EARLY DIAGNOSIS OF CANCER
RAISING AWARENESS,
STRENGTHENING SYSTEMS,
SAVING LIVES
Cancer Research UK

Every year around 300,000 people are diagnosed with cancer in the UK and more than 150,000 people die from this collection of diseases. Cancer Research UK is the world’s leading cancer charity dedicated to saving lives through research. Together with our partners and supporters, our vision is to bring forward the day when all cancers are cured.

We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. In 2012/13 we spent over £330 million on research. We will bring about a major shift in early diagnosis research, investing around £20 million a year by 2019.

The charity’s pioneering work has been at the heart of the progress that has already seen survival rates in the UK double in the last forty years. Our new ambition is to accelerate this process again, to 3 in 4 patients surviving the disease within the next 20 years.

We receive no government funding for our research.

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Credits and Acknowledgements

Report compiled by Kate Aldersey, Jennifer Boon and Daniel Hunt (Policy Department) in collaboration with staff from across Cancer Research UK UK.
INTRODUCTION

Early diagnosis saves lives. The earlier a person with cancer is diagnosed, the more likely they are to be successfully treated.

It is vital that politicians and policy makers renew efforts now and into the next Parliament to promote the earlier diagnosis of cancer.

This report sets out what you can do to promote the earlier diagnosis of cancer.

It also asks:

- What can politicians do now and in the next Parliament to diagnose more cancers sooner?
- Why is early diagnosis important?
- How is Cancer Research UK making a difference?
- What progress have we made already?

When I was first told I had cancer, I just went numb from head to toe. I thought perhaps it wasn’t real – it couldn’t be happening to me. Luckily the cancer was caught in its early stages, and thanks to the excellent treatment I received, my cancer experience has been a very positive one and I have made a good recovery. I am so glad to be able to spend more time with my family, especially my five grandchildren, but I know that not everyone is so lucky.

We need to keep improving early diagnosis so that more people like me can survive cancer.

Clive, bowel cancer survivor
WHAT CAN POLITICIANS DO NOW AND IN THE NEXT PARLIAMENT TO PROMOTE EARLIER DIAGNOSIS OF CANCER?

Renew efforts to promote the earlier diagnosis of cancer

Support must be maintained for early diagnosis initiatives in England (NAEDI) and Scotland (Detect Cancer Early). Establishing a clear vision for early diagnosis in Wales and Northern Ireland must be a priority, alongside effective screening and access to diagnostic tools.

A commitment to increase the proportion of cancers diagnosed at an early stage, when chances of successful treatment are higher

We have already seen great progress in the early diagnosis of cancer, but it is not enough. Nearly a quarter of all cancers in England are diagnosed via an emergency route. In these situations cancer has often progressed to a later stage and is harder to treat.

A commitment to continue support for campaigns to raise public awareness of the signs and symptoms of cancer

Be Clear on Cancer has demonstrated the impact that public symptom awareness campaigns can have. In England, the NHS and Local Authorities should be incentivised to work together to promote awareness campaigns.

A commitment to increase participation in the bowel screening programme

To set a clear ambition for increasing participation in the bowel cancer screening programme across the UK, subject to informed choice. For example local areas should aim for an increase in uptake of at least 10%.

A commitment to HPV testing for cervical screening

Following successful pilots, HPV testing should be rolled out nationally as the primary test in the cervical screening programme.

Fundamentally, we need to be thinking differently about how we diagnose cancer

This means improved access to primary care. But also better use of alternative pathways to diagnosis, such as walk-in chest X-rays for people with a persistent cough and ‘one-stop’ clinics where patients can get tests done and see specialist doctors at the same time.
WHAT CAN INDIVIDUAL MPs DO?

Use your local statistics profiles
Make use of your local statistics profiles when you speak to your local health decision makers, for example those commissioning health services. Ask the questions we suggest and find out how local health bodies in your area are working together to promote early diagnosis.

Support national, regional and local cancer awareness campaigns
Consider using your local newspaper column, website, Twitter and other media to encourage your constituents to be aware of cancer signs and symptoms. Show your support for awareness campaigns taking place in your constituency.

Promote our Talk Cancer training workshops in your local area
The workshops can be commissioned by anyone with an interest in improving cancer outcomes. They are good value for money and make a real difference in local communities.

Meet our Policy and Public Affairs team
To find out more, please contact us via publicaffairs@cancer.org.uk
WHY IS EARLY DIAGNOSIS IMPORTANT?

Survival from cancers detected early is far higher than those caught at a later stage. Earlier diagnosis makes it more likely that patients will receive treatments such as surgery and radiotherapy which contribute to the majority of cases where cancer is cured. Drug treatments can be used to extend the life of patients with advanced cancer, but they rarely cure.

There is clear evidence of the importance of early diagnosis

When bowel cancer is diagnosed at the earliest stage, more than 9 in 10 people survive at least five years. But fewer than 1 in 10 people with bowel cancer are diagnosed at the earliest stage. When lung cancer is diagnosed at the earliest stage, 7 in 10 people survive for at least a year, but less than 2 in 10 people are diagnosed at the earliest stage. Despite significant developments in early diagnosis, there’s still more that needs to be done. Almost a quarter of newly diagnosed cancer patients in England still receive their diagnosis through an emergency route, often at an advanced stage.

Variation in the stage at which cancers are diagnosed is linked to geographic location, ethnicity, gender and socio-demographic factors. The number of people diagnosed with cancer in England who survive for at least a year can differ by over 10% for some cancer types depending on geographical location.
It is estimated each year that thousands of advanced stage diagnoses could be avoided if socio-demographic inequalities at stage of diagnosis were eliminated\(^5\).

The UK has low survival when making international comparisons

Internationally, despite improvements, the UK continues to have lower cancer survival compared with other developed nations. We are working to understand what is contributing to these differences and how we can address them. Early diagnosis and access to optimal treatments are two factors amongst others. There is some evidence of later stage diagnosis in the UK compared to other countries, notably for lung and colorectal cancer\(^6,7\).

Public awareness of cancer is vital

Public awareness of the signs and symptoms of cancer is vitally important. Knowing which symptoms to look out for and that seeing a GP is justified can empower people to seek help. As well as awareness of symptoms, it is important that people are fully informed about the screening options available to them for some cancer types and feel able to make an informed choice about taking part.

Primary care has an important role to play

Signs of cancer may not be clear or obvious and GPs see, on average, less than eight new cancer cases a year. And they will only have around 10 minutes per appointment to identify warning signs that could be cancer but equally may be a symptom of a less serious condition. With more than 200 different types of cancer, often with vague symptoms, the role of GPs in early diagnosis of cancer is challenging.

GPs can benefit from training and support in making decisions about investigating symptoms and referring to specialists effectively and swiftly. Systems should support primary and secondary care to work together to support early diagnosis.

Delays lead to avoidable deaths

Delays in diagnosis and treatment can lead to avoidable deaths. Early diagnosis is a multifaceted problem and it requires a multifaceted solution. In this report, we lay out some of the approaches which Cancer Research UK is taking to improve early diagnosis, including funding research; public awareness campaigns; benchmarking the UK’s performance internationally; and working with individual GPs and local commissioners. We’ve set out examples of the positive impacts we’re already having, but there is still a lot more progress to be made. Working together we can ensure that more cancers are being diagnosed at the earliest possible stages and that we can save more lives sooner.
HOW IS CANCER RESEARCH UK MAKING A DIFFERENCE?

Cancer Research UK will bring about a major shift in early diagnosis research, investing around £20 million a year by 2019.

We publish statistics on all aspects of cancer, including tailored cancer statistics for Parliamentarians which are local to their constituency. We provide information for patients on cancer through our website and our nurse helpline.

Our primary care programmes are engaging and training healthcare professionals, whilst our awareness campaigns seek to test new ways to engage the public with our early diagnosis messages.

RESEARCH

Funding research

There is still a lot of work to be done to build up the evidence base around early diagnosis. We fund a wide range of research through our Population Research Committee\(^8\), the National Awareness and Early Diagnosis Initiative (NAEDI)\(^9\) and our Early Diagnosis Advisory Group\(^10\). Our researchers are looking at a wide range of issues, from improving screening uptake, to international comparisons, understanding what stops people going to their GP and understanding more about the behaviour of GPs themselves. By 2019, we will be investing around £20 million a year in early diagnosis research.

The International Cancer Benchmarking Partnership (ICBP)

Understanding why cancer survival varies between countries is a challenge and it is one that the ICBP\(^11\) is looking to address. It is a unique and innovative global partnership of clinicians, academics and policy-makers. The programme is co-ordinated by Cancer Research UK. As the first study of its kind, the partnership aims to generate insight and understanding that will help all partners improve cancer survival outcomes by optimising cancer policies and services.

INFORMATION

Provision of local statistics

We produce local statistics profiles\(^12\), giving insights into regional variation across the UK. These are accessible and interactive, allowing us to look at the detail of early diagnosis across the UK and to provide valuable information to everyone from politicians to commissioners to the general public.
Cancer Awareness Measure (CAM)

The CAM\textsuperscript{13} is a validated set of questions designed to reliably assess cancer awareness, developed by Cancer Research UK, University College London, King’s College London and the University of Oxford in 2007-8. Tools like this equip us to understand the public perception of cancer and provide a robust evidence base for our interventions. We are also piloting a version of the CAM for health professionals.

**PRIMARY CARE**

**Primary Care Engagement**

Primary care has a huge role to play in effective early diagnosis and we recognise this in our work. We provide face-to-face support to 1,200 GP practices around the UK, in partnership with the NHS. Our specialist team holds educational events for staff, raising awareness of the importance of early diagnosis. They also work with individual practices to provide up-to-date local information, look at how referrals for more tests or specialist assessment could be made faster and encourage practices to develop their own action plans, which are known to help improve early diagnosis.

Our partnership with doctors.net, an online professional networking site for doctors, provides continuing medical education for GPs in a number of cancer types and symptoms and an online forum for GPs to share experiences with cancer doctors. Cancer Research UK delivers regular content to GPs and Practise Nurses via printed and digital newsletters.

**Primary Care Decision Support Tool**

Electronic Clinical Decision Support (CDS) tools are designed to support GPs to assess cancer risk. In a project part-funded by the Department of Health, implemented by Macmillan Cancer Support and evaluated by Cancer Research UK, we have assessed the usability, acceptability and impact of these tools in general practice. Although evaluation is ongoing, initial results show that, of the patients referred or investigated after using the CDS tool, the GPs reported that they would not have taken this action for a fifth of those patients without the tool. Cancer Research UK partnered with the British Association of Dermatologists to provide a skin cancer recognition toolkit which has increased GPs confidence in making skin cancer referrals.
PUBLIC AWARENESS

Health Marketing

Innovative approaches are needed to engage the general public with early diagnosis messages and we have run a number of creative health marketing campaigns designed to test and engage hard-to-reach audiences, including social marketing to overcome fear of presentation, a partnership with the Mail Online and a Spot Cancer Early online film using humour to convey our messages15.

Be Clear on Cancer

Cancer awareness campaigns are a vital way of encouraging the public to identify symptoms and go to their GP quickly. Be Clear on Cancer16 is a public information campaign, run by Public Health England in partnership with the Department of Health and NHS England and supported by Cancer Research UK. By March 2014, the brand had already been used to promote symptom awareness and early diagnosis of eight different cancers, as well as a more generic campaign which focused on four key signs of many types of cancer.

Community Engagement

Our Cancer Awareness Roadshow17 consists of four mobile units with trained nurses on board. We travel around the UK talking to people about ways to reduce cancer risk and the importance of early diagnosis. We also explore people’s attitudes and beliefs around cancer and help reduce barriers that stop people going to their GP.

We’re also helping to equip and empower frontline health staff (e.g. pharmacists and nurses) and local volunteers to raise cancer awareness in their community. Our Talk Cancer18 training workshops give trainees the knowledge, skills and confidence to talk about cancer awareness messages in their community. They are commissioned by local authorities, Strategic Clinical Networks and other organisations.
WHAT PROGRESS HAVE WE MADE ALREADY?

Our portfolio of work on early diagnosis is already making a lot of progress in this area, building the evidence base, informing and empowering the public and engaging with GPs. Here are some examples of our recent successes.

Bowel Scope Screening

Bowel cancer is the fourth most common cancer in the UK, accounting for 13% of new cases. Screening is vital for the early diagnosis of bowel cancer and Cancer Research UK supported a 16 year trial into an innovative new screening technique called Bowel Scope. The technique involves a flexible tube being used to examine the lower bowel and allows pre-cancerous polyps to be identified and removed before they can develop into cancer. This trial showed that this technique not only cut deaths by 40%, it also prevented bowel cancer in a third of those screened. As soon as the trial results were published in 2010, we asked the Government to add Bowel Scope to the existing bowel screening programme, and later that year, they agreed, setting aside £60m to fund it. The technique is now being piloted in the NHS and by 2016 should be available to everyone in England at the age of 5519.

Be Clear on Cancer Lung Campaign

From May to July 2012, Be Clear on Cancer ran a national campaign (in England) to tell the public that a persistent cough can be a sign of lung cancer and emphasise the value of early diagnosis. Cancer Research UK led on the evaluation for this campaign and results have shown that there were an estimated 700 additional lung cancers diagnosed during that period than the same period the previous year. Approximately 400 more people had their cancers diagnosed at an earlier stage and around 300 additional patients had surgery as a first treatment for diagnosed lung cancer20.

Differences in Cancer Awareness and Beliefs

In 2013, ICBP research on awareness and beliefs about cancer suggested that people in the UK are more worried and embarrassed about seeing their doctor with a symptom that might be serious compared to those in other countries. Results showed that there was a similar level of awareness of cancer symptoms and generally positive beliefs about cancer, although knowledge that cancer risk increases with age
was low across all countries. Overall the research suggested that awareness and beliefs about cancer are unlikely to explain international survival differences but may form part of a more complex picture. We are working hard to understand and address these potential barriers to early presentation.

Health Marketing in Wales

Cancer Research UK recently ran an early diagnosis campaign in Port Talbot, which aimed to improve awareness of cancer survival to reduce fear and fatalism of cancer. This was in response to the Cancer Awareness Measure survey, which had demonstrated that over 37% of respondents might put off going to their GP due to fear of what they might find. The campaign ran a range of interventions with a target audience of over 50s, especially those from lower socioeconomic groups. The campaign used local cancer statistics so people could identify with key messages. When surveyed, 81% of respondents felt that the messages were relevant to them, whilst the recall of key messages was high. Importantly, 94% of respondents stated they were more likely to say they would go to the GP if they had a ‘persistent or unusual change’ after the campaign, a significant increase from 81% pre campaign. The use of positive and localised communications is effective in increasing engagement, relevance and impact.

Cancer Awareness Roadshow

While our health marketing campaigns reach large audiences through mass communications, our Roadshow nurses hold over 60,000 individual conversations with people every year. Published results show that the Roadshow is especially effective at reaching people most in need, including lower socioeconomic groups, and that we have a positive impact on visitors’ intentions to make health behaviour changes and access local services. Nearly 80% of visitors who discussed early diagnosis felt more confident in noticing a possible cancer sign or symptom as a result of their visit. Barriers to seeing the GP also reduced significantly, with fewer visitors worried about what the doctor might find (38% pre-visit versus 28% post).
Talk Cancer

The evaluation of our pilot training programme in 2010-11\textsuperscript{22} showed a clear need for cancer awareness training and demonstrated the impact. 82% of attendees said that they had not previously received any cancer awareness training. The training significantly increased knowledge of cancer risk factors, with 79% of participants correctly identifying 10 out of 11 known risk factors, compared to 21% before training. There were clear improvements in the knowledge of some common signs and symptoms, and 96% of people reported confidence to discuss signs and symptoms of cancer with the public, a considerable increase from 32% beforehand.

Based on these results, we launched Talk Cancer in 2012. We have since delivered 70 workshops to over 1,000 people including pharmacists, community volunteers and other frontline staff. Recent qualitative evaluation showed the training also helped to de-stigmatise cancer and break down negative attitudes towards the disease.

Primary Care Engagement

Our primary care facilitators have already met with over 500 practices to encourage the use of tools which can help in the early diagnosis of cancer. Over 80% have developed cancer action plans to support improvements in early diagnosis, which include mechanisms to learn from previous cases.
We’re already working hard to diagnose more cancers sooner.

But there’s still more to do.

And we need your help.
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