



All Party Parliamentary
Group on Cancer

Briefing on *Cancer across the Domains*

Briefing for: **Members of Parliament**

Purpose: **To provide a briefing for the Backbench Debate on the All Party Parliamentary Group on Cancer's (APPGC) new report, *Cancer across the Domains***

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1. Introduction

In advance of the Backbench Debate on Thursday 13 February, this briefing provides an overview of the All Party Parliamentary Group on Cancer's (APPGC) latest report, *Cancer across the Domains*. It also sets out the key recommendations of the APPGC to NHS England, which it believes are vital to improve outcomes for people with cancer.

This debate comes at a particularly important time. Recent reports have shown that the **UK lags behind its European counterparts in cancer survival**, with survival rates being labeled "low" for people with kidney, stomach, ovarian, colon, and lung cancers.¹ This comes against a backdrop of increased incidence of cancer: by 2020 **one in two** people will receive a cancer diagnosis in their lifetime. The rising numbers of cancer patients poses a significant challenge to the NHS, with scarce resources and tightening budgets. If the Government's goal set out in the National Cancer Strategy to save 5,000 additional lives every year by 2014/15 is to be met, action is needed **now** to ensure that services and outcomes improve for people living with and beyond cancer. Given this urgency, the APPGC wants to ensure that cancer remains a top priority for this and the next Government.

Cancer across the Domains is the culmination of a year-long programme of work examining the priorities in creating an NHS that delivers world class cancer outcomes and care. It analyses cancer care through the five areas that the NHS is held to account on: preventing people dying prematurely, enhancing quality of life for people with long-term conditions, helping people to recover from episodes of ill-health or injury, ensuring that people have a positive experience of care and treating and caring for people in a safe environment. We believe that **each of the five Domains has an important role to play** in improving outcomes for people living with or beyond cancer. As such, this briefing presents a brief overview of our analysis and recommendations on:

- Accountability
- Surviving cancer
- Patient experience
- Quality of life after cancer and
- Rehabilitation.

To improve outcomes and services for people affected by cancer, the APPGC calls on the **Government to respond to the recommendations** included in *Cancer across the Domains*. In so doing, it urges the **Government to work with NHS England to ensure implementation** of its recommendations in a thorough and timely manner.

¹ EURO-CARE-5, Cancer Registry Based Study on Survival and Care of Cancer Patients, 2013.

2. Accountability on cancer services

The role of the Secretary of State

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 & Social Care Act states that the Secretary of State has overall responsibility for health in England, this means that **NHS England is not directly accountable to Parliament**. It remains to be seen whether reporting requirements in the Mandate are sufficient to ensure proper accountability. Furthermore, it is unclear what steps the Department of Health will take to **hold NHS England accountable**, and encourage improvement, if it underperforms against the NHS Outcomes Framework.

CCG Accountability

Further, commissioning of services has been split between Clinical Commissioning Groups (CCG) for general services and NHS England for specialist commissioning. Although NHS England retains oversight of all commissioning, through the CCG Outcomes Indicator Set, it is not clear how NHS England will **hold CCGs accountable for underperformance** and work with them to **improve outcomes**.

The APPGC calls on the Government to set out the steps it will take to ensure that both NHS England and CCGs are **held to account** on their performance against the NHS Outcomes Framework and the CCG Outcomes Indicator Set, respectively, in order to improve cancer outcomes.

3. Surviving cancer

Survival rates and early diagnosis

Through the CCG Outcomes Indicator Set (CCG OIS), NHS England requires CCGs to report on their performance in certain areas to hold local bodies to account. The APPGC has campaigned over the past few years to improve the picture painted on cancer diagnosis and survival, ensuring the inclusion of:

- one- and five-year cancer survival rates for all cancers;
- the stage at which cancer patients are diagnosed; and
- the number of cancers diagnosed via emergency presentation.

With this information, NHS England and CCGs could identify shortcomings and target resources to increase early diagnosis.

However, the APPGC is concerned that the existing indicators on five-year survival (for all cancers and breast, lung and colorectal cancers) were **removed from the framework**:

- Early diagnosis increases survival rates, but without data on longer-term survival, it will be **harder for NHS England to ensure that early diagnosis is being improved by CCGs**.
- The removal of the five-year survival indicators was **not recommended** by the NICE Advisory Committee, **nor was part of the public consultation**.

The APPGC calls on the Government, in fulfilment of its commitment in the NHS Mandate, to set out how it will work with NHS England to ensure that **five-year survival rates** are included in accountability frameworks **at a local level** in order to improve survival rates for cancer.

Access to treatment

The APPGC welcomes the Government's announcement that the Cancer Drugs Fund will continue until 2016, however, this is not a long term solution. The planned new system for assessing drugs in the NHS, Value Based Pricing (VBP), has shown little progress, raising concerns over access to treatment in the future. The implementation of VBP has now been delayed until autumn 2014.

The Government should use this extra time to **review the impact of the Cancer Drugs Fund** and **provide more information on VBP**, in order to ensure that access to the best treatment is available to all cancer patients.

4. Improving Patient Experience

The NHS has placed an increased focus on positive experiences of care, which the APPGC welcomes. However, following recent controversies, including the Mid Staffordshire NHS Foundation Trust and the Liverpool Care Pathway, it is also one of the biggest challenges the NHS faces.

The National Cancer Patient Experience Survey, run by NHS England, shows a strong correlation between access to a Cancer Nurse Specialist (CNS) and patients reporting a positive experience of care.² CNS are registered nurses who are clinical experts within a speciality area. They oversee and personalise cancer care for patients and liaise with the different teams handling the patient's care, provide psychological support, and lead on service redesign in response to patient need.

Despite this positive correlation, access to a CNS varies across the country. The area with the lowest number of CNSs has just 34, while the area with the highest has 195.³ 54% of patients did not have a named nurse or did not know who to contact if they had a concern about their cancer care.⁴ In addition, the Target Ovarian Pathfinder study, which ran in both 2009 and 2012, showed a marked decrease in CNS capacity to provide time and support to women.⁵ As such, NHS England should recognize their important role and protect and support these services.

To ensure the experience of cancer patients, the Government should support an **indicator in the CCG OIS to measure performance on patient access to a CNS**, to help tackle variation across the country, in fulfillment of the NHS Mandate.

5. Quality of life after cancer

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.⁶ However, this does not mean that people's lives will return to normal following treatment: **more action is needed to improve the quality of life for cancer survivors.**

The Recovery Package was developed by the National Cancer Survivorship Initiative, combining a number of initiatives to improve outcomes for people living with and beyond cancer. This includes:

- 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 so that patients are aware of available support services.

Evidence suggests that HNA and care plans contribute to patient-centred care. They identify specific needs, including after treatment ends and can facilitate self-management, which could **save the NHS in England £86 million.**⁷

The APPGC calls on the Government to work with NHS England in pursuance of **best practice guidance** and models available to CCGs to help them **commission the Recovery Package**. NHS England's specialist commissioning team should **include it in service specifications**. Further, NHS England should conduct further research into the **health economic benefits** of the Recovery Package.

6. Rehabilitation

The end of treatment can be a considerable adjustment for cancer patients. If managed inappropriately, it can leave patients feeling **lonely and scared**, which can be detrimental to the recovery process.

- It is estimated that 100,000 people diagnosed with cancer would benefit from participating in a rehabilitation scheme.

² National Cancer Improvement Network: *2011-2012 National Cancer Patient Experience Survey*

³ National Cancer Action Team: *Census of the Cancer Nurse Workforce 2011*

⁴ Quality of Life for Cancer Survivors in England: *Report on a pilot survey using Patient Reported Outcome Measures (PROMS)*

⁵ Bridging the Gap: *Improving outcomes for women with ovarian cancer, Pathfinder 2012*

⁶ Macmillan Cancer Support: *Cured but at what cost?* (2013)

⁷ NHS IQ: *Stratified care pathways: Redesigning services for those living with or beyond cancer* (2013)

- Studies show that a physical activity intervention can reduce the risk of cancer reoccurring for colorectal patients by up to 50%, and for breast cancer patients by 40%.⁸ Accordingly, a full assessment of rehabilitation needs should be done as soon as possible.

The APPGC is concerned that despite the evidence, the benefits of rehabilitation are not widely acknowledged across the NHS; whereas it should be viewed as an integral part of high quality care.

The Government should **promote rehabilitation**, including physical activity interventions and work with NHS England to develop **better models of care**. These models should be provided to CCGs to inform commissioning. In order to hold CCGs accountable, a **rehabilitation indicator should be included in the CCG OIS**.

7. Suggested questions to be posed during the Backbench Debate

We would be extremely grateful if you could raise the APPGC's recommendations during the debate and ask the following questions:

1. Will the Government formally respond to the *Cancer across the Domains* report and adopt its recommendations?
2. What steps will the Government alongside NHS England take to deliver the duties of the Mandate and address current low survival rates and deliver rapid progress?
3. How will the Government work with NHS England to ensure that implementation of the recommendations of *Cancer across the Domains* is thorough and timely?
4. What steps will the Government take to ensure full accountability of NHS England and CCGs to Parliament in the pursuit and delivery of improved cancer outcomes?
5. What assurances can the Minister give to ensure that five-year cancer survival rates will be adequately monitored at a local level?

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⁸ Department of Health: *At least five a week: Evidence on the impact of physical activity and its relationship to health* (2004)