



# Cancer across the Domains

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Cancer priorities  
for the new NHS

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# The All Party Parliamentary Group on Cancer

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>Rt Hon Paul Burstow 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), the Teenage Cancer Trust, the Rarer Cancers Foundation and Independent Cancer Patients' Voice.

Five charities formed a Steering Group and contributed funding to the development of this report: Macmillan Cancer Support, Breakthrough Breast Cancer, Cancer Research UK, the Teenage Cancer Trust and Prostate Cancer UK.



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

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**My fellow Officers and I are pleased to present the final report of the All Party Parliamentary Group on Cancer's (APPGC) 'Cancer across the Domains' project. Of the two big ideas contained in the recent health reforms – the restructuring and focus on outcomes – the latter was always promoted by the APPGC. However, since the reforms were first introduced, the APPGC has taken an active role in monitoring how the changes in their entirety will affect cancer patients.**



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

Working with experts from across the cancer community, we have sought to gain consensus on where NHS England should focus its efforts to ensure that, in this changed landscape, cancer patients will continue to have access to high quality treatment and care – the continuing objective being to close the gap with Europe when it comes to survival rates.

The APPGC has been successful in its campaign to promote earlier diagnosis by calling for the introduction of the one- and five-year survival rates in both the NHS Outcomes Framework and the Clinical Commissioning Group (CCG) Outcomes Indicator Set. As late diagnosis results in poor survival rates, ensuring that CCGs focus on one- and five-year survival rates should promote earlier diagnosis.

We then recommended that indicators to measure the cancer stage at diagnosis and cancer diagnosed via emergency routes be included in the 2014/15 CCG Outcomes Indicator Set. NICE has now accepted these recommendations. Having again campaigned hard on this issue, we look forward to NHS England's final recommendations.

These indicators will go a long way in re-focusing efforts on improving early diagnosis in different types of cancer. However, on their own this is clearly not enough. Our report explores what else NHS England should prioritise across each of its Domains to improve cancer care overall, including whether financial flows can better encourage earlier diagnosis. Our objective is to encourage NHS England to embed best practice across the organisation to ensure that cancer patients receive the best possible care and support.

Special thanks go to Professor Sir Mike Richards, Former Director of Domain 1, Sean Duffy, National Clinical Director for Cancer Services, Colonel John Etherington, National Clinical Director for Rehabilitation and Recovery in the Community and Jeremy Taylor, Chief Executive of National Voices who took an active role in helping us shape these priorities. We also extend our thanks to all who contributed to the APPGC's public consultation and those who contributed to the project's development.

Our final thanks go to Macmillan Cancer Support for providing excellent support as the APPGC's Secretariat during the project. On a personal note, I would like to thank my fellow Officers for their help and support over the last year.

I hope that together we can take forward the ideas and recommendations we have set out in the report – to achieve real transformational change in the way we deliver care and join Europe's elite in tackling cancer.

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

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

# Executive summary

**The APPGC believes the five thematic Domains within NHS England have an important role to play in improving the experiences and outcomes of cancer patients. This report sets out the priorities the APPGC believes NHS England must focus on to deliver these improvements.**

## **Domain 1 Preventing people dying prematurely**

The Government aims to drive up cancer survival rates to save an additional 5,000 people every year by 2014/15. To do this, the APPGC believes NHS England must clearly define how it will use CCG Outcome Indicators to hold CCGs to account for improving survival rates in their area.

GPs need more support to help them identify cancer signs and symptoms, which would lead to earlier diagnoses. Research should also be undertaken into the financial flows incentivising best practice in GP practices.

NHS England needs to take steps to tackle variations across the country in the accessibility of the latest life-saving treatments and the time patients have to wait to see a cancer specialist.

NHS England must also set out how it will honour its duty to promote research, including by signposting to existing competent information services such as CancerHelp UK.

Campaigns to raise awareness of cancer signs and symptoms, which have proven successful, need to continue. NHS England should set out how it will work with Department of Health and Public Health England on prevention, symptom awareness and screening.

The APPGC would also like to see greater clarity on the functions and goals of Strategic Clinical Networks who have a vital role to play in the coordination of cancer services across the country.

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

To improve the quality of life of cancer survivors, the adoption of the Recovery Package should be promoted to improve patient care and support. NHS England should encourage CCG uptake of the Recovery Package by officially endorsing it.

NHS England should develop guidance for healthcare professionals on the consequences of cancer treatment.

The APPGC believes NHS England should work with CCGs to commission Stratified Care Pathways that improve aftercare services by matching support to a person's needs.

Greater incentives must be provided to improve support for people living with cancer to return to work or education. The APPGC calls on NHS England to include an indicator on employment for people with long-term conditions in the CCG Outcomes Indicator Set.

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

Rehabilitation programmes should be an integral part of care to improve patient outcomes post treatment. The APPGC believes NHS England should commission models of care that integrate rehabilitation and medicine alongside improving patient access to allied health professionals.

Following an encouraging pilot, the APPGC would like to see the continued use of Patient Reported Outcome Mechanisms surveys (PROMs) for cancer patients.

More must also be done to improve the management of the end of active treatment, as too many people feel isolated and abandoned after treatment has ended.

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

The APPGC calls on NHS England to conduct research to understand the costs and benefits of regularly conducting the Cancer Patient Experience Survey to drive further improvements in outcomes and care.

NHS England should also work with local authorities and CCGs to make carers of people with cancer aware of available support. This is because there is a correlation between a better carer experience and a better patient experience.

Access to Clinical Nurse Specialists varies greatly across the country. The APPGC would like to see NHS England take steps to ensure cancer patients are able to benefit from the invaluable support Clinical Nurse Specialists provide.

At the end of life, far too many cancer patients are unable to die in their preferred place of care. Improving the availability of 24/7 community nursing and carrying out more advance care planning can change this. The APPGC also calls on NHS England to include an indicator on preferred place of death at the end of life in the CCG Outcomes Indicator Set.

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

The APPGC welcomes the Francis and Berwick reviews, alongside the Government and NHS England's response to the Francis report. We call on NHS England and the Department of Health to be clear on how they will deliver on the Berwick report's recommendations.

The APPGC would like to see comprehensive data maintained and collected to compare different patient outcomes, learn from mistakes and disseminate best practice. The rollout of the Cancer Outcomes and Services Dataset, National Radiotherapy Dataset and Systemic Anti-Cancer Therapy Dataset presents opportunities to demonstrate improvements in quality and safety in cancer services.

NHS England should also clearly set out how it intends to implement the recommendations of the NHS hospitals complaints system review which the APPGC believes is fundamental to improving patient safety.

# Cancer priorities for the new NHS

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## Priorities for Domain 1

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.
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.
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.
4. NHS England should undertake research as to whether financial flow mechanisms could better encourage earlier diagnosis.
5. NHS England should clearly set out the functions of Strategic Clinical Networks.

## Priorities for Domain 2

1. NHS England should encourage the uptake of the Recovery Package by officially endorsing it and encouraging CCGs to commission it within acute contracts.
2. 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.
3. 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.
4. 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.

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### **Priorities for Domain 3**

1. 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.
2. 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.

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### **Priorities for Domain 4**

1. 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.
2. 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.
3. NHS England should include an indicator on death in the preferred place of care in the CCG Outcomes Indicator Set.
4. 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.

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### **Priorities for Domain 5**

1. NHS England should clearly set out what role it will play in implementing the recommendations of the Berwick report.
2. 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.
3. 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.

# Introduction

**In April 2013 the NHS reforms of the Health and Social Care Act 2012 came into full effect. Amongst the most significant of the changes was the establishment of NHS England, the body that now oversees health services in England.**

Through its Mandate to NHS England, the Government sets out its ambitions for the NHS. However, the extent of ministerial accountability remains unclear. Although the Health and Social Care Act states that the Secretary of State has overall responsibility for health in England, it says that NHS England is not directly accountable to Parliament. It is yet to be seen if the reporting requirements through the Mandate are enough to ensure proper accountability.

The creation of NHS England also marked a shift from a more centrally managed health service. Adopting a new non-condition specific approach, the new body is divided into five Domains, each with a thematic responsibility for delivering improved outcomes and reducing health inequalities.

The five Domains are:

- 1. Preventing people dying prematurely**
- 2. Enhancing quality of life for people with long-term conditions**
- 3. Helping people to recover from episodes of ill health or injury**
- 4. Ensuring that people have a positive experience of care**
- 5. Treating and caring for people in a safe environment**

The All Party Parliamentary Group on Cancer (APPGC) committed itself to an ambitious programme of work to better understand NHS England. The starting point of this project was the APPGC's belief that all five of the Domains have an important role to play in improving the outcomes and experiences of people living with or beyond cancer.

This report is the result of this programme of work. It sets out the position of cancer within the new system. Importantly, it also identifies the key issues the APPGC believes NHS England must prioritise if it wants to deliver improvements in cancer services and care.

In developing this report, the APPGC consulted with as wide a range of people and organisations as possible. This included hosting three workshops in Parliament that looked at the context of cancer within each Domain. We also ran a public consultation over the summer seeking the views of the cancer community.

Building upon this work, we undertook further evidential research and engaged with senior officials within NHS England to develop a series of priorities that had the support of the NHS as well as our supporters. In total, the APPGC consulted over 67 stakeholders including organisations, clinicians and people affected by cancer. We therefore believe the recommendations in this report have the full weight of the cancer community behind them.

Looking at the structure of this report, it considers each separate Domain and identifies priority areas where we believe improvements can be made. In some cases, our recommendations do not neatly sit in one Domain, or responsibility may lie in one Domain but have implications for other areas of the NHS. With this in mind, it is important to read the full report rather than focus on an individual Domain.

Finally, it is important to state that this report is not a comprehensive study of the entire fabric of the new NHS. It focuses solely on recommendations for NHS England and clearly highlights where we believe NHS England must work with a partner to achieve an objective. The APPGC also recognises that there remain a number of important and compelling issues which lie beyond the scope of this report.

**“People are living longer, this means they need more support for the ill-health they may experience during their later years, including a greater likelihood that they will suffer from cancer in some form or other.”**

**John Lancaster, Cancer Patient Advocate**



# Domain 1: Preventing people from dying prematurely

The focus of the first Domain in the new NHS structure is to reduce mortality. This is of particular importance to cancer since the United Kingdom's cancer survival rates still lag behind international averages.<sup>1</sup>

There are a number of key areas within Domain 1 where the APPGC believes NHS England should focus to have the largest impact on cancer survival: improving early diagnosis rates; ensuring better and fairer access to cancer treatments; setting out a strategy for how it will honour its duty to promote research; setting out the functions of strategic clinical networks and raising awareness of the symptoms and causes of cancer.

## Improving survival rates

Too many people are still being diagnosed in the advanced stages of cancer.<sup>2</sup> This gives them a lower chance of survival. Gaining an accurate picture of how cancer services are being delivered at a local level is fundamental to improving survival rates. The APPGC calls on NHS England to introduce an indicator into the CCG Outcomes Indicator Set on the stage at which cancer patients are diagnosed and cancers diagnosed via emergency presentation. These indicators have already been recommended by NICE and would help CCGs to plan, improve local services and reduce variation across England.

In the new health system it is still unclear how NHS England will hold CCGs to account for driving up standards and improving their performance. For example, NHS England has not provided any guidance on how one- and five-year survival rates will be used to drive improvements in CCGs. NHS England should set out how these measurements will be used to improve early diagnosis. When CCGs fail to deliver these improvements, NHS England should offer support and guidance.

More must also be done to promote the identification of symptoms by practitioners. As the 'public face' of primary care, general practitioners are often a patient's first point of contact. Both patients and GPs responding to this report's consultation pointed to improving GPs' awareness of cancer symptoms as vital to helping identify cancer earlier and improve survival rates.

"It is imperative that NHS England, health organisations, NGOs and charities work together to improve premature mortality in the face of changing circumstances."

**Professor Sir Mike Richards, former Director of Domain 1**

1. Cancer Research UK and King's Fund: *How to improve cancer survival: Explaining England's relatively poor rates* (2011)  
2. Ibid



NHS England needs to set out how it will work with Health Education England, the Royal Colleges and other education providers to ensure that training programmes for healthcare professionals are available and appropriate. Furthermore, NHS England should outline how it will work with Monitor and the NHS Trust Development Authority to facilitate and encourage the releasing of NHS staff to training courses in order to support improvement across the wider NHS.<sup>3</sup>

Finally, one area that CCGs are not directly responsible for in the new system is specialised commissioning. The responsibility for this lies with NHS England and there is a need for further guidance on how NHS England will be held accountable for monitoring improvements in this area.

#### **Deliver better access to cancer treatments**

The APPGC feels there is unacceptable variation across the country with regards to accessing services and treatments such as radiotherapy and cancer drugs.

The establishment of the Radiotherapy Innovation Fund in October 2012 provided a huge boost to the accessibility of radiotherapy. Over the short time that the Fund was administered, the proportion of patients across England receiving Intensity Modulated Radiotherapy Therapy increased from 13.6% to 22.3%.<sup>4</sup>

However, the NHS still does not have the capacity to deliver radiotherapy to all the patients who need it. The most recent figures suggest that, to keep up with demand, 254 additional linear accelerators will be required by 2016 along with the expert workforce to operate them.<sup>5</sup> NHS England should provide sustained investment in radiotherapy and work with hospital trusts to plan and deliver the necessary capacity.

“We’re making sure that more people get the drugs and treatments they need. We already have a guarantee for drugs – that if they’re safe, cost-effective and doctors say you need them, you will get them. From April 2013, for the first time ever, we’re extending that guarantee to radiotherapy too. This is going to help thousands of people at one of the hardest times of their lives.”

**David Cameron, Prime Minister**

3. Sir Bruce Keogh: *NHS Review into the quality of care and treatment provided by 14 hospital trusts in England* (2013)

4. Cancer Research UK: *The Radiotherapy Innovation Fund* (2013)

5. Cancer Research UK: *The Radiotherapy Innovation Fund* (2013)

As of April 2013, NHS England took over responsibility for the commissioning of chemotherapy, including the management of the Cancer Drugs Fund (CDF). Established in April 2011, the Fund was expected to run until 2014, when the Government planned to introduce a new system for assessing drugs within the NHS. This will be known as Value Based Pricing.

Despite the Government’s commitment to continue the Cancer Drugs Fund until 2016, there has been little progress or information on the new system, raising concerns about how patients would continue to access life extending drugs. The implementation of Value Based Pricing has now been delayed until Autumn 2014. NHS England should use this additional time to review the impact of the Fund and provide more information on Value Based Pricing.

Through the Health and Social Care Act, NHS England has a statutory duty to promote research. This is positive as 95% of patients who had a conversation about research stated they were glad to have been asked.<sup>6</sup> However, there remains variation in access, with hard to reach groups such as teenagers and young adults facing specific barriers to joining clinical trials.<sup>7</sup> The APPGC believes that NHS England should publish a comprehensive strategy on how it will honour its duty. This should include signposting them to existing competent information services such as CancerHelp UK.

“It is imperative that the Be Clear on Cancer campaigns continue. They have ability to not only improve awareness of signs and symptoms amongst the public but also amongst GPs.”

**Target Ovarian Cancer**

#### **Raising awareness of the symptoms of cancer**

Public awareness of the signs and symptoms of cancer is key to improving survival. Diagnosis in the later stages of cancer is less likely to lead to survival. In addition, between 2006 and 2008 in England, 24% of all cancers were diagnosed by an emergency presentation when outcomes are also likely to be worse.<sup>8</sup>

One driver behind awareness campaigns is the Government’s ambition to save an additional 5,000 lives by 2014/15 and match the average cancer survival rates for Europe. Despite this being a part of NHS England’s Cancer Strategy, the Government has not indicated whether this aim has been met or how progress is being measured, if there has been any.

The Be Clear on Cancer campaigns have consistently improved awareness of cancer signs and symptoms, although the degree of improved awareness varies for each tumour site. As an example the national bowel cancer campaign, which ran January to March 2012, saw a statistically significant increase in the awareness of blood in stools: from 27% pre campaign to 47% post campaign.<sup>9</sup>

6. National Cancer Intelligence Network. *Cancer Patient Experience Survey 2011–2012*

7. Cancer Research UK and Teenage Cancer Trust: *Teenage and young adult cancer* (2013)

8. Dr S McPhail et al.: *Routes to diagnosis for cancer – Determining the patient journey using multiple routine data sets. British Journal of Cancer* (2012)

9. Department of Health: *Improving Outcomes: A strategy for cancer, second annual report* (2013)

NHS England and its partners need to focus on the importance of national awareness and screening programmes and how they are delivered. Key to this is clearly setting out the responsibilities of NHS England, the Department of Health, Public Health England, local authorities and Health and Wellbeing Boards with regards to prevention, symptom awareness and screening.

These bodies must also work together to outline how they will ensure that services are joined up to make a patient's route to diagnosis smooth, helping to increase early diagnosis. Also, tailored awareness programmes need to be developed for hard-to-reach groups such as black and minority ethnic communities.

#### GP financial flows

During the scoping of this project, the APPGC heard that clinicians can find cancer difficult to diagnose. More than a quarter of people diagnosed with cancer see their GP three times or more before being referred to a specialist.<sup>10</sup> This is compounded by the infrequency with which GPs are presented with genuine cases of cancer – on average less than nine per year.<sup>11</sup> A concern was also raised that since each referral costs the CCG, and there are financial incentives for staying within budget, this may lead the member GPs to regulate their referral rate.

The Quality Outcomes Framework, which is designed to pay practices for delivering better quality care, also assigns fewer points to cancer than other areas such as NHS Health Checks or diabetes, which can influence GP behaviour.

At a local level, there is evidence that attaching incentive payments to initiatives through local enhanced services or directed enhanced service schemes is a key way to drive improvement in primary care.<sup>12</sup> The APPGC believes NHS England should look into replicating this and providing a best practice model for GP practices that rewards them for improvements in early diagnosis. This should form part of a wider review into the mechanisms to improve GP referral for cancer patient investigation.

Furthermore, where a person lives should not determine whether or not they are sent to a specialist to have potential cancer symptoms investigated. But, in 2012 there were 784 two week wait referrals per 100,000 of people in the lowest referring area compared to 3,356 in the highest.<sup>13</sup>

NHS England should set out how it will work to improve equitable access around GP-ordered diagnostic tests. In the NHS's Improving Outcomes Strategy, £450 million was set aside for early diagnosis of cancer, including GP access to diagnostic tests. However, it is unclear what the impact of this funding has been.

“Bowel cancer is very treatable if caught early, so we'd like to see incentives for GPs for early diagnosis and penalties for late diagnosis.”

**Mark Flannagan, Chief Executive of Beating Bowel Cancer**

10. National Cancer Intelligence Network. *Cancer Patient Experience Survey 2011–2012*  
11. Department of Health. *Improving Outcomes: A strategy for cancer (2011)*  
12. NHS Tayside. *Evaluation of the Tayside Qualitative Cancer Referral Local Enhanced Service (2009)*  
13. National Cancer Intelligence Network. *General practice profiles for cancer (2012)*

#### Strategic Clinical Networks

Cancer Networks were established in 2000. Since then their work has improved outcomes for patients, including increased survival, better patient experience and improved treatment and recovery.<sup>14</sup> Networks worked in local areas with clinicians, patients and service managers to deliver the national cancer strategy, improve the performance of cancer services and encourage discussion and engagement around cancer issues.

However, the move to the new NHS structure has seen Cancer Networks transformed into Strategic Clinical Networks. These are designed to sit across NHS England Domains and coordinate activity at a local level to improve outcomes for specific conditions. The conditions covered include cancer, but also new areas such as maternity, mental health and dementia.

There has been a move from 27 Cancer Networks, to 12 Strategic Clinical Networks covering a larger area with fewer dedicated cancer staff. This has resulted in a significant reduction in the number of Cancer Network staff. Despite there being an increase in funding for all networks – from £33 million to £42 million – Cancer Networks will see their funding reduced in the future because they will receive a smaller proportion of a larger budget. A freedom of information request revealed that overall this means Cancer Networks will lose 25% of their funding and 20% of their staff.<sup>15</sup>

Responses to our public consultation suggest that there is still a great deal of uncertainty around what Strategic Clinical Networks will be able to deliver in comparison to Cancer Networks. There is a considerable fear in the cancer community

that the work of Strategic Clinical Networks may be inconsistent and delayed, due to a lack of clarity around their role. This will impact on future improvements to outcomes for cancer patients.

Because of the important role Cancer Networks played in the past, and because of reduced levels of staffing and funding provided to the new Strategic Clinical Networks, the APPGC believes NHS England must take action now. It is vital that NHS England clearly sets out the functions of Strategic Clinical Networks to make sure the future outcomes of cancer patients do not suffer because of a lack of clarity.

#### Priorities for Domain 1

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.
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.
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.
4. NHS England should undertake research as to whether financial flow mechanisms could better encourage earlier diagnosis.
5. NHS England should clearly set out the functions of Strategic Clinical Networks.

14. Macmillan Cancer Support. *The role of cancer networks in the new NHS (2012)*  
15. Labour Party press release. *Funding for cancer networks slashed by a quarter, Labour survey finds (2012)*

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

**It is a sign of how far cancer treatment has progressed that 4 in 10 people today who develop cancer will not die from it.<sup>16</sup> However, not dying doesn't mean a person's life returns to 'normal' after treatment.<sup>17</sup> Cancer is increasingly and rightfully being seen as a long-term condition, which means more action needs to be taken to improve the quality of life of cancer survivors.**

There are four areas where the APPGC believes significant progress can be made to improve the overall quality of life of cancer survivors. These are: the Recovery Package; ensuring healthcare professionals have the right information on the consequences of cancer treatments; providing the right level of aftercare support to make sure the individual needs of a patient are met throughout their cancer journey (known as Stratified Care Pathways); and supporting people who are living with and beyond cancer so they can return to work, education or choose other options that are right for them.

## **Improving coordination of care through the Recovery Package**

Developed by the National Cancer Survivorship Initiative (NCSI), the Recovery Package is a combination of different interventions that aim to improve the outcomes and coordination of care for people living with and beyond cancer. The interventions include: a holistic needs assessment (HNA) and care plan; a treatment summary and GP-led cancer care review; and access to a health and wellbeing clinic to educate patients on available support services.

Because cancer patients often have multiple and complex needs, it is important that they receive an HNA at regular intervals. These help to make sure the specific needs of an individual are identified and met throughout their cancer pathway, improving patient experience and outcomes. Importantly, this includes a patient receiving the right support after treatment ends.

90% of Clinical Nurse Specialists (CNS) state that providing a structured HNA and care plan contributes to patient-centred care. And 89% of CNSs say that HNAs address patients' needs that would otherwise remain unknown.<sup>18</sup> This type of assessment also ensures time and resources are focused where there is the greatest need for support.<sup>19</sup>

Treatment summaries facilitate the sharing of information between GPs, cancer services and patients. They can help professionals with readmissions, keep patients informed and ultimately reduce mortality. Treatment summaries can also reduce costs by helping patients to self-manage, with 83% of patients saying they feel confident in managing their own condition.<sup>20</sup>

The APPGC recommends NHS England makes best practice guidance and models available to CCGs to help them commission the Recovery Package. NHS England's specialist commissioning team should include the Recovery Package in service specifications. NHS England should also commission further research into the health economic benefits of the Recovery Package.

## **Information on consequences of cancer and its treatment**

In the UK 500,000 people struggle with poor health or disability after cancer.<sup>21</sup> Failure to manage the consequences of treatment has a negative impact on the cancer patient and has wider implications for the NHS, including an increase in hospital readmissions.

Currently, less than half of patients receiving pelvic radiotherapy treatment reported receiving verbal and written information on the potential long term effects of treatment.<sup>22</sup> 22% of respondents to the Patient Reported Outcome Measures survey (PROMs) said that it would have been helpful to receive more advice or information on diet and lifestyle changes that often occur because of cancer. 29% said it would have been helpful to have more information on the physical effects of cancer and treatment.<sup>23</sup>

The APPGC would like to see NHS England take a more proactive role in developing guidance and standards to ensure that healthcare professionals have access to and use information on the consequences of treatment. Professionals must then discuss the consequences of treatment at the right time with patients so everyone has confidence in managing these consequences appropriately.<sup>24</sup>

This is especially true if consequences of treatment are more complex and severe. Currently, patients affected in this way often have very poor access to specialised services. The APPGC would like to see significant progress made in this area, for example through specialist staff facilitating the sharing of information on fertility issues, anxiety and fatigue.

For the more common cancers, the APPGC would like NHS England to outline how it will encourage CCGs to commission follow-up pathways that include local referrals to deal with common consequences of treatment.

16. Macmillan Cancer Support. *Cured but at what cost* (2013)

17. Ibid

18. Ipsos Mori: *Evaluation of eHNA baseline report* (2013)

19. National Cancer Survivorship Initiative: *Living with and beyond cancer: Taking action to improve outcomes* (2013)

20. NHS Improvement: *From concept to innovation* (2012)

21. Macmillan Cancer Support: *Throwing a light on the consequences of cancer and its treatment* (2013)

22. Watson et al.: *The effects of pelvic radiotherapy on cancer survivors. Epub ahead of print* (2013)

23. Department of Health. *Quality of life of cancer survivors in England* (2012)

24. Macmillan Cancer Support: *Throwing a light on the consequences of cancer and its treatment* (2013)

### Personalised care plans

Stratified Care Pathways, which could be described as personalised care plans, are designed to improve aftercare services for those living with or beyond cancer by matching the level of support offered to the person's needs and preferences. These pathways will become increasingly important as the number of people living with multiple long term conditions increases.

The 2012/13 Cancer Patient Experience Survey confirmed that aftercare services are not currently meeting cancer patients' needs. It revealed that only 22% of patients were offered a written care plan. The PROMs survey also showed that patients have significant unmet financial, emotional and practical needs after treatment.<sup>25</sup>

In October 2013, NICE approved adult Stratified Care Pathways as a proven case study and published a Quality, Innovation, Productivity and Prevention case study on its website. The APPGC is calling on NHS England to set out how it will work with CCGs to commission these pathways.

Supporting patients to self-manage their condition can boost a patient's own health and wellbeing. By identifying a patient's individual needs through a holistic needs assessment, a Stratified Care Pathway can be designed to facilitate self-management. We commend the excellent NHS Improvement *Innovation to implementation: A how to guide*<sup>26</sup> as a way of introducing Trusts to these changes, and recommend that NHS England publicise this guide to CCGs.

Evidence suggests that if self-management increased in England the net saving for the NHS would be £86 million.<sup>27</sup> This would be as a result of released outpatient resources that were previously used to support patients with breast, colorectal and prostate cancer.<sup>28</sup>

The APPGC would also like to see greater recognition of the role of physical activity and its impact on a patient's health and wellbeing, both physiologically and psychologically. NHS England should encourage CCGs to integrate physical activity into the cancer care pathway. The Chief Medical Officer has already recognised this benefit by supporting the *Walking Works* report published by Macmillan Cancer Support and The Ramblers.

**“A personalised care plan would enable cancer patients to manage their condition better and take into account a variety of needs which may arise during or after cancer treatment, including physical, psychological, practical and financial.”**

**British Lung Foundation**

25. Armes, J. et al. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *J. Clin. Oncology*. (2009)  
26. NHS Improvement. *Innovation to Implementation: Stratified pathways of care for people living with or beyond cancer* (2013)  
27. NHS IQ. *Stratified cancer pathways: Redesigning services for those living with or beyond cancer* (2013)  
28. Ibid.

### Supporting people living with cancer

In England, around 100,000 cases of cancer are diagnosed in people of working age every year.<sup>29</sup> In a recent survey, 82% of people with cancer who were working when they were diagnosed said it is important for them to continue to work.<sup>30</sup> Work or education can help people gain a sense of normality after a cancer diagnosis, but it can also be a financial necessity. Providing the right cancer support to young people in education or training is equally important, as 80% of young people diagnosed with cancer now live for five years or more.<sup>31</sup>

As well as helping individuals, providing effective return-to-work support for people with cancer is also good for the economy. In 2008, Policy Exchange estimated that £5.3 billion in productivity was lost that year as a result of cancer survivors not returning to work.<sup>32</sup>

The NHS Mandate contains an objective of 'supporting people with ongoing health problems to live healthily and independently' and a commitment to employment in the 'furthering economic growth' priority area. There is also an indicator on the employment of people with long-term conditions in the NHS Outcomes Framework. However, there are insufficient incentives across all levels of the NHS to drive improvements that meet these objectives and no means of measuring progress.

29. Office for National Statistics: *Cancer Registration Statistics England* (2009)  
30. Macmillan Cancer Support/YouGov online survey of 2,217 people living with cancer in the UK  
31. Cancer Research UK and Teenage Cancer Trust: *Teenage and young adult cancer* (2013)  
32. Policy Exchange Research Note: *The cost of cancer* (2010)

To achieve these objectives, NHS England needs to ensure similar commitments are put in place in other key accountability frameworks, such as the CCG Outcome Indicator Set. NHS England also needs to outline how it will work with the Department for Work and Pensions to implement these priorities.

### Priorities for Domain 2

1. NHS England should encourage the uptake of the Recovery Package by officially endorsing it and encouraging CCGs to commission it within acute contracts.
2. 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.
3. 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.
4. 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.



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

Given the focus on cancer as a long term condition, this Domain is less specifically relevant to cancer. But there are still important considerations to make, especially since, as people live longer, they are more likely to be diagnosed with cancer while already suffering from another condition or comorbidity.

The end of active treatment can be a considerable adjustment for cancer patients. If managed inappropriately it can leave patients feeling lonely and scared, which can have a detrimental effect on the recovery process.<sup>33</sup> The APPGC believes there needs to be a move towards a more holistic approach to recovery and to measure patient outcomes across the NHS.

### Cancer rehabilitation

Whilst we recognise there are many patients who receive very good quality care, the APPGC is concerned that too many people still feel isolated after treatment and are suffering from disjointed care; the PROMS survey suggests this number is as high as one in four people.<sup>34</sup>

It is estimated that 100,000 people diagnosed with cancer would benefit from participating in a rehabilitation programme, including those that focus on physical activity. Therefore, the APPGC

would like NHS England to recognise the benefit of cancer rehabilitation programmes to a patient's recovery process when introduced early on after the end of treatment.<sup>35</sup>

Studies show that a physical activity intervention can reduce the risk of cancer reoccurring for colorectal cancer patients by up to 50% and by 40% for breast cancer patients. It is also estimated this type of intervention can reduce a cancer patient's risk of developing other long-term conditions, such as cardiovascular disease, by 20–50%.<sup>36</sup>

Furthermore, a full assessment of rehabilitation needs should take place as soon as possible. An assessment before or during treatment, is known as 'pre-habilitation' and has been recognised as an area that needs much more consideration.<sup>37</sup> The Department of Health survivorship survey suggests that very few people are suitably prepared for what to expect when treatment finishes.<sup>38</sup>

“From prevention through diagnosis, treatment and palliative care to the end of life, rehabilitation improves patient outcomes, not only preventing premature deaths but also enhancing the quality of life for people with long-term conditions and supporting swift recovery.”

**National Cancer Action Team: Cancer Rehabilitation, Making excellent care possible**

33. Macmillan Cancer Support: *Worried sick: The emotional impact of cancer* (2006)

34. NHS England: *Quality of Life of Cancer Survivors in England* (2012)

35. Department of Health. *At least five a week: Evidence on the impact of physical activity and its relationship to health* (2004)

36. Ibid.

37. Li C et al. *Impact of a trimodal prehabilitation program on functional recovery after colorectal cancer surgery: a pilot study* *Surgical Endoscopy* (2013)

38. Corner J et al. *Qualitative analysis of patients' feedback from a PROMS survey of cancer patients in England* *BMJ Open* (2013)

The APPGC is concerned that despite the evidence base the benefits of rehabilitation are not being widely acknowledged across the NHS. We believe it should be viewed as an integral part of high-quality care, an opinion supported by a National Cancer Action Team (now part of NHS Improving Quality) report published in March 2013. It stresses that “[rehabilitation] should no longer be viewed as a bolt on to treatments such as surgery”.<sup>39</sup>

The National Cancer Action Team (NCAT) began looking at cancer rehabilitation in 2007, before that there had been no national policy or guidance to help local managers to make improvements. By collecting examples of best practice, academic evidence and expert opinion NCAT was able to develop an effective cancer rehabilitation pathway. However, this work is far from complete and with the move to the new NHS structure, NCAT has been abolished and it is unclear who has responsibility for rehabilitation pathways. The APPGC wants NHS England to provide clarity on where responsibility for cancer rehabilitation now lies.

The APPGC believes that NHS England should develop better models of care and define how they will integrate rehabilitation and medicine. In the APPGC’s view, these new models should also be supported by improving patients’ access to allied health professionals and encouraging more appropriate use of relevant rehabilitation services.

Furthermore, the APPGC wants to see the emergency admissions indicator in Domain 3 expanded to include cancer. This will help to incentivise CCGs to identify where improvements are needed, since it is an indicator of patient access to care and is a credible proxy for survival rates.<sup>40</sup>

“The use of PROMs should be extended for cancer patients and investment made in setting up appropriate data collection systems.”

**Association of the British  
Pharmaceutical Industry**

39. National Cancer Action Team: *Cancer Rehabilitation* (2013)  
40. Department of Health: *Improving Outcomes: a strategy for cancer* (2011)

### **Patient outcomes**

To ensure that NHS England continues to improve patient outcomes, the APPGC wants to see continued investment and roll out of robust metrics in the form of Patient Reported Outcome Measures surveys (PROMs) for cancer patients.

Analysis of the 2011 PROM survey suggests that people are not always receiving adequate help or treatment. Many problems that affect a person’s quality of life were just as prevalent five years after diagnosis as they were after one year.<sup>41</sup> A scaled up PROMs programme would provide an excellent opportunity to measure whether improvements in survivorship care, as recommended by the National Cancer Survivorship Initiative,<sup>42</sup> result in improved quality of life for the majority of people.

The pilot survey using PROMs published by the Department of Health in December 2012 clearly demonstrated the value of evaluating these outcomes for patients. For instance, it revealed for the first time how specific problems affect the quality of life of people diagnosed with a particular tumour type. These ongoing problems may have not been uncovered otherwise. Therefore, it is critical that NHS England clarifies its position on the use of these metrics.

### **Priorities for Domain 3**

1. 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.
2. 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.

41. Glaser AW et al.: *Patient-reported outcomes of cancer survivors in England 1–5 years after diagnosis: a cross-sectional survey*. *BMJ Open* (2013)  
42. Department of Health: *Living with and beyond cancer: Taking action to improve outcomes* (2013)

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

**The new NHS has an increased focus on positive experiences of care, with Domain 4 focusing exclusively on the experience of the patient. Whilst this is to be welcomed, recent controversies surrounding the Mid Staffordshire NHS Foundation Trust and the Liverpool Care Pathway mean patient experience is also one of the biggest challenges the NHS faces.**

The measurement and improvement of patient experience should not be seen solely as a Domain 4 issue. It is an essential prerequisite for all of the NHS to deliver outcomes that matter to patients. In fact, there is an emerging picture of the link between patient experience and other elements of quality of care such as clinical effectiveness and safety.

## Cancer Patient Experience Survey

Understanding what matters to patients is critical if we are to improve services and deliver quality healthcare. The Cancer Patient Experience Survey (CPES) is a proven tool to drive improvements. Responses to questions in the 2011/12 survey revealed greater patient satisfaction compared to answers provided for the 2010 survey.

Hospital trusts have used the transparency of the CPES to create improvement plans.<sup>43</sup> Linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals, through commissioning quality and innovation payments (CQUINs), is also important. To further drive improvements, NHS England should outline how it will work with CCGs to encourage them to include patient experience in their business plans and include an indicator on cancer patient experience in the CCG Outcomes Indicator Set.

The Francis Inquiry recommended that information must be made available about the performance of services and relevant metrics need to be established to measure the quality of different areas of care.<sup>44</sup> The CPES is a tool that fulfils this purpose.

Ahead of a review of the entire CPES programme, NHS England has confirmed that there are no plans to stop carrying out the survey. The APPGC is calling on NHS England to conduct research to understand the costs and benefits of regularly conducting the Cancer Patient Experience Survey (CPES). An indicator on the CPES should then be added to the CCG Outcomes Indicator Set to ensure changes are implemented at a local level.

Furthermore, NHS England should clearly set out how it intends to improve the experience of care for hard-to-reach groups. Children and young people are one such group but are not included in the CPES. There is an indicator in the Outcomes Framework on improving children and young people's experience of care. There is a need for more detailed information on how this will be measured and improved.

43. National Action Cancer Team: *Improvements in cancer patient experience ratings: How have they been made?*  
44. Robert Francis QC: *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. (2013)

## Beyond the immediate patient experience

It is clear that a patient's experience of care is also affected by the experience of their carers or family members and the morale of health professionals they come into contact with.

The involvement of carers, including friends and family, is widely recognised as an important element of patient experience. This is identified in the Institute of Medicine Healthcare Quality Framework and the Picker Principles of Patient-Centered Care, which defines seven primary dimensions of patient-centred care.<sup>45</sup>

A large part of improving the carer experience is making sure carers are identified in the first place and then signposted to support. Almost half of carers of people with cancer say they would benefit from at least one type of additional support, such as advice or training.<sup>46</sup> The APPGC wants NHS England to define how it will work with CCGs and local authorities to ensure that all health and social care professionals aim to identify carers of people with cancer and signpost them to support that is already available.

Furthermore, there was a strong feeling from the cancer community that NHS England should pay closer attention to the morale and experiences of professionals to improve patient experience. When staff feel valued and respected, they are more likely to treat patients in the same way and be happier in their role.<sup>47</sup> One way to achieve this is through an indicator on staff experience in the Outcomes Framework.

Finally, following the NHS reforms, the APPGC is keen that NHS England supports staff to ensure there is capacity to meet the expectations of patients, carers and families. Following the Government's response to the Francis report and a proposed website detailing hospital staffing levels, this is something that the APPGC will be keeping a close eye on.

**"Patients are more likely to report positive experiences if their carers themselves are involved and satisfied with the support offered."**

**Prostate Cancer UK**

45. National Clinical Guidance Centre: *Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services* (2012)  
46. Macmillan Cancer Support and Ipsos MORI: *More than a million* (2011)  
47. The King's Fund: *Leadership and engagement for improvement in the NHS* (2012)

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

Research reveals that 73% of people living with cancer want to die at home. Currently, only 30% are able to.<sup>48</sup> One barrier that prevents people from dying in their preferred place of care is the inconsistent provision of 24/7 community nursing in England. The Palliative Care Funding Review describes this absence as ‘stark’.<sup>49</sup> This is despite the National End of Life Care Strategy highlighting the need for this service as a priority.<sup>50</sup> The APPGC calls on NHS England’s Seven Day Services Forum, which looks at the limited availability of services at certain times, to look into the provision of community nursing.

Another barrier to people dying at home is the lack of advance care planning and the recording of people’s end-of-life care preferences. Currently, where people live has a significant bearing on whether they are able to die at home. In 2011, the area with the highest proportion of cancer deaths at home in England was 49%. This compared to 16% in the area with the lowest figure.<sup>51</sup>

As a result, the APPGC believes that NHS England should include an indicator on death in the preferred place of care in the CCG Outcomes Indicator Set. NHS England should then set out how it will work with CCGs and local authorities to encourage them to support people so they can die in their preferred place of care.

### Clinical Nurse Specialists

Clinical Nurse Specialists (CNS) are a key element in ensuring that a patient’s overall experience of care is a positive one. They are registered nurses with a graduate level nursing preparation, usually at Master’s level, who are clinical experts in evidence-based nursing practice within a speciality area.<sup>52</sup>

CNSs oversee and personalise ‘the cancer pathway’ for individual patients, act as an accessible professional for the multidisciplinary team handling the patient’s care, alleviate the patient’s psychosocial suffering and lead on service redesign in response to patient need.<sup>53</sup>

The Cancer Patient Experience Survey (CPES) shows a positive correlation between access to a CNS and many other experience outcomes.<sup>54</sup> CNSs play an important role throughout a patient’s entire cancer journey, and the scope of their work is relevant to each of the five thematic Domains.

However, access to these specialists around the country varies, the area with the lowest number of Clinical Nurse Specialists has 34, compared to 195 in the area with the highest.<sup>55</sup> The Patient Reported Outcome Measures (PROMs) survey indicated that 54% of patients either did not have a named nurse to contact or did not know who to contact if they had a concern about their cancer care.<sup>56</sup> Meanwhile, the Target Ovarian Pathfinder study which ran in both 2009 and 2012 showed that in 2012 there had been a marked decrease in the capacity of Clinical Nurse Specialists to provide support and time for women.<sup>57</sup>

CNSs are fundamental to the provision of high quality cancer care, and NHS England should recognise their important role in the patient care pathway and continue to support and protect these services. To do so, the APPGC believes that an indicator should be included in the CCG Outcome Indicator Set (based upon data collected by the CPES) to measure performance on patient access to a CNS and to tackle the variation across the health service.

### Priorities for Domain 4

1. 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.
2. 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.
3. NHS England should include an indicator on death in the preferred place of care in the Clinical Commissioning Group Outcomes Indicator Set.
4. 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.

“They are vital and there aren’t enough of them”

**Dr Riyaz Shah, Kent Oncology Centre**

48. Macmillan Cancer Support. *Online survey of 1,019 people living with cancer (2010)*

49. Tom Hughes-Hallett, Prof. Sir Alan Craft, Catherine Davies. *Palliative care funding review (2011)*

50. Department of Health: *End of life care strategy (2008)*

51. Office for National Statistics. *Cancer deaths in own home by local authority, England (2011)*

52. Excellence in Cancer Care: *The Contribution of the Clinical Nurse Specialist, NCAT, 2010*

53. Excellence in Cancer Care: *The Contribution of the Clinical Nurse Specialist, NCAT, 2010*

54. National Cancer Improvement Network: *2011–2012 National Cancer Patient Experience Survey*

55. National Cancer Action Team – *Census of the Cancer Nurse Workforce 2011*

56. Quality of Life for Cancer Survivors in England: *Report on a pilot survey using Patient RMeasures (PROMS)*

57. Bridging the Gap: *Improving outcomes for women with ovarian cancer, Pathfinder 2012*





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

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**Domain 5 focuses on patient safety. In the wake of the recent hospital scandals, patient safety has been brought sharply into focus. The Government's response was to announce a full public inquiry into the reasons behind the systemic failures at the Mid Staffordshire NHS Foundation Trust, which was accompanied by a full review of patient safety.**

Patient safety is of particular relevance to cancer patients due to the risks associated with becoming unexpectedly ill during or after treatment. It is vital that health professionals are educated so they become familiar with cancer management and know which interventions may be inappropriate and potentially life threatening to cancer patients.<sup>58</sup>

The APPGC's calls in Domain 5 focus on NHS England's response to the Berwick report, their response to Ann Clwyd's report on complaints and on the collecting of data on patient safety.

### **Positive culture change**

According to the NHS Mandate, improving patient safety involves many things: "treating patients with dignity and respect; high quality nursing care; creating systems that prevent both error and harm; and creating a culture of learning from patient safety incidents, particularly events that should never happened, such as wrong site surgery, to prevent them from happening again."<sup>59</sup>

Speaking on patient safety in the spring of 2013, the Health Secretary, Jeremy Hunt, called it the "silent scandal of the NHS" and reaffirmed the need for patient safety to improve.<sup>60</sup>

The APPGC welcomes the Government and NHS England's responses to the Francis report. We are keen to see a similar response setting out how NHS England and the Department of Health will deliver on the recommendation of the Berwick report. We need to know how best practice and a new culture will be embedded that makes the patient the priority and leads to positive change, not just for cancer patients but for all patients.

### **Data collection systems**

Collecting comprehensive data is incredibly important for patient safety. It can be used to compare and contrast different patient outcomes and ensure lessons are learnt from mistakes.

58. Royal College of Physicians and Royal College of Radiologists. *Cancer patients in crisis* (2012)

59. Department of Health: *The NHS Mandate* [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213131/mandate.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213131/mandate.pdf)

60. Jeremy Hunt speech to UCLH: *The silent scandal of patient safety* (2013)

Data on quality of care and patient safety is enormous but held in a very fragmented way.<sup>61</sup> To resolve this, England is moving to a national registration system called Encore. The APPGC is keen to see that data is not lost within the new system, given the difference in previous regional data and registration systems. The new system must also protect and improve the dataset alongside access to it. This is becoming increasingly important, especially in light of cancer patient records being falsified in Colchester General Hospital.<sup>62</sup> The Department of Health has recognised difficulties of migration in its second review of the cancer strategy.<sup>63</sup>

In addition, the APPGC believes that the collection and data capture of the Cancer Outcomes and Services Dataset, National Radiotherapy Dataset and Systemic Anti-Cancer Therapy Dataset present a good opportunity to demonstrate when cancer services have improved the quality of care and patient safety. Their rollout should be completed nationally.

Furthermore, not all CCGs have the skills to use this data to drive improvements, which is why NHS England needs to provide details on how it will work with partners to address this skills deficit.

Finally, critical incident reports are a vital part of what is required for patient protection.<sup>64</sup> Currently there are problems with incident reporting systems. These include fear of punitive action, poor safety culture in an organisation, lack of understanding about what should be reported, lack of awareness of how the reported incidents will be analysed and how the reports will ultimately lead to changes which will improve patient safety.<sup>65</sup> NHS England should set out how it intends to improve critical incident reporting and then NHS England should begin publishing data on these incidents publicly, meeting the transparency recommendation in the Berwick review,<sup>66</sup> to hold CCGs to account.

“Investment [should be] made in setting up appropriate data collection systems, including potentially extending the use of the Systemic Anti-Cancer Therapy database, which needs to be fully rolled out.”

### Association of the British Pharmaceutical Industry

61. Sir Bruce Keogh: *NHS Review into the quality of care and treatment provided by 14 hospital trusts in England* (2013)  
62. Care Quality Commission: *Inspection Report of Colchester General Hospital* (2013)  
63. Department of Health: *Improving outcomes. A strategy for cancer, second annual report* (2013)  
64. Robert Francis QC: *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (2013)  
65. R P Mahajan: *Critical incident reporting and learning. British Journal of Anaesthesia* (2010)  
66. National Advisory Group on the Safety of Patients in England: *Improving the Safety of Patients in England* (2013)

### Complaints

In the Autumn of 2013 Ann Clwyd MP and Professor Tricia Hart published a report on complaints, openness and transparency in the NHS.<sup>67</sup> The report makes recommendations in four areas, the quality of care, handling complaints, independence in the complaints process and whistle-blowing.

The complaints process is fundamental to patient safety, since if patients do not feel able to complain or that their complaints will not be taken seriously then they will not raise any issues and systemic risks will not be identified and corrected. The report recommends that NHS England sets out how it will work with the Department of Health to develop a ‘cultural barometer’ to determine if a workplace has problems with staff attitudes or organisational approach.

Even more important to patient safety is whistle-blowing. The report highlights the disquiet around opportunities for staff to be heard when they believe there is bad practice within hospitals and the wider regulatory system.

The APPGC wants NHS England to outline how it will work with partners to act on the recommendations set out in the review.

### Priorities for Domain 5

1. NHS England should clearly set out what role it will play in implementing the recommendations of the Berwick report.
2. 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.
3. 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.

67. Ann Clwyd & Prof Tricia Hart: *A Review of the NHS Hospitals Complaints System Putting Patients Back in the Picture* (2013)

# Conclusion

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**From the outset, the APPGC believed that all five Domains in the new health system would play an important role in improving the outcomes and experiences of people with cancer. With the focus of the new system moving away from processes and towards improving overall outcomes, we wanted to explore how each Domain could play its role in ensuring a high standard of care for all cancer patients.**

Through a combination of workshops, a public consultation and direct engagement with our stakeholders, the APPGC's recommendations are guided by a wealth of expertise and knowledge. This has been instrumental in helping us clearly define where we believe efforts should be focused over the next two to three years.

We believe changes can and must be made to increase the number of early cancer diagnoses, improve the outcomes and quality of life of cancer survivors, and provide a better and safer patient experience. Despite the autonomy of Clinical Commissioning Groups to determine priorities and deliver outcomes in their local areas, they must listen to NHS England guidance, particularly for complex conditions like cancer. The APPGC stands firm that NHS England can still bring about improvements nationally by working with the Government and other partners.

The report's recommendations aim to reflect the ways in which the cancer community feels it can be better supported. In addition, we acknowledge good progress has already been made in some areas to put in place the mechanisms that will deliver improvements.

However, this work needs to be maintained and monitored. Furthermore, there must be greater clarity on the roles and responsibilities of different bodies, as there remains confusion on the ground about how improved care and outcomes will be delivered in practice.

In putting together our final report, the APPGC is particularly grateful for the support of key NHS England staff, who played a key role in shaping our priorities. Over the coming year, we look forward to working with them on how best to implement these priorities. We will also continue to speak to organisations such as the Department of Health, Public Health England and Health Education England, which, in partnership with NHS England, will be vital in creating a new NHS landscape that delivers improvements in cancer outcomes.

Together, we hope that we can achieve the Government's ambition in the Cancer Strategy of saving an additional 5,000 lives by 2014/15.



# Appendix 1: Acknowledgements

## Workshop attendees

**Professor Sir Mike Richards**  
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**Holly Mitchell**, Prostate Cancer UK

**Ross Kester**, Breakthrough  
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**Debbie Sedgewick**, Mother of  
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**Tony Selman**, Cancer Research UK

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**South East London Cancer  
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**Dr Alison Tree**

**Ms Andrea Hirst**

**College of Radiographers**

**ABPI**

**Beating Bowel Cancer**

**British Oncology Pharmacy  
Association**

**Bowel Cancer UK**

**Brain Tumour Research  
Brainstrust**

**Bristol Myers Squibb**

**British Lung Foundation**

**Cancer Campaigning Group**

**Cancer Research PPI  
Cancer Research UK**

**Cancer User Involvement  
Group**

**The Christie NHS Foundation  
Trust**

**The Haven**

**Celgene**

**CLIC Sargent**

**The Ipswich Hospital NHS Trust**

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**Radiotherapy Board**

**GSK**

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## Appendix 2: References

Ann Clwyd & Prof Tricia Hart: *A Review of the NHS Hospitals Complaints System Putting Patients Back in the Picture* (2013)

Armes, J. et al.: *Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey*. *J. Clin. Oncology*. (2009)

Cancer Research UK and King's Fund: *How to improve cancer survival: Explaining England's relatively poor rates* (2011)

Cancer Research UK and Teenage Cancer Trust: *Teenage and young adult cancer* (2013)

Cancer Research UK: *The Radiotherapy Innovation Fund* (2013)

Care Quality Commission: *Inspection Report of Colchester General Hospital* (2013)

Corner J et al.: *Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England* *BMJ Open* (2013)

Department of Health: *At least five a week: Evidence on the impact of physical activity and its relationship to health* (2004)

Department of Health: *Quality of life of cancer survivors in England* (2012)

Department of Health: *End of life care strategy* (2008)

Department of Health: *Improving Outcomes: a strategy for cancer* (2011)

Department of Health: *Improving outcomes : A strategy for cancer, second annual report* (2013)

Department of Health: *Living with and beyond cancer: Taking action to improve outcomes* (2013)

Department of Health: *The NHS Mandate* [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213131/mandate.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213131/mandate.pdf)

Dr S McPhail et al.: *Routes to diagnosis for cancer – Determining the patient journey using multiple routine data sets*. *British Journal of Cancer* (2012)

Glaser AW et al.: *Patient-reported outcomes of cancer survivors in England 1–5 years after diagnosis: a cross-sectional survey*. *BMJ Open* (2013)

Information Services Division Scotland: *Cancer Incidence Scotland* (2009)

Ipsos Mori: *Evaluation of eHNA baseline report* (2013)

Jeremy Hunt speech to UCLH: *The silent scandal of patient safety* (2013)

Labour Party press release: *Funding for cancer networks slashed by a quarter, Labour survey finds* (2012)

Li C et al.: *Impact of a trimodal prehabilitation program on functional recovery after colorectal cancer surgery: a pilot study* *Surgical Endoscopy* (2013)

Macmillan Cancer Support and Ipsos MORI: *More than a million* (2011)

Macmillan Cancer Support: *Cured but at what cost* (2013)

Macmillan Cancer Support: *Online survey of 1,019 people living with cancer* (2010)

Macmillan Cancer Support: *The role of cancer networks in the new NHS* (2012)

Macmillan Cancer Support/YouGov online survey of 2,217 people living with cancer in the UK.

Macmillan Cancer Support: *Throwing a light on the consequences of cancer and its treatment* (2013)

Macmillan Cancer Support: *Worried sick: The emotional impact of cancer* (2006)

Maddams J et al.: *Cancer prevalence in the United Kingdom: estimates for 2008*. *British Journal of Cancer* (2009). This estimate is for 18 to 64-year-olds at the end of 2008.

National Action Cancer Team: *Improvements in cancer patient experience ratings: How have they been made?*

National Advisory Group on the Safety of Patients in England: *Improving the Safety of Patients in England* (2013)

National Cancer Intelligence Network: *General practice profiles for cancer* (2012)

National Cancer Intelligence Network: *Cancer Patient Experience Survey 2011–2012*

National Cancer Survivorship Initiative: *Living with and beyond cancer: Taking action to improve outcomes* (2013)

National Clinical Guidance Centre: *Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services* (2012)

NHS Improvement: *Innovation to Implementation: Stratified pathways of care for people living with or beyond cancer* (2013)

NHS Improvement: *From concept to innovation* (2012)

NHS IQ: *Stratified cancer pathways: Redesigning services for those living with or beyond cancer* (2013)

---

NHS Tayside: *Evaluation of the Tayside Qualitative Cancer Referral Local Enhanced Service (2009)*

Royal College of Physicians and Royal College of Radiologists: *Cancer patients in crisis (2012)*

Northern Ireland Cancer Registry: *Cancer Incidence Northern Ireland (2009)*

Sir Bruce Keogh: *NHS Review into the quality of care and treatment provided by 14 hospital trusts in England (2013)*

Office for National Statistics: *Cancer deaths in own home by local authority, England (2011)*

The King's Fund: *Leadership and engagement for improvement in the NHS (2012)*

Office for National Statistics: *Cancer Registration Statistics England (2009)*

Tom Hughes-Hallet, Prof. Sir Alan Craft, Catherine Davies: *Palliative care funding review (2011)*

Policy Exchange Research Note: *The cost of cancer (2010)*

Watson et al.: *The effects of pelvic radiotherapy on cancer survivors. Epub ahead of print (2013)*

R P Mahajan: *Critical incident reporting and learning. British Journal of Anaesthesia (2010)*

Welsh Cancer Intelligence and Surveillance Unit: *Cancer Incidence Wales (2004–2008)*

Robert Francis QC: *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013)*

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

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