former networks. As a consequence, clinical knowledge, best practice, and meaningful patient and user engagement – all of which contribute to an integrated person-centred pathway – have also been lost.'<sup>30</sup>

Similarly, a Cancer Research UK commissioned report on NHS cancer services looked into SCNs and made a number of recommendations. Firstly, it recommended that the Department of Health, NHS England and Public Health England urgently clarify and communicate the responsibilities of the different commissioners of cancer services. It also said that SCNs should map out commissioning responsibilities for their geographical area. Finally it recommended that SCNs should ensure commissioning organisations are working together to provide coordinated cancer services.<sup>31</sup> This report shows that it is still unclear what SCNs' responsibilities are, who

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27. Ibid

28. Macmillan Cancer Support: *Lost in transition: a review of cancer commissioning*. (2014)

29. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer. (Received 6 May 2014)

30. Ibid

31. Health Services Management Centre at the University of Birmingham, ICF GHK Consulting and Cancer Research UK: *Measuring up? The health of NHS cancer services*. (2014)

# Domain 2: Enhancing quality of life for people with long-term conditions

they are accountable to, and the definition of their relationship with CCGs.

**The APPGC calls on NHS England to clarify the responsibilities of SCNs, lines of accountability and their relationship with CCGs and other local bodies.**

## **h. Caring for older people**

There is general recognition that older people in the UK with a cancer diagnosis experience poorer outcomes than younger people, this is particularly stark in relation to mortality rates.<sup>32</sup> The APPGC's inquiry into inequalities in cancer in 2009 corroborated these findings.<sup>33</sup> The variation in the UK of age related outcomes is significant, urgent and not yet well understood. People over 65 make up a large proportion of the current cancer population.<sup>34</sup> The number of older people living with multiple morbidities, as well as increasing prevalence has led to greater demands to review the way we care for and support older people with cancer. The APPGC believes that by addressing inequalities associated with age the UK has the potential to drastically improve outcomes for a large number of people with cancer now, and in the future.

The NHS Outcomes Framework and the CCG Outcomes Indicator Set include an indicator on cancer mortality for people aged under 75, in order to identify premature death from cancer.<sup>35</sup> This means that data is not currently collected to identify premature death from cancer for people over 75. The APPGC is concerned that this sends out an unhelpful message about the importance of older people with cancer and may not provide an appropriate incentive for the NHS to improve outcomes for people over 75 years old.

The APPGC welcomes NHS England's Call to Action on Older people with cancer, which is led by the National Clinical Director for Cancer. The Call to Action will investigate the root causes of poor outcomes in older people with cancer and provide information, guidance and tools to commissioners to improve outcomes for older cancer patients.

The APPGC is also pleased to see momentum building on this important issue. For example, the work by the National Cancer Equality Initiative (NCEI) and Pharmaceutical Oncology Initiative (POI) to review the evidence on the benefits and side effects of drug treatment in older people will help support informed clinical practice, ensuring that treatment decisions are based on what is most appropriate for the patient and not simply on the basis of a patient's age.

**The APPGC calls on NHS England to introduce a cancer mortality indicator for people over 75 in the NHS Outcomes Framework and the CCG Outcomes Indicator Set.**

## **1. Introduction**

By 2020 almost 1 in 2 people will be diagnosed with cancer during their lifetime but almost 4 in 10 will not die from the disease.<sup>36</sup> *Cancer across the Domains* reiterated that this is testament to improved cancer treatment. However, for many patients there are enduring consequences of their cancer, and living with these is much like living with any long term condition.

These consequences of cancer and cancer treatment are physical, emotional and practical. Physical effects range from general fatigue to reduced functional capability, osteoporosis, incontinence, sexual problems and chronic pain. Furthermore, patients often report fear and anxiety of recurrence which can impact significantly on their wellbeing. Patients are also often faced with financial difficulties and challenges of getting back to work once their treatment is completed. For children and young people with cancer, there is the additional challenge of returning to education or training.

## **2. Cancer across the Domains previous recommendations**

To address these issues, the APPGC recommended that NHS England:

- Encourage the uptake of the 'Recovery Package' by officially endorsing it and encouraging CCGs to commission it within acute contracts.<sup>37</sup>
- Outline how it will work with CCGs and education bodies to ensure that professionals have access to and use the latest information about the consequences of cancer and its treatment. This should include late effects and recurrence.
- Define how it will ensure that best practice stratified care pathways (personalised care plans) are in place to allow CCGs to commission them for cancer patients within their acute contracts. Assessment and care planning should be undertaken whenever needed post diagnosis and at the end of treatment.
- Publish plans detailing how it will support people with long-term health conditions to stay in or return to work. This includes fulfilling the commitments to employment set out in the NHS Mandate.

32. All Party Parliamentary Group on Cancer: *Report on the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer*. (2009)

33. Age UK, Department for Health and Macmillan Cancer Support. *Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project*. (2012)

34. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer*. (2012); 107: 1195-1202

35. Indicator 1.4 in the NHS Outcomes Framework 2014. NHS England: *NHS Outcomes Framework 2014/15 at a glance*. (2014)

36. Macmillan Cancer Support estimate based on; Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 107: 1195-1202. (Scenario 1 presented here) Forman D, et al. Cancer prevalence in the UK: results from the EUROPREVAL Study. *Annals of Oncology*. 2003. 14: 648-654; Office for National Statistics; Information Services Division (ISD) Scotland; General Registrar Office Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency

37. The Recovery Package is a series of key interventions which, when delivered together, before and after treatment, can improve outcomes for people living with and beyond cancer. The interventions are: Holistic Needs Assessment, Treatment Summary, Cancer Care Review which takes place within 6 months of diagnosis and Health and Wellbeing Clinics. These elements are part of an overall support of self management – physical activity as part of a healthy lifestyle, managing consequences of treatment, and information, financial and work support. The Recovery Package was developed and tested by the National Cancer Survivorship Initiative (NCSI) – a partnership of Macmillan Cancer Support, Department of Health and NHS England.

### 3. APPGC's assessment of delivery

#### a. Living With and Beyond Cancer Programme and the recovery package

The APPGC is pleased that NHS England is encouraging the implementation of the recommendations of *Cancer across the Domains* on survivorship.

Progress has been made on this area through a new 'Living With and Beyond Cancer Programme' in August 2014.<sup>38</sup> This programme is a two year partnership between NHS England and Macmillan to develop and implement a transitional plan for the National Cancer Survivorship Initiative (NCSI) following the health reforms.

This programme will focus on access to the Recovery Package, developing and commissioning risk stratified pathways of post treatment management, promoting physical activity and understanding and commissioning for improved management of the consequences of treatment.

In the Government and NHS England's October 2014 response to our report, they stated that maximising the number of cancer patients benefiting from the components of the Recovery Package is a priority work programme for 2014, alongside work programmes focused on consequences of cancer treatment amongst others.<sup>39</sup> The APPGC welcomes this programme to build on the essential work of the NCSI.

**The APPGC would like to see significant progress made on implementing and embedding this work across the health service, including in CCG and SCNs plans as well as in commissioning and day to day service provision.**

The Department of Health stated, in the third report on the cancer strategy, that the Recovery Package is 'roll-out ready'.<sup>40</sup> Despite this assurance, anecdotal evidence suggests that the recovery package is not being rolled-out fully, with some parts of the package taking precedence over others.

**The APPGC urges NHS England to incentivise CCGs to commission the whole of the Recovery Package within acute contracts.**

#### b. Information on the consequences of treatment and supporting professionals

The Government and NHS England's response to *Cancer across the Domains* stated that NHS England is primarily a commissioning organisation; it is for the employers of healthcare professionals to ensure that staff have the appropriate skills and knowledge for their roles and have the opportunity for continuing professional development.<sup>41</sup> NHS England also added that they are supporting the roll-out of the revalidation of doctors in England, ensuring that all registered medical practitioners are informed of the latest information about the consequences of cancer and its treatment.

The APPGC believes that the Government and NHS England's response fails to grasp the extent of the challenge in this area. The 2014 CPES showed that only 56% of patients who responded to the survey were definitely told about treatment side effects that could affect them in the future (compared to 55% in 2013).<sup>42</sup> Thus, the APPGC believes that NHS England, Public Health England and others should be taking a more active role to address this issue without placing the full responsibility of this area on the employers of healthcare professionals.

The APPGC understands that the Recovery Package should include information about potential consequences of treatment. As such, the APPGC urges NHS England to ensure this vital information is prioritised by the Living With and Beyond Cancer Programme.

Charities such as Breast Cancer Care, Cancer Research UK, Prostate Cancer UK and others, fund and produce written information on the consequences of treatment and distribute them across the country. Likewise, these charities conduct educational events for professionals. The APPGC welcomes these initiatives and pays tribute to the role that these charities play in the provision of information. However, the APPGC would like to see NHS England taking a more proactive role in developing guidance and standards to ensure that professionals offer this information to patients more widely.

**The APPGC calls on NHS England to ensure hospital trusts improve the provision of information on the consequences of treatment as part of their actions plans on the Cancer Patient Experience Survey. CCGs and NHS England should also measure progress attained on this area.**

#### c. Personalised care plans

NHS England stated in its May 2014 response to *Cancer across the Domains* that they were promoting the House of Care model, a framework intended to deliver excellent, patient-centred standards of care from diagnosis to the end of treatment, with partners such as the Royal College of GPs and patient organisations.<sup>43</sup> In addition the Government

and NHS England's response from later in the year indicated that NHS England will 'develop and implement a best practice standard that defines what good, personalised digital care plans and planning process look like'.<sup>44</sup>

Personalised care plans aim to match the person's needs and preferences with the necessary support to facilitate self management. Despite its importance, the latest CPES showed that just 22% of patients were offered a written assessment and care plan. The APPGC is concerned by a marginal decline in this area, as the survey results for 2013 showed that 24% of patients had been offered a plan.

**The APPGC urges NHS England to ensure personalised care plans are embedded in the service specifications and commissioning of cancer services.**

#### d. Supporting people with long-term health conditions to stay in or return to work or education.

The Government response to *Cancer across the Domains* stated that research will be completed in 2015 into the impact on the employment rate of people with long term conditions and the health and care interventions that are most important. NHS England will then consider their next steps in light of this new evidence.

Existing evidence suggests that over 700,000 people of working age are living with cancer and around 100,000 more are diagnosed with cancer each year.<sup>45</sup> Most people with cancer want to stay in work or return to work when they are ready and able to<sup>46</sup> and this has demonstrable benefits for them.<sup>47</sup>

38. NCSI <http://www.ncsi.org.uk/news/new-living-with-and-beyond-cancer-programme/>

39. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

40. Department of Health, Public Health England, NHS England: *Improving Outcomes: A Strategy for Cancer Third Annual Report* (2013)

41. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

42. NHS England: Cancer Patient Experience Survey 2014 National Report. (2014)

43. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer. (Received 6 May 2014)

44. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

45. Office for National Statistics. Cancer Statistics Registration England. 2009. Information Services Division Scotland. Cancer Incidence Scotland. 2009. Welsh Cancer Intelligence and Surveillance Unit. Cancer Incidence Wales. 2004–2008. Northern Ireland Cancer Registry. Cancer Incidence Northern Ireland. 2009.

46. Macmillan Cancer Support/MORI. *Working with cancer – A survey of people with cancer*. 2001. 70% of respondents felt it was 'very important' to continue to work, with a further 13% thinking it was 'fairly important'.

47. Rasmussen DM, Elverdam B. *The meaning of work and working life after cancer: an interview study*. *Psycho-Oncology*. 2008. 17: 1232–1238; Kennedy F, Haslam C, Munir F, Pryce J. *Returning to work following cancer: a qualitative exploratory study into the experience of returning to work following cancer*. *European Journal of Cancer Care*. 2007. 16 (1): 17–25

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Unfortunately, people who have had a cancer diagnosis are 1.4 times more likely to be unemployed than those who have not.<sup>48</sup>

Before returning to work, people with cancer and employers need to acknowledge the impact that it can have on their ability to work and put support in place to ease the transition. Some people may only need information and support to self manage their conditions, others may need more comprehensive vocational rehabilitation.<sup>49</sup>

The Department of Work and Pensions will launch the new Health and Work Service in December 2014, which will offer people on sickness absence an assessment and a back to work plan. The APPGC hopes that this will provide information to people so that they can self manage their condition and return to work. However, despite this positive step forward there is very little vocational rehabilitation provided in the UK to help people with higher intensity needs, with only 2% of people with cancer accessing specialist return-to-work services.<sup>50</sup>

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**The APPGC want to see national commissioning of vocational rehabilitation services that meet the health and work needs of people affected by cancer. This will help NHS England to enhance the quality of life for people with long-term conditions, with specific reference to employment, which is outlined in the NHS Outcomes Framework.**

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48. De Boer AG, Taskila T, Ojajarvi A, van Dijk FJ, Verbeek JH. *Cancer survivors and unemployment: a meta-analysis and meta-regression*. The Journal of the American Medical Association. 2009. 301: 753–762

49. Macmillan Cancer Support/YouGov online survey of 2,142 UK adults living with cancer. Fieldwork conducted 26 November to 14 December 2012. Survey results are unweighted. Figures presented in this report are based on 928 respondents who had completed treatment within the past five years.

50. Ibid

# Domain 3: Helping people to recover from episodes of ill health or injury

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## 1. Introduction

The end of treatment continues to be challenging for cancer patients, many of whom report feeling abandoned by the health service. The APPGC believes more focus should be placed to help patients recover after treatment.

## 2. Cancer across the Domains previous recommendations

To address these challenges, the APPGC recommended:

- NHS England should provide CCGs with an outline of the core elements of model rehabilitation programmes and also introduce an indicator on rehabilitation in the CCG Outcomes Indicator Set.
- NHS England should invest in and rollout Patient Reported Outcome Measures: (PROMs) for cancer patients at a national level and introduce a cancer Quality of Life indicator to drive service improvement.

## 3. APPGC's assessment of progress

Responding to *Cancer across the Domains*, NHS England reported that they are developing a rehabilitation framework that will promote and encourage CCGs to commission best practice for all those recovering from injury and ill health whether they have generic or specialist needs.<sup>51</sup> The framework will draw on examples of successful models of evidence based implementation.

Earlier this year, Leeds University began work on pilot PROMs data collection looking at quality of life for survivors of uterine, ovarian and cervical cancers. NHS England has agreed to consider including an indicator on rehabilitation in the CCG Outcomes Indicator Set. Furthermore, NHS England is also a key stakeholder in the Prostate Cancer UK/ Movember call for applications to conduct a nationwide PROMs data collection on prostate cancer. NHS England will work with the successful bidder to develop and roll the survey out. This work is currently in the planning phase.

In addition to this, February 2013 saw the publication of 'Quality of Life of Cancer Survivors in England – One year on', a survivorship update commissioned by the Department of Health which provides important information on recovery, unmet needs and consequences of treatment.

These steps are welcomed by the APPGC. However, we remain concerned about the lack of clarity on where responsibility for cancer rehabilitation lies and the slow progress on this area. The APPGC understand that there has been limited involvement of the cancer community in the analysis of the datasets or the reports for PROMs, which would contribute to the speedy analysis and publication of the data. It is also uncertain whether there is patient representation on the committees of the bodies that are analysing the results.

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**The APPGC calls on NHS England to scale up the PROMs programme as recommended by the National Cancer Survivorship Initiative. We also call for further clarity on where responsibility for cancer rehabilitation lies.**

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51. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer . (Received 6 May 2014)



# Domain 4: Ensuring that people have a positive experience of care

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## 1. Introduction

The APPGC has welcomed the increased focus on positive experiences of care in the health service with the NHS Mandate setting the ambition for NHS England to be a 'global leader in standards of caring'.<sup>52</sup> In the past 12 months and in the wake of the Francis report into the Mid Staffordshire scandal, there has been recognition from the highest levels of the NHS and the Department of Health that improving people's experiences of care is one of the biggest challenges the NHS faces.

## 2. Cancer across the Domains previous recommendations

Having identified these issues, last year the APPGC recommended the following measures to address them:

- NHS England should conduct research to understand the costs and benefits of regularly conducting the Cancer Patient Experience Survey (CPES). An indicator on CPES should then be added to the CCG Outcomes Indicator Set to ensure changes are implemented at a local level.
- NHS England should outline how it will take into account the experiences of carers, family members, friends and professionals and how these affect a patient's experience of care.
- NHS England should include an indicator on death in the preferred place of care in the CCG Outcomes Indicator Set.
- NHS England should outline how it will recognise the valuable role of Clinical Nurse Specialists and include an indicator on access to Clinical Nurse Specialists in the CCG Outcomes Indicator Set.

## 3. APPGC's assessment of progress

### a. Priority of patient experience in the health service

The APPGC is pleased with the ambition to deliver improvements on compassionate care. In the last year, innovations such as the NHS Staff Friends and Family Test (FFT) and a new legal duty that will help guide carers towards available support demonstrate a welcome increasing focus on the importance of the care experiences of the key people around patients, not least their loved ones and the health professionals.

However, research from Macmillan Cancer Support shows that patient experience is still not prioritised throughout the NHS alongside clinical effectiveness and patient safety. Experts they spoke to indicated that this is because patient experience is not meaningfully prioritised at all levels of the system.<sup>53</sup> For example relational care, which includes the relationship between staff and patients, being treated with dignity and respect, and effective communication, is an area that is essential for patients and that is not adequately reflected in the health system.<sup>54</sup>

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**The APPGC calls on NHS England to ensure that improving patient experience and relational care are key priorities for the health service. CCGs should include a strong patient experience focus in their business plans.**

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52. Department of Health. The mandate from the Government to NHS England: April 2014 to March 2015.

53. Macmillan Cancer Support: *Improving Care for People with Cancer*. (2013). p10

54. Ibid

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## **b. National Cancer Patient Experience Survey**

The vital CPES, conducted by NHS England, has been repeated in 2014. The APPGC is pleased that the official responses to *Cancer across the Domains* confirm the ambition for it to continue in the future and recognise its value by stating that ‘clinical teams use the survey to drive improvements and groups such as Macmillan also use this valuable data to great effect.’<sup>55</sup>

As it becomes more firmly established, the APPGC believes more needs to be done to maximise its huge value in driving up standards and improving cancer patients’ experiences of care. In accord with *Cancer across the Domains’* recommendations, a review of the survey programme, including CPES, is being undertaken and NHS England is working with NHS Improving Quality to develop better ways of using CPES data in order to maximise the impact of the survey and to be able to spread best practice.<sup>56</sup> The APPGC welcomes the work being done to ensure the continuity of the survey and to improve its content and reach.

Despite this, efforts are still needed to ensure that the hugely valuable data is properly understood at a national, CCG and Trust level and is used to drive improvements. For example, we understand that CPES data is not available from NHS Patient Choices and that although the ‘my cancer treatment’ tool on that website includes five questions from CPES for each trust, it does not seem to link to the trust level reports, show national averages or offer an accessible comparison of results.

Furthermore, those patient groups who have worse engagement rates with the survey, such as black and minority ethnic BME patients, or those who are not currently included, such as children and young people, should also be considered and targeted in future versions of the CPES. Similarly, there are concerns about important questions being removed, such as that which ascertains if patients who had not been asked if they wished to take part in cancer research would have welcomed the opportunity.<sup>57</sup>

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### **The APPGC urges NHS England to improve the accessibility of the results of the Cancer Patient Experience Survey and to produce an official comparison of the results to help improve patients’ choice.**

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The APPGC understands that a number of trusts are using action plans based on CPES data to drive improvements. However, CCGs do not seem to always actively measure trusts’ progress against them. All of this leads to a gap in accountability on cancer patient experience. Improvements in this area will help to give patient experience further prominence in the health system.

This is especially important in the wake of the 2014 CPES results published recently, which show that although many trusts have made marginal and consistent improvements, many have remained broadly static. The same is true of certain low scoring areas of cancer patient experience, with the proportion of patients reporting having a discussion about research remaining static at around 30% nationally since 2010.<sup>58</sup>

Disappointingly, an indicator on CPES was not included in the latest CCG Outcomes Indicator Set. However, the Government and NHS England assured, in their October 2014 response to *Cancer across the Domains* there is potential for the inclusion of this indicator into the future development of the CCG Outcomes Indicator Set.<sup>59</sup> The APPGC encourages NHS England and NICE’s Advisory Committee to revisit the potential of this indicator to drive improvements and set priorities for CCGs on cancer patient experience.

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### **The APPGC calls on NHS England to ensure all trusts publish action plans based on the CPES and to report against progress.**

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#### **c. Beyond the immediate experience of care: supporting carers and NHS staff**

The APPGC is delighted that NHS England is formulating an action plan on the experiences of carers and that our recommendation on carers of cancer patients would be considered. It is also encouraging that NHS England is looking at how it might work with the Cancer Patient Experience Advisory Group to extract better information about carers and family members from the CPES in future.<sup>60</sup>

With the passage of the Care Act in 2014 and the statutory guidance attached to it, the NHS will now have to work with local authorities to identify as carers those dedicating time to look after their loved ones affected by cancer and signpost them towards information and support. However, the APPGC remains convinced that NHS England needs to outline how it will work with CCGs and local authorities to do this effectively.

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### **The APPGC urges NHS England to outline how it will work with CCGs and Local Authorities to identify carers effectively.**

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The recent review of staff engagement and empowerment in the NHS, commissioned by the Minister for Care and Support, Norman Lamb MP in November 2013 showed that there is a strong correlation between staff engagement and the delivery of high quality care. It indicated that organisations with high levels of staff engagement report lower mortality rates, better patient experience and lower rates of sickness absence and staff turnover.<sup>61</sup>

Research from Macmillan Cancer Support on this issue also shows that the treatment of hospital staff is intrinsically linked to patient experience.<sup>62</sup> Yet, the 2013 NHS Staff Survey shows that a significant proportion of staff is lacking adequate support to deliver a good user experience. For example, only 44% of NHS Staff have received training on how to deliver good patient/service user experience in the past year.<sup>63</sup>

The APPGC is still waiting for NHS England to include an indicator on staff experience in the Outcomes Framework. They should develop measures to deliver consistent and measurable improvements on staff engagement.

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### **The APPGC calls on NHS England and Health Education England to support NHS staff to deliver the best possible care. For instance, all frontline staff should have time to access training to deliver care with dignity and respect.**

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55. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)  
56. The Parliamentary Under-Secretary of State, Department of Health Earl Howe. Response to Written Parliamentary Question from Lord Judd, 26 September 2014  
57. A comparison of the 2011/12 survey , questions 27 – 29 and the 2012/13 and the 2013/14 surveys Qs #29 – 31  
58. NHS England: *Cancer Patient Experience Survey 2014 National Report*. (2014 )

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59. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)  
60. Ibid  
61. Ham, Chris: *Improving NHS Care by Engaging Staff and Devolving Decision-Making Report of the Review of Staff Engagement and Empowerment in the NHS* (2014)  
62. Picker Institute Europe, Macmillan Cancer Support: *The relationship between cancer patient experience and staff survey results*. (2013). Picker Institute Europe was commissioned by Macmillan Cancer Support to investigate the relationship between the results for the Cancer Patient Experience Survey (CPES) and the NHS Staff Survey. The data were from the 2011 CPES and the 2011 NHS Staff Survey.  
63. NHS England, Picker Institute: *NHS Staff Survey 2013 Results* (2014)

# Domain 5: Treating and caring for people in a safe environment

## d. Preferred place of care at the end of life

Evidence suggests that the vast majority of people (79%) want to die at home. However, less than a quarter (23%) are able to.<sup>64</sup> It is encouraging that NHS England stated in its response to *Cancer across the Domains* the Government's commitment to improving choice at end of life and confirmed that it will explore the potential for an indicator on death in the preferred place of care in the future development of the CCG Outcomes Indicator Set.<sup>65</sup>

More positively, however, there has been a rapidly growing recognition of the importance of all patients being supported to die at home if they wish in the wider health sector and across Britain's political landscape. Building on this, research suggests the average cost of keeping someone in a hospital bed is £250, compared to £145 per day for a comprehensive package of community support. From this, Macmillan Cancer Support estimates that £345 million per year could be saved by introducing free social care as a package of support at the end of life.<sup>66</sup> As such, the APPGC supports the idea that free social care at the end of life would help cancer patients to spend their final weeks and days in the place of their choosing.

## e. Access to Clinical Nurse Specialists

The latest CPES results indicated that the presence of a Clinical Nurse Specialist (CNS) has the strongest association with high patient experience scores. This is seen as the most important factor for positive patient experience.<sup>67</sup> Despite this the NHS is still not measuring performance on patient access to a CNS. NHS England stated that it has no intention to include an indicator on access to a CNS for cancer patients in the CCG Outcomes Indicator Set as 'it is for local providers to determine the optimum configuration of their workforce'.<sup>68</sup>

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**The APPGC calls on NHS England to work with providers to improve access to CNSs for all cancer patients.**

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64. Data on preferences for and actual place of death at the end of life are from the Office for National Statistics National Survey of Bereaved People (VOICES) 2013: <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html#tab-Key-findings>

65. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer . (Received 6 May 2014)

66. Macmillan Cancer Support: *Can we live with how we're dying? Advancing the case for free social care at the end of life.* (2014).

67. NHS England: *Cancer Patient Experience Survey 2014 National Report.* (2014)

68. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer . (Received 6 May 2014)

## 1. Introduction

There has been significant progress on patient safety since the publication of *Cancer across the Domains* last year. For instance, the introduction of an expanded and strengthened Care Quality Commission inspection regime including 'experts by experience' – patients – as part of the inspection teams – is real progress and has contributed to the improvements seen at the 14 trusts identified by the Keogh review as having significant problems relating to quality and safety.<sup>69</sup>

There has been a drive from the Department of Health and NHS England to capitalise on the seminal moment of progress in addressing failures of patient safety that the series of inquiries and reports – notably those of Berwick, Keogh and Francis – and the Government's responses represented at the end of 2013.

## 2. Cancer across the Domains previous recommendations

To improve patient safety, the APPGC recommended:

- NHS England should clearly set out what role it will play in implementing the recommendations of the Berwick report.
- NHS England should set out how it will improve the collection of patient safety data and improve leaders' ability to use the data to drive improvements and improve critical incident reporting.
- NHS England should outline how it will work with partners on the recommendations set out in the review by Ann Clwyd MP and Professor Tricia Hart of the hospital complaints system.

69. Care Quality Commission, Monitor, The Trust Development Authority: *Special measures: one year on. A report into progress made at 11 NHS trusts that were put into special measures in July 2013.* (2014)



### 3. APPGC's assessment of progress

#### a. Implementation of the recommendations of the Berwick report

Responding to *Cancer across the Domains*, NHS England reported that it is working with NHS Improving Quality to support the implementation of the recommendations of the Berwick report.<sup>70</sup> The APPGC is pleased that this is being done through a national patient safety collaborative programme with the aim of developing a learning and safety culture which empowers staff and patients in the design and delivery of safer systems of care.<sup>71</sup> Furthermore, NHS England launched a revised National Patient Safety Alerts system and has increased the transparency of patient safety data by publishing detailed never events data.

#### b. Patient safety – culture and record systems

Following the Government's response to the excellent Berwick, Keogh and Francis reports at the beginning of 2014,<sup>72</sup> the Secretary of State for Health introduced an ambitious programme of new measures, statutory and otherwise with the aim to reduce avoidable harm in the NHS by half over three years, cut costs and save up to 6,000 lives.<sup>73</sup> In a drive to improve the collection and analysis of patient safety data, NHS England stated that some of the measures adopted include:<sup>74</sup>

- The NHS Safety Thermometer 'classic' Commissioning for Quality and Innovation (CQUIN) payment is being extended to incentivise sustained improvement in key safety measures alongside the development of new patient safety thermometers.

- The NHS Standard Contract and the NHS Serious Incident Framework will be revised to enhance safety incident reporting.

The Government and NHS England's October 2014 response to *Cancer across the Domains* also highlighted data demonstrating progress on the NHS' ability to recognise and report patient safety incidents alongside an improvement in the number of patients recorded as 'harm free' by the NHS Safety Thermometer which is now at 93.4% up from 92% at the same time last year.<sup>75</sup>

The APPGC also welcomes other innovations such as the new Duty of Candour to notify patients about incidents where 'significant harm' has occurred and provide an apology.<sup>76</sup> We are also pleased that there is more comprehensive patient safety data, by hospital, accessible to the public on the NHS Choices website.<sup>77</sup> Furthermore, the initiative of recruiting 5,000 safety champions to act as local change agents to improve the avoidance and reporting of breaches of patient safety standards will contribute to improvements in this area.

The APPGC is also pleased to see that so many CCGs and trusts have now 'Signed Up for Safety' since the scheme was launched in June 2014.<sup>78</sup> It also looks forward to reports of the initial impact of these measures following their coming into effect over summer and autumn 2014.

#### c. Implementation of the hospital complaints system review

*Cancer across the Domains* made clear that whistle blowing was vital to patient safety. As such, the APPGC is pleased that improvements to the complaint system have been prioritised by the Government. NHS England stated in its response that it is trialling 'a simplification of the complaints process and is establishing an advisory group of patients and patient representatives to ensure the NHS is able to learn and develop as a result of patient complaints'.

Furthermore, the Department of Health in 2014 pledged to put in place reforms to ensure that whistleblowers speaking out about poor care are confident they will be heard and crucially not disadvantaged due to their actions. NHS employment contracts will also include the right to raise concerns about care and the NHS Constitution has seen its commitment to support staff who raise concerns strengthened.<sup>79</sup> However in October 2014, Sir Robert Francis acknowledged that there was still a very long way to go and that many complaints about patient neglect are still falling through the gaps in the NHS regulatory bodies.<sup>80</sup>

#### The APPGC calls on NHS England to ensure the complaints mechanisms across the health service are robust and effective.

The APPGC recognises that the cultural change that is needed throughout the NHS will not have been achieved in the 12 months since *Cancer across the Domains* was published. However the response from across the health sector to the incidents of the preceding years has been determined and positive. This encouraging start must not be allowed to lose momentum or atrophy. Instead the outcomes of these initial measures must be thoroughly analysed by the NHS leadership to ensure a complete cultural step change has occurred by 2020.

#### d. Peer Review programme

In order to ensure continued high quality services are delivered within the NHS, it is vital that robust quality assurance tools are in place. The APPGC feels that the Cancer Quality Improvement Network system's National Cancer Peer Review programme provides valuable information on patient safety, particularly for areas of specialist care and the workforce. The Peer Review programme is vital for monitoring the quality of services and is an important way of collecting data on adherence with key guidelines and quality standards.

NHS England is currently reviewing the programme with a view to considering how its success might be extended into other new areas of specialised commissioning; however proposed changes to Peer Review, moving towards focusing on hospitals in special measures and using greater self-review, may impact on patient safety. Although there have been assurances that 'cancer peer review will continue to play a critical part of any broader peer review programme that the NHS may look to introduce' it is uncertain of what this will mean in practice.<sup>81</sup>

The APPGC acknowledges that there are some concerns about the level of resources needed to ensure the National Cancer Peer Review Programme is effective and impactful. However, the APPGC is concerned that some of the most important aspects of the Cancer Peer Review Programme that are important for maintaining and improving performance could be under threat.

#### The APPGC calls on NHS England and Ministers to ensure the most important parts of the Cancer Peer Review Programme are identified, maintained, and strengthened in the health service.

70. Ibid.

71. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

72. Department of Health: *Hard Truths The Journey to Putting Patients First Volume Two of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry: Response to the Inquiry's Recommendations*. (2014)

73. <https://www.gov.uk/government/news/halving-avoidable-harm-and-saving-up-to-6000-lives>

74. Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer. (Received 6 May 2014)

75. Letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)

76. <https://www.gov.uk/government/news/halving-avoidable-harm-and-saving-up-to-6000-lives>

77. <http://www.nhs.uk/nhsengland/thenhs/patient-safety/pages/about-patient-safety.aspx>

78. <http://www.england.nhs.uk/signuptosafety/whos-signed-up/>

79. The Secretary of State for Health, Jeremy Hunt MP: *Jeremy Hunt: Message to NHS staff on supporting compassionate care* (2014)

80. The Sunday Times: *NHS patients 'passed round like parcels'* 5 October 2014

81. The Parliamentary Under-Secretary of State, Department of Health, Jane Ellison MP. Response to Written Parliamentary Question from John Baron MP, 23 October 2014



## Conclusion

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**This report is the All Party Parliamentary Group on Cancer's (APPGC) examination into the progress of cancer care in England. It makes clear that there has been progress in implementing the recommendations of *Cancer across the Domains* during 2014.**

However, progress has not been wholesale and there are still many areas where action has not met expectation. We call on NHS England, the Department of Health, CCGs, hospital trusts and other relevant organisations to use this report as a clear reminder of where there is still work to be done.

The APPGC's vision for 2020 is clear: the Government and the health service must ensure all cancer patients are diagnosed early, treated compassionately and with kindness, provided the best possible treatment and care for their individual needs and adequately supported after treatment ceases. This ambition cuts across the five domains of the healthcare system.

In the run-up to the General Election there is also a need for a clear determination across all political parties to prioritise cancer care to address the nature and size of this challenge. The APPGC hopes that this report helps to make our vision a reality for all cancer patients, their families and loved ones.

# Appendix 1: Letter from Sean Duffy National Clinical Director for Cancer for NHS England to John Baron MP, Chair of the APPG on Cancer. (Received 6 May 2014)

Mr Sean Duffy  
National Clinical Director,  
Cancer

Our Ref:  
Your Ref:

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SW1A 0AA

  
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6<sup>th</sup> May 2014

Dear John,

Thank you for the APPG on Cancer's report examining the new structures of NHS England and their capability to continue to improve cancer outcomes. Though good progress in cancer outcomes is being made, the APPGC is right to note that further improvement is necessary. It raised many interesting points, some of which are already part of NHS England's programme of improvements and initiatives, and others that we will be happy to consider. While further detail will be forthcoming, I have briefly outlined the responses below, by domain.

## Domain 1:

We understand that accountability was a central concern of the report, particularly how CCGs would be held accountable to NHS England for improving outcomes, especially in early diagnosis. NHS England holds CCGs to account for meeting their core duty of improving outcomes. Our assessment is made using the CCG Assurance Framework and its comprehensive delivery dashboard. When CCGs fall short of these requirements, NHS England uses Area Teams or, as a last resort, statutory intervention powers to assist CCGs. Whilst the CCG Outcome Indicator set (CCG OIS) does not form part of the delivery dashboard, CCGs can themselves monitor their improvements using the CCG OIS, which includes measures in relation to the stage of cancers at diagnosis, and percentage of invasive cases which present through an emergency route.

My own view is that these are very useful benchmarks to enable discussions between GPs and secondary / tertiary care to find solutions in order to reduce emergency presentation and increase earlier stage at presentation. CCGs will also be set benchmarks by commissioners, through the 'Everyone Counts' Planning Guidance for 2014/15.

We particularly agreed with the report's recommendation that alterations to the current financial flow mechanisms could encourage earlier diagnosis. There is potential for this to be incorporated into the current work aligning tariff and pricing arrangements with NHS England's priorities.

The report also asked for clarification around the division of responsibility within national awareness, prevention and screening programmes. Our commitment to prevention and early diagnosis has been laid out in *Improving Outcomes: A Strategy for Cancer* (2011) and the current Mandate to NHS England. NHS England, Public Health England and the Department of Health work together to develop and manage the Be Clear on Cancer campaigns. As for screening campaigns, Public Health England is responsible for the piloting and roll-out of screening programmes, and for subsequent QA of national programmes. NHS England manages these programmes once they have been successfully rolled-out, through the Section 7a agreement between PHE and NHS England.

There was also a request for clarification on the roles of the 12 SCNs which cover cancer. They are intended to support an integrated, holistic approach to commissioning, engaging with clinicians across the health economy to provide innovative guidance to commissioners. We are currently exploring how to increase the efficacy of SCNs. As I am sure you are aware I am also working very closely with the cancer SCNs across the country, for example on joint pieces of work, improvements in data flows and clinical engagement (especially around earlier diagnosis).

## Domain 2:

The National Cancer Survivorship Initiative has prompted several streams of work relevant to the report's Domain 2 recommendations. I am currently working with Macmillan Cancer Support to encourage the implementation of its recommendations, which includes the uptake of the Recovery Package; and we are also considering how to implement best practice Stratified Care Pathways in the wake of the Initiative's findings.

More generally, NHS England is working with partners such as the RCGP and patient organisations to promote the House of Care model, a framework intended to deliver excellent, patient-centred standards of care from diagnosis to the end of treatment. Our cancer survivorship work is completely consistent with the House of Care model and I am ensuring that this is reflected in the Domain 2 framework. NHS England is also supporting the roll-out of revalidation for doctors in England, ensuring that all registered medical practitioners are informed of the latest information about the consequences of cancer and its treatment, though it falls to the direct employers of healthcare professionals to ensure their staff is appropriately trained.

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**Domain 3:**

The Domain 3 recommendation that NHS England should invest in PROMs for cancer patients at a national level aligns with NHS England's collaboration with the Prostate Cancer UK/Movember on their call for applications to conduct a nationwide PROMs data collective. The bid has been won by a team in Leeds who have had previous experience with the colorectal cancer PROMS and we are committed to work closely with them for the duration of the project. Pilot PROMs data collection, looking at quality of life for survivors of uterine, ovarian and cervical cancers began in February 2014 and is due to report soon. What we must now decide is how to best capitalise on the wealth of information from both the national and pilot studies. Finally, we will also consider including an indicator on rehabilitation in the CCG OIS.

**Domain 4:**

The APPGC report asked for the Cancer Patient Experience Survey (CPES) to be reviewed, and for a CPES indicator to be added to the CCG Outcomes Indicator Set to ensure local implementation of its findings. We have no plans to terminate the CPES, which produces data of great use to clinical teams and NGO monitoring groups – indeed we are carrying out research into the further optimisation of our use of survey data. NHS Improving Quality are helping us to maximise the use of the data and to help struggling trusts to improve. While we will consider making better use of the CPES when reviewing our Patient Experience indicators for the CCG OIS – and will look into including a 'death in the preferred place of care' indicator – these indicators intentionally do not focus on a specific disease area in order to better reflect the breadth of NHS activity. The same principle applies to the report's recommendation that an indicator for Clinical Nurse Specialists be included in the CCG OIS – while CNSs play a valuable role in multidisciplinary teams, it would be inconsistent for the OIS to make provision for specific professional groups.

NHS England is currently formulating an action plan for the general experience of carers, following a December 2013 event where a number of priorities were identified. We will consider the specific case of cancer in response to the APPG's recommendations on the experiences of carers and family members, and are currently considering how to best use CPES data to gain insights into the experiences of carers for cancer patients.

**Domain 5:**

NHS England and NHS IQ intend to support Don Berwick's recommendations through a national Patient Safety Collaborative programme, collating all current knowledge of patient safety with a vision for the improvements to come in the next 5 years. We will also establish a network of safety improvement fellows to support national improvement in safety across institutions, and have recently launched a revised National Patient Safety Alerting System.

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Furthermore, NHS England is improving the collection and analysis of patient safety data through alterations to the NHS Safety Thermometer 'classic' CQUIN, the requirements in NHS Standard Contract around patient safety incident reporting, and the NHS Serious Incident Framework. We are also developing further NHS Safety Thermometers as well as a new single national reporting and learning system for incident reporting and management. We have seen great improvements in patient safety and data collection in the last 12 months, with incident reporting up 6.4% over the last year, and the number of patients recorded as 'harm free' by the NHS Safety Thermometer is now at 93.4%.

Though the Clywd and Hart report was focused on complaint systems within provider organisations, for which NHS England is not responsible, we are trialling new systems of registering complaints and establishing an advisory group of patients and patient groups to examine how we can make improve consistency and responsiveness in our approach to complaints.

I hope these responses will assuage some of your concerns about how cancer will fare in the new system. The new system presents many opportunities for compelling, evidence-based change to be heard by CCGs and reports such as yours will play an integral part in the continuing improvements to cancer services.

I thank you, the APPGC and your supporting organisations for your hard work.

Yours sincerely,

**Sean Duffy MD FRCS (Glasg) FRCOG**  
**National Clinical Director for Cancer**

## Appendix 2: Letter from Jane Ellison MP to John Baron MP, Chair of the APPG on Cancer. (Received 21 October 2014)



Department  
of Health

POC877396

John Baron MP  
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From Jane Ellison MP  
Parliamentary Under Secretary of State for Public Health

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SW1A 2NS  
Tel: 020 7210 4850

Dear John

Thank you for your letter of 24 July in your capacity as chairman of the APPG on cancer.

I was pleased to be able to address the APPG's parliamentary reception on 8 July. I would like to take this opportunity to thank you again for all the vital work the APPG does in raising the profile of cancer on the parliamentary agenda.

I note your comments on cancer data. We know the importance of good data in helping commissioners to drive up outcomes. As you may be aware, the National Cancer Intelligence Network (NCIN) has been working with the Health and Social Care Information Centre on cancer related indicators for use in the clinical commissioning group (CCG) 2014/15 Outcomes Indicator Set (OIS), including indicators on patients diagnosed through emergency presentations and patients diagnosed at an early stage of their cancer. The NCIN also continues to expand on its range of cancer profiles to add to the Cancer Commissioning Toolkit, and together with the National Cancer Registration Service and other partners continues to develop its open access online learning programme called Understanding Cancer. The course is completely free to all UK users.

The Diagnostic Imaging Dataset was a specific commitment of the Cancer Outcomes Strategy which has been successfully implemented, and in due course there will be a time series to show trends. We know we need also to consider how best to provide user-friendly information for GP practices about variations in use of diagnostic tests.

I also note your continued concerns about the role of the CCG Delivery Dashboard and the CCG Outcomes Indicator Set (OIS) in commissioner accountability. With respect to the comment that CCGs have a view that the Delivery Dashboard is very important, we do understand this to be the case. The Dashboard is used by CCGs and Area Teams as a source of information during the quarterly assurance meetings. Where there are performance concerns on any of the indicators, the Area Team will use the Delivery Dashboard to challenge the CCGs on what actions they are taking to improve performance.

At present, there are no plans to include the one-year cancer indicator in the Delivery Dashboard for 2014/15, its content having been finalised. At the moment the only indicator being reported under Domain 1 is on potential years of life lost. However NHS England is currently undertaking a review of CCG assurance for 2015/16 and will explore how outcomes, including those indicators in the CCG OIS, can be further embedded into assurance. A review of the Delivery Dashboard and other supporting material to support assurance will also be part of that review.

Finally, I enclose my response to the APPG's report Cancer across the Domains. Please accept my apologies for the long delay in issuing this response. I hope you find it helpful.

With kind regards  
Jane Ellison

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## Domain 1: Preventing people dying prematurely

### 1. NHS England should define how it will use the Clinical Commissioning Group Outcomes Indicator Set to hold CCGs to account and improve early diagnosis.

NHS England's role is to ensure that Clinical Commissioning Groups (CCGs) deliver their statutory functions, rather than to directly performance manage them. CCGs are autonomous organisations, whose strength lies in their clinical leadership and freedom to commission those services that deliver outcomes that are both clinically effective and cost effective for local populations. The CCG OIS does not in itself set thresholds or levels of ambition for CCGs. It is a tool that supports commissioners to drive improvement and set priorities. It is important to recognise that outcomes covered by the CCG OIS indicators are influenced not only by services commissioned by CCGs, but also by primary care and those services nationally commissioned by NHS England. It would therefore be inappropriate to use the CCG OIS as a tool of accountability or to view the indicators therein as the primary measure of a CCG's effectiveness in commissioning a particular aspect of local healthcare. However, the CCG OIS, together with a range of other measures, plays an important role in informing an overall picture for a CCG of how local health outcomes are improving together with helping identify local priorities for improvement. The 2014-15 CCG OIS contains a range of indicators to support commissioners to understand key local issues in relation to cancer survival and early diagnosis including:

- Under 75 mortality rate from cancer;
- Cancer: diagnosis via emergency routes;
- Cancer: record of stage at diagnosis;
- Cancer: early detection;
- Lung cancer: record of stage at diagnosis; and
- Breast cancer: mortality.

A key theme across the above indicators is that of early detection. This is affected both by the stage that patients present themselves at their GP with relevant symptoms and also the GP response in making appropriate identification and referral for suspected cancers. Therefore, knowledge of the proportion of cancers that are detected via emergency routes and the stage that a cancer has reached when identified are important tools for commissioners in understanding key possible drivers behind variation in cancer survival rates and for them to use with local GPs and secondary care services to agree actions for improvements.

The under-75 mortality rate and the one year survival rate, when read in conjunction with early detection indicators, will also help CCGs to consider whether variation in survival rates may be related to detection, treatment or some other cause. NHS England, through its Local Area Teams, uses the CCG Assurance Framework to assess whether CCGs are meeting their statutory duty to deliver continuous overall improvement in the health outcomes of local populations. Integral to the assurance assessment is consideration of a range of timely indicators, quality metrics and other outcomes measures to make an overall assessment of progress towards delivering improved outcomes. This includes using the CCG OIS to form a rounded picture of local outcomes. NHS England would expect CCGs to be able to clearly

demonstrate the work they are doing to improve quality and outcomes with appropriate governance arrangements to support this.

NHS England is currently undertaking a review of CCG assurance for 2015/16 and will explore how outcomes, including those indicators in the CCG OIS, can be further embedded into assurance as part of this review.

### 2. NHS England should outline how it will ensure that access to the best treatment is available to all cancer patients and how it will honour its statutory duty to promote research.

Ensuring that cancer patients have access to the best treatments is critical to improving outcomes. Considerable progress in this area has been made since the publication of the Cancer Outcomes Strategy in 2011, and in the months since NHS England assumed its full commissioning responsibilities on 1 April 2013. Highlighted below are some of the key areas in which NHS England is ensuring access to the best treatment for all cancer patients, including:

- Creating national, evidence based service specifications for a wide range of cancer types. These set out what providers must have in place to offer high quality cancer treatment, care and support
- Commissioning radiotherapy at a national level, which means first time, cancer patients are considered for the most appropriate, including innovative radiotherapy, regardless of where they live
- Through the Radiotherapy Innovation Fund, increasing the proportion of radiotherapy treatments delivered with Intensity Modulated Radiotherapy (IMRT) from 13.6% before the fund to a national average of 35% at March 2014
- Making up to £6m available over the next five years to support trials by Cancer Research UK into the use of stereotactic ablative radiotherapy (SABR). This will allow patients to receive SABR treatment now, where clinicians think they could benefit, through the trial. At the same time doctors can fully assess the effectiveness of these treatments so that in future, if it proves to be effective, they will be available for all relevant patients on the NHS
- In partnership with Cancer Research UK publishing a ten year vision for radiotherapy which considers the appropriate technology and capacity requirements needed to provide radiotherapy services to cancer patients in England
- Creating the new 'Evaluation through Commissioning' scheme, to introduce new technologies, including for cancer, in a systematic way
- Ensuring consistently high standards of chemotherapy across providers in England through the service specification
- Supporting the introduction of Proton Beam Therapy at two hospitals in England from 2018

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In August we announced that the value of the Cancer Drugs Fund would be increased from £200 million per year to £280 million. To ensure patients continue to have access to the best innovative treatments now and in the future, NHS England will re-evaluate some of the drugs on the list to ensure the drugs provide maximum benefits to patients and that the CDF incentivises responsible pricing by drug companies. Further, to create a sustainable Cancer Drugs Fund that will ensure patients don't miss out on innovative treatments that are on the horizon NHS England will work with NICE, patient groups and the Association of the British Pharmaceutical Industry to develop options for ensuring greater alignment between CDF and Nice assessment processes.

Regarding NHS England's statutory responsibility to promote research, as set out in NHS Constitution 2013, Health and Social Care Act 2012, the Department's Mandate requires NHS England to "ensure that the new commissioning system promotes and supports participation by NHS organisations and NHS patients in research funded by both commercial and non-commercial organisations".

NHS England has recently carried out an open consultation on a draft Research and Development Strategy to deliver its statutory responsibilities and NHS Mandate duties.

### **3. NHS England should set out how it will work with partners to continue national awareness programmes on the causes and symptoms of cancer and clearly set out the division of responsibility for prevention, symptom awareness and screening.**

Subject to successful evaluation and any reassessment of priorities, funding was provided to Public Health England over the course of the four years of the Spending Review to run campaigns to raise awareness of cancer symptoms, as part of the work to achieve earlier diagnosis. The Mandate to NHS England for 2014/15 also sets out the role of earlier diagnosis in helping to tackle avoidable premature mortality.

NHS England works with Public Health England (PHE) and the Department to determine the focus, development and management of the Be Clear on Cancer campaigns, and will continue to do this during 2014/15.

In terms of screening, the NHS Constitution has made a commitment that the Government will implement any screening programme recommended by the UK National Screening Committee. Public Health England is responsible for piloting and roll-out of screening programmes, working in partnership with NHS England. Once programmes are rolled out, NHS England becomes responsible for their management through the section 7A agreement between the Department and NHS England. However, PHE continues to have a role in areas such as the Quality Assurance of screening programmes.

### **4. NHS England should undertake research as to whether financial flow mechanisms could better encourage earlier diagnosis.**

NHS England agrees in principle with this recommendation and will give further consideration to how it could be implemented in the context of ongoing work to support early diagnosis of cancer.

### **5. NHS England should clearly set out the functions of Strategic Clinical Networks (SCNs)**

It is essential to have effective arrangements in place at a local level to coordinate efforts and ensure that there is a comprehensive strategy in place for the provision of services to support the diagnosis and treatment of cancer patients. NHS England is actively reviewing its clinical advisory structures and the role and remit of SCNs with the aim of better supporting the alignment of the commissioning system. Also key to this are Health and Wellbeing Boards, which are responsible for overseeing local delivery plans.

NHS England has had to prioritise carefully which conditions and patient groups should be covered by the first SCNs that are being supported by NHS England. These were selected according to criteria set out in The Way Forward: Strategic clinical networks which was prepared by NHS England (then the NHS Commissioning Board) in July 2012, as a result of which cancer was prioritised. SCNs are designed to drive improvements through an integrated, whole system approach and help local commissioners reduce unwarranted variation in services and encourage innovation. NHS England expect the conditions and patient groups for which a SCN is prescribed will change over time in line with changing national priorities and as the improvement work of a specific network is concluded.

## **Domain 2: Enhancing the Quality of Life for People with Long Term Conditions**

### **6. NHS England should encourage the uptake of the Recovery Package by officially endorsing it and encouraging CCGs to commission it within acute contracts.**

NHS England agrees that the National Cancer Survivorship Initiative's 'Recovery Package' should be a key element of care provided to cancer survivors. The National Clinical Director for Cancer, Sean Duffy, is working closely with Macmillan Cancer Support to encourage implementation and spread of evidence based findings from the National Cancer Survivorship Initiative.

Maximising the number of cancer patients benefiting from the components of the Recovery Package is a priority work programme for 2014. The other priority work programmes are focused on stratified pathways of care, consequences of cancer and its treatment (including PROMS), and physical activity. More information can be found at the following link <http://www.ncsi.org.uk/>

### **7. NHS England should outline how it will work with CCGs and education bodies to ensure that professionals have access to and use the latest information about the consequences of cancer and its treatment, including late effects and recurrence.**

NHS England is primarily a commissioning organisation, and it is for the employers of healthcare professionals to ensure that staff have the appropriate skills and knowledge for their roles, as well as for supporting their continuing professional development. This is enforced through the Care Quality Commission's registration requirements.

Furthermore, it is important that information about outcomes is published to ensure that practices and provider organisations are able to reflect on how they perform relative to other services. NHS England will continue to work with PHE, the National Cancer Intelligence Network, the Health and Social Care Information Centre and others to deliver greater transparency about outcomes.

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**8. NHS England should define how it will ensure that best practice Stratified Care Pathways are in place to allow CCGs to commission them for cancer patients within their acute contracts. Assessment and care planning should be undertaken whenever needed post diagnosis and at the end of treatment.**

NHS England agrees with this recommendation in principle and will consider how to ensure that best practice Stratified Care Pathways are in place as part of the work in hand on the cancer patient survivorship initiative, mentioned in response to recommendation 6.

More generally, at the conceptual level, NHS England is working with delivery partners to promote the House of Care Model as an organising framework to deliver proactive, holistic and patient-centred care for people with long-term conditions, including cancer survivors.

This model has been proven effective in diabetes care and differs from others in that it encompasses all people with long-term conditions (not just those with a single disease or in high-risk groups) and it assumes an active role for patients through collaborative personalised care planning. The 'House of Care' is one example of how a proactive, person-centred approach can be achieved. It is made up of four inter-dependent components:

- I. Commissioning – driving quality improvement
- II. Engaged, informed individuals and carers – enabling individuals to be involved in all decisions about their care, to self-manage and truly say 'No decision about me without me'
- III. Organisational and clinical processes – structured around the needs of patients and carers using the best evidence available
- IV. Health and care professionals working in partnership – listening, supporting, and collaborating for continuity of care. Professionals starting with patients not services

A coalition is forming to drive the change needed to make the House of Care including: the Royal College of General Practitioners (RCGP), NHS England, professional bodies, specialist agencies, charities and patient organisations. At a strategic level, there is broad consensus of the function and possible structure of the Coalition.

Alongside this work, NHS England will develop and implement a best practice standard that defines what good, personalised, digital care plans and planning processes look like, in order to support GPs and health professionals during 2014.

**9. NHS England should publish plans detailing how it will support people with long-term health conditions to stay in or return to work, fulfilling the commitments to employment set out in the NHS Mandate.**

NHS England agrees with this recommendation in principle and is already taking forward work in this area. An invitation to tender has been issued for a piece of work to identify and quantify, through the literature, factors that are likely to have an impact on the employment rate of people with long term conditions and, where possible, identify the health and care interventions that are important. This research is to be completed in 2015 and NHS England will consider next steps in light of the evidence provided.

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**Domain 3: Helping People to recover from episode of Ill Health or Injury**

**10. NHS England should provide CCGs with an outline of the core elements of model rehabilitation programmes and also introduce an indicator on rehabilitation in the CCG Outcomes Indicator Set.**

NHS England is developing a rehabilitation framework that will promote and encourage CCGs to commission best practice for all those recovering from injury and ill health whether they have generic or specialist needs. The framework will draw on examples of successful models of evidence based implementation.

NHS England will consider the possibility of an indicator on rehabilitation in the future development of the CCG OIS.

**11. NHS England should invest in and roll out Patient Reported Outcome Measures surveys (PROMs) for cancer patients at a national level and introduce a cancer Quality of Life indicator to drive service improvement.**

NHS England recognises the value of the Patient Reported Outcome Measures surveys (PROMs) for cancer and has already begun work to extend the programme. A new pilot PROM data collection has recently started looking at quality of life issues for survivors of womb, ovarian and cervical cancer.

NHS England is also a key stakeholder in the Prostate Cancer UK/Movember funded call for applications to conduct a nationwide PROM data collection on prostate cancer. NHS England will work with the successful bidder, the University of Leeds, to develop and roll the survey out. This work is currently in the planning phase.

In addition to this, February 2013 saw the publication of Quality of Life of Cancer Survivors in England – One year on, a survivorship update commissioned by the Department which provides important information on recovery, unmet needs and consequences of treatment.

The Health related quality of life for people with Long Term Conditions indicators is a feature of both the NHS Outcomes Framework and the CCG OIS and it includes those that had cancer in the last 5 years.



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## Domain 4: Ensuring That People Have a Positive Experience of Care

### **12. NHS England should conduct research to understand the costs and benefits of regularly conducting the Cancer Patient Experience Survey (CPES). An indicator on CPES should then be added to the CCG Outcomes Indicator Set to ensure changes are implemented at a local level.**

NHS England has no plans to stop carrying out the CPES, which will continue in 2014/15. NHS England knows that clinical teams use this survey to drive improvement, and that groups such as Macmillan also use this valuable data to great effect. The results of the latest CPES were issued on 25 September 2014. NHS England is conducting a review of the full survey programme it inherited from the Department to understand how to get the best from survey data. It wants to make sure that all the data it collects on patient experience can be used to make a real difference, coherently, effectively and efficiently, and the review aims to strengthen an already valuable programme of work.

There are already a range of Patient Experience Indicators included in the CCG OIS. However, the potential to make better use of the Cancer Patient Experience Survey will be explored further during 2014/15 and the potential for an indicator will be explored as part of the future development of the CCG Outcomes Indicator Set.

The patient experience indicators in the current NHS Outcomes Framework cover broad settings such as outpatient care, inpatient care, GP care and community mental health. It comprises of indicators based on patients' responses to surveys covering both their experience of care in different settings and two measures of access to care in primary care settings. It does not cover patient's experience of treatment for a particular condition.

Although such surveys can provide a rich source of more detailed information, a deliberately generic approach has been taken to the national framework in recognition of the fact that people often have more than one condition.

Whilst the Department is committed to keeping the NHS Outcomes Framework under review, it is keen to maintain its balance so that the framework represents the breadth of NHS activity.

### **13. NHS England should outline how it will take into account the experiences of carers, family members, friends and professionals and how these impact a patient's experience of care.**

To help deliver on the Mandate commitment "to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment" NHS England and NHS Improving Quality agreed a series of commitments for action at a workshop in December 2013 that NHS England will take forward.

The Commitment for Carers event brought together carers and care representatives, healthcare professionals, commissioners, senior clinical managers, and allied health professionals. More information on the event can be found at the following link <http://www.nhs.uk/improvement-programmes/experience-of-care/commitment-for-carers.aspx>

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An action plan is being formulated at the moment, and whilst this work is focused on the experience of carers generally, NHS England will consider the APPG's specific recommendation about cancer patients as part of that work.

Further to this, and specifically in relation to cancer, NHS England is looking at how it might get better information on the experience of carers and family members from the CPES with the support of the Cancer Patient Experience Advisory Group.

### **14. NHS England should include an indicator on death in the preferred place of care in the Clinical Commissioning Group Outcomes Indicator Set.**

The Government is committed to improving quality and choice in end of life care. In *Liberating the NHS: Greater choice and control – A consultation on proposals*, we set out our commitment to move towards a national choice offer to support people's preferences about care at the end of life.

A review this year will determine what this will look like, the changes necessary to make it happen and the timescale for its introduction. This review will involve stakeholders, clinicians and the public.

NHS England will explore the potential for an indicator on Preferred Place of Care at the End of Life in the future development of the CCG Outcomes Indicator Set.

### **15. NHS England should outline how it will recognise the valuable role of Clinical Nurse Specialists and include an indicator on access to Clinical Nurse Specialists in the CCG Outcomes Indicator Set.**

NHS England recognises the valuable role that clinical nurse specialists provide as part of a multi-disciplinary team. However, it is for local providers to determine the optimum configuration of their workforce. NHS England's role is to focus on outcomes from healthcare services and it does this, in part, by monitoring the indicators in the CCG OIS and through other mechanisms, such as the CPES. NHS England believes it would be inconsistent with the overall approach to monitor access to a particular professional group within the CCG OIS. The outcomes that are important are ensuring that patients have a good experience of care and that the care they receive is safe and clinically effective. Whilst clinical nurse specialists support these outcomes, it is not necessarily the case that these outcomes can only be achieved through the inclusion of a clinical nurse specialist role as part of a multi-disciplinary team.

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## Domain 5: treating and caring for people in a safe and environment and protecting them from harm

### 16. NHS England should clearly set out what role it will play in implementing the recommendations of the Berwick report.

NHS England, working with NHS Improving Quality, has announced its intention to support the development of what Don Berwick called “a system devoted to continuous learning and improvement” through a national Patient Safety Collaborative programme, which builds upon previous learning of patient safety improvement and supports all health care settings to improve patient safety over the next five years as a minimum. NHS England wants this programme to:

- help support the development of a learning and safety culture
- enhance leadership skills and commitment
- empower staff and patients in the design and delivery of safer systems of care
- build capability for patient safety improvement
- support local and national improvement in key clinical and patient safety areas.

NHS England will also establish a network of safety improvement fellows and will deliver a programme of patient safety capability improvement thereby building a vibrant set of connected safety improvement leaders and experts, all skilled in improvement at an advanced level and supporting others to grow within and outside their organisations. NHS England has already launched a revised and refreshed National Patient Safety Alerting System as recommended and has increased the transparency of patient safety data by publishing detailed and in-depth and regular never events data. This will be enhanced by on-going work to publish a wider range of patient safety data on a single website, and increasing the data available on safe staffing

### 17. NHS England should set out how it will improve the collection of patient safety data and improve leaders’ ability to use the data to drive improvements and improve critical incident reporting.

NHS England is improving the collection and analysis of patient safety data by:

- extending the NHS Safety Thermometer ‘classic’ CQUIN<sup>1</sup> to incentivise demonstrable and sustained improvement in key safety measures with a particular focus on pressure ulcer reduction
- supporting the development of further NHS Safety Thermometers around medication error, maternity care, mental health, paediatrics and potentially other areas so that frontline clinicians have a range of data collection tools to support safety improvement work The Commissioning for Quality and Innovation (CQUINs) payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers’ income to the achievement of local quality improvement goals.

<sup>1</sup> The Commissioning for Quality and Innovation (CQUINs) payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers’ income to the achievement of local quality improvement goals.

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- placing clearer requirements in the NHS Standard Contract around patient safety incident reporting and serious incident reporting
  - reviewing and revising the NHS Serious Incident Framework to further support best practice in identification, reporting, investigation, learning and implementation of robust improvement actions following a serious incident
  - working with CQC and others to provide consistent and clear information for all, including leaders on what patient safety data is available, what it can and can’t tell you and what it should be used for, as well as increasing the breadth and timeliness of such information to further support patient safety improvement
  - developing and commissioning a new, improved, single national reporting and learning system for incident reporting and management

The NHS is becoming much better at recognising and reporting patient safety incidents, with incident reporting up 6.4 per cent over the last year in general and the number of serious incidents reported up 3 per cent. This shows how the patient safety culture we all want to see is developing. At the same time;

- Risk assessment for VTE now happens for over 95% of patients;
- MRSA cases are 3.3% lower than this time last year. C. diff cases are 6.4% lower
- Data on pressure ulcers from the NHS Safety Thermometer suggests a reduction in pressure ulcer prevalence of 1.9% over the previous six months
- The number of patients recorded as ‘harm free’ by the NHS Safety Thermometer is now at 93.4%, up from 92% this time last year

### 18. NHS England should outline how it will work with partners on the recommendations set out in the review by Ann Clwyd MP and Professor Tricia Hart of the hospital complaints system.

NHS England is looking forward to engaging with the patient-led vision for the management of complaints and concerns to be developed on the recommendations in the review by Ann Clwyd MP and Professor Tricia Hart. However, it should be noted that the review was focused on hospitals, and NHS England is not responsible for overseeing the system of complaints within provider organisations.

NHS England is already working to improve its management of complaints and is trialling an approach which will simplify the process. NHS England is also establishing an advisory group of patients and patient representatives, including Health Watch, to help make further improvements to the complaints system and to ensure that the NHS learns from the complaints it receives.

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