



Cancer in 2020 and beyond

Cross-sector insights into improving
outcomes for cancer patients

Winter 2020

Foreword



It has been an incredibly difficult year for cancer patients, clinicians, researchers and charities. Although we don't yet know the full extent of the impact, devastatingly, all predictions suggest that the coronavirus pandemic will result in avoidable loss of life among people with cancer.

Before the pandemic, cancer outcomes in the UK were improving. Data published by the Institute of Health Economics in Sweden earlier this year – comparing cancer care and outcomes in 31 European countries – demonstrated that, although cancer incidence in the UK was rising, deaths due to cancer actually declined and survival was increasing. However, the UK's survival across a number of tumour types fell behind many European countries, including those of comparable size and wealth.

The challenge we face in both reversing the impact of the pandemic on cancer services and improving UK cancer outcomes in the long term is significant, and will only be achieved if the entire cancer community works hard together to make it happen.

The ABPI is determined to play its part in this effort, utilising our experience of working in partnership with Government, the NHS, NICE, industry and the wider life sciences community. We believe that a comprehensive and systemic approach is needed. For this report, we consulted experts across the UK cancer ecosystem on both challenges and opportunities for improvement, qualified by the responses we received about the pandemic. This report summarises these discussions and draws out recommendations for change that, if implemented, our contributors believe would lead to meaningful improvements for cancer patients in the UK far beyond the pandemic recovery.

The message is clear – we now need to see the Government, NHS, industry, charities and all other stakeholders build on the effective partnerships that have been made stronger since the beginning of the pandemic to drive the implementation of good practice and spread of innovation and learnings from other countries. We owe it to current and future patients to do nothing less.

Paul Catchpole, PhD
Director, Value and Access Policy

The Association of the British Pharmaceutical Industry

Demonstrating ambition in strategy and funding

- The Department of Health and Social Care (DHSC) should reassess the timelines and resources required to deliver cancer outcomes that are comparable with other European and G7 countries, and mandate NHS England & Improvement (NHSE&I) to work with the cancer community to develop an updated strategy for achieving this goal.
- Government should commit to implementing the recommendations of *Diagnostics: Recovery and Renewal* – the independent review of diagnostic and workforce capacity of cancer services, led by Professor Sir Mike Richards.

Improving early diagnosis and prevention

- DHSC should deliver national public awareness programmes for cancer, to increase awareness of cancer screening programmes and knowledge of cancer symptoms – particularly amongst at-risk populations – as well as highlight the importance of reporting changes in health to their GP.
- Integrated Care Systems should be provided with funding to establish Community Diagnostic Hubs – as described in Professor Sir Mike Richards' independent review – to accelerate diagnostic turnaround time for cancer patients and reduce the risk of COVID-19 transmission.

Reducing variation in the delivery of care

- National Institute for Health and Care Excellence (NICE), working with NHSE&I, the independent Cancer Taskforce and relevant Clinical Expert Groups, as well as charity and industry representatives, should develop and consistently implement optimal end-to-end pathway guidelines for each cancer type, and rarer cancers, including:
 - Optimal routes to diagnosis
 - The delivery of optimal treatment pathways, including the use of companion diagnostics
 - A holistic needs assessment to help improve a patient's wellbeing and treatment outcomes
 - Advice on approaches to joint decision-making to ensure each patient has their own unique situation and quality of life considered
 - Clearer guidance and implementation standards on the management of metastatic disease.
- NHSE&I should strengthen the role of centres of excellence in providing 'hub and spoke' models for cancer care, and Cancer Alliances should monitor and assess adherence to national cancer guidelines across all hospitals to reduce unwarranted variation.
- Health Education England should work in partnership with NHSE&I, the Royal Colleges, charities and others to undertake research into the effectiveness of remote consultations for cancer care from the perspective of the patient and healthcare professional and develop training programmes for clinicians in delivering these consultations to ensure a consistent high level of service.

Recommendations

Speeding up the adoption of innovation


- NHSE&I must invest in integrated IT infrastructure and data to improve medical research as well as the speed at which this can be translated into patient benefit.
- NHSE&I should work in partnership with the Health Research Authority, the National Institute for Health Research (NIHR) and the clinical research community to undertake an audit of the lessons learnt from the response to the pandemic to help accelerate the design, approval and set-up of clinical trials.
- Guided by the objective that access to and uptake of new cancer treatments in the UK should be comparable with the best in Europe:
 - NICE should adopt changes that support faster and wider access to treatment innovations in cancer, including for patients with rarer cancers and that support the introduction of histology-independent (tumour agnostic) treatments.
 - NHSE&I should invest in expanding capacity nationally that supports the implementation of innovative new treatments, including companion diagnostic services, as a priority so that all cancer patients – irrespective of what type of cancer they have or where they live in the country – are able to benefit from the best possible treatment available for their disease.
- NHSE&I must collect data on interim treatment regimens introduced during the pandemic and assess their relative performance to the current approved standard of care. Changes to treatment schedules were brought in to protect patients from COVID-19, but there is currently little or no evidence regarding whether these changes provide the intended benefit for patient survival and quality of life.

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Introduction



The coronavirus (COVID-19) pandemic has disrupted many areas of healthcare, and this is particularly true of cancer services. The impact has been felt across the entire cancer care pathway, from disruption to screening programmes and delays in diagnosis, to reduced access to care and changes to treatment protocols. Many patients inevitably had their treatment interrupted or their diagnosis delayed. This is likely to affect cancer outcomes and it is important that NHS services do all that they can to address the implications of disruption. It is therefore welcome that NHS England & Improvement has identified cancer as a priority for Phase 3 of its COVID-19 response.



Just before the pandemic hit, the Swedish Institute for Health Economics (IHE) published its *Comparator Report on Cancer in Europe*.¹ The report provides an overview of the state of cancer care across European countries before the pandemic and reflects on major trends, including disease burden, patient access to care and treatment as well as patient outcomes. The results show that while progress in prevention, diagnosis, cancer treatment and care is helping to improve patient outcomes in the UK, more needs to be done to ensure that the UK closes the gap to countries in Europe of comparable size and wealth, such as France and Germany. This comparison provides an important starting point in assessing how NHS cancer services can not only recover from COVID-19 but can also deliver a step-change in cancer outcomes.

The ABPI interviewed representatives of the UK cancer community – from the NHS, academia, industry and patient-facing charities – to review the findings of the IHE report, explore the impact of COVID-19 and identify opportunities for improving the care for those affected by the disease in the UK.

The challenges to improving cancer outcomes in the UK, as identified by our interviews, appear to stem from national coordination and infrastructure, rather than a lack of knowledge and innovation. The successful adoption of innovation and resulting favourable outcomes delivered by some hospitals in the UK – including specialist cancer hospitals such as The Royal Marsden NHS Foundation Trust and The Christie NHS Foundation Trust – proves that well-resourced hospitals within the NHS are capable of delivering world-leading care. But the rest of the system needs to be brought up to their level, supported by the development of clear, consistent clinical pathways and infrastructure to diagnose cancer earlier.

This report details the findings from the interview process and draws out recommendations that, if implemented, could make an important contribution to delivering better outcomes for cancer patients, improving survival as well as enhancing quality of life.

Methodology

This report draws on research carried out by the IHE, which has been published in its *Comparator Report on Cancer in Europe*,¹ and an accompanying slide deck *UK in Focus: Comparator Report on Cancer in Europe 2019 – Disease Burden, Costs and Access to Medicines* produced by the IHE for the ABPI. This data is now available on the ABPI's cancer toolkit: <https://www.abpi.org.uk/cancer-toolkit>

A series of interviews were carried out to gain the perspectives of key stakeholders from across the cancer community on the IHE findings, the current challenges facing cancer services in light of COVID-19 and to discuss ways in which care and treatment provided to people with cancer in the UK can be improved.

The interviews were conducted between May and August 2020 and the list of interview questions can be found in the Appendix.



The ABPI would like to thank the following stakeholders for their participation in the interviews:

- ◆ **Professor David Baldwin,**
Chair, UK Lung Cancer Clinical Expert Group
- ◆ **Lorraine Dallas,**
Director, Roy Castle Lung Cancer Foundation
- ◆ **Dr Erling Donnelly,**
Oncology Lead, Pfizer
- ◆ **Richard Erwin,**
UK General Manager, Roche
- ◆ **Dr Iain Frame,**
Chief Executive, National Cancer Research Institute
- ◆ **Emma Greenwood,**
Director of Policy and Public Affairs, Cancer Research UK
- ◆ **Brad Groves,**
Associate Director, National Institute for Health and Care Excellence
- ◆ **Professor Pamela Kearns,**
Consultant Paediatric Oncologist and Director of the Cancer Research UK Clinical Trials Unit (CRCTU) at the University of Birmingham
- ◆ **Dame Laura Lee,**
Chief Executive, Maggie's
- ◆ **Baroness Delyth Morgan,**
Chief Executive, Breast Cancer Now
- ◆ **Jon Neal,**
Managing Director, UK and Ireland, Takeda
- ◆ **Professor Sanjay Popat,**
Consultant Medical Oncologist, The Royal Marsden NHS Foundation Trust
- ◆ **Professor Sir Mike Richards,**
Chair, Independent review of national cancer screening programmes
- ◆ **Mari Scheiffele,**
UK & Ireland, General Manager, Novartis Oncology

The recommendations set out in this report have been informed by these interviews but do not necessarily reflect the views of all participants.

Cancer patient outcomes in Europe

How did the UK compare before the COVID-19 pandemic?

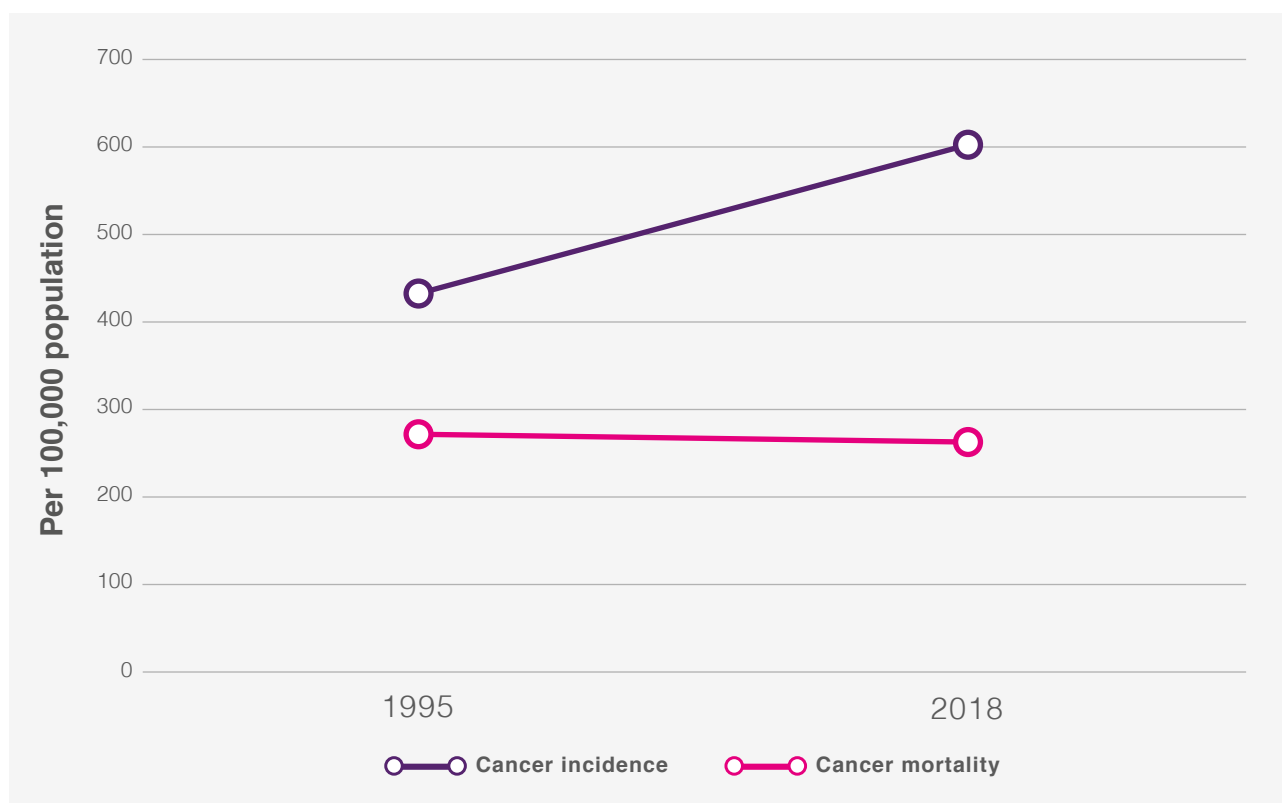
Outcomes in the UK are improving

The number of cancer diagnoses in the UK has increased over the past two decades from 439 in 1995 to 603 per 100,000 in 2018 (Figure 1).² This is slightly above the European average of 589 per 100,000 population. The number of cases for the most common cancers (breast, lung and prostate cancer) in the UK is above the European average.³

There are a variety of factors that contribute to the higher cancer incidence rate in the UK, including exposure to risk factors such as alcohol and tobacco use, rising levels of obesity, population growth and ageing, as well as improved public awareness and effective screening programmes.

Whilst the mortality rate due to cancer across the European continues to increase, the UK is amongst the few countries in Europe to have achieved a decrease, from 272 per 100,000 population in 1995 to 267 per 100,000 population in 2018.⁴ *Note these figures are the crude rates, rather than age standardised.*

Figure 1. The number of cancer cases in the UK is increasing whilst the number of cancer deaths is decreasing^{2,4}

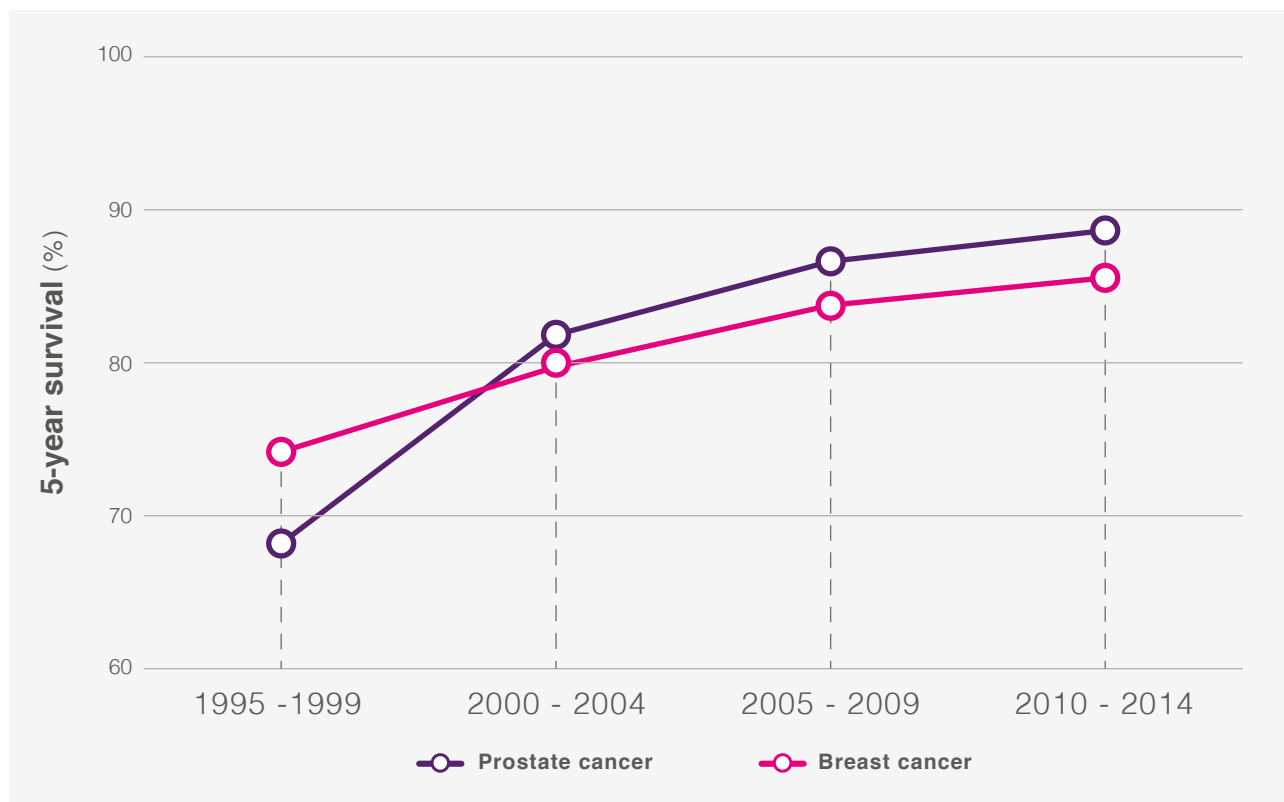


In line with increasing incidence and decreasing mortality, cancer survival in the UK has improved.³ For example, five year survival for prostate cancer in the UK improved from 68.2% (1995 – 1999) to 88.7% (2010 – 2014)⁵ and breast cancer from 74.2% (1995 – 1999) to 85.6% (2010 – 2014) (Figure 2).⁶

Improvements in outcomes are driven by a number of factors, including better screening and early detection programmes, as well as advances in diagnostics and treatment. Recent years have seen a step-change in the quality of treatment, which has helped contribute to improvements in cancer care in the UK and across the EU overall.

There has been a significant shift in cancer treatment from traditional chemotherapies towards more targeted therapies.⁷ These therapies are tailored to the specific characteristics of the tumour, resulting in more effective treatment with fewer side effects. In addition, the introduction of immunotherapies, which work with the body's own immune system to target cancer, has led to marked improvements in skin and lung cancer survival specifically.^{8,9} New gene and cell-based therapies are also being introduced, providing potential one-off curative treatment for some cancers.¹⁰ As a result of these innovations, cancer is increasingly transforming from an acute into a chronic disease.

Figure 2. Breast (female only) and prostate cancer 5-year survival between 1995 and 2014 in the UK (ages 15-99 years)^{5,6}



But not as fast as in other European countries

Although cancer outcomes are improving, survival rates in the UK are lagging behind comparable European countries for some cancers.

The IHE report shows that the UK's five-year survival rates ranked below the European average for five out of seven tumour types analysed.¹¹ In lung cancer, the UK five-year survival rate ranked at 21 out of 28 European countries between 2010 and 2014, with only 13.3% of people in the UK with the condition surviving five or more years after diagnosis.¹² The picture is similar with colorectal cancer, with the UK ranking 19 out of 28 European countries (Figure 3).¹²

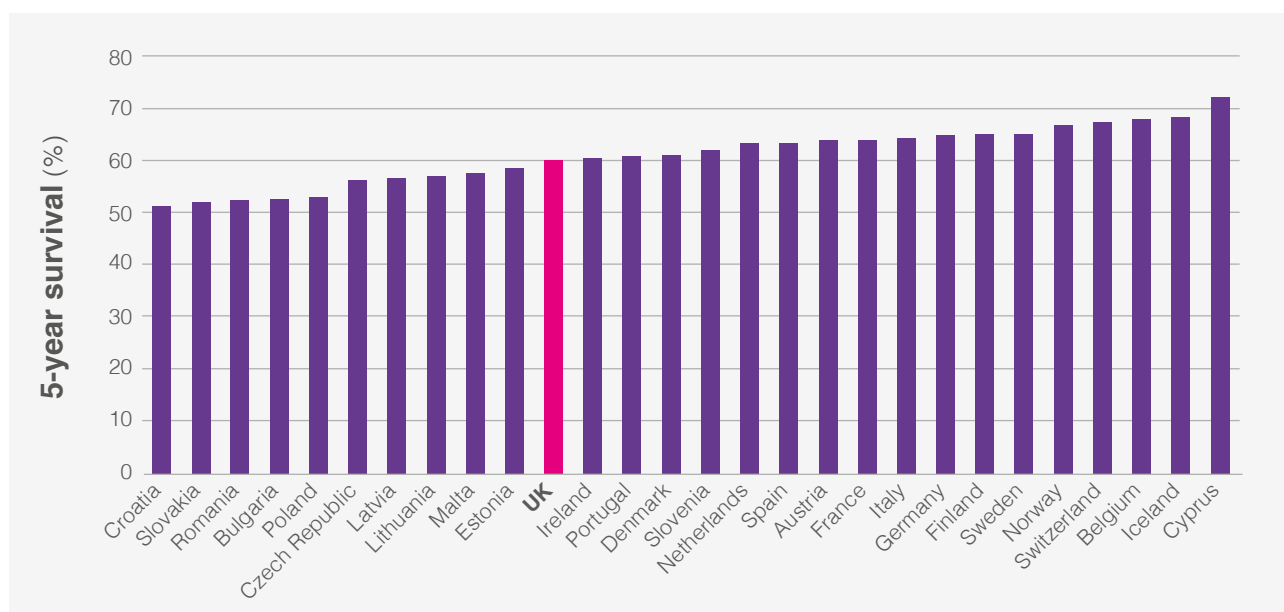
UK ranked

21 out of 28

European countries for five-year survival rate in lung cancer between 2010 and 2014



Figure 3. Colorectal cancer five-year survival 2010-2014 (age standardised, ages 15-99 years)¹²



The findings indicate that while progress in prevention, diagnosis and treatment is helping to improve patient outcomes, more could, and indeed should be done to ensure that the UK closes the gap in cancer outcomes when compared to other European countries.

The majority of stakeholders interviewed recognised the findings of the IHE report as an accurate reflection of the UK's cancer environment and highlighted the urgent need for action by policymakers. It was noted that some disparities in UK cancer outcomes when compared to those of other European countries may also be a result of the way in which countries collect cancer data. Some consider the UK to have a more comprehensive health data collection system than in other parts of Europe, providing the potential for a more complete picture than the data collected by some other European healthcare systems.¹³

Closing the cancer survival gap

Areas for improving cancer care in the UK

In order to understand why the UK has lower cancer survival rates than some European countries, the ABPI asked key experts in the cancer community what areas the UK needs to focus on in order to improve cancer outcomes. From the interviews, a number of areas of focus were identified, alongside actions which should be undertaken to address the cancer survival gap.

A need to focus earlier in the pathway

14 out of the 14 people interviewed highlighted the importance of improving early detection and diagnosis of potential cancers, including through prevention, screening and an accelerated referral pathway as a route to achieving this.



The biggest barrier to improving cancer outcomes is the stage at which we're diagnosing cancers in the UK. The British public tend to be more reluctant to go to the GP with symptoms than in other comparable countries, GPs are less likely to send patients for diagnostic tests, and we have significant issues around capacity to deliver diagnostics.

Interview with Emma Greenwood,
Director of Policy and Public Affairs,
Cancer Research UK

Prevention: It is estimated that 38% of cancer cases in 2015 developed as a result of lifestyle or environmental triggers and could be prevented.¹⁴ Some of the most common risk factors for cancer – smoking, obesity, sedentary lifestyle, alcohol consumption – are also risk factors for other common diseases such as diabetes and cardiovascular disease (CVD);¹⁵ therefore, taking active steps to modify a person's risk could not only delay or prevent cancer, but have wider benefits for the NHS.

The UK currently spends 5.2% of its total healthcare budget on prevention activities.¹⁶ Although this is higher than most other nations analysed by the Organisation for Economic Co-operation and Development (OECD), it remains a relatively small proportion of the health budget. The stakeholders interviewed welcomed the Government's recent commitments both in the NHS Long Term Plan¹⁷ and its recent Prevention Green Paper¹⁸ to shift focus onto what can be done to prevent or delay ill health.



Although approximately 40% of cancer cases could be prevented, only 5.2% of the total healthcare budget is spent on prevention^{14,16}

Screening: Early detection of cancer, at stage I or II, increases the chance of receiving curative treatment. In lung cancer for instance, the current one-year survival rate is approximately 83% if diagnosed at stage I but decreased to only 17% for those diagnosed with stage IV disease.¹⁹ With nearly half (45-46%) of lung cancers diagnosed at an advanced stage (stage III or IV) in the UK, more must be done to detect tumours earlier.²⁰ Screening programmes for cancer can improve early detection. In breast cancer for instance, screening accounted for 28% of breast cancer diagnoses in 2015/16 and 93% of those detected were stage I or II.²¹ In the UK, there are currently screening programmes for breast, bowel and cervical cancer, each of which have an above average survival rate of 85.0%,²² 58.4%²³ and 61.4%²⁴ respectively, compared to the countries studied. There is now good evidence that CT screening of individuals deemed 'high risk', such as people who smoke, can reduce mortality from lung cancer.²⁵ NHS England is piloting the use of CT scanning for the detection of lung cancer as part of their 'Lung Health Checks' programme in 14 sites around England.²⁶ Although England is leading in Europe in designing this pathway, not all pilot sites are currently fully funded and operational.²⁷

**45-
46%**

**of lung cancers in the UK
are currently diagnosed as
late stage (stage III or IV)²⁰**



10% of cancer patients are waiting up to 6 months before reporting their initial symptoms to their GP.²⁹



Reporting symptoms and onward referrals:

The primary route of diagnosing cancers is via GP referral.²⁸ To increase the level of early diagnosis, stakeholders highlighted the importance of 1) patients' ability to recognise potential symptoms, 2) their willingness to report symptoms to their GPs, and 3) the GP's recognising the symptoms and referring the patient for further tests. Public awareness initiatives can help increase symptom awareness. However, representatives of the cancer community cited barriers to early engagement with primary care due to patients' fear of a potential cancer diagnosis and their reluctance to be a burden to their GP, as well as difficulties in getting a timely appointment.

NHS England's National Cancer Patient Experience Survey 2019 showed that the majority of people reported symptoms to their GP within 3 months of thinking something might be wrong. However, 10% waited 3-6 months, 3.3% waited 6-12 months and 2.6% waited more than a year to report symptoms to a GP.²⁹ After deciding to contact their GP, less than half of patients (43%) were referred to hospital for further tests after 1 appointment. It took 2 appointments for 15% of patients before onward referral, 10% attended 3 or 4 appointments, and 5% had 5 or more appointments before GP referral. Several interviewees expressed concern about patients falling through the gaps at this stage of the patient pathway. In order to improve earlier diagnosis, it may be necessary to reassess the GP's role as a gatekeeper of onward referral.

Recommendation:
DHSC should deliver national public awareness programmes for cancer, to increase awareness of cancer screening programmes and knowledge of cancer symptoms – particularly amongst at-risk populations – as well as highlight the importance of reporting changes in their health to their GP.

Diagnostics: As discussed above, improving early diagnosis is crucial to improving survival. In October 2020, Cancer Research UK published a comprehensive roadmap to improving early detection and diagnosis with specific and detailed recommendations for all aspects of the UK cancer ecosystem – from capitalising on the UK’s excellence in research and innovation, to adequately resourcing diagnostic services and making changes to automate diagnostics within the cancer patient pathway.³⁰ The importance of investment, implementation and streamlining of cancer diagnostics – especially in light of the coronavirus pandemic – is a recurring theme throughout this report and different aspects will be discussed in subsequent sections.



Translating world-class research into patient benefit

The information collected by the NHS – on family and medical history from birth, primary and secondary care, treatment responses and outcomes – has the potential to help us understand, predict and prevent disease, as well as develop and optimise new treatments. In addition, the UK houses some of the leading universities and research institutions in Europe and its researchers

are often at the forefront of ground-breaking medical discoveries. However, some interviewees suggested that the collection, analysis and review of data amassed by the NHS thus far have all been poor and not lived up to their potential. They highlighted a number of barriers that need to be addressed in order to ensure cancer patients in the UK are able to benefit from pioneering research at pace and scale.

NHS IT infrastructure: To unlock the full value from the vast amount of data the NHS collects, effective IT systems are required. However, the lack of interoperability of the current NHS IT infrastructure creates a significant barrier to the effective use of its data, which is often held in disconnected silos. Addressing this will not only offer opportunities for medical research, through emerging technologies such as machine learning and artificial intelligence, it will also support uptake of innovative treatments by providing the necessary infrastructure to enable real-world data collection.

Clinical trial regulation: Negotiating peer review, ethics approval, regulatory approval and hospital site agreement has in the past taken a significant time. Whilst steps were already underway, the need to fast track clinical research in support of the COVID-19 response has shown how such processes can be significantly streamlined, whilst maintaining robust regulation. There is a need to ensure that this impetus is sustained, helping to streamline the process for clinical trial approval and set-up going forward to ensure that the UK can keep at the forefront of cutting-edge medical research and continue to offer an attractive environment for carrying out clinical research.



When it comes to research and development, we're good at the 'R' but not at the 'D' in the UK and a large part of the reason for that is due to workforce and funding restraints. The Government needs to have ambition to improve cancer outcomes through the implementation of research innovations.

Interview with Baroness Delyth Morgan,
Chief Executive, Breast Cancer Now





What the NIHR has done for clinical trials in the UK is excellent. But trying to set up a clinical trial on the NHS is still a painfully slow process and is only done if we have time. Many of my European colleagues are based in university hospitals where research and clinical work is tied up together, whereas we have academia on one side, the NHS on the other and we attempt to mix the two. We need trust Chief Executives to come at this with the mindset that we have to be able to offer and deliver research to all of our patients. This needs to be much more than good intentions; we have to make it happen.

Interview with Professor Pamela Kearns,
Director of the Cancer Research UK Clinical Trials Unit, University of Birmingham

Improving access and uptake of innovation:

Advances in science have meant that the number of cancer drugs granted marketing authorisation by the European Medicines Agency has doubled between 2000-2008 and 2009-2016, with 51% of the drugs approved deemed 'highly innovative'.³¹

But patients can only benefit from these advances in treatment if they are able to access them. The IHE report shows that the UK provides fast access to some innovative cancer treatments for common cancers, in line with France and Germany.³² However, uptake of these medicines by clinicians for use in patients remains low relative to comparator countries.

Figure 4. Uptake of lung cancer medicine crizotinib (sales in mg per case)³³

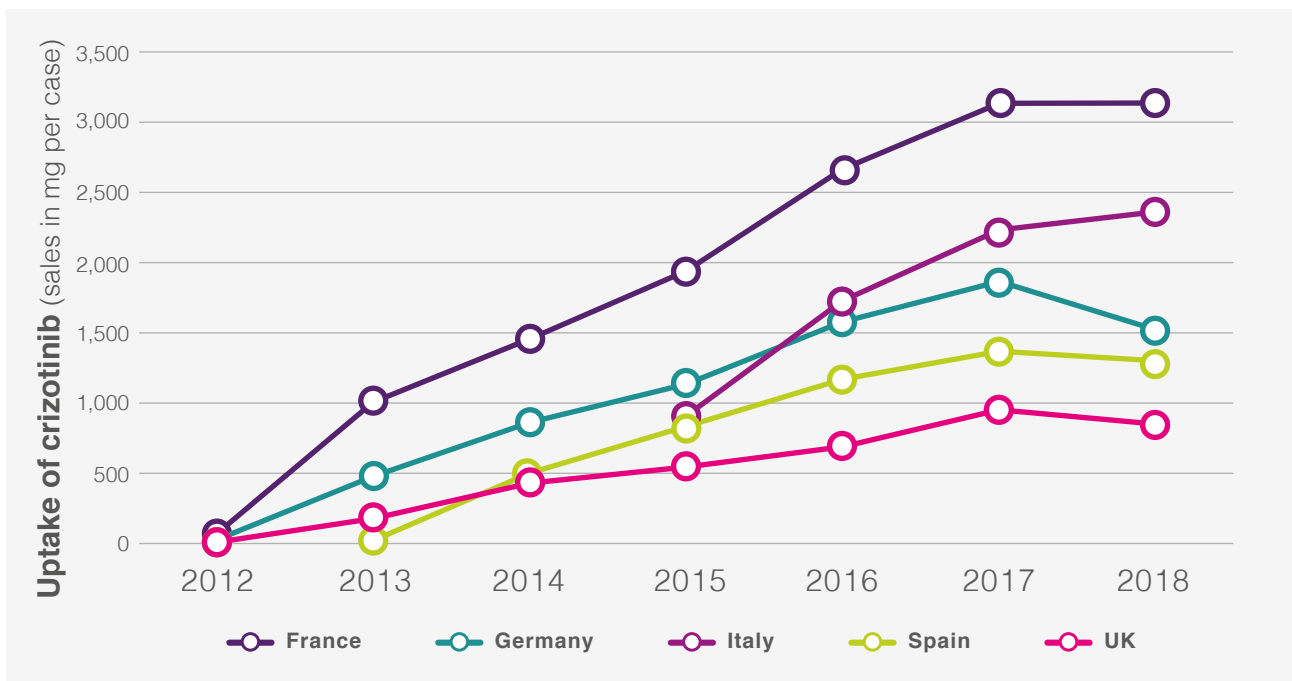
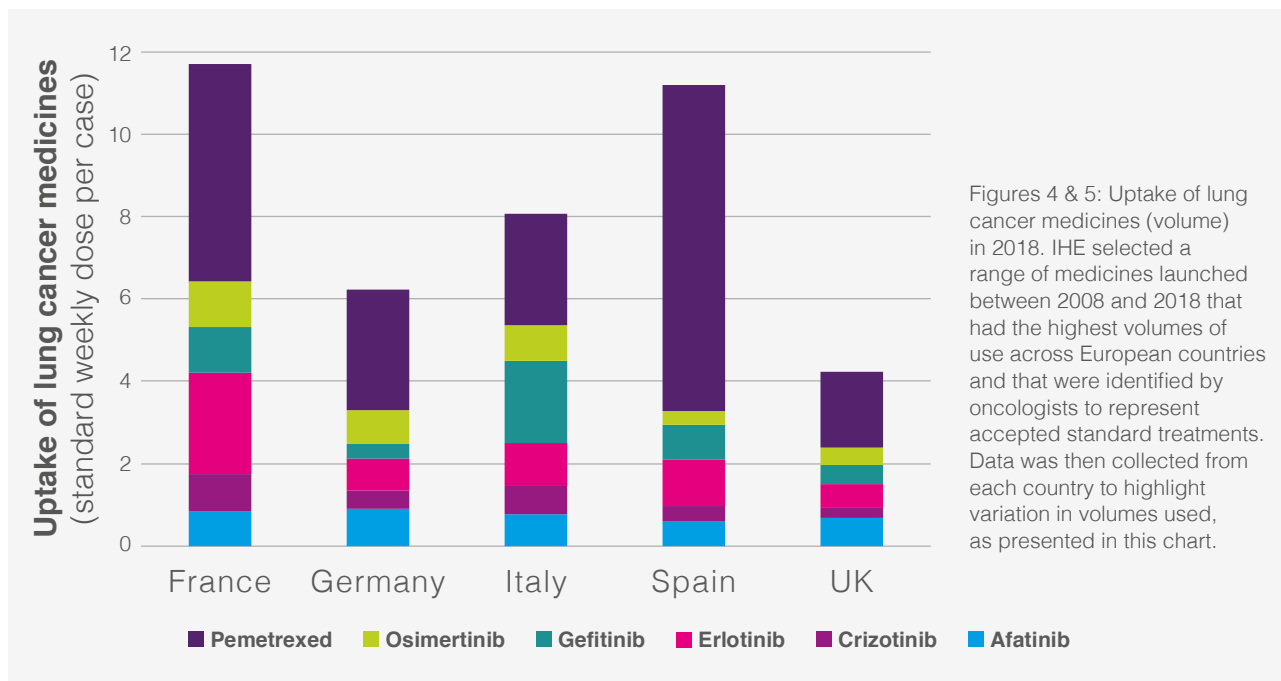


Figure 5. Uptake of lung cancer medicines (standard weekly dose per case) in 2018³⁴



In lung cancer, for example, the report finds that the UK was among the countries that provided fastest access to new treatments (Figure 5), yet the level of subsequent uptake is amongst the lowest of the countries with a comparable GDP (Figures 4 & 5).^{33,34} Although there are several reasons why uptake of individual drugs may differ between countries – such as the availability of alternative treatments or the targeting of specific patient populations – the trend of fast access but lower uptake is seen across several cancer types. As well as lung cancer, this is also true for ovarian³⁵ and prostate cancer.³⁶

While the introduction of the Cancer Drugs Fund has helped increase cancer treatment uptake, interviewees highlighted the need to ensure that patients in the UK benefit from the same level of uptake of innovative treatments as other comparable European countries – no matter where they live in the UK or what cancer type they have. The interviews identified two key areas to help improve the uptake of innovative new treatments.



Companion diagnostic tests are crucial for the uptake of modern targeted cancer therapies. Although the use of these diagnostic tests is increasing, it's not standard or consistent across the country. France has a more centralised approach to companion diagnostics and therefore uptake of targeted drugs is higher. The lower adoption of companion diagnostics in the UK is contributing to lower uptake.

Interview with Dr Erling Donnelly, Oncology Lead at Pfizer

Tumour diagnostics services: Once a patient has been diagnosed with cancer, further investigation is required in order to select the treatment that is most likely to be effective. Many modern cancer treatments target specific features of a person's tumour, such as a genetic fault or a molecule on the tumour's surface that subverts the immune system. In lung cancer, for example, patients with an EGFR mutation in their tumour may benefit from an EGFR inhibitor treatment. NICE have worked hard to speed up access to these treatments, but levels of uptake are contingent on diagnostic capacity, which is currently perceived as acting as a bottleneck. Investment in this area is currently lacking, the roll-out of the National Genomic Medicine Service has been set back and capacity issues in histopathology laboratories have led to delays or an inability to carry out molecular testing.³⁷ The shared genomics hubs as part of the National Genomic Medicine Service should help improve uptake of tumour molecular profiling in future. However, interviewees noted there is a need to expand capacity in histopathology laboratories in order to facilitate companion diagnostic testing.

Even when actionable mutations are discovered, patients are not always given the relevant therapy. A recent audit by the Royal College of Physicians and the National Lung Cancer Audit found that although 83% of patients with lung cancer underwent testing, only 75% of patients with a confirmed EGFR mutation and 58% of patients with an ALK mutation received the approved first-line therapies that target those genetic faults.³⁸ Regular national audits of these targeted treatment pathways should take place to ensure they are being implemented equally.

Using real-world data and flexible pricing

structures: The IHE report looks at the uptake of drugs for common cancers, but interviewees highlighted a need to improve access and uptake to innovative treatments in smaller patient populations – such as children or adults with rarer cancers. NICE is currently undertaking a review of its methods for evaluating medicines for use in the NHS. In order to improve drug access for these groups, some interviewees said they would like to see NHS England support the adoption of more flexible pricing structures, such as multi-indication pricing, and take real-world evidence into account in its technology appraisals. Without these changes, there is a risk that patients will continue to face delays to new treatments.

Recommendations:

NHSE&I must invest in integrated IT infrastructure and data to improve medical research as well as the speed at which this can be translated into patient benefit.

Guided by the objective that access to and uptake of new cancer treatments in the UK should be comparable with the best in Europe:

- **NICE should adopt changes that support faster and wider access to treatment innovations in cancer, including for those with rarer cancers and that support the introduction of histology-independent (tumour agnostic) treatments**
- **NHSE&I should invest in expanding capacity nationally that support the implementation of innovative new treatments, including companion diagnostic services, as a priority so that all cancer patients – irrespective of what type of cancer they have or where they live in the country – are able to benefit from the best possible treatment available for their disease.**

Optimising pathways to address variation in care

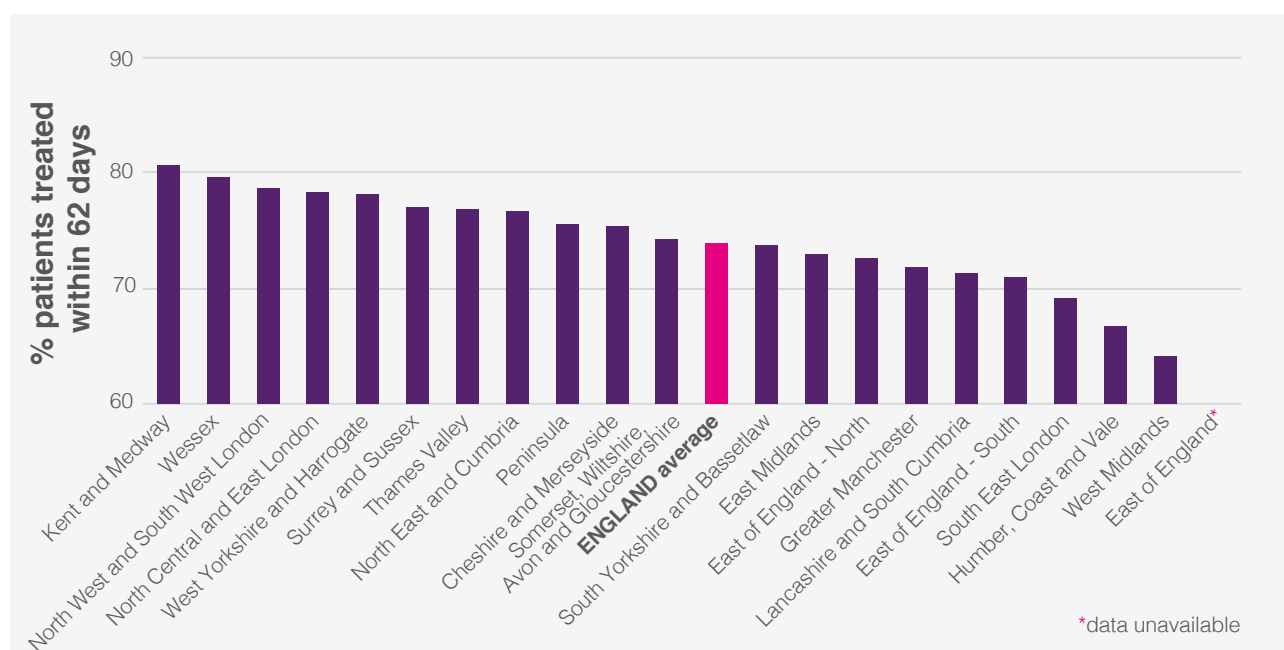


The way you improve patient survival is to streamline the entire pathway – arriving at general practice and rapidly starting the process, so by the time the patient sits in front of an oncologist, all the necessary diagnostic tests have been done and they're ready to start their treatment.

Interview with Professor Pamela Kearns, Professor of Paediatric Oncology at the University of Birmingham

There is variation in cancer care between – and even within – regions of the UK. Cancer Alliances were introduced by NHS England following the recommendations of the National Cancer Strategy, *Achieving World-Class Cancer Outcomes*, published in 2015 by the Independent Cancer Taskforce.³⁹ Their objective was bring together leaders from different hospitals and other health and social care organisations to help plan activity more effectively and transform the diagnosis, treatment and care of cancer patients in their local area. However, there remains a disparity in care between Cancer Alliances, illustrated in Figure 6 by the variation in the number of cancer patients receiving treatment within 62 days of referral – from 80.7% in Kent and Medway to 64.1% in West Midlands Cancer Alliance.⁴⁰

Figure 6. 62-day wait for first treatment following an urgent GP referral in each Cancer Alliance for all cancers (%) Feb 2020⁴⁰

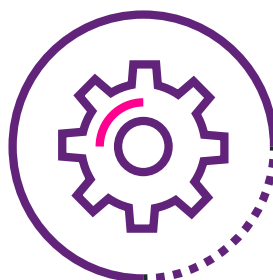
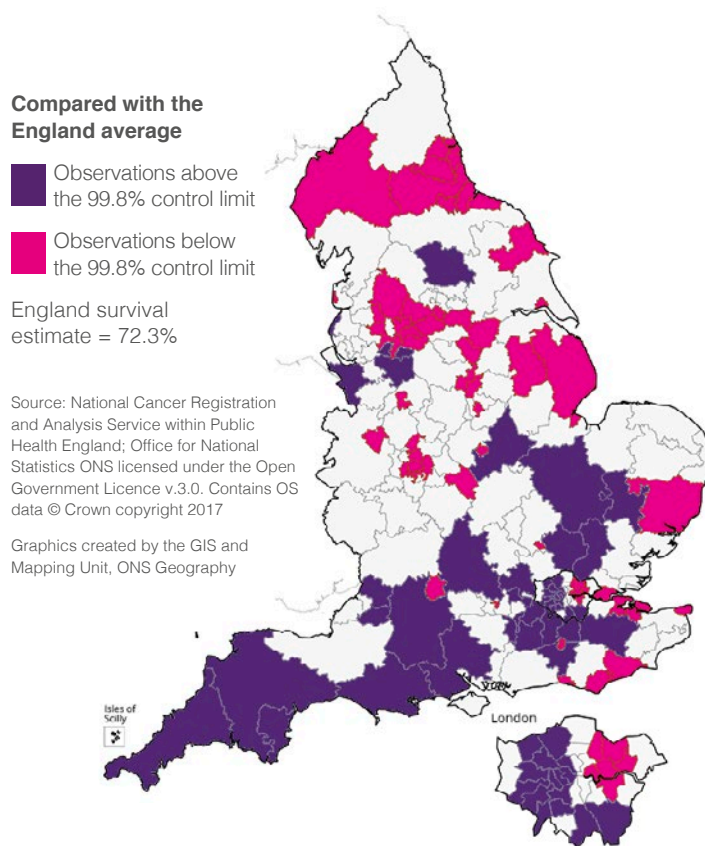


Although two of the three national 'Cancer Vanguards' – the flagship Cancer Alliances – are found in Greater London, the region has both the worst (NHS Barking and Dagenham) and best (NHS Richmond) performing clinical commissioning groups (CCG) in the country in terms of one-year survival estimates for all cancers.⁴¹ Survival is also generally lower in the North of England and Midlands than the South of England (see Figure 7).⁴¹

The decentralised nature of cancer care in England is believed by some of the people interviewed to be contributing to the variations observed in care. Two potential approaches were suggested to reduce disparities in care provision across the country.

Introduction and consistent implementation of optimal care pathways: Interviewees suggested that a clearly defined pathway, with national oversight and accountability, for each cancer type would support the uniform application of high standards of care across the country. The pathways would set out the gold standard for diagnosis and treatment at each stage of the disease – particularly important for late stage cancers where most new medicines enter the pathway. The early part of the pathways could be modelled on the National Optimal Lung Cancer Pathway (NOLCP), which has reduced the time it takes from first referral to treatment decision from 62 to 49 days.⁴² Many in the cancer community would like to see end-to-end extended pathways, which cover the onset of symptoms through to end-of-life care, for all of the common cancers as well as guidance for the management of rare cancers.

Figure 7. One-year survival index for all cancers compared with the England average per CCG, 2015⁴¹



Guidelines such as the NOLCP can help accelerate diagnostic turnaround time from 62 to 49 days⁴²

Increasing the role of national centres of

excellence: As discussed in a previous section, advances in science have led to big changes in the way we treat cancer over the past two decades. There has been huge innovation in cancer medicines – 97 cancer drugs for 177 indications were given European market authorisation between 2000 and 2016³¹ – as well as in the delivery of radiotherapy and surgical procedures. This has the effect of increasing the complexity of cancer treatment, presenting challenges for healthcare professionals in keeping up-to-date with the most recent standards of care.

Strengthening the ‘hub and spoke’ model could further help ensure coherent application of standards of care across the country. Although this system operates to a certain extent already, our interviewees note that regional variation persists and there is a lack of accountability for improvement. Cancer centres of excellence, or their local Cancer Alliances, should be responsible for the monitoring and training required to consistently implement national standards of care in their areas and should be held to account if national standards are not met.

Supporting patients to live with and beyond

cancer: A cancer diagnosis is life-changing. The impact of the disease not only affects the patient’s family and social life but often requires time off work to undergo treatment – for some resulting in a significant loss of earnings and financial hardship – further adding to the psychological impact of the diagnosis.

The NHS Long Term Plan set a goal that by 2021, “where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.”¹⁷



Every single patient is now supposed to get a holistic needs assessment, but many hospitals have been taking a tokenistic view to this approach. These assessments are talked about, but they’re not implemented in a standardised way. The prescribed package is often the lowest common denominator rather than what’s best for the patient.

Interview with Dame Laura Lee, Chief Executive of cancer care charity Maggie’s

Despite this goal, representatives from cancer charities explained that cancer care is still predominantly focused on the delivery of treatment, with holistic needs support perceived as a lower priority. Those affected often have to opt in, rather than opt out, of holistic support – such as open communication and guidance ahead of treatment, psychological and dietary support throughout treatment or rehabilitation once treatment has ended. A lack of effective communication about treatment options and what to expect during and after treatment further increases the patient’s uncertainty about what lies ahead.

The important role of charities such as Macmillan Cancer Support or Maggie’s, who offer support groups, counselling, drop-in centres, courses and workshops to help people live with cancer and beyond, is widely recognised and should be supported. With increasing evidence of the impact that poor mental health can have on treatment outcomes,⁴³ more needs to be done to support patients – and charities should not shoulder this responsibility alone.

Recommendations:

NICE, working with NHSE&I, the independent Cancer Taskforce and relevant Clinical Expert Groups, as well as charity and industry representatives, should develop and consistently implement optimal end-to-end pathway guidelines for each cancer type, and rarer cancers, including:

- ◆ Optimal routes to diagnosis
- ◆ The delivery of optimal treatment pathways, including use of companion diagnostics
- ◆ A holistic needs assessment to help improve a patient's wellbeing and treatment outcomes
- ◆ Advice on approaches to joint decision-making to ensure each patient has their own unique situation and quality of life considered
- ◆ Clearer guidance and implementation standards on the management of metastatic disease.

NHSE&I should strengthen the role of centres of excellence in providing 'hub and spoke' models for cancer care, and Cancer Alliances should monitor and assess adherence to national cancer guidelines across all hospitals to reduce unwarranted variation.



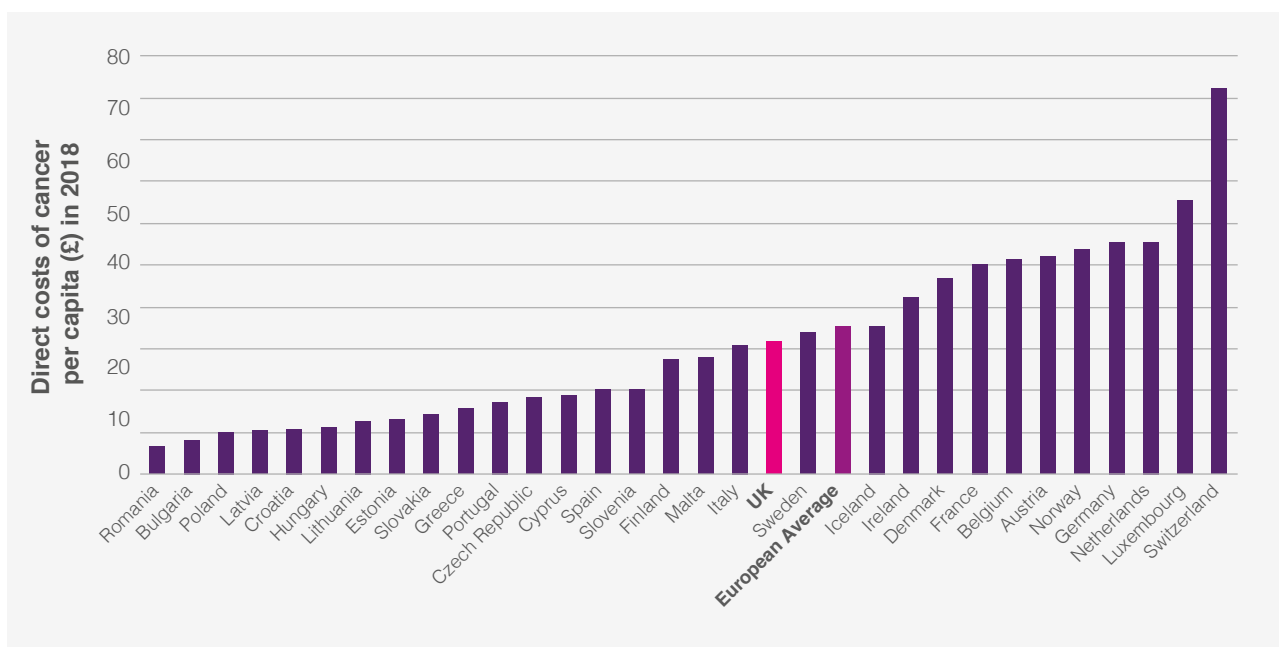
Overall investment in the health service

A common concern among interviewees is the need for greater investment in the health service in general if the UK is to achieve better outcomes for people with cancer.

In the decade following the financial crisis of 2008, the annual growth of investment in the UK health service slowed – increasing by only 1.4% on average from 2009/10 to 2018/19, compared to 6.0% annual growth between 1996/97 and 2009/10 or an average of 3.7% a year since the NHS was founded in 1948.⁴⁴

During the same period, cancer incidence and its burden continued to increase.¹ The IHE data illustrates how the UK’s investment in cancer care compares to other European countries. In 2018, the UK spent £159 per person per year on cancer care, which is below the European average of £176 and considerably less than countries of comparable size and wealth such as Germany and France (see Figure 8).⁴⁵

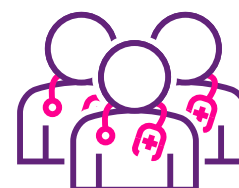
Figure 8: Direct costs of cancer per capita (£) in 2018⁴⁵



Two key areas of cancer care were singled out during the interviews as being particularly impacted by the current level of available funding:



Diagnostic capacity



Cancer workforce



Our diagnostic capacity is woefully poor. CT scanning rates, for instance, are much lower than those in France, Germany or Spain.

Interview with Professor Sir Mike Richards, former National Cancer Director and Chair of the independent review of national cancer screening programmes

Diagnostic capacity and infrastructure

Throughout our interviews, a lack of diagnostic capacity was implicated in the UK's lower cancer survival rates – not only in molecular profiling of tumours but in imaging as well. The UK has eight CT scanners per million population, which is significantly lower than the European average of 21.4. The same is true for MRI scanners at 6.1 per million population, compared to an EU average of 15.4 (although this data does not include diagnostic scanners based in non-NHS providers that are used by the NHS).⁴⁶ This problem is particularly acute in rural areas where patients have to travel long distances to access CT and PET-CT scan facilities. The Government's announcement to invest an additional £200 million in MRI and CT scanning capacity in September 2019⁴⁷ is welcome, although doubts were raised by those we interviewed as to whether the commitment would be sufficient to close the gap with the best-performing countries. An independent review of diagnostic services, undertaken by Professor Sir Mike Richards for NHS England, recommended that CT scanning capacity should be doubled over the next five years to meet increasing demand and to bring the UK in line with other high-income countries, and it will be important that this is delivered.⁴⁸

Workforce

Limited availability of radiographers, radiologists and oncologists as well as cancer nurse specialists (CNS) was also cited as a continuing barrier to improving cancer outcomes in the UK. For example, in 2019 the Royal College of Radiologists estimated that there was a shortfall of 1,876 radiologists, or 33% of the workforce, and this number is predicted to rise to 3,331 (43%) in the next five years. Some 71% of radiology clinical directors feel there are insufficient clinical radiologists to deliver safe and effective levels of patient care.⁴⁹ The recent publication of part 1 of the NHS People Plan for 2020/21 should help address some of the challenges within the cancer workforce. However, Professor Mike Richards' independent review of diagnostic capacity in the NHS recommended that in the next five years the imaging workforce will need to be expanded by 2,000 radiologists and 4,000 radiographers to deliver meaningful improvements to the service.⁵⁰

Recommendations:

DHSC should reassess the timelines and resources required to deliver cancer outcomes that are comparable with European and other high-income countries, and mandate NHS England & Improvement to work with the cancer community to develop an updated strategy for achieving this goal.

Government should commit to implementing the recommendations of *Diagnosics: Recovery and Renewal* – the independent review of diagnostic and workforce capacity of cancer services, led by Professor Sir Mike Richards

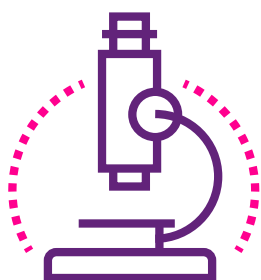
The impact of the COVID-19 pandemic on cancer care in the UK

The COVID-19 pandemic has presented unprecedented challenges to patients, the healthcare system and society. For many cancer patients, the impact on services – particularly in increasing delays to early detection and diagnosis – is unfortunately predicted to result in premature loss of life, reversing much of the progress made in recent years.

A recent report published by Institute for Public Policy Research (IPPR) estimates that five-year survival will fall from 16.2% to 15.4% for lung cancer, from 85% to 83.5% for breast cancer, and 58.4% to 56.1% for colorectal cancer.⁵¹

Challenges created by the pandemic for cancer care

Many of the existing challenges identified by our interviews will further be exacerbated by the pandemic:



7,000 people are not being referred for diagnostic tests and 380 cancers are missed for every week that screening is suspended⁵⁶



The UK doesn't just spend less on cancer; a sustained lack of investment in the NHS has led to the workforce and capacity issues that left the country ill-prepared for this pandemic.

Interview with Richard Erwin, UK General Manager of Roche

Screening and referrals: Screening programmes to detect breast, bowel and cervical cancer were suspended in Scotland,⁵² Wales⁵³ and Northern Ireland⁵⁴ early on in the pandemic to help protect the public from the virus. Although cancer screening was not officially suspended in England, there was widespread disruption to the service.⁵⁵ Cancer Research UK estimates that for every week that screening was suspended, 7,000 people were not referred for diagnostic tests and 380 cancers were being missed.⁵⁶

NHS England data shows that the most common route to a cancer diagnosis (39% of cases) is through the 'two-week wait' pathway for urgent GP referrals.⁵⁷ However, between April and June 2020 there was a 40% reduction in two-week wait referrals,⁵⁸ suggesting that some cancer diagnoses are being missed.

Diagnostic and workforce capacity: Existing workforce challenges, detailed in the previous section, were exacerbated by shielding and redeployment of frontline staff to COVID-19 wards. Diagnostic capacity was also further impacted by the pandemic. Procedures associated with aerosol generation, such as endoscopies, reduced by up to 90% in April 2020 compared to the previous three months due to the risk of spreading the virus.⁵⁹ Diagnostic throughput for non-aerosol-generating procedures also fell significantly. The number of MRI and CT scans fell in April 2020, by 70% and 45% respectively, compared to the same month the previous year and whilst activity has increased, it remains below normal levels.⁵¹ For example, MRI and CT activity was only 66% and 87% of 2019 levels in June respectively.⁶⁰ The requirement for social distancing and enhanced infection control is likely to continue to impact on capacity, increasing waiting times as we move into the endemic COVID-19 period.

Cancer treatment: Cancer treatment schedules were altered to keep vulnerable groups of patients away from acute hospitals, reducing their risk of contracting the virus. Surgery, a potentially curative treatment for many forms of cancer, was frequently delayed. A 3–6 month delay in surgery can have a significant impact on survival.⁶¹ Some patients were offered radiotherapy to help delay the need for surgery.⁶²

To reduce the risk of those needing chemotherapy, NHSE&I and NICE worked together to offer interim treatment options which are less immunosuppressive, can be administered at home, are less resource-intensive, and not likely to require significant service change or training, to help protect cancer patients and reduce the burden on the NHS.⁶³ For example, targeted prostate cancer drugs abiraterone and enzalutamide were brought forward in the treatment pathway, to be offered alongside androgen deprivation therapy for men with advanced prostate cancer as a first-line treatment, instead of docetaxel chemotherapy.⁵⁰

Research and clinical trials: Research is a crucial part of the cancer treatment pathway, with one in six patients receiving treatment in clinical trials.⁶⁴ In reaction to the pressures caused by the pandemic, the NIHR announced that any new or ongoing clinical trials at NHS sites would be paused, other than those nationally prioritised for COVID-19. The Association of Medical Research Charities (AMRC) reported that more than half of their members had to stop, pause or delay the majority of their clinical trials.⁶⁵ Only 14% of institutions in Europe were able to continue to enrol patients at the usual rate between the end of March and the beginning of April 2020.⁶⁶ The NIHR launched a framework to support the restart of clinical trials at the end of April 2020;⁶⁷ however, many of these trials were still not back up and running as of August 2020.

In addition, laboratory-based medical research – other than that which related directly to the effort to tackle the pandemic, including cancer research – was stopped during the lockdown period as the Government advised that all but key workers should work from home.⁶⁸

The pandemic has also impacted on the ability to fund current and future research. As a result of the inability to fundraise, Cancer Research UK, one of the key funders of cancer research in the UK, announced a predicted loss of £300 million over three years and has been forced to reduce research expenditure by £150 million per year, as well as losing a quarter of its employees.⁶⁹



75-100% of AMRC members' clinical trials were paused during the pandemic⁶⁵

Opportunities for cancer care emerging from the health system's response to the pandemic

Whilst COVID-19 poses additional challenges for those affected by cancer in the UK, the health system's response to the pandemic has also paved the way for the acceleration of a number of innovations in cancer care.

Digital innovation: Remote consultations and virtual consultant triage services have the potential to improve turnaround times, increase NHS capacity, reduce waiting times and clear patient backlogs. NHS leaders have been considering adopting these types of services as a way of improving capacity for years, but the pandemic saw them implemented within weeks.

During the pandemic, there has been an increase in the number of multidisciplinary team (MDT) meetings held virtually, which enables a greater attendance in discussions around complex cases. Routine use of these clearly has the potential to reduce the time that the specialist would previously have to spend on travelling to attend meetings and to benefit from expertise from a wider variety of specialists.

Remote consultations have been adopted to avoid patients needing to come into hospital. They can offer a potentially safer and more convenient way for some patients to speak to their treating specialist or clinical nurse specialists. A recent survey found that the British public now prefers telephone consultations to face-to-face appointments for non-urgent care.⁷⁰ However, interviewees shed light on a number of challenges that still needed to be addressed to ensure that remote consultations deliver adequate benefit to the patient and the clinical team. These challenges include the ability to 1) pick up on non-verbal cues, 2) convey empathy



While COVID-19 has presented many challenges, it has also provided important learnings around cancer care pathways in the UK. Now is the time to come together and fully embrace this opportunity to accelerate innovation — to not just restore, but to create a step change so that all UK cancer patients can achieve their best outcome

Interview with Mari Scheiffele, General Manager UK & Ireland, Novartis Oncology

when sharing difficult news, 3) build trust in the treating clinical team, 4) cope with the additional burden put on clinical nurse specialists when providing advice over the phone, and 5) overcome limitations of the NHS IT infrastructure. A tailored blend of face-to-face and remote consultations was therefore recommended by those interviewed, as well as training for clinical staff in effective remote consultations and care support.

Diagnostic hubs: To reduce the risk from the pandemic, COVID-19 'free' diagnostic hubs were established to enable the delivery of diagnostic tests in the community, away from acute care settings that are treating COVID-19 patients. This development is an acceleration of the adoption of the Rapid Diagnostic Centres (RDCs) already recommended in the NHS Long Term Plan to meet its target of three in four cancers being diagnosed at an early stage (before it has spread to other parts in the body) by 2028. Such diagnostic hubs not only have the potential to provide safer diagnostic appointments

for patients during the COVID-19 endemic period but can further accelerate diagnostic turnaround times by reducing the number of visits required to obtain the necessary test result ahead of the first MDT meeting. Professor Sir Mike Richards' independent review of NHS diagnostic services recommended the establishment of 'COVID-19 minimal' Community Diagnostic Hubs – which would act as a 'one-stop shop' for testing, and include cardiac, respiratory and other diseases, as well as cancer. Initially there would be three hubs per million population and should mean testing could take place closer to home.⁷¹

Changes in treatment schedule: As discussed above, during the pandemic, NICE published amended guidelines to allow therapies with lower toxicity profiles to be used earlier in the treatment pathway and at a less frequent delivery schedule. These changes – such as preferentially prescribing medicines that can be taken orally as opposed to intra-venous delivery or more targeted, less aggressive drugs that preserve the body's immune response – have the potential to reduce the impact of cancer care on patients by minimising side effects and the need to travel to hospital; but also offer opportunities to free up NHS capacity, helping services address the backlog in treatment caused by the pandemic.

However, a number of respondents noted that it was important to evaluate these alternative treatment pathways to ensure they were delivering optimal care and, where not, amend them accordingly. The NHS should now be collecting real-world data about the impact of the interim treatment regimens introduced during the pandemic to ensure these changes provide the intended benefit for patient survival and quality of life. Changes to the treatment schedule were introduced to protect patients from COVID-19, but there is currently little or no evidence that these treatment changes are providing equivalent outcome benefits relative to the current standard of care towards the management of the patient's cancer.

Clinical trial design and approval: Although many cancer clinical trials were paused, or recruitment was limited or delayed, our interviewees reported that clinical trials for COVID-19 treatments and vaccines were initiated within weeks. This process can take months or years for some trials. While it won't always be possible to administrate a trial in the same short period, there is a desire amongst the clinical research community that learnings from COVID-19 trials regarding how this process can be accelerated in the longer term are taken forward.



Recommendations:

Health Education England should work in partnership with NHSE&I, the Royal Colleges, charities and others to undertake research into the effectiveness of remote consultations from the perspective of the patient and healthcare professional, and develop training programmes for clinicians in delivering these consultations to ensure a consistent high level of service.

Integrated Care Systems should be provided with funding to establish additional Community Diagnostic Hubs – as described in Professor Sir Mike Richards’ independent review – to accelerate diagnostic turnaround time for cancer patients and reduce the risk of COVID-19 transmission.

NHSE&I should work in partnership with the Health Research Authority, the NIHR and the clinical research community to undertake an audit of the lessons learnt from the response to the pandemic to help accelerate the design, approval and set-up of clinical trials.

NHSE&I must collect data on the interim cancer treatment regimens introduced during the pandemic and assess their performance relative to the current approved standard of care. Changes to treatment schedules were brought in to protect patients from COVID-19, but there is currently little or no evidence regarding whether these changes provide the intended benefit for patient survival and quality of life.

Shaping the future of cancer care in the UK

Concluding remarks


Despite the wide range of expertise among those interviewed for this report, a strong common theme emerged from the interviews – that the UK, as a G7 country, should be achieving some of the best cancer outcomes in the world. Yet, currently, the UK is behind – particularly in terms of overall survival – countries of comparable size and wealth in Europe. British patients deserve better.

The IHE report showed that countries that invest more in cancer care and treatment per person tend to achieve better patient outcomes. The UK cancer community believes that as a country we do not invest enough in cancer prevention, treatment and care, and that increasing investment would lead to improved cancer survival. The community would like to see the Government show the same ambition it displayed when setting up the Cancer Drugs Fund in 2010 to make significant infrastructure and workforce investments now, in order to prevent further disruption from the pandemic and improve the country's cancer outcomes into the future. Due to the impact of the pandemic on income, the charity sector is now less able to plug the gaps in cancer care and research, and should not be relied upon to do so.

As well as increased Government investment, NHS leaders must stand ready to make the necessary changes to improve coordination of services and consistent implementation of national standards and guidelines across the entire patient pathway to help remove regional variation in care. Focussing earlier in the pathway will yield more detections at an earlier stage and improved survival – but patients must also receive the same standards of treatment and holistic support across the country and at every stage of their disease.

With the NICE methods review underway, there is an opportunity to introduce improved processes that help ensure all patients can benefit from fast access to innovations in treatments that provide them with much-needed hope and options.

Addressing the challenges identified by the cancer community cannot be achieved by one group alone. It is only through concerted, cross-sector collaboration that we can hope to reverse the impact of the pandemic on cancer services while re-imagining a system that works harder to improve patients' lives. The new Cancer Recovery Taskforce will look to help restore cancer screening and urgent referrals and reduce waiting list backlogs,⁷² but as a community we also need to think in the longer term.

The page features several large, overlapping geometric shapes. A dark purple shape is on the left side. A bright pink shape is at the bottom center. A medium purple shape is on the right side. The text is centered in the white space between these shapes.

**At this critical
turning point,
the ABPI stands
ready to play
its part.**

Interview questions

During the interviews, stakeholders were asked the following questions:

- 1** Do you recognise the findings of the IHE's EU cancer comparator report?
 - ◆ If yes, then how did we get to where we are now?
 - ◆ If no, then please explain.
- 2** Where do you think we should be in 2020 in terms of cancer care and patient outcomes? In five years? Ten years? What can we learn from countries that achieve better overall cancer survival outcomes than the UK?
- 3** How do you think we can get from where we are now to where we want to be?
 - ◆ What should we be doing now?
 - ◆ What is the most important thing we should be working on?
- 4** The COVID-19 pandemic further highlights some of the challenges that cancer services have been facing but it also presents an opportunity to introduce innovations across the cancer care pathway. What changes / best practice examples would you like to see implemented across the cancer pathway as part of service recovery from the pandemic?
- 5** What more could the pharmaceutical industry and the ABPI be doing in helping to get us to where we want to be?

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