

Delay Kills

A Cancer Research UK and Tesco report on the problems of diagnosing cancer early and why we need to solve them



TESCO
working with
CANCER RESEARCH UK

Help us beat cancer

Tesco Charity of the Year 2012



Foreword from Dr Harpal Kumar

Cancer, and the fear that it generates, is being conquered gradually. For many of us though, the progress seems too slow. People want a magic bullet to banish cancer from our world.

But step by step, project by project, trial by trial, research into this most feared disease is paying off. Survival has doubled in the last 40 years.

Publicly funded research is constantly finding new discoveries that lead to improved treatments which keep cancer under control. In more and more cases – even if the cancer cannot be permanently eradicated – at least patients can return to a normal routine and expect to live for many more years than their predecessors.

So, while we can all benefit from the work done so far, there is still much more to do. And senior cancer clinicians believe that early diagnosis lies at the heart of the cancer conundrum. When cancer is caught early the chances of survival often increase enormously. The new improved treatments available can sometimes cure and often extend survival by years.

The joint partnership between Tesco and Cancer Research UK is a vital step forward in working together to make further serious inroads into this disease.

Together with Tesco we aim to raise £10 million over the next year which will fund around 30 projects focused on early diagnosis. We will also work together on a campaign to increase cancer awareness and highlight the importance of early diagnosis to the UK public. Tesco's support of Cancer Research UK will help the charity achieve its goal of diagnosing more cancers at an early stage where successful treatment is more likely so that many more lives can be saved.

We are excited about the opportunities to raise funds, and awareness, that come from working with the UK's biggest retailer. Tesco's reach and ability to engage every customer coupled with Cancer Research UK's scientific expertise will make this a great partnership from which we will all benefit.



Dr Harpal Kumar
Cancer Research UK Chief Executive

Introduction

Every year cancer kills around 73,000 more people than coronary heart disease and around 78,000 more than respiratory diseases like pneumonia, bronchitis and emphysema.

The most recent annual figures state that around 309,500 people were diagnosed with cancer in 2008 in the UK. That's around 850 people every single day. And every day in 2009 more than 425 people died from cancer. That's one person every four minutes.

Senior cancer doctors believe that early diagnosis is vital in the fight to beat cancer. In fact, it has been estimated that if cancer survival rates in Great Britain matched the European average, then 6,000–7,000 deaths could be avoided each year. And if they matched the best, around 11,500 deaths could be avoided.

But a key part of early diagnosis is public awareness of what could be signs or symptoms of cancer. And this is worryingly low as our new report shows.

The results of our research show that more than three quarters of people asked to list possible warning signs and symptoms of cancer failed to mention either pain, coughing or problems with bowels or bladder.

And more than two thirds of the 2090 people surveyed for the report also failed to list bleeding. Only around one quarter mentioned weight loss or mole changes as being a potential sign of cancer.

But even when people recognised signs they thought might be serious the survey found that nearly 40 per cent said they might delay getting symptoms checked out because they would be worried about what the doctor might find. And more than 25 per cent might delay because they would be worried about wasting the doctor's time.

This report is being published as Cancer Research UK and Tesco mark the beginning of a groundbreaking new partnership which aims to raise £10 million to support the funding of 30 projects designed to research early diagnosis.

Tesco will also support an awareness campaign targeting millions of its customers and employees across the UK with life-saving cancer awareness messages. For example millions of customers pass through the Tesco tills each week, and as a result of the new partnership they will be able to find Cancer Research UK leaflets on checkouts, to help them to spot the early signs and symptoms of cancer.

By working together the partnership will make a real difference in the battle against cancer and help save thousands of lives.

Asked to list possible warning signs and symptoms of cancer, more than three quarters of people failed to mention either pain, coughing or problems with bowels or bladder.



Identifying the problem

People are more likely to survive cancer if it is found at an early stage, before it has had a chance to spread to other parts of the body.

We know that men and women simply do not recognise many of the symptoms that could be cancer. And, added to this, delays in referring patients to specialists and diagnosing the disease are all too common. While we are gradually making progress there is still a long way to go.

Cancer tends to be diagnosed at a later stage in Great Britain than in other countries with comparable health care systems. Too many cancer patients are diagnosed once the disease has already spread when there are fewer treatment options. This is one of the reasons that our survival rates are worse than in some other parts of the world. In fact, it has been estimated that if cancer survival rates in Great Britain matched the European average, then 6000–7000 deaths could be avoided each year. And if they matched the best, around 11,500 deaths could be avoided.

But diagnosing cancer earlier is not easy. There are several reasons why cancer might be diagnosed late and several occasions when delays can happen. We know there are three things that could make a significant difference – public awareness and attitudes, awareness and behaviour of health professionals and better access to the best diagnostic tests.

Attitudes towards cancer

It is well known that people sometimes put off seeing their doctor when something is wrong. Often this is because they do not recognise how serious their symptoms might be; perhaps it is something they've had before, or something they know a friend or family member has had. It could also be because people are not aware of the warning signs of cancer.

People's attitudes towards cancer also play a role. Although people generally believe in the benefits of early diagnosis and are reasonably optimistic about the chances of surviving cancer, a significant proportion have negative attitudes towards cancer treatment. Many people also believe cancer is down to fate and there is

nothing that can be done about it. People might prefer to remain in the dark and let life run its course thinking: 'What will be, will be'. These negative attitudes towards cancer lead to pessimism about early detection, fear of reporting symptoms to others and being less likely to seek help for them.

The Cancer Reform Strategy, published in 2007, launched the National Awareness and Early Diagnosis Initiative – NAEDI – a partnership between the Department of Health and Cancer Research UK. NAEDI's role is to coordinate activities and research to promote the early diagnosis of cancer.

Key aims are to help raise public awareness of cancer signs and symptoms, encourage those experiencing symptoms to visit the doctor and understand and tackle the reasons why people might put off going to their GP.

Cancer awareness measure

One of NAEDI's early achievements was to develop something called the Cancer Awareness Measure (CAM). Cancer Research UK developed the CAM with a group of researchers from University College London, King's College London and the University of Oxford.

The CAM provides a way of assessing how much the public know about cancer, helping to identify what information the public need. It also provides a way of monitoring the effectiveness of campaigns designed to raise awareness.

The CAM was first used in a national population survey in 2008 and was repeated in 2010. The idea was to find out levels of cancer awareness among people throughout Great Britain, to see how these levels changed over time, and to discover if and – by how much – they improved after various campaigns to boost awareness of cancer signs and symptoms.

In both 2008 and 2010, the CAM was included in the Office for National Statistics (ONS) Opinions Survey which is recognised as the gold-standard way to get a sample of the population that is genuinely representative and is used to collect government data. We have used the CAM survey of 2,090 people and the results are outlined below.

Using the CAM in the Opinions Survey means that the results are as accurate as possible in reflecting actual awareness levels in the population. Each person is asked the questions in their own home using a face-to-face, computer-assisted interview.

Key results from the cancer awareness measure 2010

In 2010 a total of 2090 respondents took part in the ONS Opinions Survey and answered questions in the Cancer Awareness Measure. The table below shows the characteristics of the sample – sex, age, marital status, ethnic background, occupation and educational level.

Table 1: Sample characteristics of the CAM survey

CHARACTERISTICS	% (N)
GENDER	
Male	44.8 (937)
Female	55.2 (1153)
AGE	
16–24	7.1 (149)
25–44	30.8 (643)
45–54	16.8 (352)
55–64	18.1 (379)
65–74	14.7 (308)
75 and over	12.4 (259)
MARITAL STATUS	
Married/civil partnership	46.1 (963)
Not married	53.9 (1127)
ETHNICITY	
White	92.9 (1941)
Other ethnic backgrounds	7.1 (149)
OCCUPATION	
Managerial/professional (Higher SES)	32.9 (688)
Intermediate/small employers/lower supervisory (mid SES)	28.3 (592)
Semi-routine/routine (lower SES)	28.3 (591)
Not classified	10.5 (219)
HIGHEST QUALIFICATION OBTAINED	
Degree or equivalent	18.5 (387)
Below degree	40.2 (839)
Other	15.0 (313)
No formal qualifications	26.3 (550)

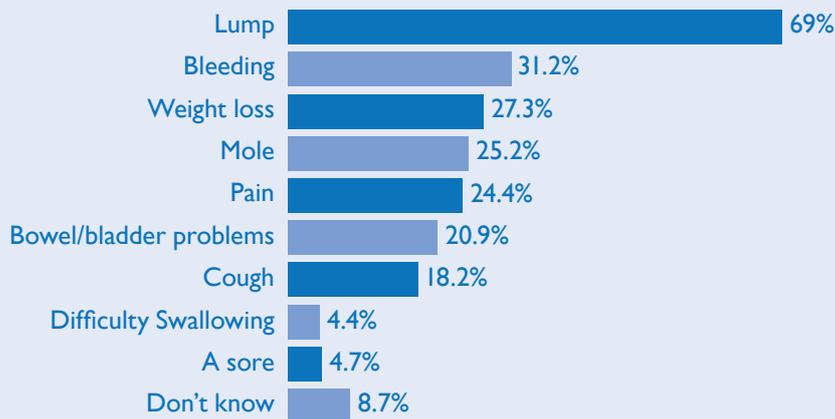
Knowledge of cancer signs and symptoms:

When asked: 'There are many warning signs and symptoms of cancer. Please name as many as you can think of' on average, respondents were able to recall just two signs or symptoms of cancer. There was relatively good knowledge that a lump or a swelling could be a sign of cancer, yet recall of other symptoms was low, with less than 32 per cent able to name any other symptom and 9 per cent saying they did not know any (see Figure 1).

Asking people whether they agreed or disagreed with a list of potential symptoms showed higher knowledge levels. There was still better recognition of a lump than of any other sign or symptom. Added to this, at least a quarter of respondents did not believe that unexplained persistent pain, a persistent cough, or a sore that will not heal could be signs of cancer.

Nearly 40 per cent of people said they might delay getting symptoms checked out because they would be worried what the doctor might find. And more than 25 per cent would delay because they feared wasting the doctor's time.

Figure 1: Recall of cancer signs/symptoms



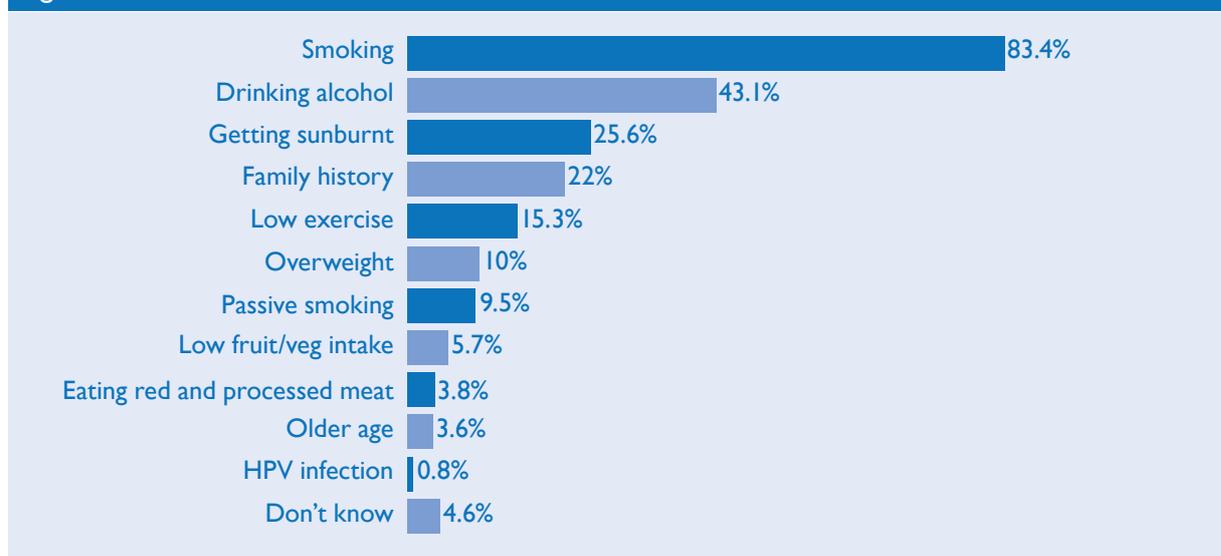
Knowledge of cancer risk factors:

When asked: ‘What things do you think affect a person’s chance of developing cancer?’ on average respondents mentioned three things. There was a high level of knowledge about smoking, with 83 per cent of respondents mentioning this, but less than half of all respondents mentioned any other factor. There was particularly poor knowledge of several lifestyle-related factors such as diet (fruit and vegetable and red and/or processed meat intake), weight and physical activity (see Figure 2).

As with signs and symptoms, knowledge of risk factors was higher when respondents were shown a list of factors, but still less than a quarter of respondents thought that diet or physical activity could play a role in a person’s risk of developing cancer and only 30 per cent believed alcohol could increase the risk.

This is important as lack of awareness of the risk factors for cancer indicates a lack of awareness of personal risk of the disease – and it is often those most at risk who have delayed diagnoses.

Figure 2: Recall of cancer risk factors

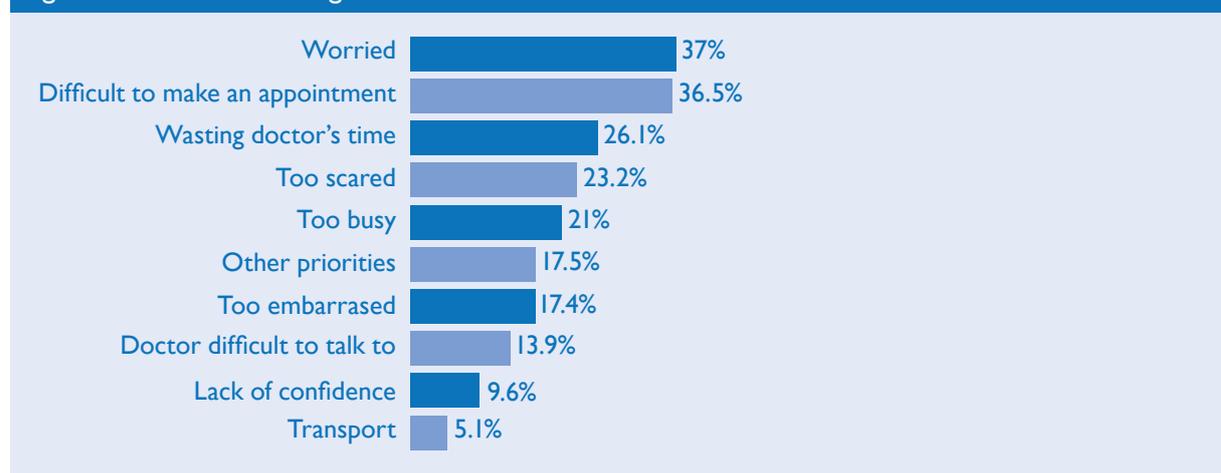


Barriers to seeing the doctor:

Respondents were asked ‘Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?’ and shown a list of potential barriers. The

three biggest barriers were: ‘being worried about what the doctor might find’ (37 per cent), anticipating that it would be difficult to make an appointment at the GP (37 per cent) and not wanting to waste the doctor’s time (26 per cent) (see Figure 3).

Figure 3: Barriers to seeing the doctor



Barriers in primary care

Diagnosing cancer earlier is a complex challenge with no easy answers. It needs a multi-faceted approach that addresses not only the public's poor symptom awareness, their fear of cancer and hesitation in presenting to the GP, but also barriers in primary care. GPs are key players because of the central role they play in recognising important symptoms, acting as gatekeepers to secondary care and, now, also as commissioners.

A recent national audit of primary care looked at the time between a patient's first presentation to the GP and date of referral, and it highlighted that the majority of patients with suspected cancer (73 per cent) are identified and referred for specialist investigations promptly. But the situation needs to get better. By making sure that GPs have access to the best diagnostic tests, and through providing tools and education to support swift identification of cancer symptoms and appropriate referral, improvements can and must be made.

Cancer Research UK is working hard to keep cancer high on the agenda in primary care. It is a sobering fact, not widely recognised, that the average GP might only see eight new cases of cancer each year.

Research saves lives

Scientific research also plays a pivotal role in early diagnosis. Bowel cancer is a good example where the development of a test to detect traces of blood in stool samples can indicate the disease. This is known as the FOB test and is part of the national bowel cancer screening programme which can catch and treat bowel cancer when it is still at an early stage.

Another revolutionary new technique to prevent and diagnose bowel cancer called flexible sigmoidoscopy – also due to become part of the screening programme and predicted to save thousands of lives – was developed after a 16 year trial which Cancer Research UK helped to fund.

There is an urgent need for more discoveries like these. Cancer Research UK relies on the generosity of public donations to commission its world class scientists to continue their ground-breaking research.

With more breakthroughs urgently needed, Cancer Research UK's partnership with Tesco is crucial as it will provide vital funding for more than 30 projects designed to improve early diagnosis. As part of the partnership Tesco will also help to raise much-needed awareness among the millions of people it reaches.

Role of government

Finally we need government support to boost public awareness of the importance of early diagnosis initiatives including:

- a) raising public awareness of the signs and symptoms of cancer;
- b) ensuring GPs and others in primary care are equipped to refer suspected cancers quickly and appropriately;
- c) ensuring delays in diagnosing cancers in secondary and tertiary care are minimised.

Formal initiatives already exist in England and Scotland though not in Wales and Northern Ireland. We urge both English and Scottish governments to commit to public cancer awareness work and training for professionals in both primary and secondary health care in a real effort to cut the death toll from this devastating disease that people fear most.

Conclusion

This report highlights the gap in public awareness of cancer symptoms and the lag in diagnosing the disease early in the UK. The partnership between Tesco and Cancer Research UK aims to help close that gap through research and awareness to ensure that thousands more people will survive cancer in the future.

A survivor's story

Justine Sheils, a 40-year-old office administrator from Liverpool, began using sunbeds when she was 15 so she could get a base tan before summer holidays and then top the tan up when she came home. When she was 32 she noticed something was wrong while she was out jogging and felt a hard lump on her chest.

Instead of hoping it would go away Justine made an appointment with her doctor straightaway and was shocked to be diagnosed with malignant melanoma – the most dangerous form of skin cancer. Since then she has had two major operations to remove cancerous tumours from her chest and the top of her head. Now she is healthy and feels back to normal. But she believes she owes her life to getting her symptom checked out quickly and being diagnosed early so that her treatment could be successful. And now she wants to warn others to keep away from sunbeds.

“The tanning salon was near my school and I used to go in for sunbed sessions on my way home,” said Justine. “There was always an occasion like a party or an outing when I had the excuse to top up my tan. Now I see girls of 14 or 15 in their school uniforms going into that same salon I once used and they come out looking like lobsters.

“They think something like cancer could never happen to them. But it has happened to me. I get so angry when I hear young celebrities say having a tan makes you look sexy. It's only when you get older you understand the risks. I just want to do something to warn young people about the possible consequences of using sunbeds. If my story can stop one girl risking melanoma then something good will have come out of my cancer diagnosis.”

‘If patients are diagnosed when the cancer is still in its early stages before it has had a chance to spread to other parts of the body it is more likely that treatment will be successful.’

Prof. Peter Johnson
Chief Clinician, Cancer Research UK



Projects

Tesco will support the funding of around 30 projects on early diagnosis. These include:

Tesco will support **Professor Peter Sasieni's** ongoing research programme investigating whether testing women aged 25–65 for the human papillomavirus (HPV) – as part of the cervical screening programme – could save even more lives than the smear test alone. Cervical cancer is the second most common cancer among women under the age of 35, and the majority of cases are caused by two strains of HPV, types 16 and 18.

Professor Peter Sasieni, Cancer Research UK epidemiologist and cancer screening expert, said: "I am very pleased that Tesco has chosen Cancer Research UK as its Charity of the Year and has decided that the money it raises should go towards early diagnosis and screening research. Over the last 25 years screening, backed by Cancer Research UK research, has had an enormous impact on cancer in the UK. The cervical screening programme has prevented many thousands of cancers and our research has led to several policy changes resulting in improved screening.

"We continue to try and improve screening and are very active in researching the role of human papillomavirus (HPV) testing in cervical screening. Within a decade, a switch to HPV testing should allow women to be screened less often while receiving even better protection against cervical cancer.

"We are also researching how to raise awareness of cancer symptoms among the public and enable doctors to make diagnoses more rapidly. The overall aim is to reduce the number of cancers diagnosed at an advanced stage, when treatment is no longer able to cure the disease.

The benefit of early diagnosis will prevent more cancer deaths. Research in to this vital area of cancer control relies on the generosity of public funding and organisations like Tesco. We will continue to make sure that any funds we receive from Cancer Research UK are used for research that will make a difference to the British public."

Another project that Tesco will help support is Professor Wendy Atkin's work on preventing bowel cancer. Bowel cancer is the third most common cancer

in the UK with nearly 40,000 people diagnosed with the disease each year. Her work focuses on preventing the disease by catching polyps and other more difficult to detect bowel lesions while they are still harmless.

Professor Wendy Atkin, a Cancer Research UK scientist based at Imperial College in London, said: "I'm delighted that Tesco are helping fund Cancer Research UK's vital research into early diagnosis and prevention of the disease. Our work has already shown that a once only screen with flexi-scope reduces the chance of getting bowel cancer by a third. And as a result of this work everyone will be offered this bowel screening at age 55. Our latest research is looking at ways of preventing many more bowel cancers."

“We are delighted that Tesco is funding vital research into early diagnosis of cancer.”



Professor Peter Sasieni



Other projects Tesco is supporting:

Pancreatic cancer in London

Professor Nick Lemoine, Director of the Barts Cancer Institute at Queen Mary University of London, oversees a programme of research looking at new ways to diagnose and treat many types of cancer. He is an international expert in pancreatic cancer and much of his work focuses on this disease – particularly studying the genes and proteins inside pancreatic cancer cells to understand how the cancer develops. If they can understand this, it may reveal new ways to diagnose pancreatic cancer at a much earlier stage in the future.

Oesophageal cancer in Cambridge

Oesophageal cancer has an extremely low survival rate that could benefit hugely from earlier diagnosis. **Dr Rebecca Fitzgerald** from the University of Cambridge is leading a study to investigate how effective a simple new test is at detecting Barrett's oesophagus. People with Barrett's oesophagus are at a higher risk of developing oesophageal cancer than the average person. It is most likely to be diagnosed in people who have a long history of heartburn. Although most people with the condition won't develop oesophageal cancer, it's still important for them to be regularly checked for early signs of the disease, so this test would help to identify people who could be monitored regularly for early signs of the disease. The only way to diagnose the condition currently is an invasive and uncomfortable procedure called an endoscopy, which involves a tube being passed down the foodpipe to look at and remove samples of, tissue. A test that is easier for patients would be big step forward.

Skin cancer in Edinburgh

Failure to recognise the early symptoms of skin cancer can sometimes mean that people with the disease are diagnosed late. This can make treatment less likely to be successful. **Professor Jonathan Rees** at the University of Edinburgh wants to see if using web-based images could be more successful at helping people detect abnormalities than the current information awareness approaches (the so called ABCD of skin cancer detection). He hopes that a web based interface could help lead to better symptom recognition and early detection of skin cancer in the future.

Genetic breast cancer in Cambridge

Professor Douglas Easton is director of the Cancer Research UK Genetic Epidemiology Group at the University of Cambridge. He is world-renowned for his research into genes that affect our risk of common cancers, particularly breast cancer. His team also works on ovarian and prostate cancer and melanoma. Their findings will help identify high-risk individuals and could lead to new ways of diagnosing the disease in the future. The team is leading a large-scale study called EMBRACE which aims to monitor women who have faults in genes called BRCA1 or BRCA2 that make a woman much more likely to develop breast and some other cancers. They hope to uncover other genes, as well as lifestyle and environmental factors that affect their likelihood of developing breast cancer, which could help lead to earlier detection of the disease in the future.

Ethnic groups and cancer symptoms in London

Dr Laura Marlow at University College London is leading a study to try and understand why some ethnic groups may be less likely to attend screening or present to their GP with cancer symptoms. Her initial investigations will involve women from several different communities. Her findings could potentially reveal new ways to encourage more people to understand cancer screening programmes and make informed decisions about attending. Limiting inequalities in screening and prevention could help save lives from the disease.

Breast screening in Surrey

The Optimam project is led by **Professor Kenneth Young** at the Royal Surrey County Hospital, to see if new digital X-ray technology could transform the face of breast cancer screening. Professor Young's team has developed complex mathematical models to test various new technologies and work out the best way to use them before testing them on women. He believes that the optimal selection and use of such new technology in screening could be more efficient than current mammography screening, particularly in women who are younger or have dense breast tissue. In the future, this could mean that more lives could be saved from breast cancer by improved early diagnosis.



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