# Transforming the Cycle in Cancer Care



Bristol-Myers Squibb developed and funded the Transforming the Cycle in Cancer Care meeting, on which this report's conclusions are based.

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# Introduction

Cancer costs the UK more than £16bn a year.<sup>i</sup> Despite this, incidence is rising and cancer survival lags behind much of Europe."" The NHS is also facing increasing demands on its services, caused by an ageing population and lifestyle factors like obesity and smoking.<sup>iv</sup> These pressures are only set to increase. By 2050, 60% of adult men and 50% of adult women are expected to be obese,<sup>v</sup> and there will be four million more pensioners than people aged under 16 by 2035.<sup>vi</sup> This is putting growing pressure on NHS services and forcing them to seek further cost savings and efficiencies year on year. Despite this, new opportunities are available in cancer care.<sup>iv vii</sup> According to the European Cancer Concord 2016, a Europe-wide long-term survival rate of 70% for all cancers is a suggested goal by 2035.<sup>viii</sup> They identify that this is only possible with rapid uptake of new innovations and the identification and effective dissemination of best practice across NHS services.viii This report aims to support the NHS to meet these aims, recognising the need to deliver 'more with less' in the current challenging financial climate.

The content and conclusions in this report have been developed from a working group meeting which brought together experts from across the cancer policy space. A list of contributors is included as an appendix to this report. Both the report and the meeting were sponsored by Bristol-Myers Squibb (BMS) and the working group was chaired by Katherine Murphy of the Patients Association.

# the patients association

# Cancer in the UK – The Negative Cycle of Cancer Care

Cancer affects hundreds of thousands of people in the UK every year.<sup>ix</sup> In 2014, there were 356,860 newly diagnosed cases of cancer, or one every two minutes.<sup>ix</sup> In the same year, cancer was responsible for more than 160,000 deaths, at a rate of 450 people per day.<sup>ix</sup> This is a growing problem and combined incidence rates for all cancers have increased by 30% since the late 1970s.<sup>ii</sup> It is now thought that one in two people born in the UK after 1960 will be diagnosed with some form of cancer in their lifetime.<sup>ix</sup> Similarly, it is now estimated that more than 2.5 million people are now living with cancer in the UK, an increase of almost half a million over a five year period.<sup>x</sup>

Not only is a cancer diagnosis a life changing experience, but it is hugely costly to both the NHS and the wider economy. Rising incidence rates place additional financial and capacity pressures on the NHS, at a time when the financial settlement is tight and efficiency savings are required to be found.<sup>vii</sup> Overall, the total cost of cancer in the UK is estimated at £16.277 billion, only a third of which is direct spending on healthcare.<sup>i</sup> Other costs include lost hours of unpaid work, with as many as 211 million hours lost in the UK each year as a direct result of cancer.<sup>i</sup>

These financial pressures can often lead to money being allocated towards short-term approaches, focused on managing immediate pressures, rather than shaping services around accepted best practice. For instance, the NHS currently spends £130m every

# How does the UK compare to the rest of Europe?

Cancer survival rates in the UK are lagging behind Western Europe.<sup>xv</sup> According to the 2015 Eurocare study, UK cancer survival rates across a range of tumour types are lower than other Western European countries.<sup>xv</sup> Similarly, one study showed that it has taken a decade longer for survival rates in some tumour types to reach the same levels achieved in comparable EU nations.<sup>xvi</sup> However, whilst survival rates in the UK have improved, they remain approximately 10% lower than the European average for patients diagnosed between 2000 and 2007.<sup>xvii</sup>

Despite lagging behind Western Europe in terms of cancer outcomes, the UK spends comparatively more money on healthcare than the rest of Europe.<sup>i</sup>

year on emergency care for discharged patients<sup>i</sup> and it is estimated that late diagnosis of cancer costs an extra £210m a year.<sup>xi</sup> More than a third of lung cases in England present as an emergency admission and one year survival for this group of patients is less than 50%. <sup>xii</sup> Investing more in early diagnosis and detection may lead to earlier diagnosis, therefore creating a longer term approach.<sup>xiii</sup>

A focus on managing these sub-optimal outcomes leads to fewer resources being available to invest in services and there are currently shortages of oncologists, pathologists, radiologists and cancer nurse specialists in England.<sup>1</sup> Similarly, sub-optimal resource allocation ensures that there is limited funding for cancer drugs and risks restricting access to new treatments like immuno-therapies, which the NHS Cancer Strategy identified as "potential game changers".<sup>xiv</sup>

Currently there is a negative cycle in cancer care, where a short-term approach leads to rising costs in cancer, makes fewer resources available, provides inadequate patient support which re-enforces the need for a short-term 'just managing' approach.

It is welcome that the NHS has set itself the target of radically improving cancer outcomes over the next five years, however it is likely that this target will have to be achieved without significant extra investment.<sup>xv</sup> We therefore need to examine how we can deliver service more efficiently.

Health represents 16.7% of government expenditure in the UK, more than the EU average of 14.8%.<sup>1</sup> However, the UK only allocates 3.8% of healthcare spending on cancer, less than the EU average of 5%.<sup>1</sup> Relative to disease burden, cancer receives less funding in the UK than other major diseases, such as stroke and dementia.<sup>1</sup>



# BREAKING THE CYCLE IN CANCER CARE

Half of all British people (under 65 years) will receive a cancer diagnosis during their lifetime.<sup>1</sup> The NHS has set itself the target of radically improving cancer outcomes over the next five years<sup>10</sup>, while developments in the diagnosis and treatment of cancer have the potential to help people live better, for longer. While investment is required to enable greater efficiencies in the NHS, with no additional funding immediately available we need to examine how we can potentially deliver more for less. To do so, we need to break the negative cycle of cancer care, where a short-term approach can often lead to longer-term costs.<sup>10</sup>



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# **Recommendations and Discussion**

Having discussed the issues related to cancer care in the UK, working group participants identified areas where the NHS can do things more efficiently, improving patient outcomes using the resources currently available. The following recommendations are drawn from these discussions:

# Identifying, incentivising and implementing best practice

There are a number of documented examples of best practice, both within the NHS and across other health services, which have a proven record of improving patient outcomes and maximising resource allocation. However, there is currently no systematic way for the NHS to identify where best practice exists and whether or not it is replicable on a wider scale.

The NHS should establish a system which can identify, analyse and, if appropriate, encourage the replication of best practice in cancer care. This system could be hosted by a rejuvenated NHS Cancer Peer Review, NICE, or by NHS Improvement (formerly known as NHS Improving Quality).

Once an alternative model of service delivery has been identified, there needs to be a stronger focus on ensuring uptake of these methods and clear dissemination of outcomes data. To facilitate this, an incentive structure is required which encourages the uptake of best practice. This could be achieved

### Developing effective prevention strategies

Around 40% of all cancers are caused by lifestyle factors and are therefore preventable.<sup>ix</sup> Smoking is linked to 19% of cancer cases in the UK, making it the largest preventable cause.<sup>xviii</sup> Other high profile and preventable causes are dietary factors (linked to 9% of cases), alcohol (4%) and obesity (5%).<sup>xix</sup> Relative income is also linked to survival – 19,200 deaths a year could be avoided in England if cancer incidence in deprived areas dropped to that of the best-off.<sup>x</sup>

The NHS could also consider how other innovative and longer term solutions might be used to tackle the lifestyle factors that cause cancer. For instance, NICE has identified a number of cost-effective steps via mechanisms such as the Quality Outcomes Framework (QOF), best price tariffs or through NHS England service specifications.

Alongside this, NHS staff should be encouraged to openly discuss how their own services could be improved, to identify weaknesses in current service design, and to develop and share their own examples of best practice. Team members in different parts of the NHS should also be encouraged to communicate and collaborate on a more regular basis, in order to help generate and share ideas. Similarly, when a new service method is adopted, staff should be fully briefed on its operation, ensuring that they are willing and able to implement these processes.

Working group members agreed that the introduction of new incentive structures would prove cost neutral, with the cost of establishing and maintaining any new system offset by the benefits of implementing successful and innovative schemes. A number of such examples are included throughout this report.

that could be taken by the NHS to reduce obesity. This cost-effective solution involved GPs prescribing a 12 week weight loss programme to obese people meeting certain requirements to encourage them to lose weight.<sup>xx</sup> This would have a number of health advantages, as well as leading to a long term cost saving for the NHS. Obesity cost the NHS almost £16 billion in 2007, a figure which is predicted to rise to £50 billion by 2050.<sup>xx</sup> As maintaining a healthy weight is seen as a key way of preventing cancer,<sup>xxi</sup> this is another example of where more effective use of services across the NHS could reduce both the risk of cancer and save the NHS money, further helping to break the negative cycle of cancer care.

### Implementing best practice in the early diagnosis of cancer

One of the key determinants of patient survival is the point at which the cancer is diagnosed. Survival chances are higher if a tumour is identified earlier and considerably lower if the patient is diagnosed with later stage (stage IV) disease.<sup>xoii xoiii</sup> For instance, for tumour types typically associated with difficulties in diagnosis or treatment – stomach, brain, oesophageal, lung and pancreatic – survival is less than 20%.<sup>xoii</sup> Not only is late diagnosis bad for patients, but it is estimated to cost the NHS just under £210m a year.<sup>xoiv</sup> Working group participants were clear that a renewed focus on early diagnosis is one of the most effective ways to improve patient outcomes. Attendees identified that in order to improve early diagnosis, it is important to raise public awareness around the risk factors and symptoms of having cancer. For instance, a number of tumour types such as lung and bowel cancer have identifiable symptoms and if patients understand this, then they are more likely to selfrefer at an earlier stage. To achieve this, it was considered that patient groups have a key role to play in educating and disseminating information and it important they are given a key role, not excluded from the NHS decision making processes.



# CASE STUDY: Beating Bowel Cancer's 'Community Bowel Screening Volunteers Project' in Greater Manchester

# The Challenge

- More than 40,000 people are diagnosed with bowel cancer each year in the UK and almost 16,000 people die as a result.xxv
- The aim of screening is to lower the burden of cancer in the population by discovering disease in its early latent stages. This permits more effective treatment than if diagnosed later when symptoms occur. Early treatment of invasive lesions can be generally less detrimental for quality of life. Randomised trials in people of

# **The Solution**

- Beating Bowel Cancer is training volunteers in selected areas of Greater Manchester to go in to GP practices and phone people who have recently been invited for screening, but have not responded. They look to have informative, non-pressured conversations about the importance of bowel screening.<sup>xxviii</sup>
- If consent is given, then a new bowel screening

### Outcomes

- It is still the early stages of the project; however we have already seen 24 volunteering sessions happen in 10 different practices. 377 people have been spoken with and 245 (65%) have decided as a result to opt in to screening and be resent a kit.<sup>xxix</sup>
- We will be tracking outcomes on an individual basis via GP practices, so when we have this data we will know the rates of the number of people who we resent a kit to who then completed.xxix

The Working Group also highlighted the importance of looking to the rest of Europe for examples of best practice and more efficient cancer diagnosis. One example is Denmark, which has a similar "GP gateway" health service to the UK. To tackle cancer diagnosis, the Danish health service has adopted a "three-legged diagnostic strategy". This involves stratifying patients and referring those with symptoms of different severities to different services.<sup>xxxi</sup>

Under the Danish system, patients with specific "alarm symptoms" are referred urgently to a fasttrack pathway, while patients with serious but nonspecific symptoms are filtered via a diagnostic centre in a hospital before being referred if necessary to the fast-track pathway. These diagnostic centres are medical units with comprehensive facilities for medical investigation, including easy access to expertise in a wide range of relevant specialities. average risk invited to attend screening have shown a reduction in mortality and incidence.<sup>xxvi</sup>

- Despite this, currently only 58% of people take part in bowel screening nationally<sup>xxvii</sup> and only 53% in parts of Greater Manchester.<sup>xxviii</sup>
- Uptake rates track closely to deprivation levels in parts of the country, increasing health inequalities. In more deprived communities participation can be lower than 40%.<sup>xxviii</sup>

FOBt kit is sent to them to complete.xxviii

- When selecting which GP practices to work with, there has been a clear prioritisation of GPs in the most deprived areas, with the lowest uptakes.xxviii
- All volunteers are fully trained in the importance of data protection and confidentiality and do not have access to patient records.<sup>xxviii</sup>
- Data from NHS Scotland's bowel cancer screening service shows that more than 60% of patients diagnosed as a result of the screening programme are diagnosed at an early stage.<sup>xxx</sup>
- As well as the survival benefits involved, treating bowel cancer patients at an early stage will also save the NHS money in the long term. The cost of treating a stage 4 bowel cancer patient is estimated at £12,519, whereas the cost of treating a stage 1 patient is just £3,373.<sup>xi</sup>

For patients with "low risk but not no risk" symptoms, GPs now lead "no-yes clinics". This involves the GP keeping responsibility for patients while they undergo diagnostics that would traditionally have required being admitted to hospital. For example, GPs may be able to send patients directly for colonoscopies or CT scans as required. Studies have shown that this has led to a reduced time to diagnosis and a more efficient use of testing resources.<sup>xxxi</sup>

# Delivering timely access to treatment

Whilst early diagnosis is key to improving patient survival, it is important that once diagnosed, patients are appropriately referred and can begin the most appropriate course of treatment.

Speeding up the diagnostic process will naturally lead to patients being able to receive treatment at a faster pace. One example included within the Cancer Strategy is to increase the provision for molecular testing and diagnosis available to cancer patients.<sup>xiv</sup> While many such tests are available to cancer patients, access is varied and as a result many patients have suffered delays in accessing treatment. In 2014, figures show that 35,600 patients needed access to testing but only 19,600 received them – leading to 3,500 people missing out on treatment. Increasing access to these tests will improve patient outcomes and focus NHS spending on the most effective treatments for each individual.<sup>xxxii</sup>

Whilst wider changes to national commissioning may be needed to address this issue, existing tools such as the Royal College of Pathologists Cancer Molecular Diagnostics Planning & Commissioning Toolkit (ImPACT) can help to address these system blockages. This tool helps services to judge whether a molecular test will be cost effective. Secondly, it also suggests adopting a "reflex testing" pathway, whereby the service goes straight to a diagnostic test, removing the need for a second MDT meeting before treatment decisions can be made. It is suggested that this can save as much as £125 per patient.<sup>xxxiii</sup>

## Engaging patients in in delivering innovative care pathways

Educating patients with cancer about self-management and empowering them to play an active role in the decision-making process was considered to likely result in an improvement of patients' knowledge, understanding of their condition, adherence to treatment and engagement in their healthcare. Whilst not all patients will want to play an active role in their treatment and care, it is important to provide patients with the opportunity and the choice to make their preferences clear and also tell us what a "good" treatment outcome looks like for them.

The Working Group described these users as "activated patients" who can lead the charge for the adoption of best practice care. According to Working Group attendees, the evidence suggests that "activated" and informed patients use an average of 20% fewer resources than less informed counterparts. Similarly, the growth of digital medical technologies provides an opportunity to better inform and engage patients and

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provide them with clear, understandable and validated information, which is consistent with the principles of shared decision-making.

Anecdotal evidence from the ambulatory lung biopsy service provided by Dr Sam Hare in Barnet (see below) suggests that patients who have heard about the service but live outside the hospital's traditional catchment area have often asked to undergo the procedure they have on offer. This advocacy from service users may, in the long term, lead to the adoption of these examples of best practice in more hospitals around the country.

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# CASE STUDY: Ambulatory Lung Biopsy: A New Model For The NHS – Dr Sam Hare<sup>xxxiii</sup>

# The Challenge

- Lung biopsies are used to collect cells from cancer tumours for further diagnosis and analysis. \*\*\*\* The use of lung biopsies are pivotal in lung cancer diagnosis, and are also essential to meet the growing demand for tissue that can be analysed by multi-disciplinary teams.\*\*\*\*
- Currently, patients due to receive a biopsy are booked into either a daycare or an inpatient bed.

# The Solution

- An innovative diagnostic pathway has been established by the Royal London Free NHS Trust at Barnet hospital which allows the performance of lung biopsies on an entirely out-patient basis, entirely independent of the need for hospital beds. The service is delivered by the hospital's radiology department using the same procedure as conventional NHS lung biopsies.<sup>xxxvi</sup>
- Instead of a standard NHS 4-to-6 hour post biopsy admission for monitoring, the patient receives a chest x-ray at 30 minutes after biopsy and is discharged if there is no lung collapse.

#### Outcomes

- Since 2011, the service has performed more than 900 outpatient biopsies. More than 98% of these biopsies were able to be used to deliver a diagnosis, and more than 99% of patients were discharged early. 85% of biopsies were performed within seven days, and just under 49% were performed within four days.\*\*\*\*
- The service has seen a 73% increase in lung cancer resection rates, especially for small, localised, lung cancers.xxxvi
- The service is also able to perform biopsies on patients who would not have previously received them due to being deemed as high-risk of developing a collapsed lung.<sup>xxxvi</sup>

The patient usually occupies this bed for between 4 and 6 hours for post biopsy monitoring. This period is extended to at least 24-48 hours for patients who develop a significant lung collapse (pneumothorax), the commonest complication of lung biopsy.<sup>xxxvi</sup> It is estimated that each day a patient spends in a hospital bed costs the NHS £400. <sup>xxxvii</sup> xxxvii</sup>

This allows 99% of patients to be discharged within 1 hour (including 82% at 30 minutes). The streamlined pathway means patients do not have to spend several hours in hospital for post biopsy monitoring, as is conventional NHS practice.<sup>xxxvi</sup>

- If patients do develop a pneumothorax, they are treated at home using a discreet, portable device called a Heimlich-valve chest drain (HVCD). This means they can be treated as outpatients rather than spend days in a hospital bed connected to a standard chest drain. XXXIV XXXVI
- This approach allows for a ten-fold increase in the number of biopsies that can be performed by the team in Barnet. It has saved at least 3.5 – 5.5 bed hours for uncomplicated biopsies, and £400/ day for patients with a significant pneumothorax (lung collapse) who would have previously occupied a bed as a result. xxxiv xxxiv
- For patients, the faster biopsy service can improve their experience of care and the speed at which they are diagnosed while avoiding unnecessary hospital admissions.<sup>xxxvi</sup>

Further details on this service can be found via: https://www.england.nhs.uk/2016/06/sam-hare/



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#### Maintaining a focus on less common cancers

Working Group attendees highlighted that whilst there may be a temptation to focus on the four tumour types with the largest patient populations – lung, prostate, breast and colorectal - it is important to maintain a targeted focus on rarer cancers. For instance, whilst bringing lung cancer survival in the UK up to the European average would statistically improve overall performance, this would not benefit many patients with rarer tumours. Similarly, since many rarer cancers fall under the remit of direct NHS England specialised commissioning there is an additional need to optimise how money is spent. The specialised commissioning budget is facing increasing financial pressure and a focus on simply optimising resources for the big four cancers, risks seeing patients with rarer cancers fall further behind. The below case study provides an example of effective service redesign for patients with a rarer form of cancer:

# CASE STUDY:

# Pancreatic Cancer - Fast Track Surgery To Minimise The Need For Biliary Stenting

### The Challenge

- Pancreatic cancer is the 11th most common cancer in the UK, xxxviii however, it has the lowest survival rate of the 20 most common types of cancer. xxii
- Most patients who need to undergo surgery for pancreatic cancer have jaundice. Delays to surgery result in most patients needing treatment for jaundice which involves placement of a stent within the bile duct.<sup>xxxix</sup>
- Evidence suggests that this procedure is potentially harmful. It is often distressing for

### **The Solution**

- University Hospitals Birmingham (UHB) is one of the largest centres for complex pancreatic surgery in Europe.<sup>xxxix</sup>
- It has developed a 'fast track' pathway to avoid biliary stenting, supported by a grant of £50,000 from Pancreatic Cancer UK.<sup>xxxix</sup>
- The pilot saw the Multi-Disciplinary team at UHB meet to discuss patients, followed by surgical and anaesthetic review, all taking place within 7 days of referral. The aim of the pilot was to deliver surgery within 7 days of that MDT meeting.<sup>xil</sup>

patients and can put patients at risk of infections and pancreatitis. The procedure itself is also costly to perform.<sup>xxxix</sup>

- It is therefore desirable to perform early surgery without stenting where possible, but this is not routine in the NHS.<sup>xxxix</sup>
- Currently, it often takes between two to three months from presentation at a local hospital to surgery. Early diagnosis could significant reduce the time to surgery.<sup>xxxix</sup>
- The median time from CT scan to resection fell from 65 days on the normal pathway, to just 16 days on the fast track scheme. This has a measurable effect on patient outcomes, which can get demonstrably worse if there is a longer wait between diagnosis and receiving surgery.<sup>xl</sup>
- The fast track scheme also cost £3,178 less per patient using the fast track scheme prior to the operation taking place.<sup>xi</sup>

# Working together to make innovation a reality

Successfully implementing the recommendations in this report and encouraging the implementation of best practice will require an engaged and collaborative approach to be adopted across the NHS. Barriers between services, as an unwillingness to cooperate between providers, need to be overcome. NHS England and other national bodies must proactively engage with local areas in order to ensure they have the support they need to adopt best practice as guickly as possible after this has been identified. Where possible, this should include sharing support such as legal advice and commissioning plans (including contracting) to avoid the unnecessary and wasteful duplication of resources. As far as is practicable, any cost savings accrued by the adoption of best practice should also be used for transforming and modernising services rather than sustaining the current, sub-optimal way services are often delivered. This is currently not occurring across the NHS, despite the importance placed on transformation planning by the Five Year Forward View.<sup>xli</sup>

One way this might be achieved is by taking a whole pathway approach, bringing key stakeholders from across the NHS on board. NHS England is working with a Clinical Expert group in lung cancer, along with partners such as NHS Right Care, to introduce a new "Optimal Care Pathway" for the condition. This is aimed at decreasing the time to diagnosis and fast tracking patients to treatment and care. The outcomes associated with this approach are still to be measured, but it is hoped that it will both improve patient survival and also make better use of NHS resources by focusing on overcoming logistical challenges in lung cancer care.<sup>xiii</sup>

### Looking to the future

The recommendations in this report are aimed at NHS cancer services as they are now and look to spread existing examples of best practice more widely. However, contributors to this report also noted that there is a significant pace of technological change that must be contended with when designing NHS services for the future.

While the current financial strain on the NHS means changes need to be made to transform cancer services now, commissioners and policy makers should also continue to look to the future and consider what younger generations will need from cancer services as well as the current patient population.



# Recommendations

1 While there are understandable pressures on the NHS, commissioners must take a long term view to break the negative cycle in cancer care. Sharing and implementing innovative examples of best practice must be a priority, particularly where it can demonstrably improve patient outcomes and reduce financial pressures on services.

2 NHS Improvement, or a similar body, should establish a system to identify best practice in cancer care and to disseminate that knowledge across the health service. It should also monitor the level of uptake of best practice, and measure the impact it has had on patient outcomes and NHS budgets.

The NHS should also reform its system of tariffs and incentives in order to offer financial incentives to NHS providers who introduce identified best practice care to their services, and remove similar incentives for outdated and more expensive systems.

4 Commissioners of cancer services must work across the NHS to prioritise health promotion and disease prevention strategies that will have the most impact on cancer incidence. For example, successful obesity prevention campaigns can considerably reduce the risk of preventable cancers.

5 Early diagnosis is central to improving cancer survival. The NHS must explore ways to widen the availability of molecular testing and to refer patients to diagnostic services as quickly as possible, including by reforming primary care services.

Once patients have been diagnosed, it is essential that patients are also able to access treatment as quickly as possible. It may be possible to use the savings accrued by introducing best practice care to help improve patient access to treatment, including new forms of care.

 Patients and staff must play an active role and be fully engaged in the process of service change.
This will help drive uptake and adherence to identified examples of best practice.

8 The NHS must ensure that any efforts to identify and disseminate best practice focus on a broad range of tumour types, including those considered to be 'rarer' cancers. This will ensure the negative cycle of cancer care is transformed for all patients.

# Conclusion

The NHS is under considerable financial pressure, and cancer services are no different. This short term approach in how services are designed and managed can in turn lead to poorer patient outcomes and a less efficient use of resources. This negative cycle of cancer care can be overcome. The examples of best practice demonstrated throughout this report show that a forward thinking approach, if replicated across the health service, can both improve the experience and outcomes felt by patients and make a better use of existing NHS resources. Our recommendations set out a clear path to implementing such an approach, and each step is a simple change requiring little to no extra funding from the NHS. Cancer services must take the initiative and set about implementing best practice now, or it risks being unable to benefit from new advances in diagnostics, care and treatment that can transform the lives of patients.

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