



ROY CASTLE
LUNG CANCER
FOUNDATION

“I’m a big supporter of social justice. I think it is wrong that the cancer that kills the most people gets less funding than other cancers. I want to change that. I don’t want my children to be motherless because lung cancer doesn’t get enough money for research.”

Joanna, 40

It's time to
OPEN YOUR EYES



IMPACT REPORT
2016-17

Expect Better

Roy Castle Lung Cancer Foundation is the only UK charity wholly dedicated to defeating lung cancer. It is a responsibility we take very seriously.

Lung cancer is the UK's biggest cancer killer - in both men and women - with 36,000 people dying from the disease each year. This is more than breast, prostate and pancreatic cancer combined.

This is simply not good enough and we should all **expect better**.

We focus on three key areas:

- **Research**
- **Information and Support**
- **Prevention**

With lung cancer receiving significantly less funding than other cancers, our research grants are essential if we are to **expect better survival rates**.

We fund research projects which give researchers the opportunity to test a hypothesis. This then gives them the necessary results needed to secure further funding.

Without our grants, they may not be able to pursue their research.

We are now starting to see some exciting results from researchers in early detection,

including the development of biomarkers in blood and sputum.



We are also committed to providing support to lung cancer patients and their families.

We do this in a number of ways - from **providing information about lung cancer** such as how to manage symptoms or details of treatments, to **offering financial support** through our patient relief grants.

Lung cancer patients often speak about feelings of isolation and even judgement. This is not right, and patients and their families should **expect better attitudes**.

We provide an inclusive support network which allows patients and supporters to share their experiences with others in a similar situation. We also offer patients the opportunity to speak out and challenge the stigma associated with lung cancer.

Prevention is a key part of what we do because the best way to beat lung cancer is to stop it from ever happening. This way we can **expect better outcomes**.

We work tirelessly to **help people reduce their risk** of getting lung cancer, from successfully campaigning for the smoking ban in public places to educating children and young people with our innovative **Cut Films project**.

But we can only do all this thanks to the incredible ongoing support we receive from our patients, fundraisers, advocates, ambassadors, researchers, nurses, corporate partners, volunteers and staff.

Striving for a world where no one dies of lung cancer is no easy feat but we have the people and dedication needed to make it a reality.



Paula Chadwick

Paula Chadwick

Chief Executive

Roy Castle Lung Cancer Foundation

Expect Better Survival Rates

Research

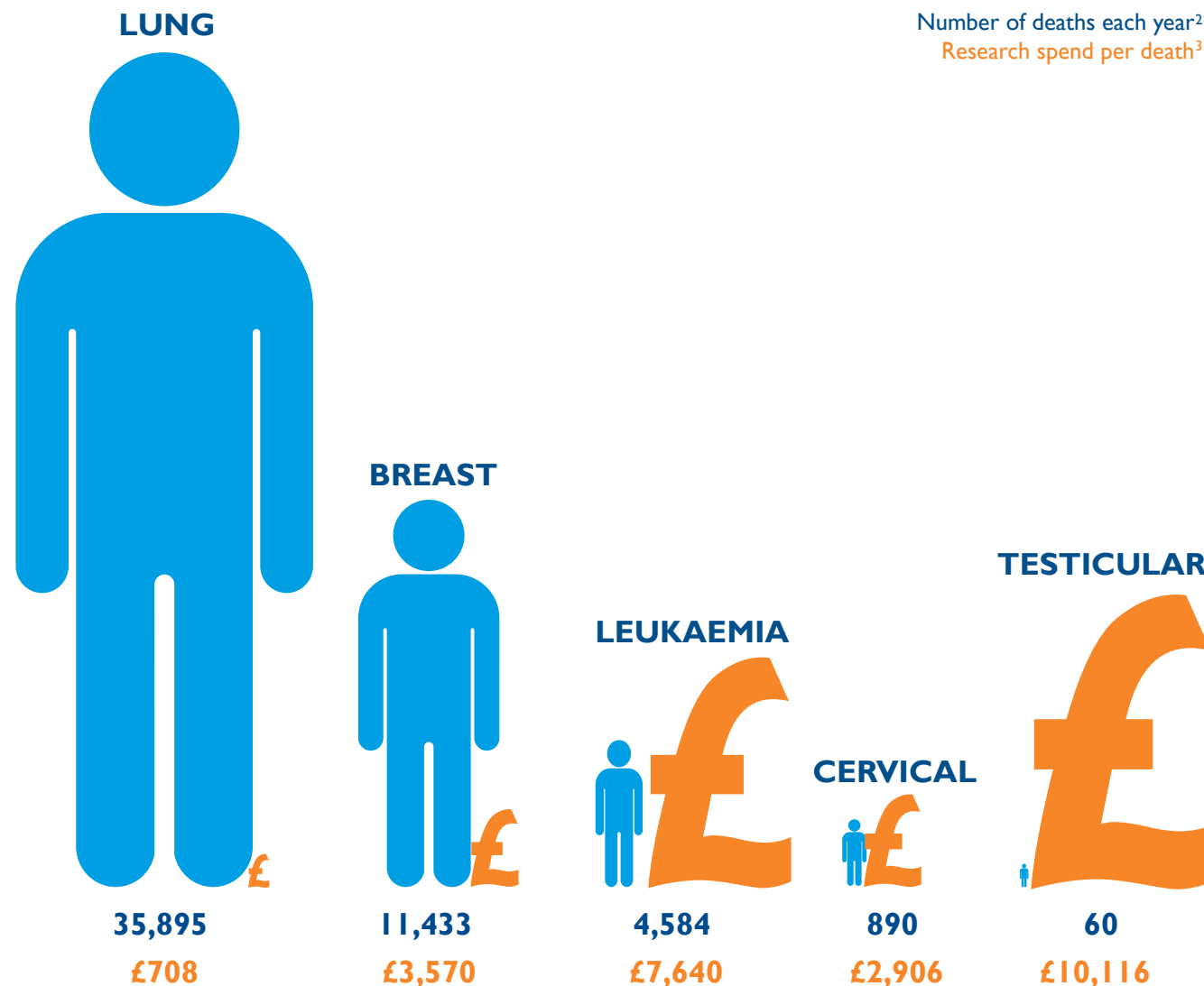
Current UK lung cancer survival rates:



“Lung cancer remains a leading cause of cancer deaths in the UK. Enduring challenges include preventing delays in diagnosis and improving the patient experience - for example by improving treatments and symptom control.

The research funded by Roy Castle Lung Cancer Foundation is vital in meeting these challenges. Research recently funded by the charity has made a great contribution to earlier detection, as well as improvements in care and treatment. Although relatively new, this research funding stream has had a major impact on patients and their families.”

Professor Angela Mary Tod
Professor of Older People and Care
University of Sheffield



Expect Better Survival Rates

In 2017, we funded our Lung Health MOT check to identify people with lung cancer before symptoms appear.

Early detection is everything in lung cancer - it saves lives.

It saved Bill's life.

“I had a call from a nurse about the check and thought I may as well go. I'd had a cough for a while but I wouldn't have gone to my doctor's about it because I didn't feel ill.

At the initial appointment I was told I needed to have a CT scan and then a PET scan. That's when I was told - yes, you have lung cancer but it's localised, it's a very small amount and hasn't spread.

One minute you've been given a death sentence, the next you're getting a reprieve! And it comes out in two sentences!

The whole process, from the initial breath tests to having the operation and getting out of hospital, took about six weeks. You're operated on and a couple of days later you can go home - you're fixed, you're mended, you feel great! You really feel elated.

My doctors said “It's given you 10 more years of your life”. That's the thing, if they do find it, you can be fixed.”

Bill is now regularly monitored and attends a check-up every three months for the first year, after which he will attend every six months.



“If I hadn't have gone for that scan I could have been dead in a years time. The doctor said it's given me 10 more years of my life.”

Bill

Expect Better Survival Rates

In addition to the patients diagnosed with lung cancer via our check, 8% of those who had a CT scan were found to have small nodules on their lungs. These are not currently malignant. However, these patients will now undergo interval CT scanning to monitor any growth or changes.

8%

Without our health check, it is highly likely these patients would have stayed under the radar and remained undiagnosed even if the nodule grew. Now, any changes would mean they should be diagnosed at a very early stage and be offered potentially curative, and far less radical, treatment.

19%

Almost a fifth of people who attended the CT scan were diagnosed with other respiratory or heart conditions including COPD, emphysema, asbestos-related plueral thickening and coronary heart calcification.



A nodule is like a mole on your lung. Just like moles on your skin, most are perfectly safe but it's important to keep an eye out for any changes.



Pat

Pat is a prime example of how our Lung Health MOT check can save lives. Just like the 8% of patients identified in our check, Pat had a nodule on her lung. When it was first found, it was non-malignant but six months later it had grown:

“My consultant said ‘It’s good news and bad news’,” Pat recalls, “meaning it was cancerous but they’d caught it early and I could have surgery. A few weeks later, in I went and out it came and, fortunately, I didn’t require any further treatment. In 2017, I celebrated five years all clear.”

The project initially ran in five practices in Bulwell, Nottingham. Patients aged between 60 and 75 with a history of smoking were invited by their GP to attend a lung health check appointment. During their health check, patients were assessed and those identified as high risk were offered a low dose CT (LDCT) scan.

Expect Better Survival Rates

In addition to our Lung Health MOT check, we provide research grants across the UK. To date, we have invested over £30 million, funding 32 projects, focusing on early detection and patient experience.

32

research projects

Early detection

22

early detection projects

One of the primary reasons why lung cancer survival rates are not in line with many other cancers is because the majority of cases are diagnosed too late.

This is because lung cancer is difficult to detect, with symptoms often only surfacing once the cancer is at an advanced stage so we have to find ways to detect lung cancer earlier.

We fund research which looks to understand how and why early lung cancer develops, demonstrate the benefit of lung cancer screening and identify biomarkers including those in blood and sputum.



Patient Experience

The focus on early detection and screening can mean that areas such as patient experience tend to be neglected.

Not by us...

We believe lung cancer patients deserve to have the best care possible and we are proud to fund research projects to ensure this happens.

10

patient experience projects

“The funding of projects aimed at enhancing the patient experience is warmly welcomed and congratulations must be given to the teams who are undertaking these valuable projects.”

The acquisition of new knowledge and new ways of working aimed at improving the care and experience of those with lung cancer cannot be underestimated and encouragement must be given to any team to apply for a grant.”

John White

Clinical Nurse Specialist
St James's Institute of Oncology
Leeds Teaching Hospitals NHS Trust



Expect **Better** Survival Rates

A photograph of Dr. Lakis Liloglou, a man with dark hair, wearing a white lab coat over a blue and white checkered shirt. He is wearing blue nitrile gloves and is focused on using a pipette to transfer liquid into a small vial. He is standing in a laboratory setting with various pieces of equipment, including a biosafety cabinet and other labware, visible in the background.

Dr Lakis Liloglou
The University of Liverpool

Dr Liloglou is researching *MicroRNA biomarkers in surrogate airway tissues for early lung cancer detection*

Dr Liloglou and his team have made a significant advance in finding a blood biomarker for lung cancer.

“Specific exosomes relate to specific diseases. We looked at blood samples from 50 people with lung cancer and a control group of 50 who smoke, matched closely with gender and age.

We isolated the exosomes and then the RNA

- tiny chains of nucleic acids. Using special techniques, we can read these chains. We have found quite a few differences between the samples from the lung cancer patients and the control group.

We found four RNA sequences in particular that seem to model for lung cancer very well. So you can use these, identified within the plasma, or liquid part of the blood, to say who has lung cancer and who has not.

So far, it's very exciting. In fact, it could be like striking oil.

We now have to refine the markers in a clinically acceptable way. What we have done so far is a discovery, now we are working towards a clinical tool.”

Dr Liloglou applied for a further research grant to conduct a full study which was accepted by our Grants Committee.

Expect **Better** for Patients

The needs of patients are at the heart of everything we do. From providing easy-to-understand information to offering emotional and financial support, we are here for all people with lung cancer.

Information

It is vitally important for lung cancer patients to have access to up-to-date information that is both accurate and easy to follow. This can help them take control, clarifying medical jargon to provide a better understanding of medical procedures such as tests or treatments. Reading about the experiences of others who have been through similar situations can also help separate fact from fear.

We provide a wide range of literature. This is readily available on our website and distributed directly to patients by lung cancer nurse specialists and GPs.

Three of our guides were **Highly Commended** at the 2017 BMA Patient Information Awards.



“ We received a ‘Lung Cancer Information Pack’ from Roy Castle Lung Cancer Foundation, providing us with information on every aspect of lung cancer. It was very important to us to know that there was the support network available, which is essential when going through the journey which is associated with any type of cancer.”

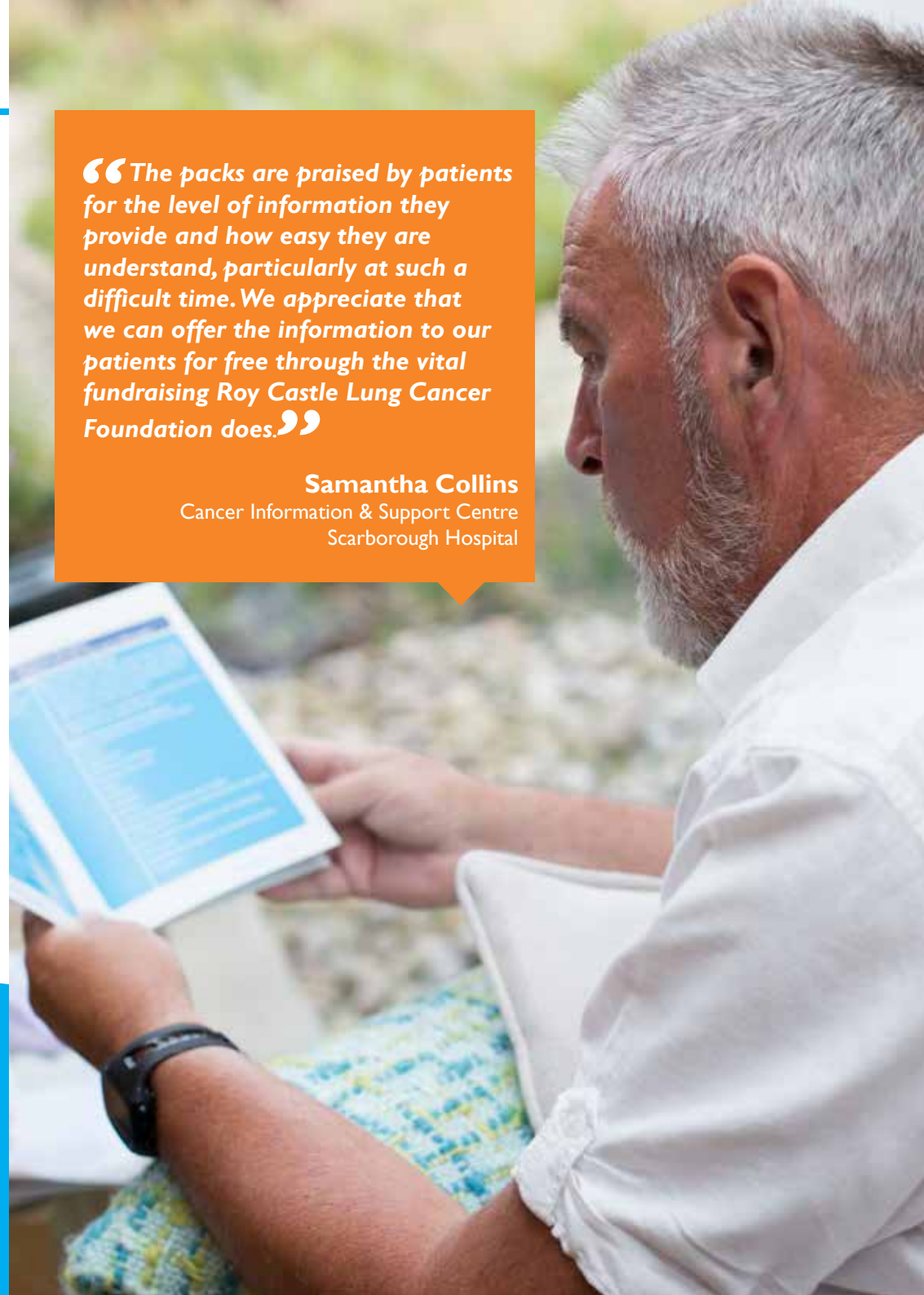
Matthew Carr

Lost his mum, Hazel, to lung cancer

“ The packs are praised by patients for the level of information they provide and how easy they are to understand, particularly at such a difficult time. We appreciate that we can offer the information to our patients for free through the vital fundraising Roy Castle Lung Cancer Foundation does.”

Samantha Collins

Cancer Information & Support Centre
Scarborough Hospital



Expect Better for Patients

Patient Grants

The devastating effect of lung cancer often means patients are unable to work. However, bills still need to be paid and loved ones provided for. Our patient grants scheme offers a financial lifeline at the most difficult of times.

£87,875

In 2017, we distributed grants totalling £87,875. Some people needed this money to pay for heating, electricity or even food. Others used them for trips away, creating precious memories with loved ones.

Ken's wife, Mary, was able to stay in a hotel near to the hospital when he had his operation. They used our patient grant to cover the cost.



Kenneth Philpott found out he had lung cancer after a chance visit to hospital. Fortunately, it was caught early and Kenneth was able to have surgery.

Being faced with a lung cancer diagnosis and imminent surgery is scary.

“ They said to me, ‘We’ve found a mass in the lung. We’ve caught it early - it’s in the lung at the moment but it could spread so we need to operate. That made me a little uneasy. I’d never had any surgery.’ ”

Fortunately, Ken received one of our patient grants which paid for his wife, Mary to stay in a hotel near to the hospital where he was having his operation.

Since then, Kenneth has gone on to fundraise for us. He turned to his passion for vintage tractors and organised a tractor run. The money raised will be able to provide grants to three patients, people just like him.

Expect Better for Patients

Lung Cancer Information Days

Our Lung Cancer Information Days give patients and their families the opportunity to hear from lung cancer professionals such as oncologists, thoracic surgeons and lung cancer nurses. There is also the chance to ask questions and share experiences with other patients and carers.

96%
would recommend
our information
days to others

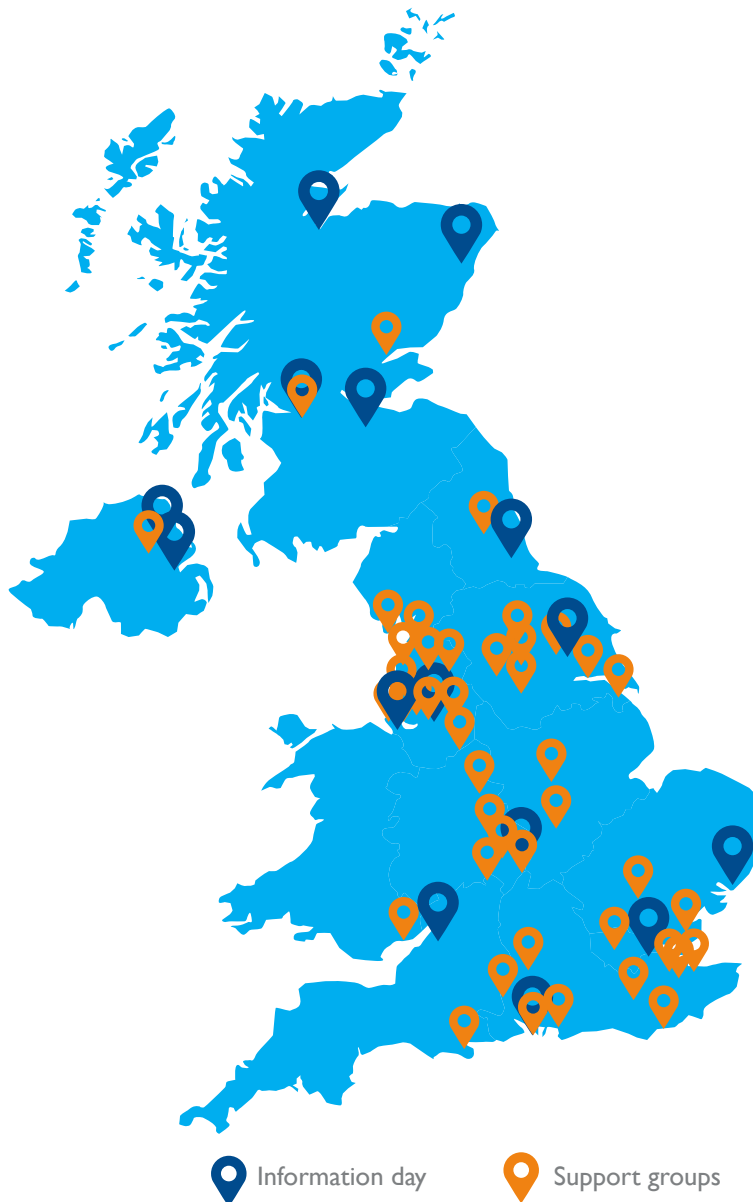
“Lung cancer information days offer more time for people to get much more information from not just one specialist but from several.”

Martin Chamberlain

Chest Surgeon, Southampton and
guest speaker at our Portsmouth Information Day

“It’s very helpful meeting other people who are suffering from a similar disease, to find out how they manage and what things they find help them enjoy life. The opportunity to share is very important. We don’t talk about lung cancer enough.”

Peter
Living with lung cancer



Face to Face Support

We have 54 support groups across the UK. We also provide facilitator training for an additional 14 lung cancer nurse specialists.

These groups provide support to those affected by lung cancer - patients, families and carers - from diagnosis, through treatment and beyond.

For those unable to come to a support group, we also provide emotional support and practical advice through our free helpline and online forum.

“The Roy Castle Lung Cancer Foundation helpline has been superb. I’ve used it to find out about the targeted therapy drugs my brother has been taking for stage 4 lung cancer. The charity has gone out of its way to find out the answers. I’m so grateful this helpline exists.”

Helen Taylor
Facebook user



“ I value the contact as I live alone.”
Member of our County Durham support group

Expect Better Treatment Options

We are a recognised voice with both the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC). These two regulatory bodies are responsible for determining which new treatments are made available on the NHS in England and Wales and Scotland.

The role of NICE, SMC and us

Pharmaceutical companies apply to NICE or SMC. The treatment is then reviewed by the recognised stakeholders, who consider:

- The **affordability** of the drug
- The **appropriateness** of the treatment.

As the only UK lung cancer charity, we are the patient representative for both NICE and SMC. We strongly consider how any new drug could impact on a patient's quality of life whilst remaining pragmatic and realistic in these challenging financial times by considering such factors as:

- Is it **better** than current treatment?
- Would it **help more** people?
- Does it provide a better **quality of life**?

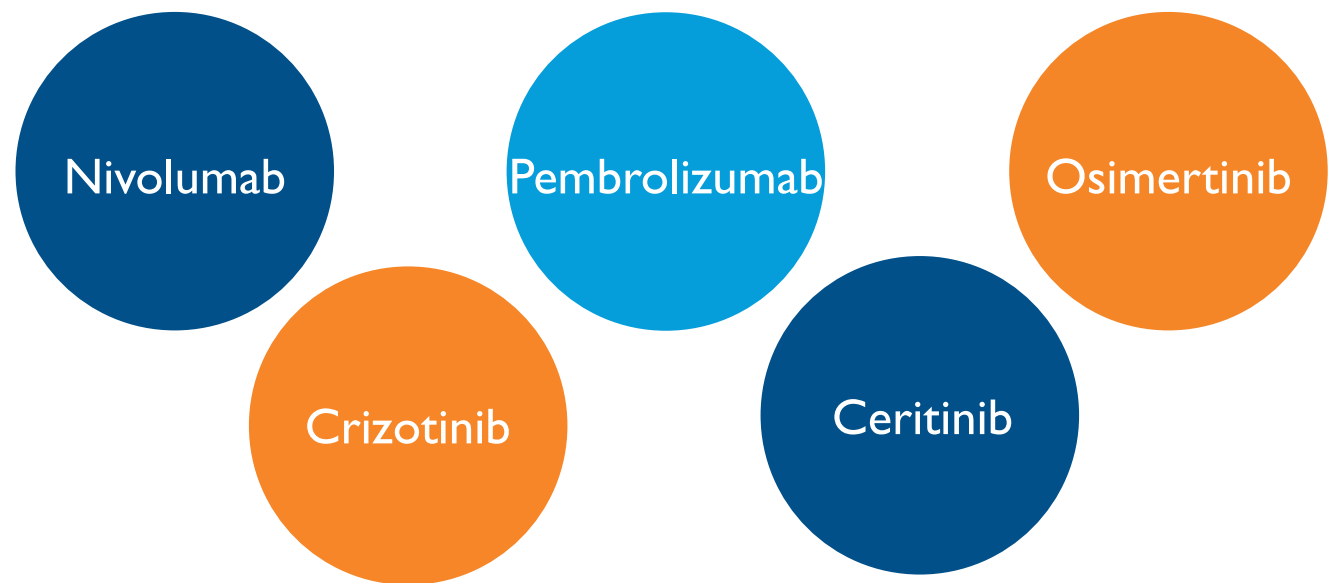
We fully appreciate the sensitivity surrounding assessability of treatments. We stand shoulder to shoulder with patients and are committed to securing genuine treatment advances.

Without us, that patient voice is not directly represented.

There has been significant advancement in the availability of treatments for lung cancer, including many new treatments such as targeted therapies and immunotherapies.

In 2017, we saw the first immunotherapy, pembrolizumab, approved as a first line treatment via the Cancer Drug Funds (CDF).

During 2016-2017, we provided evidence on the impact of several new medicines to NICE and SMC. The following are now available for patients in England, Wales and/or Scotland:



We know firsthand the value these new treatment options can offer to a patient.

Many people currently undergoing treatment live with the knowledge that, when the current treatment runs out or stops working, their only remaining option is palliative care. The advancement and increased availability of new treatments provides hope to people with lung cancer; they know that this is not the end, that there are new ways to keep them alive and, to ultimately, give them more time with their families.



Jackie

Thanks to advances in treatment, lung cancer is not the immediate death sentence it used to be.

Just ask Jackie:

“In April 2014, at the age of 44, I was diagnosed with terminal lung cancer. My diagnosis came completely out of the blue - I'd been living a relatively healthy life, exercising regularly, eating well. I needed to be in good shape; we were trying to have a baby.

But that wasn't to be. Instead scans found lung cancer, widespread lung cancer, terminal lung cancer. I had metastasis in my bones, brain, left adrenal gland and a small but active primary tumour in my left lung. I wasn't going to have a life growing inside me. Chances were, I wasn't going to live long myself.

That was three years ago and, contrary to original expectations, I'm still here.

I'm currently on my sixth line of treatment. I'm fortunate that my first biopsy was EGFR positive. This meant I could be treated with a first generation tyrosine kinase inhibitor (TKI). Since then, I've also had 13 cycles of chemotherapy.

I tried immunotherapy but it didn't work for me and I had radiotherapy five times. I'm currently on Tagrisso (osimertinib), a third generation TKI. Without it, it's unlikely I'd be here today.”

Expect Better Attitudes

#HeadHigh

Kay took part in our #HeadHigh campaign.
She was just 17 when she was diagnosed.

One in four people in the UK has less sympathy for people with lung cancer than those with other forms of cancer*. We believe this is due to its links to smoking, the assumption being that people 'brought it on themselves'. This is not right.

#HeadHigh challenged the stigma of lung cancer, raises awareness and dispels myths by sharing stories of the people lung cancer really affects.

Because it doesn't matter if someone smoked or not. What matters is that they are mums and dads, sons and daughters, husbands and wives, grandparents and friends. They are people and they matter.

Every 15 minutes, a person dies of lung cancer.
Open Your Eyes



Our #HeadHigh parliamentary event and calendar prompted contact from several MPs, including a reply from the office of the Secretary of State for Health and Social Care, Jeremy Hunt MP.

“ I've had chest and shoulder pain for a month and been given anti inflammatories (which I'm allergic to!) I wonder!! ”

“ An amazing campaign that really hits home. ”

“ All credit for running a fantastic campaign. Every person who has participated should be very proud. If it even saves one life it will be well worth it. ”

“ Thanks for the calendar. it is very powerful. ”

“ The Government recognises that progress in improving survival rates for some cancers, such as lung cancer, has been slow and survival rates remain low. For many of these cancers, the Government does not currently have the answer so the focus needs to be on research and innovation, and ensuring that proven innovations, once they are discovered, are adopted swiftly across the health service. ”

Department of Health on behalf of Secretary of State for Health and Social Care, Jeremy Hunt MP



www.roycastle.org/headhigh

*Global Lung Cancer Coalition

#HeadHigh Joanna

“ I always thought if I was ever diagnosed with cancer and it wasn't curable, I would probably find a way to commit suicide.

Then, in February 2015, I was diagnosed with stage 3b lung cancer. I did have curative radiotherapy but the doctors then found a tumour in my left lung and metastasis in my brain. They thought it had been there for about five years before it was discovered.

So there I was, a 37-year-old, never smoked, with two young children and incurable lung cancer.

Lung cancer attracts a lot less funding than other cancers even though it kills more people and it is the UK's biggest cancer killer.

You just need to look at the numbers and it will add up. If you want to reduce the amount of deaths from lung cancer, you need to invest in research and support campaigns that improve the quality of life for survivors.

I'm a big supporter of social justice so I think it is wrong that the cancer that kills the most people gets less funding than other cancers from the health budget. I want to change that. I want to help make it more equal. It should at least be the same!

I don't want my children to be motherless because lung cancer doesn't get enough money for research.

There has been some research and treatments have advanced to the extent that it's not a death sentence. That's why I'm still here three years after diagnosis.

I still have a future. I just hope, as each month turns into a longer survival period, that new treatments will be found and I never have to think about ending my life.”





#HeadHigh Tom

Tom is the third generation of his family to be affected by lung cancer, having lost both his father and grandfather to the disease.

“I’m so tired of being asked whether I smoked. It’s a ridiculous question. It could just as easily be caused by diesel fumes, and in my case, I didn’t smoke and I got cancer. I wish people would stop asking me, but they don’t.”

I think the reason people assume you smoke is because it’s more of a concern for them if you didn’t smoke and you got lung cancer. They almost think they’re safe because they didn’t smoke. But I know that’s not the case and I want to make sure more people know that too.

It’s really so important that the #HeadHigh campaign reaches MPs, especially.

I’m just one person, I can’t change things, but if you’re an MP, you can change things, and if you know more about it, you can make sure money goes to the right place.

An awful lot of people don’t survive lung cancer. An awful lot of people survive other forms of cancer that have been given funding.

If more funding was given to lung cancer, more people would survive, and it’s really up to the MPs – they’re the ones with their hands on the purse-strings that can sort this out.

I want to be part of this calendar, not because I’m a model, but really because I don’t know what else to do. The fact is there’s medication out there but not made available for financial reasons is a disgrace.

www.roycastle.org/headhigh

Expect Better for Nurses

For many patients, their lung cancer nurse specialist (LCNS) is an essential part of their support team, helping them from initial diagnosis, through treatment and recovery. They are also instrumental for patients in palliative care.



“The lung cancer nurse that looked after me was always there to support me. My nurse, Kay, was reassuring, kind, and made that extra bit of time even when she was busy. They’re amazing people. The reassurance of knowing I could and still can talk to her about anything, and the way she cares is priceless.”

Gaynor Wall
Living with lung cancer

We’re proud to support LCNS so they can continue to support patients.

Secretariat
for the first
Scottish
Lung Cancer
Nurse forum

Provide
facilitator
training for our
nurse-led
support
groups

Commission
a report to
show the value
of lung cancer
nurses

Offer a nurse
bursary for
further
education

“Excellent training, I have really enjoyed the two-day course. A great deal of knowledge from the facilitator with great interaction from the group.”

Lung Cancer Nurse Specialist, Surrey



Karen is a lung cancer nurse specialist from Edinburgh. She sees the devastating effects of lung cancer on a daily basis. It's a hard job but it's one that Karen simply loves.

“People wonder how I do what I do. They think it must be very depressing. My job, though, is one of the most fulfilling parts of my life. To be able to help, reassure and advise patients at the worst times of their lives, to be there for them and their families is a feeling second to none.

As a nurse, you will always get attached to patients. I had one patient who was given a stage 4 diagnosis 18 months ago. He has his own business and a young family of three and was really worried about being able to support and look after them.

I had another patient who was a huge heavy metal fan. I remember meeting them for the first time and I couldn't help smiling at the thought of them headbanging to a bit of AC/DC! And that's what's often forgotten. They aren't simply a lung cancer patient, they are people with families and lives and passions.

Part of what I do is provide support to the patients and their families, both in person and over the phone. I'm with them right through their pathway, from initial presentation and pre-diagnosis, through investigations, then diagnosis, treatment and supportive care. If it matters to them, it matters to me.

One common fear is lack of time. Lung cancer is often, too often, diagnosed at a late stage so many people die very quickly. They are scared about not having time to do the things they wanted to do, about leaving their wife, their husband, their children and their grandchildren behind, or not even having enough time to get their affairs in order. Sometimes it feels like they are here one day, and gone the next. Just like that.

People do have the common thought that lung cancer is a smokers' disease. I've known some people who truly think they are immune to lung cancer because they have never smoked. As a result, they dismiss signs and symptoms and then it's too late. But the truth is, lung cancer can, and does, affect anyone. I know. I see it ””



Expect **Better** Futures

The best way to beat lung cancer is to stop it from ever happening. We work tirelessly to help people reduce their risk of getting lung cancer, from successfully campaigning for the smoking ban in public places to educating children and young people with our innovative Cut Films project.

New Issues and Age-Old Challenges: A Review of Young People's Relationship with Tobacco

Our latest report revealed how the government's failure to deliver its promised strategy for preventing smoking among young people - particularly the most vulnerable - is creating a potential health 'time-bomb' which could impact the NHS for decades to come.

The report lays bare how sustained cuts to public health budgets have left the NHS and local authorities without the resources to sustain existing services or adapt to changing conditions:

Smoking tobacco remains the leading cause of preventable death and ill-health in the UK and our report reveals the new challenges facing public health and cancer prevention, including:

- Smoking becoming entrenched among the most deprived and hardest to reach elements of society
- Links with mental health issues: depression in adolescence linked to smoking in adulthood

- Tobacco industry evading advertising restrictions by promoting cigarettes in films, videos, gaming and social media - fostering a 'cool' image of smoking
- Proliferation of different forms of tobacco consumption, including increased use of cannabis and shisha or waterpipes
- Availability of cheap illicit tobacco.

207,000

young people under 15
who start smoking every year

Two-thirds

of smokers start before the age of 18

40%

of smokers start regularly smoking
before the age of 16

“Inequalities are without a doubt the biggest challenge. The risks of becoming a smoker cluster in particular groups of young people. Young people who have been excluded from school, for example, or truanted from school are more likely to smoke, as are those aged 16+ who are not in further or higher education or employment.”

We still have high tobacco taxes, but current investment in mass media is low and has been since 2010. Programmes like Roy Castle Lung Cancer Foundation's Cut Films project may have a particularly important role to play in today's context - giving young people accurate information about the harms of tobacco but also providing them with new skills around media and film-making.”

Professor Linda Bauld

Deputy Director of the
UK Centre for Tobacco
and Alcohol Studies





93% of young people said taking part in Cut Films made them more aware of the harm caused by smoking.

Expect Better Futures



What we do is only possible because of our incredible supporters - our volunteers, our staff, our corporate partners, our advocates and ambassadors, our researchers and nurses and the thousands of fundraisers who never fail to surprise us with their creativity and generosity.

“Thank you” never quite covers it but we do thank you from the bottom of our hearts, because with your help we can all continue to expect better.