

All Party Parliamentary Group on Cancer (APPGC) Submission to the Cancer Taskforce Call for Evidence

Executive Summary

- The three commitments the APPGC would like to see in the new cancer strategy are improved survival rates through early diagnosis, a reduction in inequalities and a focus across the whole cancer pathway which includes support for patients living with and beyond cancer.
- The UK's survival rates are amongst the worst in Europe. The cancer strategy should build on the momentum gained on this issue over the last few years and set a clear ambition for the UK to achieve the best cancer outcomes in Europe.
- Achieving the best survival rates will mean making significant improvements in early diagnosis through better awareness, training and ensuring that once diagnosed, patients can access the appropriate treatment quickly.
- The APPGC places great importance on the decision to put the one-year survival indicator, broken down by CCG, in the Delivery Dashboard of the CCG Assurance Framework from April 2015, as a means of promoting earlier diagnosis.
- Ensuring that the right accountability levers are in place will be essential. In particular, the cancer strategy should consider how this indicator will ensure underperforming CCGs raise standards on behalf of patients. This was raised again in the House of Commons during Health Questions to the Secretary of State on 24th February 2015.
- Inequalities have been a key issue in cancer care for a number of years, particularly where patient experience and the older people are concerned.
- On patient experience, the APPGC is pleased that mechanisms such as the Cancer Patient Experience Survey are now in place however greater focus is needed on accountability in this area.
- Whilst there has been a welcome focus on the outcomes of older people, the under 75 age limit on cancer mortality indicators in the key NHS accountability frameworks sends the wrong message about the priority of older patients in the NHS, and the cancer strategy should set out actions to rectify this.
- The number of people living with and beyond cancer is growing. If the cancer strategy is to deliver on the commitments around wellbeing and self-management set out in the NHS Five Year Forward View, it needs to have a strong focus on how it will support people with cancer to manage their condition. This should include better provision of information, personalised care plans and supporting people to stay in or return to work.
- The APPGC has identified four areas of good practice which should be rolled out more widely across the NHS – the Electronic Decision Support Tool to promote early diagnosis, the Values Based Standard to help Trusts implement improvements in patient experience, the Recovery Package, to help people live well with and beyond cancer and specialised services for teenagers and young adults.
- The key barriers to improving cancer services are limited accountability on key issues including survival rates, patient experience and access to data; and concerns about commissioning structures in the new NHS

1. Introduction

1.2 The All Party Parliamentary Group on Cancer (APPGC) welcomes the opportunity to respond to the Cancer Taskforce's first call for evidence.

1.3 With over three million people expected to be living with cancer by the end of the next Parliament (2020), the challenge for the NHS has never been greaterⁱ. The APPGC is

pleased that NHS England's Five Year Forward View' (5YFV) sets out the changes needed in the NHS, including its ambition for cancer which will be realised through a new cancer strategy. The renewed strategic focus on cancer is very welcome, and vital if we are to achieve the best cancer outcomes in Europe.

- 1.4 Our response to the Call for Evidence is based on research undertaken by the APPGC over a number of years, which has included extensive engagement with key stakeholders from across the cancer community. Many of our recommendations below are drawn from our latest report, published in December 2014, *Cancer across the Domains: a vision for 2020*.

2. Response to the Call for Evidence

Outline the three commitments that you would like to see in a new cancer strategy that would significantly improve cancer services for patients/the health of the public, referencing any relevant evidence and costing information

2.2 Commitment 1: The NHS will improve cancer survival rates by diagnosing cancer patients earlier

- 2.2.1 The UK's cancer survival rates are poor in comparison with other European countries, including those who have similar levels of wealth and health systems as our ownⁱⁱ. A key reason for this is that many cancer patients are diagnosed too late. Currently 1 in 5 patients are diagnosed as an emergency, and these patients are on average twice as likely to survive for less than a year compared to patients diagnosed via an urgent referral from a GPⁱⁱⁱ. The APPGC's Inquiry into Cancer Inequalities in 2009 also found that variations in early diagnosis were a key contributor to inequalities – more people from disadvantaged groups tend to be diagnosed later^{iv}.
- 2.2.2 The NHS 5YFV stated that if the initiatives set out in the vision are implemented effectively, the NHS can deliver a 10% increase in patients diagnosed early – equivalent to around 8,000 more patients. To achieve this, the new cancer strategy will need to be ambitious in addressing all of the causes of late diagnosis, including awareness amongst both patients and GPs of signs and symptoms, access to diagnostics and ensuring that the right accountability levers are in place.

Measuring survival rates and holding CCGs and local bodies to account on early diagnosis of cancer

- 2.2.3 The 5YFV emphasised the importance of using data to monitor and drive improvements, and the APPGC believe that early diagnosis of cancer is an area where this is particularly important. We were therefore pleased to hear the Chief Executive of NHS England, Simon Stevens, announce that from April 2015 an indicator on one year cancer survival rates will be included in the Delivery Dashboard of the Clinical Commissioning Groups (CCG) Assurance Framework—which is ultimately used to hold individual CCGs to account. The APPGC believes that by putting survival rates up in lights, individual CCGs will be encouraged to use local leadership to drive improvements.
- 2.2.4 Furthermore, it will give NHS England the ability to hold underperforming CCGs to account. The Minister for Public Health, Jane Ellison MP, recently stated in a debate in Parliament 'where the evidence [...] is that local providers are not meeting the standards, that will be challenged by NHS England'^v.
- 2.2.5 Other additional measures that will also help to achieve this aim and paint a complete picture of cancer at local level are the indicators on diagnosis via emergency routes, record of stage at diagnosis and other cancer specific indicators that are currently included in the 2014/15 CCG Outcomes Indicator Set.

- 2.2.6 The APPGC believe that NHS England now has the right ‘tools in the toolbox’ to drive improvements in early diagnosis, however the new cancer strategy has an important role to play in ensuring that this is implemented effectively.

Box 1:

The APPGC believes that the cancer strategy should:

- set out the standards expected of commissioners on one year survival rates for all cancers, and practical details of how CCGs will be held to account for improvements in early diagnosis.
- set out how NHS England will provide support for CCGs that are underperforming. This could include helping CCGs to identify appropriate interventions, or providing expert advice and training.
- be ambitious on improving early diagnosis, and recognise that whilst it is crucial to get the survival rates of underperforming CCGs up to the national average, it is equally important that those CCGs with the highest survival rates are still making significant improvements for the country to have the best outcomes in Europe.
- recognise the importance of accurate and timely data in monitoring improvements in early diagnosis and commit to the continued inclusion of the cancer indicators currently included in the NHS Outcomes Framework, CCG Outcomes Indicator Set, and the Delivery Dashboard of the NHS Assurance Framework.

Awareness campaigns

- 2.2.7 The 5YFV emphasises the importance of personal responsibility and the role of communities – including local authorities, employers and the NHS - in encouraging healthy lifestyles. As part of this, it is vital that patients are educated on the signs and symptoms of cancer, and empowered to seek help. There is a clear opportunity for the cancer strategy to lead the way in delivering on the 5YFV in this area by improving awareness of the signs and symptoms of cancer.
- 2.2.8 Since the publication of the 2011 cancer strategy, there has been welcome national leadership on the issue, particularly through the Be Clear on Cancer (BCOC) Campaign. The fourth annual report on the 2011 cancer strategy noted good progress on BCOC, with a number of campaigns resulting in increased diagnosis, reduced emergency presentation, and increased awareness and knowledge of symptoms.
- 2.2.9 However, the report also stated that ‘further decisions on BCOC activity will be made in 2015’, and whilst the Minister for Public Health, Jane Ellison MP, recently said that she would ‘argue strongly for their continuation’ it is essential that this commitment is embedded in the cancer strategy. Furthermore, the cancer strategy should look to demonstrate how it will deliver the 5YFV through involving schools, employers and local authorities in the drive to improve awareness of cancer signs and symptoms.
- 2.2.10 It is also important to ensure that awareness programmes are tailored to particular groups, including young people. Teenage Cancer Trust run an free education programme which provides education and advice about the signs of cancer, cancer treatments and prevention as well as healthy living to secondary schools, colleges and universities across the UK. An independent evaluation of this programme has found that schools talks increase the recognition of the number of cancer risk factors and warning signs and improves confidence to seek help when there are concerns^{vi}. Young

people also share the information they learn with their families meaning that this one intervention has a huge reach.

- 2.2.11 In addition to ensuring that the public are aware, it is also vital that GPs are supported to identify the signs and symptoms of cancer. Again, this is particularly important for young people. Research from Teenage Cancer Trust has shown that while two thirds of young people with cancer visited GPs with at least one of the most common cancer symptoms, one in four had to visit their GP at least four times before being referred. Similarly the 2014 Cancer Patient Experience Survey (CPES) showed that 25% of respondents saw their GP more than once/twice before referral.^{vii}
- 2.2.12 Improving GP awareness can be partly addressed through technological innovations such as the Electronic Decision Support Tool (see paragraph 2.5) however it is essential that key national bodies such as NHS England, Health Education England, and the Royal Colleges work together to ensure that training programmes on early diagnosis are available, appropriate and tailored to individual needs.

Box 2:

The APPGC believes that the cancer strategy should:

- reaffirm commitment and funding for the Be Clear on Cancer awareness campaign.
- set out how it will improve awareness of cancer symptoms for young people.
- set out roles and responsibilities of key national bodies in relation to the delivery of training on early diagnosis for GPs.
- harness the role of technology by promoting the value of electronic decision support tools.

Access to the best possible treatment

- 2.2.13 In *Cancer across the Domains*, the APPGC highlighted the unacceptable variations across the country with regards to accessing services and treatments such as radiotherapy and cancer drugs. Some progress has been made on the issue however significant improvements are needed if the NHS is to deliver 'better treatment and care for all' as set out in the 5YFV.
- 2.2.14 An area which is of particular concern is the Cancer Drugs Fund (CDF). The APPGC 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. Whilst additional funding for the CDF announced last year was welcome, it has been widely acknowledged that the Fund is not a long-term solution to the problem of fair and sustainable access to cancer drugs. The APPGC recognises the significant challenge of developing a sustainable system of drug pricing and assessment, and welcome the recent formation of the working party chaired by Professor Peter Clark. However, it is vital that momentum on developing a sustainable solution is maintained.
- 2.2.15 On radiotherapy, a number of recent initiatives have improved access to treatment, including the Radiotherapy Innovation Fund, and funding for trials by Cancer Research UK into the use of stereotactic ablative radiotherapy (SABR). In addition, the APPGC particularly welcomed the 10 year *Vision for Radiotherapy*, developed by NHS England and Cancer Research UK which considers the appropriate technology and capacity requirements needed to provide radiotherapy services to cancer patients in England.

Box 3:

The APPGC believes that the cancer strategy should:

- clarify plans for the future of the CDF.
- set out how the NHS will collaborate with partners including NHS England, NICE, cancer charities and the pharmaceutical sector to develop a new, sustainable and fair health technology appraisal process.
- use the *Vision for Radiotherapy* to inform the development of its plans for access to radiotherapy.

2.3 Commitment 2: The NHS will ensure that all cancer patients, regardless of age, ethnicity or socio-economic group, receive the very best cancer care and treatment.

2.3.1 In 2009 the APPGC conducted a nine-month Inquiry into Cancer Inequalities which included a number of oral evidence sessions and received around 90 written submissions from a range of stakeholders across the health sector. Many of the recommendations from our inquiry have been implemented; however there remain a number of key areas where further action is needed. Two areas of particular concern on this issue - which we believe should be given particular focus in the cancer strategy - are patient experience, and the poor outcomes of older people.

Patient Experience

2.3.2 The 5YFV places patients at the centre of the NHS. The cancer strategy must therefore ensure that patients are at the heart of the delivery of cancer care and services. A crucial part of this will be improving the experience of cancer patients, and addressing the inequalities which currently exist. This means ensuring that patient experience is prioritised throughout the NHS on the same level as patient safety and clinical outcomes.

2.3.3 There has been welcome progress on this issue, following the Francis report into the failings at Mid Staffordshire NHS Trust, including innovations such as the NHS Staff Friends and Family Test, and a new legal duty which will help carers receive the support they need. However, despite these developments, significant inequalities persist. The latest results from the CPES showed wide variations in the care that cancer patients receive^{viii}. For example:

- People affected with rarer cancers continue to report poorer experiences than people with more common tumours.
- People with a long term conditions, younger patients, older patients, some ethnic minority patients and patients being treated in London hospitals report poor care.

2.3.4 Addressing this issue requires stronger leadership from NHS England to ensure that all Trusts make improvements, and are held to account on the results of the CPES.

Box 4:

The APPGC believes that the cancer strategy should:

- reaffirm NHS England's commitment to continue undertaking the CPES
- commit to strengthening the CPES by:
 - ensuring that it has a specific focus on under-represented groups including young

people

- extend it to cover cancer patient experience in all settings
- improving the timeliness of data collection and analysis to ensure that results are relevant and Trusts are able to act on them efficiently
- set out a requirement for all Trusts to publish action plans based on CPES results and report progress on them annually.

2.3.5 Evidence has shown that there is a strong link between staff health and wellbeing and patient experience. A recent review of staff engagement in the NHS found that organisations with high levels of staff engagement report lower mortality rates, better patient experience and lower rates of sickness absence^{ix}.

2.3.6 Addressing inequalities in patient experience will require the NHS to ensure that all staff are supported in their roles. This includes improving health and well-being, as well as ensuring access to relevant training on issues such as patient experience.

Box 5:

The APPGC believes that the cancer strategy should:

- set out an ambition that all NHS staff are supported to deliver the best possible care.
- set out how this will be delivered, for example by mandating access to relevant training and requiring Trusts to be able to demonstrate action taken to improve staff health and well-being.

2.3.7 Whilst the experience of patients is key, it is important to recognise that cancer affects not only the person diagnosed but those around them, and particularly those who are carers. The APPGC was pleased to see this reflected in the 5YFV which set out an ambition to 'find new ways to support carers, building on the new rights created by the Care Act and especially helping the most vulnerable amongst them the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85'. This follows work from NHS England's work to formulate an action plan based on the experiences of carers, and to look at how CPES might be used to capture information about carers and families.

Box 6:

The APPGC believes that the cancer strategy should:

- ensure that it leads the way on delivering on the 5YFV ambition to find new ways to support carers.
- look at practical ways it can support local authorities to deliver on the statutory requirement to identify carers and signpost them towards information and support.

2.3.8 Delivering good patient experience is crucial throughout the cancer pathway, including 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 do so. There has been a growing consensus on the importance of ensuring that patients can die in a place of their choosing. In addition, it has been recognised that this could release significant cost savings across the NHS as the cost of keeping someone in a hospital bed is £250, compared to £145 per day for a comprehensive package of community support. Estimates from Macmillan suggest that around £345 million per year could be saved by introducing free social care at the end of life.

Box 7:

The APPGC believes that the cancer strategy should:

- set out a clear ambition on the number of people able to die in a place of their choosing.
- look at appropriate ways to measure quality of care in different settings, including at home.

Older people

- 2.3.9 Evidence has shown that older people generally have worse cancer outcomes. A report published by the National Cancer Intelligence Network in December said that there was 'substantial scope for improvement' in the outcomes of older people, and whilst it acknowledged that 'the reasons for poorer outcomes in older people are complex', it also acknowledged that there is 'a growing body of evidence to suggest under-treatment is a contributing factor'^x.
- 2.3.10 This finding was also corroborated by a recent National Audit Office report which said that cancer patients aged 55-64 are 20% more likely to survive for at least 1 year after diagnosis than those aged 75-99^{xi}.
- 2.3.11 Both of these reports echo the findings of the APPGC's Inquiry into Inequalities in 2009 which found that 'in general, older people with cancer receive less intensive and less radical treatment than younger people'.

Delivering improvements in the care and treatment of older people also requires the right accountability levers to be in place to incentivise change at a local level. The cancer mortality indicators in the NHS Outcomes Framework and the CCG Outcomes Indicator Set are only for people aged 75 and under. Whilst the APPGC understands that the increased likelihood of comorbidities in older people makes it difficult to develop robust cancer mortality indicators for people aged over 75, we believe that the lack of measurement sends the wrong message about the importance of the outcomes of older people with cancer and leaves a gap in accountability on a crucial issue.

Box 8:

The APPGC believes that the cancer strategy should:

- include a specific focus on the needs and outcomes of older people.
- make a commitment that all older people with cancer will receive a comprehensive needs assessment and appropriate advice on what treatment is best for them.
- commit to developing an appropriate indicator for people aged over 75 to measure the outcomes of older people with cancer.
- clearly set out how commissioners and providers will be held accountable for improving the outcomes of older people.

2.4 Commitment 3: The NHS will provide appropriate support and care to enable cancer patients to live well with and beyond cancer

- 2.4.1 Latest figures from Macmillan show that there are now 2.5 million people living with and beyond cancer in the UK, and this figure is expected to rise to 3 million by 2020, and 4 million by 2040^{xii}. Whilst this increase shows that we are getting better at treating cancer (people diagnosed with cancer now on average live for another 10 years, compared to just one year in the 1970s^{xiii}) it also means that there is an increasing number of people coping with the physical, emotional and practical consequences of cancer.
- 2.4.2 Ensuring that patients can live well with and beyond cancer requires a holistic approach, tailored to the needs of the individual. The APPGC has been pleased to see progress on this issue in the last few years through the National Cancer Survivorship Initiative (NCSI) and we welcomed the launch in August 2014 of the ‘Living with and Beyond Cancer Programme’ which will develop and implement a transitional plan for the NCSI following the health reforms. In particular, we welcome the focus of this Programme on the roll-out of the Recovery Package (see paragraph 2.7).
- 2.4.3 However, whilst there are a number of solutions to support people living with and beyond cancer, our 2013 report, *Cancer across the Domains*, found that many of these are not yet being delivered effectively across the NHS. Below we have outlined three examples of solutions which can improve the lives of those living with and beyond cancer, but are not yet being implemented fully. The cancer strategy has a key role to play in ensuring that all commissioners and providers are aware of solutions such as those outlined below, and are equipped with the right tools to implement them.
- 2.4.4 In addition, if the NHS is to tackle this issue and sustainably support the growing number of people living with and beyond cancer, we need to ensure that we understand where needs are not being met. Improving the lives of people living with and beyond cancer should involve routinely measuring quality of life post-treatment, and embedding this measure across the appropriate accountability frameworks. This is particularly important for groups such as young people who have unique care and survivorship needs

Provision of information on the consequences of cancer and its treatment

- 2.4.5 It is important that patients receive information on the consequences of cancer and its treatment, to help them cope and to prevent an increase in hospital readmissions. Evidence from the CPES suggests that this is not happening, with only 56% of the respondents saying they were definitely told about the side effects of treatment^{xiv}.
- 2.4.6 One example where provision of information is particularly important is for prostate cancer patients. Men with prostate cancer often live for a long time with their diagnosis, and with the side effects of treatment, which can include erectile dysfunction, urinary and bowel incontinence, aches and pains and hot flushes. Research commissioned by Prostate Cancer UK has found that erectile dysfunction in particular is a distressing side effect of treatment with significant ramifications for male self-identity. In addition, this can be difficult to discuss, which creates barriers to accessing support. Information is available (in the form of Macmillan/Prostate Cancer UK quick guides for health professionals supporting men with erectile dysfunction after surgery for pelvic cancer), however it is vital that this information is available and utilised by health professionals across the NHS^{xv}.
- 2.4.7 NHS England have previously been reluctant to take a proactive role in the provision of information, arguing that it is for the employers of healthcare professionals to ensure that

staff are equipped with the skills to deliver information on the consequences of cancer and its treatment. Whilst employers do have an important role to play, the APPGC believe that the cancer strategy provides an opportunity for NHS England to show clear leadership on this issue

Box 9:

The APPGC believes that the cancer strategy should:

- clearly define roles and responsibilities for ensuring that every patient receives information on the treatment and consequences of cancer.
- commit NHS England to developing standards on the level and quality of information which should be offered to all cancer patients throughout their journey.
- set out how providers will be held to account for the provision of information, which could include reporting as part of an action plan on the CPES.

Personalised care plans

- 2.4.8 Supporting patients effectively after treatment can boost their health and wellbeing, as well as releasing significant savings in the NHS. A key way of helping patients to self-manage is through Stratified Care Pathways, also known as personalised care plans. These plans, approved by NICE in 2013, 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.
- 2.4.9 NHS England has committed to developing and implementing a best practice standard for personalised, digital care plans, however the recent CPES results showed that only 22% of patients were offered a written assessment and care plan, a 2% reduction in the previous year's results^{xvi}.

Box 10:

The APPGC believes that the cancer strategy should:

- emphasise the importance of personalised care plans and set out how they will be embedded in service specifications and commissioning of cancer services.
- set an ambition for improvements in the number of patients offered personalised care plans and monitor progress of this target through the CPES.

Supporting people to stay in or return to work

- 2.4.10 Existing evidence suggests that over 700,000 people of working age are living with cancer^{xvii}. However, despite the fact that most people with cancer want to stay in work or return to it after treatment has finished, people who have had a cancer diagnosis are 1.4 times more likely to be unemployed than those who have not^{xviii}.
- 2.4.11 Research has shown that staying in or returning to work has demonstrable benefits for people living with and beyond cancer^{xix}. It is therefore important that employers are equipped with the right tools to support them. Whilst some people may simply need support to self-manage, others may need more specialist support such as vocational rehabilitation. However, currently only 2% of cancer patients access specialist return-to-work services.^{xx}

Box 11:

The APPGC believes that the cancer strategy should:

- recognise the personal and economic case for supporting cancer patients to stay in or return to work.
- commit to national commissioning of vocational rehabilitation services that meet the health and work needs of people affected by cancer.

Supporting young people to live healthily and independently

2.4.12 There are almost 17,000 15-24 year olds in the UK who have had cancer as a child or young person, and these young people have unique care and survivorship needs. It is important that any late effects of cancer or its treatments, both physical and psychosocial, are addressed in order to give them the best chance of going on to live long and productive lives.

2.4.13 The cancer strategy must set out how it will help to meet the NHS Mandate objective of 'supporting people with on-going health problems to live healthily and independently'. For young people with cancer this will involve commissioning that encompasses services from fertility preservation to self-management of anxiety and fatigue. These services must be complemented by the provision of specialist staff who can communicate effectively with young people to make them aware of the possible long term impacts of their treatment, and consequently better able to make informed choices.

Box 12:

The APPGC believes that the cancer strategy should:

- set out how it will support young people with cancer once treatment has finished, with a focus on commissioning services tailored to the needs of younger people.

Examples of good practice in cancer services that you would like to see replicated across the country

2.5 Electronic Decision Support Tool to support early diagnosis

2.5.1 As GPs might only see eight or nine new cases of cancer every year, it is important to ensure that they are equipped to recognise the signs and symptoms of cancer when they do appear. *Cancer across the Domains: a vision for 2020* highlighted recent technological innovation in this area by Macmillan. Macmillan worked with BMJ Informatica to develop an Electronic Cancer Decision Support Tool. The tool complements GP records software, helping GPs to recognise the symptoms of five cancer types, including those which are hard to detect such as ovarian and pancreatic cancer. The cancer strategy should consider how tools such as this which support early diagnosis and referral can be rolled-out across the NHS effectively.

2.6 Macmillan Values Based Standard® to improve patient experience

2.6.1 The Macmillan Values Based Standard® was co-designed with more than 300 patients, staff, carers and family members to provide a practical and innovative solution to improving the experience of patients and staff experience. The Standard is based on eight moments that patients and staff said mattered most to them. Patients wanted staff

to get these right and staff wanted to be empowered to deliver them. It empowers staff to improve the way they deliver care, and enables them to practice eight essential behaviours on a daily basis that embody dignity and respect.

- 2.6.2 The Macmillan Values Based Standard® is currently being implemented by providers in a number of areas across the UK, including London, Birmingham and Scotland. Early findings have demonstrated that implementing the Macmillan Values Based Standard® has led to improvements in patient experience
- 2.6.3 The APPGC is pleased that the Parliamentary Under-Secretary of State for Health, Jane Ellison MP, has confirmed that NHS England was encouraging use of the Values Based Standard. The Cancer Strategy should encourage further adoption of practical tools such as this which can ensure that all cancer patients receive a good experience of care.

2.7 Recovery Package to support people to live well with cancer

- 2.7.1 The Recovery Package has been developed by Macmillan as part of the NSCI. The Package is a combination of interventions including a holistic needs assessment 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. This combination of interventions - when delivered together - will improve outcomes.
- 2.7.2 The package addresses the problem identified by the National Patient Report Outcome Measures (PROMS) which have found that people who have experience cancer often have ongoing, unmet needs. If rolled out in full it will enable the NHS to adopt a more proactive approach to supporting cancer recovery, and reduce unnecessary hospital readmissions. The Recovery Package also represents a significant shift in focus from a 'one size fits all' approach to one which has the patient at the centre and is based on addressing individual needs.
- 2.7.3 In response to the APPGC's *Cancer across the Domains* report, the Government and NHS England confirmed that maximising the number of cancer patients benefiting from the components of the Recovery Package was a priority work programme for 2014. This was welcome; however despite assurances from the Department of Health that the Recovery Package is roll-out ready, anecdotal evidence suggests that this is not happening and that some parts of the package are being prioritised over others. The cancer strategy should reaffirm the need for significant progress on implementing and embedding this work across the health service in the plans of CCGs and Strategic Clinical Networks.

2.8 Specialist services for teenagers and young adults

- 2.8.1 Every year there are around 2,500 newly diagnosed 13-24 year olds with cancer in the UK, including around 2,000 in England alone.
- 2.8.2 There has been significant progress in this area over the last few years based on increasing recognition of the specific needs of teenagers and young adults^{xxi}. It is vital that this focus continues so we can continue to see progress and develop relevant models of care.
- 2.8.3 Teenage Cancer Trust has worked with the NHS and health professionals to establish the new specialism of Teenage and Young Adult Cancer in the UK. This includes significantly investing in their partnership with the NHS, building 28 dedicated units specifically for teenagers and young adults with cancer and funding nearly 50 specialist staff. This work is having a considerable and proven positive impact on patient

experience and the quality of care received within the UK. Internationally other countries are beginning to adopt this model of care.

- 2.8.4 Unfortunately, half of all young people with cancer are still not able to access the expert support they need that Teenage Cancer Trust provide. This means they may miss out on specialist age-appropriate care and the opportunity to gain peer support through meeting other young people with cancer.
- 2.8.5 Continuing their partnership with the NHS, Teenage Cancer Trust have been piloting a new Teenage Cancer Trust Nursing & Support service to extend current services beyond their existing units.
- 2.8.6 Trialed in the North West, the pilot included the Principal Treatment Centre in Manchester (The Christie) and 18 designated hospitals across the region. A range of specialist staff were put in place to support young people wherever they were treated, both at hospital and at home. These staff included one Lead Nurse, two Clinical Nurse Specialists, two Youth Support Coordinators and a Multi-disciplinary Team Coordinator. Towards the end of treatment young people will move on to Teenage Cancer Trust's new end of treatment programme preparing them for life with or beyond cancer.
- 2.8.7 The Teenage Cancer Trust Nursing & Support Service pilot was independently evaluated. The evaluation found that the new service model increased collaboration between the hospitals and entirely changed the culture and understanding of young people's support and care needs. Teenage Cancer Trust estimate that they are reaching close to 100% of all young people newly diagnosed in the region.
- 2.8.8 In addition to the impressive reach of this pilot, Teenage Cancer Trust have also provided what young people told us they need and the right age-appropriate holistic care is now available to all young people with cancer in the region.
- 2.8.9 Over the coming years the organisation will be working with hospitals and regions across the whole of the UK to roll out the new Nursing & Support Service.

The biggest barrier to improving cancer services

2.9 Accountability across the health service on cancer care

- 2.9.1 There are a number of areas on which the APPGC have concerns about accountability. These include accountability for improving survival rates, for improving patient experience and on access to data.

Survival rates

- 2.9.2 The APPGC has campaigned over the last few years to ensure that indicators on cancer survival rates are included in the key accountability frameworks used to monitor NHS performance – the NHS Outcomes Framework, CCG Outcomes Indicator Set and the Delivery Dashboard of the CCG Assurance Framework.
- 2.9.3 However, following the enactment of the Health and Social Care Act 2012, accountability for improving services and outcomes in the NHS has been unclear. Though the Government sets out its ambitions for the NHS through its Mandate, NHS England is not directly accountable to Parliament and there is uncertainty around what steps the Government is able to take if NHS England underperforms against the NHS Outcomes Framework.

- 2.9.4 This is a key issue which should be addressed by the cancer strategy, particularly with regard to the inclusion of an indicator on one year survival rates in the Delivery Dashboard of the CCG Assurance Framework. More detail on our views on this are set out in Box 1 however it is essential that the cancer strategy ensures that the accountability frameworks are used to full effect by NHS England to drive improvements at a local level.
- 2.9.5 In addition, if the Strategy is to deliver improved cancer outcomes in a climate of financial pressure and significant change for the NHS, it is essential that its implementation remains a priority for NHS England and the Department of Health.

Box 13:

The APPGC believes that the cancer strategy should:

- have a clear focus on how the NHS will be held accountable for delivering against the outcomes measures set out in the Frameworks, and set out clear roles and responsibilities for delivering against them.
- set clear realistic ambitions, outline how progress will be monitored and set out how the NHS – from the Department of Health down to commissioners and providers – will be held accountable for its successful implementation.

Improving patient experience

- 2.9.6 As outlined in paragraph 2.3.2 to paragraph 2.3.8 there has been a welcome focus on patient experience over the last few years, and the APPGC are pleased to see continued commitment to the CPES. However, we remain concerned that there are significant gaps in accountability of Trusts and CCG for using the results to deliver tangible improvements. Details on our recommendations for how to address this are set out in Box 4.

2.10 Concerns about effective commissioning

- 2.10.1 Whilst the Health and Social Care Act 2012 provided a welcome shift in focus from process to outcomes, the structural changes it introduced have resulted in a fragmented pathway for cancer patients.
- 2.10.2 Under the new structures, the responsibilities for cancer commissioning are fragmented with early and end of life stages of the pathway being commissioned by CCGs, specialist services being commissioned by NHS England local area teams, and prevention and awareness raising by Public Health England. This has resulted in no single body or person having overall accountability for the patient pathway.
- 2.10.3 In addition, many commissioners have reported a lack of clarity over the boundaries between specialised and non-specialised commissioning, as well as between CCG and local authority responsibilities. In particular, there is confusion about who is responsible for what aspects of end of life and palliative care and for the social, psychological and emotional aspects of cancer care.
- 2.10.4 There is a danger that some services are not being commissioned at all, as each commissioning body assumes the responsibility falls to another. Many commissioners are concerned that this could lead to patients “falling through the cracks” because of referrals not being picked up, or information not being properly shared between professionals^{xxii}.

- 2.10.5 Research from Macmillan Cancer Support has also shown that during the transition from Primary Care Trusts to CCGs, expertise and organisational memory on cancer commissioning was lost^{xxiii}. Specifically, the transition from Cancer Networks, which had a dedicated focus on cancer, to Strategic Clinical Networks, which look at a range of conditions, have meant that vital facilitation, coordination and communication in cancer commissioning has been lost. This means that:
- Commissioners now have very limited capacity to consider cancer specifically
 - There is a lack of information and training for people to commissioning cancer
 - Commissioners are struggling to performance manage providers to ensure they are delivery outcomes that matter to people affected by cancer
- 2.10.6 It is vital that the cancer strategy emphasises the importance of commissioning effectively across the whole cancer pathway, and sets out actions to deliver this.

Box 15:

The APPGC believe that the cancer strategy should:

- clarify cancer commissioning roles and responsibilities.
- allocate accountability at a local, regional and national level for commissioning of the whole cancer pathway.
- ensure that there is adequate resource to support cancer commissioning.

2.11 Access to Data

- 2.11.1 If the cancer strategy is to deliver transformational improvements in cancer care and services, it is vital that the NHS, and other organisations including charities, are able to use data to provide new insights into patient outcomes and improve services.
- 2.11.2 However, a number of charities and other organisations including Macmillan Cancer Support, Cancer Research UK and the London School of Hygiene and Tropical Medicine, have reported experiencing significant delays which have left vital projects stranded for months. In a recent Public Accounts Committee hearing, Cancer Research UK indicated that a research group has been waiting 16 months to access data on cancer waiting times, whilst Macmillan Cancer Support have been waiting over 18 months for access to outpatient and A&E data for a project which aims to improve the care of patients with head and neck, bladder, cervical and ovarian cancers.
- 2.11.3 There have been a number of reasons cited for the current issues around access to data. A report from the National Audit Office on cancer services highlighted changes to the way data is handled by the Health and Social Care Information Centre (HSCIC) as the cause. However, changes to the legal status of several of the bodies which hold data has also contributed. Many of these bodies have also been reorganised under the recent health reforms which has resulted in a reduced capacity for data analysis (a notable example of this is the NCIN which has been moved into Public Health England). Furthermore, poor communication and relationships between different organisations responsible for holding and releasing data are also a contributing factor.
- 2.11.4 In a recent Parliamentary debate, Jane Ellison MP announced that Public Health England has agreed the legal basis for the transfer of data with HSCIC, and that a new agreement is now in place which should allow the Health and Social Care Information Centre to release data to Public Health England.

- 2.11.5 Whilst this represents a positive step, it is important to ensure that this data is able to flow out of Public Health England to organisations using it for improvement projects and research such as those carried out by Macmillan and Cancer Research UK.
- 2.11.6 In a recent report, the National Audit Office focused on this issue, and recommended that the Health and Social Care Information Centre (HSCIC) should ‘introduce a system through which it can be held to account for how effectively it is discharging its responsibility to disseminate data to help drive improvements in health and social care’. It went on to recommend that as a minimum the HSCIC should seek and publish the results of regular feedback from NHS data users.

Box 14:

The APPGC believes that the cancer strategy should:

- play a key role in recognising the power and potential of data to improve outcomes, as emphasised in the 5YFV.
- echo the National Audit Office recommendation to introduce a system through which it can be held to account for how effectively it is discharging its responsibility to disseminate data to help drive improvements.
- set out clearly the type of data that health bodies can and cannot share with external organisations (such as Macmillan and CRUK) and the instances where discretion could be used by officials.

2.12 About the APPGC

- 2.12.1 The APPGC was founded in 1998 to keep cancer at the top of the political agenda and to ensure that policy-making remains patient centered. The Group brings together MPs and Peers from across the political spectrum to debate key issues and act as the voice of the cancer community in Parliament. We annually host one of the largest one-day conferences on cancer in the UK, Britain Against Cancer, which has been addressed by the Secretary of State, Shadow Secretary of State, Chief Executive of NHS England, and National Clinical Director for Cancer.

For more information on any aspect of this submission, please contact the APPGC Secretariat, Rebecca Leech at rleech@macmillan.org.uk or on 020 7091 2013

ⁱ Maddams J, Utlely M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 107: 1195-1202. (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015.

ⁱⁱ Eurocare 5 Survival Analysis 2000 – 2007, 2013, (<https://w3.iss.it/site/EU5Results/> accessed January 2015)

ⁱⁱⁱ National Audit Office, 2015, Progress in Improving Cancer Services and Outcomes in England

^{iv} All Party Parliamentary Group on Cancer, 2009, Inquiry into Cancer Inequalities

^v House of Commons, Improving Cancer Outcomes, 2015

(<http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150205/debtext/150205-0003.htm#15020561000002>)

^{vi} Kyle et al. *BMC Public Health* 2013, 13:190 <http://www.biomedcentral.com/1471-2458/13/190>

^{vii} NHS England, 2014, Cancer Patient Experience Survey 2014 National Report

^{viii} These findings are based on analysis of the 2011-12 CPES by the University of Cambridge, funded by Macmillan Cancer Support. This uses mixed effects logistic regression models to predict positive/negative experience and calculate ranks within each socio-demographic category considered.

<http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/2013CPESInsightBriefingFINAL.pdf>

^{ix} Chris Ham. Improving NHS care by engaging staff and devolving decision making. July 2014

^x National Cancer Intelligence Network and NHS England, 2014, Older People and Cancer

^{xi} National Audit Office, 2015, Progress in Improving Cancer Services and Outcomes in England

^{xii} See i.

^{xiii} Macmillan Cancer Support, *Cancer: A colossal Challenge: the 2.5 million, 2015*

(<http://www.macmillan.org.uk/Images/GetInvolved/Campaigns/GeneralElection2015/25-Million-Infographic-full-Jan2015.jpg?origin=GE2015-bodylink> accessed February 2015)

^{xiv} NHS England, 2014, *Cancer Patient Experience Survey 2014 National Report*

^{xv} Prostate Cancer UK conducted a paper and online survey of 600 men who had experienced ED as a result of prostate cancer treatment between August 2013 – February 2014. Publication expected in 2015.

^{xvi} Ibid

^{xvii} 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.*

^{xviii} 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

^{xix} 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

^{xx} 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.

^{xxi} This includes NICE guidelines (NICE CYP IOG (2005), NICE TYA Quality Standard, NHS England Teenagers and Young Adult Clinical Reference Group and Public Health England's framework for improving young people's health and wellbeing)

^{xxii} Macmillan Cancer Support, 2014, *Lost in Transition*

^{xxiii} Ibid