



Marie Keating  
FOUNDATION



MSD

INVENTING FOR LIFE

# 'Time, Toughness & Treatment'

Understanding the Experiences of People Living with Lung Cancer



 Ipsos MRBI

An Ipsos MRBI report, in partnership with the Marie Keating Foundation and MSD Ireland

# Foreword



LIZ  
YEATES

CHIEF EXECUTIVE  
OFFICER

THE MARIE KEATING FOUNDATION

Lung cancer accounts for more deaths than any other cancer type in Ireland, with survival rates at just 18%. Low symptom awareness, a negative stigma around the disease and a lack of focus historically in terms of research and attention means patients often present at late stage, significantly impacting their treatment options and survival prospects.

Two years ago, the Marie Keating Foundation began our mission to try to change this. We launched the first ever national lung cancer awareness campaign held during International Lung Cancer Awareness Month in November 2017, with our Listen To Your Lungs campaign, which focused on symptom awareness particularly focused on a persistent cough. We built on this with a second campaign in 2018, 'I Am Lung Cancer', which again highlighted key symptoms but also sought to challenge the often negative stigma associated with lung cancer. However to really understand the patient perspective, we undertook this piece of qualitative research, with the support of MSD, hoping to better understand the full lung cancer patient journey and to identify areas where more information and support is needed.

We are thankful to MSD for their ongoing commitment and support of our work in this area. I would also like to thank Ipsos MRBI who assisted us with the interviews and findings and finally, we would like to pay tribute most sincerely to the oncology nurses and patients who gave their time so generously to contribute to this research.

We are delighted to present this 'Time, Toughness & Treatment; Understanding the Experiences of People Living with Lung Cancer' report. We hope it goes some way to allow the patient voice to be heard, and to highlight the twists and turns that lung cancer patients in Ireland are faced with on their cancer journey.



GER  
BRENNAN

MANAGING  
DIRECTOR

MSD IRELAND (HUMAN HEALTH)

Equal access to healthcare is a goal of all healthcare systems, however not all conditions are treated equally when it comes to awareness, early diagnosis, innovation or investment. One such condition is lung cancer.

Lung cancer is one of the most common cancers in Ireland and rates are on the increase. Yet, for too long, lung cancer has not received the same attention or generated as much discussion as other forms of cancer.

For the past two years, MSD Ireland have been very proud to support the ongoing work conducted by the Marie Keating Foundation to raise awareness about lung cancer and to support patients with this condition. This report represents a significant milestone in that partnership.

Previous research revealed a significant knowledge gap amongst the general population on the current and future prevalence and impact of lung cancer in Ireland. This report aims to give people with lung cancer a voice and to highlight their experiences, as well as shining a light on the challenges they face, the emotions that they undergo and their advice to those facing a similar diagnosis.

MSD Ireland is committed to continuing to work to highlight the inequalities related to lung cancer as well as working to improve awareness of this condition and identifying ways we can better support patients and their families.

Thank you.

# 'Time, Toughness & Treatment'

Understanding the Experiences of People Living with Lung Cancer

## Contents

---

- 02 Executive Summary
- 05 Introduction
- 11 Before Diagnosis
- 15 Diagnosis & Beyond
- 21 Treatment Journey
- 29 Living With Lung Cancer
- 33 Conclusions & Recommendations



# Executive Summary



## Introduction

Lung cancer is the biggest cause of cancer-related death in Ireland. The incidence of lung cancer in Ireland continues to rise in men but particularly in women.

Commissioned by the Marie Keating Foundation, supported by MSD Ireland, this research was designed to explore the patient journey in relation to lung cancer. The objective was to understand the reality of living with this condition and to explore the experiences of patients. A qualitative methodology was employed, with a series of in-depth interviews conducted with Stage 3 & 4 lung cancer patients and Oncology Nurse Specialists.

## Before Diagnosis

This research demonstrates the need to increase awareness of lung cancer among both the public and community-based healthcare professionals. Early symptoms such as a persistent cough and unexplained tiredness are not unique and can sometimes be attributed to other conditions, often resulting in delays in diagnosis. Lung cancer is intrinsically linked to smoking, which can result in a stigma, but non-smokers can also develop the disease.

## Diagnosis & Beyond

Delivery of a lung cancer diagnosis will result in a multitude of emotions for the patient, such as devastation, fear and anger. Acceptance of one's diagnosis is often seen as the first step forward for patients, but lung cancer is a unique, personal challenge which does not follow a set formula.

Communication is a critical success factor in the patient's journey and this research highlights the need for compassionate and honest dialogue, treating the patient with dignity and respect. Nurse Specialists in particular are praised for the pivotal, wide-ranging, supportive role they play for patients throughout their journey, though they face resource and capacity challenges in the delivery of their services.

## Treatment Journey

The medical treatments provided for Stage 3 & 4 lung cancer are undoubtedly challenging, with side effects taking a physical, mental and emotional toll on the patient. However, the advent of immunotherapy and targeted treatments may offer new options for patients.

## Living with Lung Cancer

The lung cancer journey is a deeply personal one. While guidance is available, there is no rulebook for how best to cope with lung cancer. Patients will require a strong support network to cope with physical, mental and emotional challenges, with family and friends proving invaluable.

Furthermore, access to relevant, trusted information is highly valued by patients and should always be proactively provided. Support organisations such as the Marie Keating Foundation have a range of patient support resources that are available.



## Conclusions

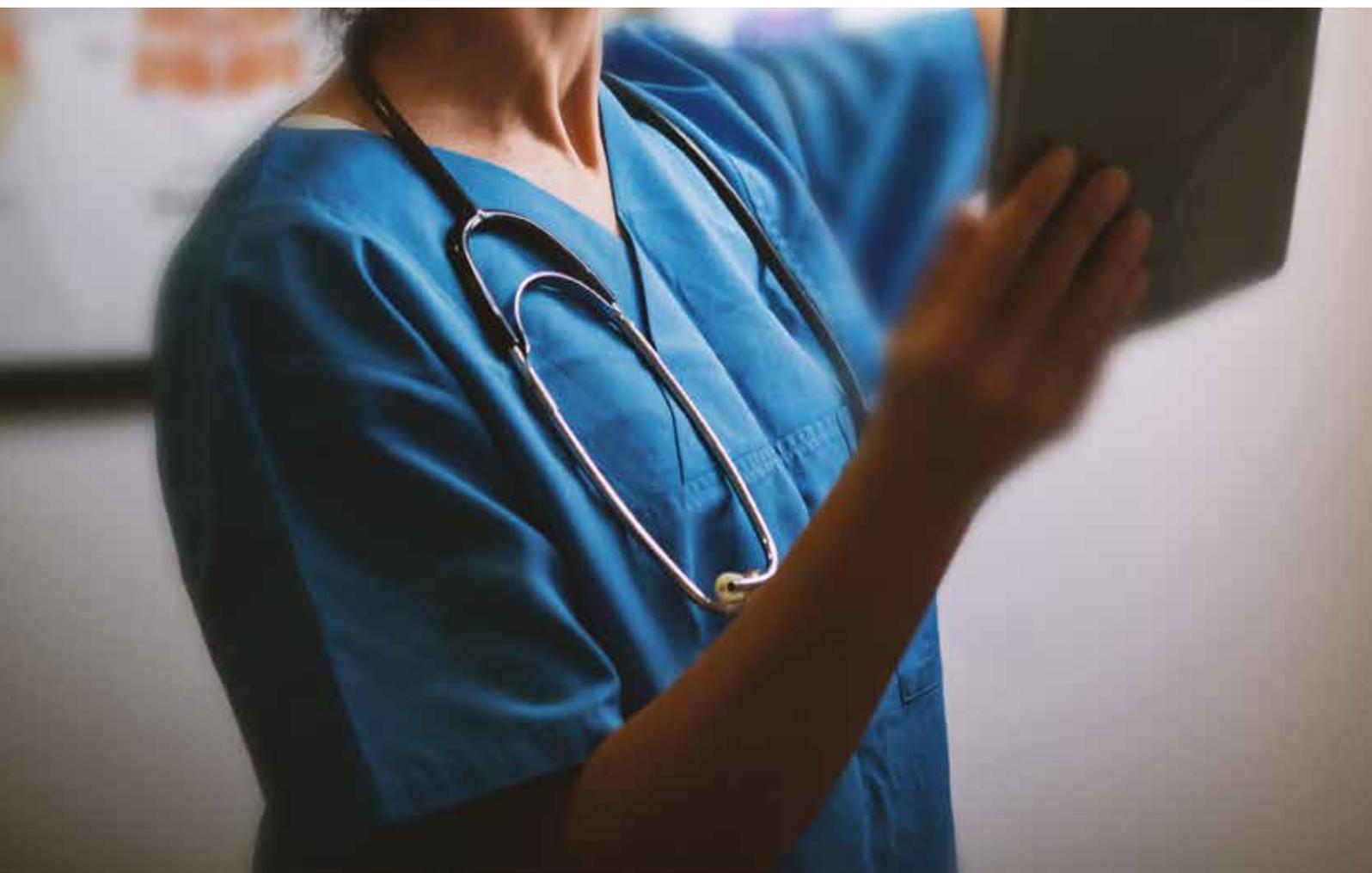
This study is not meant to be an exhaustive examination of the journey from every perspective, as it is qualitative in nature and focuses on patients and Nurse Specialists. There is scope to conduct further research to explore this area further, with more patients and a wider range of stakeholders who are involved in the journey.

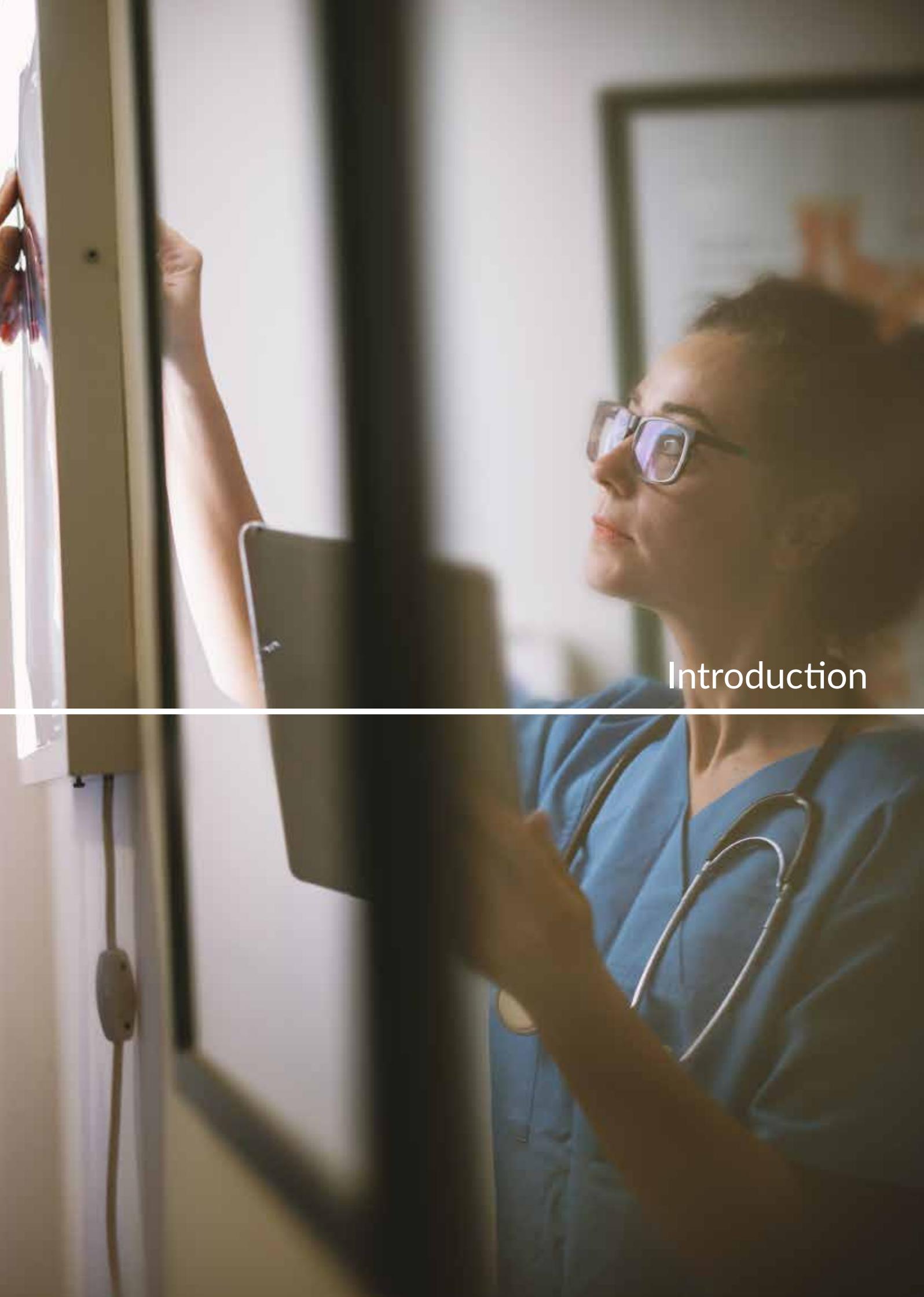
It is hoped that this report illustrates the multi-dimensional nature of the patient journey for those with Stage 3 & 4 lung cancer. First-hand quotations from research participants are used throughout to highlight their perceptions and experiences.

Despite their diagnosis, patients display remarkable determination and resilience and provide the following advice to those who may be diagnosed with lung cancer in the future: *accept it for what it is; be positive and persistent; talk to people and ask questions; take it day by day; and keep fighting, there's always hope.*

## Recommendations for Policy Makers

- Campaigns to raise awareness of the early symptoms of lung cancer, among both smokers and non-smokers.
- Emotional and psychological supports to be made available to patients at the time of diagnosis.
- Development of communications protocols and guidelines for healthcare professionals who communicate a diagnosis of lung cancer.
- Ensure proper resourcing of the Nurse Specialist role, so all lung cancer patients have access to a Nurse Specialist.
- Improve access to innovative treatments.
- Provision of relevant, trusted information about lung cancer in a format suitable to the patient's needs.





## Introduction

# About Lung Cancer



Lung cancer is one of the most common cancers in Ireland. It is also the biggest cause of cancer related death, due to the late stage that patients often present at. Five-year survival rates for lung cancer are just 18%, significantly lower than many other cancer types.

There are low levels of symptom awareness, with recent figures putting this at just 16% for those who say they feel well informed<sup>+</sup>. This is one of the reasons that the majority of lung cancers are only detected at stage 3 or 4. Symptoms for lung cancer can be easily attributed to other ailments and education is key in ensuring that the public is better able to recognise early symptoms.

Another key factor, which can often contribute to a delay in diagnosis and poorer outcomes, is the stigma that is often associated with this disease due to its association with smoking. For smokers, ex-smokers and non-smokers, this plays a role in how quickly they act when symptoms first appear.

These themes and more are explored in this research, which hopes to portray an authentic look at the stage 3 and 4 lung cancer patient experience in Ireland.

## The Facts

- More than 2,500 people are diagnosed with lung cancer annually.
- More people die from lung cancer in Ireland (1,827 in 2017) than any other type of cancer.
- Lung cancer is the fourth most common cancer in Ireland.
- The incidence of lung cancer has been rising steadily over the past three decades and is projected to increase by 141% in women and 61% in men by 2030\*.
- The net 5-year survival rate for lung cancer is 17.9%.
- Only 3% of all new cases occur before the age of 50.
- If lung cancer is detected early, there is a better chance of successful treatment. However the majority of lung cancer patients are presenting at late stage (approximately 35% in women and 38% in men).
- Smoking avoidance/cessation is the most important preventative strategy as over 90% of lung cancers can be attributed to cigarette smoke\*. However, lung cancer can occur in patients without any of the known risk factors.





## Causes and Risk Factors

- Smoking - Causes 90% of lung cancers. The more you smoke, the more likely you are to get lung cancer.
- Age - Lung cancer is more common in older people, 75% of cases are in people aged 65 and over.
- Passive Smoking - Breathing other people's cigarette smoke is a risk factor, but it is still much less than if you smoke yourself.
- Chest Problems - People who have chronic bronchitis, emphysema, pneumonia or tuberculosis have an increased risk.
- Exposure to radon - This natural gas can be found in the air or trapped in buildings. It increases the risk, especially in smokers.
- Exposure to asbestos and some chemicals.
- Employment as a painter.
- Indoor emissions from household combustion of coal.
- Family history of lung cancer.

## Symptoms of Lung Cancer

- Having a cough most of the time and/or for a prolonged period.
- A change in a cough you have had for a long time.
- Being short of breath.
- Coughing up phlegm (sputum) with signs of blood in it.
- An ache or pain when breathing or coughing.
- Unexplained loss of appetite.
- Unexplained tiredness (fatigue).
- Unexplained weight loss.

Some of these symptoms are common and may not be caused by cancer, but it is important to see your GP to be sure. Knowing about lung cancer at an early stage could save your life.



# Background And Objectives

Commissioned by the Marie Keating Foundation, supported by MSD Ireland, this qualitative research was designed to explore the patient journey in relation to lung cancer and understand the reality of living with this condition.

The main objective of the research was to understand the experiences of patients as they move through this process, from initial signs and symptoms through to the present day.

Specific research objectives included an assessment of the emotional and physical effects on the patient, investigating the impact of the disease and its treatment. This study also sought to understand any challenges and frustrations at key moments in the journey and identify unmet needs, system gaps or barriers to care, with a view to looking at how to address these challenges to optimise outcomes for patients.

A journey-based approach was adopted in order to understand the different phases that patients and healthcare professionals go through. The journey is summarised into four broad phases, which form the basis for this report, as follows;



However, it is worth noting that the third part of the research was to explore the experience of being on treatment generally. While specific medications were mentioned on occasion, this study was not designed to focus on specific agents.

Given the nature of the research undertaken, it is important to note that this report is not an attempt to provide an exhaustive picture of the lung cancer journey for patients in Ireland. Each individual case is different and every journey is unique to each patient.

For the purposes of this study, the focus was on patients with Stage 3 and Stage 4 disease, using the tumour, node and metastasis (TNM) staging system for lung cancer. The stage of a cancer reveals how big it is and whether it has spread, while also helping healthcare professionals decide which treatment is needed. Due to the fact that the majority of lung cancer cases in Ireland are diagnosed at stages 3 and 4\*, focusing on these patients was felt to be a more representative sample.

It is hoped that this research delivers a true picture of the experiences of those patients with Stage 3 and 4 lung cancer and allows their voice to come to the fore, which in time will help a variety of stakeholders to better understand this condition and guide future decision-making.

[\*Source: NCRI, Lung Cancer Factsheet. Available at <https://www.ncri.ie/sites/ncri/files/factsheets/Factsheet%20lung.pdf>]

# Research Approach

## Research Design

The project was conducted by Ipsos MRBI, an independent company with a specialism in healthcare research.

A qualitative methodology was applied to ensure the issues under investigation could be explored in-depth in an open, free-flowing manner. This research was not about quantitative measurement, rather it was about exploring the subject matter in considerable detail with a small sample of people.

Critical to the success of this study was to incorporate different perspectives on lung cancer. While patients and their experiences were the central focus of the research, the inclusion of lung cancer Oncology Nurse Specialists with experience in lung cancer allowed a 360° view of the journey to emerge.

In order to fully investigate all aspects of the journey, the research instruments to be used in the interviews (discussion guides) were designed by Ipsos MRBI in consultation with The Marie Keating Foundation and MSD Ireland.

Ipsos MRBI has developed a qualitative technique for this type of research that enables it to understand the dynamics and influences involved along the journey and care pathway. This is done by asking patients to tell us their story starting from signs and symptoms through to the present day, using an established framework for the interviews.

It is also important to understand the full context of the patient's world, e.g. their living situation, or work situation, as well as what health means to them and how they describe their health overall, including any co-morbidities or previous illnesses they may have had.

Healthcare professionals, meanwhile, were asked about their overall experiences as well as being invited to think about specific (anonymised) patients and talk through the journey and key decision points from their perspective.

This approach reveals the multi-dimensional nature of the journey. It highlights emotional forces, the ecosystem of influence and the opportunities within the journey, addressing unmet needs and moments of frustration. Emotions are explored using story, imagery and metaphors in the interviews to understand the successes and frustrations in both the journey and care pathway to help understand the opportunities and key drivers throughout.





## Research Sample & Recruitment

A total of 9 in-depth interviews were conducted between 26th October and 14th December 2018, with the following;

- 4 interviews with Oncology Nurse Specialists
- 5 interviews with Stage 3-4 Lung Cancer Patients
  - Males and females, age 50 to 63, smokers and non-smokers, across Dublin, Midlands and West of Ireland.
  - Most had been diagnosed 1-2 years ago.

Participation in the research was entirely on a voluntary basis. Bespoke patient materials were designed including a patient information leaflet (with frequently asked questions about the study), as well as a consent form.

Patients interested in participating were required to opt-in by signing and returning the consent form, after which they were contacted by Ipsos MRBI for recruitment. This ensured confidentiality throughout the entire process.

Patient recruitment was attempted via a number of sources, including; Oncology Nurse Specialists in hospitals; the Marie Keating Foundation; Consultant Oncologists; Cancer patient support centres across the country; General Practitioners; and the Ipsos MRBI nationwide network of researchers. However, it is worth noting that given the nature of the condition under investigation where patients can be quite ill, recruitment was challenging.

All interviews lasted at least one hour or longer. Patients were free to ask a friend or relative to be present with them during the interview. Given the nature of the interview, describing the journey they had been on was an emotional experience for many patients.

We would like to thank all respondents for sharing their stories so openly and honestly. All participants and intermediaries are acknowledged at the end of this report.





Before Diagnosis



# Early Warning Signs

The patient interviews typically began by asking respondents about their life prior to any symptoms of lung cancer appearing. While a mix of smokers and non-smokers were interviewed, it was clear that some patients had been living what would be considered normal and relatively healthy lives prior to the first appearance of their lung cancer symptoms.

Many had been working and some were also active in terms of their participation in fitness and sports activities. In fact, some considered themselves in good health and were not in the habit of visiting (or needing to visit) their GP. For that latter group in particular, who were typically non-smokers, it is noteworthy that a previously healthy life can make the ultimate diagnosis of lung cancer more difficult to accept.

Patients may not know or have control over when a diagnosis of lung cancer may ultimately emerge. To that end, we cannot look at lung cancer in isolation. It is important to note that other life circumstances can affect general health and well-being, for example the person may also be dealing with major life events while living with lung cancer, such as personal relationship issues, problems at work, family bereavements, parents that are elderly or unwell, dependents such as children etc.

Regardless of one's health prior to their lung cancer, the early, preliminary symptoms mentioned by patients were consistent and described as follows;

- A lingering cough, or coughing up blood
- Coughing with such severity as to even pull muscles, e.g. in one's shoulder or arms
- Eating behaviours affected, e.g. a loss of appetite, or a change in one's sense of taste
- Weight loss, which is often noticed or commented upon by friends/family
- Significant fatigue, or atypical tiredness, e.g. during the day
- Episode(s) of incontinence
- Flu-like shaking
- Vomiting

---

*"I have never been sick, I was never on antibiotics...I was very fit, I used to walk all the time."*  
[Patient]

---

---

*"I'd rarely if ever had to see a doctor. I carried a bit of weight, I ate well! But I exercised two or three times a week. I didn't smoke, took a drink, wasn't a heavy drinker but enjoyed a couple of pints. Longevity is in the family, there's no cancer in the family. So I thought I was going to live forever. Well, how wise we weren't."* [Patient]

---

---

*"It was like clots of blood, but I thought nothing of it, I thought I must have bitten myself."*  
[Patient]

---

---

*"I kept pulling muscles behind my arm from the coughing."*  
[Patient]

---

The nature of these symptoms is not unique to lung cancer and therefore their potential seriousness may not be acknowledged at first. They can also be inconsistent, with some being gradual and others arriving relatively suddenly. On occasion, it may be a more severe moment of truth (for example, passing out) that can ultimately trigger a response.

# Preliminary Investigations & Onward Referral



For most people, the first port of call when one is feeling unwell is the local General Practitioner in the community. The nature of the early lung cancer symptoms described previously warranted such a visit, though in many cases the patient did not suspect anything particularly sinister to emerge.

---

***“This wasn’t a cancer thing. As far as I was concerned it was an irritating cough probably caused by sinus and I just didn’t think I was going to be a candidate for cancer.”*** [Patient]

---

What may seem like innocuous symptoms at first will, if persistent, usually result in referral by the GP for further investigation. No two cases are the same and the time that elapses between the patient’s initial presentation and their referral can vary, depending on the perceived severity of the symptoms by both the GP and the patient. However, it is notable that most patients believed that their referral onwards by their GP had been timely and appropriate.

The referral by the GP is often for a chest x-ray, the results of which can start to raise more serious concerns. Patients often described hearing about a “spot” or “shadow” on the lung which can begin to raise questions in their mind that this may not be a straightforward, transient medical issue that they are experiencing. At this stage, the patient will usually be referred to a lung clinic because of concerns about their symptoms and/or their chest x-ray.

The Health Service Executive’s Rapid Access Lung Clinic provides direct access to Consultant-led assessment and diagnostic services for patients with suspected lung disease or cancer. This service was rolled out by the National Cancer Control Programme (NCCP) in 2012\*.

The referring doctor or patient can contact the service directly with referrals made by completing the standard NCCP Rapid Access Lung Form.



---

[\*Source: <https://www.hse.ie/eng/services/list/3/acutehospitals/hospitals/ulh/hospitals/uhl/hospdept/deptmed/edicaloncology/rapidaccess/ralung.html>]

# Diagnosis Can Be Difficult

This research demonstrates that the route to diagnosis for a lung cancer patient can vary depending on a number of factors. The speed and specificity of their referral will play its part, as will where they are being referred to. Almost all patients in this study were first diagnosed at stage 3 or 4.

However, lung cancer by its nature is difficult to diagnose. Some of the initial symptoms are not unique to lung cancer, for example coughing, weight loss, fatigue or vomiting. The importance of these symptoms and their possible link to lung cancer can be missed by both the patient and by healthcare professionals. This is particularly so in cases of non-smokers, or those with no family history. Even smokers at times do not notice a change in cough and continue to associate their cough with smoking as opposed to something different occurring.

Patients described examples of where those involved (both themselves and healthcare professionals) may not have related all of the symptomology towards lung cancer initially – described by one patient as a case of “*not putting the dots together*”.

Both patients and Nurse Specialists in this research acknowledged that the lack of immediate visibility of the symptoms of lung cancer can make diagnosis challenging. A comparison was made to breast or testicular cancer, where in those cases a visible lump may be present.

---

***“I didn’t smoke you know. And you know with the benefit of hindsight perhaps my GP or the ENT guy should have thought better of it, but I just think that people don’t associate a healthy active person with lung cancer.”***

[Patient]

---

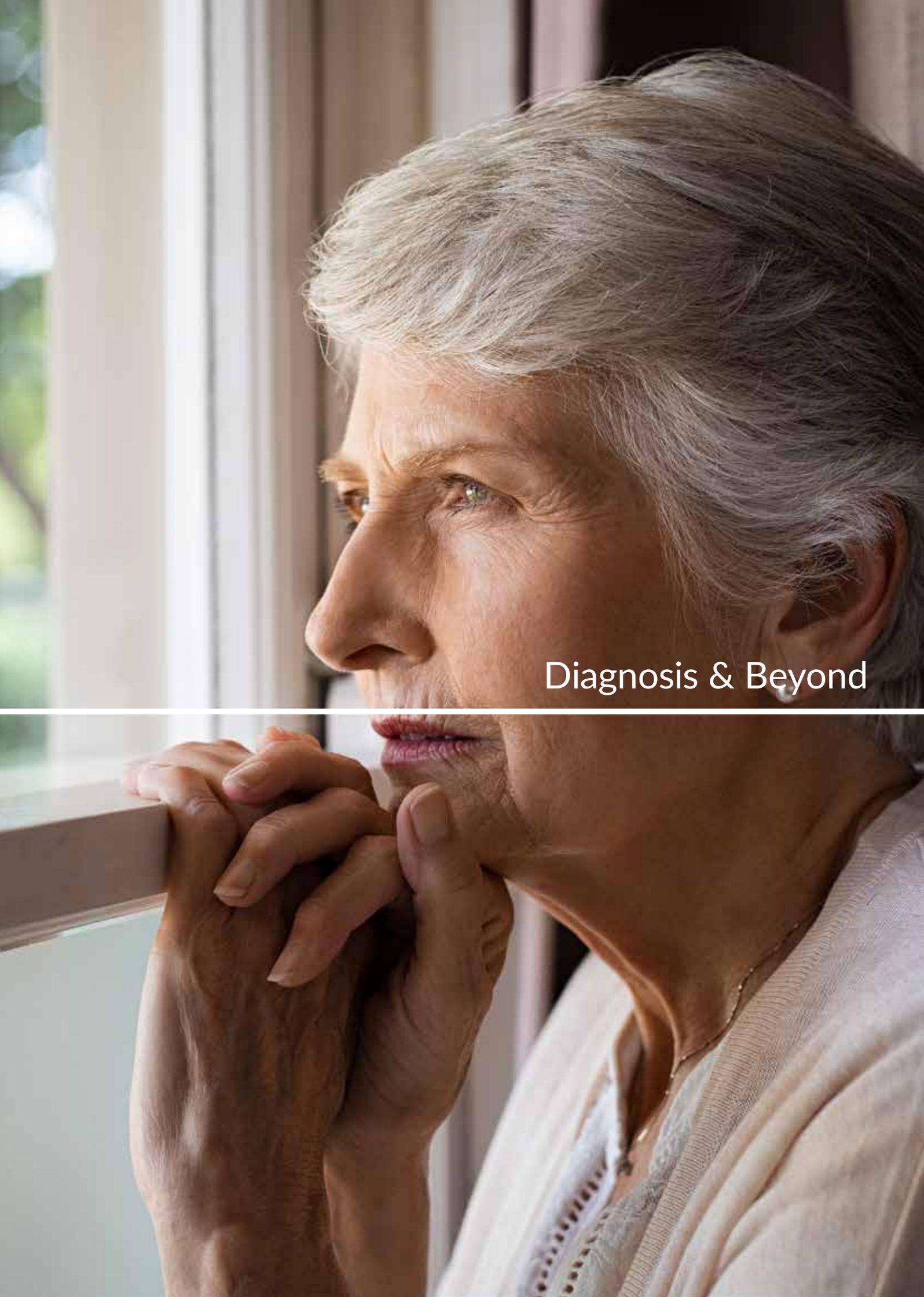
Patients may react in two ways to the fact that their diagnosis could have been picked up earlier. It can result in anger and upset, with a degree of blame being attributed to one or more Healthcare Professionals (HCPs) who they may feel could have realised the potential severity of their symptoms and referred them on earlier. However, other patients may react with acceptance, not blaming any individual and focusing their energies on their health, treatment and family.

Oncology Nurse Specialists have a considered perspective on the challenges of picking up cases early given the cross-section of patients that they encounter in their role. While Nurse Specialists accept that lung cancer can be difficult to identify early with no screening programme in place for lung cancer, they acknowledge its complexity and point out that disease processes are different across tumour types and that the nature of symptoms can simply mean that referrals can take longer to occur.

*“I don’t know if there’s a discrimination per se, I think it’s a different disease process. It probably reflects on the fact that people with breast cancer may be coming in earlier and sooner, because it’s a lump on your breast that shouldn’t be there, so you go to your GP and then the GP feels the lump and then you get referred on.*

*Whereas if you have a chest infection, the first thing a GP is going to do is give you an antibiotic. And if that doesn’t work you try another one, and when that doesn’t work then have an X-ray. So that in itself takes a longer time to get from the point of first chest infection to X-ray.*

*But I don’t know that it’s fair to say it’s a discrimination. I think it’s more to do with the complexity of how lung cancer presents.”* [Nurse Specialist]



Diagnosis & Beyond

# The Investigation Phase



Nurse Specialists suggest that significant numbers of lung cancer cases come via the Rapid Access Service. Following triage, suitable patients are offered an appointment which will typically entail a review with a Respiratory Consultant, a medical history and physical examination. Any further diagnostic appointments will also be scheduled e.g. bronchoscopy, bloods, CT guided biopsy.

*“If they are for resectable disease they’ll go straight to surgery. So generally early stage disease will go for surgery and Stage 3 will probably go chemo-radio-therapy. And then Stage 4 would just go chemo.”* [Nurse]

It has been observed in recent times by Nurse Specialists that though significant proportions of these cases are older patients who are or have been smokers (i.e. the typical preconception some of us may have of a lung cancer patient), they are also noticing younger, “healthier”, non-smokers starting to come through their clinics with diagnoses of lung cancer.

Nurse Specialists describe the typical stages of the lung cancer diagnostic journey. Each lung cancer case must be classified by stage, type and grade to allow healthcare professionals to decide on the most appropriate route of treatment. The stage of a cancer will tell how big it is and whether it has spread. The type tells which type of cell the cancer started from and the grade means how abnormal the cells look under the microscope. Patients in this research had Stage 3 and Stage 4 lung cancer which by their nature are more advanced forms of the disease. The investigations that are conducted on lung cancer patients at the outset were explained by Nurse Specialists. As well as the staging and biopsy outlined earlier, tests can include the following;

**CT Scan:** A CT (or CAT) scan stands for computerised (axial) tomography scan. It uses X-rays and a computer to create detailed images of the inside of your body. The X-ray scanner rotates in small movements around your body as you lie on a bed that moves backwards and forwards. As you move through the machine, the scanner uses a series of X-ray beams to scan parts of your body and build up detailed images. The images produced by a CT scan are more detailed than standard X-rays and can give views of structures inside the body including internal organs, blood vessels, bones and tumours.

**PET Scan:** A PET scan produces three-dimensional, colour images that show how the tissues inside your body work. PET stands for positron emission tomography. It works by detecting a radioactive substance inside the body and making images that show where the radiation is concentrated. Radiation is introduced into the body before a PET scan using a medicine called a radiotracer. A PET scan can be used to diagnose a condition or to see how a condition is developing. It can also measure how well a treatment is working.

**Pathology:** Clinical pathology is a medical specialty that is concerned with the diagnosis of disease based on the laboratory analysis of bodily fluids such as blood and urine, as well as tissues, using the tools of chemistry, clinical microbiology, haematology and molecular pathology.

**Gene Mutation Analysis:** Some lung cancers have changes in particular genes and proteins. Doctors can use these changes as targets for specific drug treatments. Scientists can look at lung cancer samples in the laboratory and search for gene changes (mutations) that change the way the cancer grows. Doctors use this information to plan the best treatment, based on the genetic type of the cancer. This is called targeted cancer treatment or personalised therapy.

All of the above investigations are used to inform the discussion of the multi-disciplinary team (MDT) who will then decide on the most appropriate route of treatment for each individual case. Patients at earlier stages of lung cancer may be suitable for surgery, or resection of the tumour, though for the purpose of this research the focus was on Stages 3 and 4 where the patient is referred to the Oncology team for treatment.

# Formal Diagnosis Can Lead To A Multitude Of Emotions



Like all serious medical conditions, a diagnosis of lung cancer is arguably almost impossible to fully understand unless experienced first-hand. However, a critical part of this research was to try and identify the range of potential emotions that might be experienced.

All participants in this study, both patients and Oncology Nurse Specialists, stressed that there are no set rules or no correct way to process this diagnosis. No two individuals will react the same way and many will go through a range of different emotions at different times. Some of these are described in turn below.

**Shock:** One of the more likely reactions upon diagnosis, undoubtedly for non-smokers if their initial symptoms were not considered that serious, but also for previous smokers.

**Devastation:** A lung cancer diagnosis is often terminal. As one patient put it, “you are hit with a death sentence.”

**Anger:** Many patients reported anger, and this was sometimes more deeply felt by non-smokers, who spoke of a sense of “why me?”

**Fear:** Receipt of a diagnosis such as lung cancer is likely to result in fear, not only for oneself but also for one’s family, particularly concerns over what may happen to dependents such as children that may be relying on the patient’s health and well-being.

**Vulnerability:** Some patients spoke of feeling vulnerable and helpless when diagnosed, often in cases where they had been in relatively good health and their previous sense of infallibility had been eroded.

**Dark humour:** Though the idea of using humour in the context of lung cancer may seem strange to many, some patients describe how humour can be used as a coping mechanism. Of course, this will not be at all appropriate in some cases, but examples were given by patients of how they use dark humour to alleviate tension and disarm their own family and loved ones who may be feeling upset for them.

**Detachment:** Receipt of such a serious diagnosis was described as somewhat surreal, “like an out of body experience.” The ability to detach oneself from the experience appears to help, with some describing how they almost felt like an observer rather than the one receiving the news.

**Calm:** Despite the strong emotions that can be experienced, some patients described how they concurrently felt a sense of rational calm and went into “coping mode”, wanting to take in all the facts and details pertaining to their diagnosis. On the other hand, some may barely hear any details beyond the diagnostic description such is its impact.

**Normalisation:** With no control over exactly when one will receive a diagnosis, some patients explained how they attempted to continue with normal life routines and stuck with social commitments they had made in the days immediately following their diagnosis.

---

*I went blank [at diagnosis]. I had never thought of cancer in a million years because I was off cigarettes for twenty years at this stage.” [Patient]*

---

---

*“I was thinking of my kids and grandkids. I wanted to see them growing up. I started crying, it all hit me.” [Patient]*

---

---

*“You felt like it wasn’t you they were talking to.” [Patient]*

---

---

*“The initial shock because the kids were small, the initial shock was dreadful. But also I think because I would be a 200% positive person, it’s just a case of getting on with it, I mean build a bridge and get over it kind of thing. And my husband is brilliant.” [Patient]*

---

# Lung Cancer Is Non-Discriminatory, Affecting Not Just Smokers



Though smoking prevalence in Ireland has declined in recent years, from 23% in 2015 to 20% in 2018\*, it remains a significant risk factor in many diseases, including lung cancer.

***“It’s men and women from all walks of life”***

[Nurse Specialist]

Some members of the public may assume that lung cancer only affects smokers, given the intrinsic link between the two. However, as this research demonstrates, lung cancer is non-discriminatory and those that used to smoke, only occasionally smoked, or never smoked can also be diagnosed.

Nurse Specialists describe how they encounter a truly diverse cross-section of society when treating lung cancer (and other cancers). Smoking is not limited to particular demographics and this cancer can similarly affect men and women, young and old, across all socio-economic categories.

***“The cancer doesn’t care who you are or what you have in your bank”*** [Patient]

***“I loved smoking but now I pity people who smoke”***

[Patient]

This research provides further evidence that a degree of stigma exists around lung cancer, with the disease’s link to smoking lying at the heart of this stigma. Nurse Specialists described how some patients who have smoked will often blame themselves for their diagnosis, and how they provide compassion and support to patients to counteract any negative perceptions that may exist.

Direct and indirect cues can make it difficult for the patient to fully accept their diagnosis. For example, for a non-smoker diagnosed with lung cancer having to walk past others that are smoking outside hospital entrances can be particularly distressing, leading to feelings of anger and that sense of “why me?”

***“You get annoyed [when you see people smoking]...that’s why people have no sympathy”***

[Patient]

***“There is this assumption or link that you’ve got to be a smoker to be a lung cancer patient. And it somewhat pissed me off.”*** [Patient]

It appears to be difficult for society to break the stigma that exists around lung cancer. Only through wider public awareness can it begin to be addressed and the condition be better understood. There must be acceptance that while smoking is a risk factor, lung cancer can also affect those who infrequently smoke or do not smoke at all. Nurse Specialists who are dealing with a range of cancer types agree. They point out that relative to other forms of cancer, lung cancer patients may garner less sympathy among the broader public.

***“I think societally it’s more acceptable to have breast cancer than to have lung cancer. And I think there probably is a perception that some of the lung cancer [patients], I think people feel that they could have avoided it. Because sometimes it’s linked to smoking. Or that they are to blame for it in some way. I think people feel that themselves.”***

[Nurse Specialist]

[\*Source: Healthy Ireland, Department of Health]



# Communication is Key

Nothing may prepare the patient for lung cancer. One patient interviewed for this study described how the reality of how a cancer diagnosis is delivered is often at odds to how it can sometimes be portrayed in films and television.

*"[When receiving the diagnosis] It wasn't a case of them taking you into a quiet room with mood music playing or anything in the background."* [Patient]

What is clear from this research is that the manner in which the diagnosis is communicated to the patient can have an enormous impact on them. This pivotal moment of truth stays with the patient for the entirety of their journey; clearly, it is a moment they will never forget. However, patients gave examples of both good and poor practice in this regard and while many praised the way they received their diagnosis and could not fault the healthcare professional that delivered the news, others had particularly negative experiences in this regard which caused them significant amounts of distress.

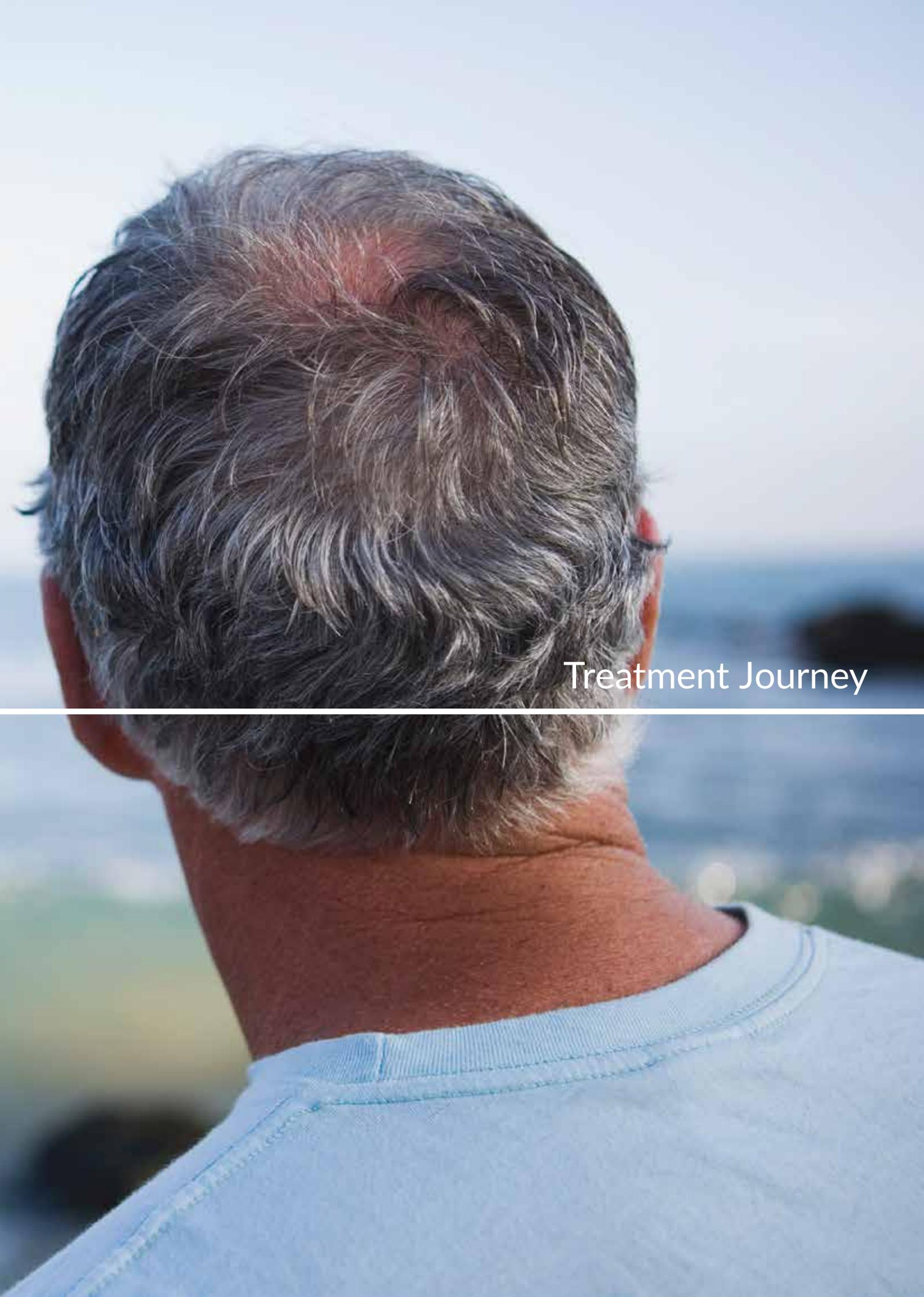
What patients ultimately want is to be treated with dignity and respect. In practice, this means a diagnosis that is delivered with compassion and sensitivity. Patients want to hear the truth, communicated with honesty and realism. However they also want clarity and direction, specifically to be told what the next steps in their journey might be in terms of the appropriateness of treatment or not.

Unfortunately, this research revealed scenarios of patients receiving their lung cancer diagnosis in a less than ideal manner. Examples included the diagnosis being delivered in a blunt, authoritarian, or overly dramatic manner, lacking compassion from the healthcare professional. Patients also expressed a preference for having a relative or friend with them when receiving the news to offer them support, however this was not always the case. In one case, a patient described how the diagnosis was delivered by an inexperienced healthcare professional who may have found the experience equally distressing.

*"And there was an intern guy who was dreadful, he was so bad, God love him. Because he brought me and (partner) into his place and he looked devastated, he was like white. And he was saying it's lung cancer, stage 4 cancer, it's bad, it's really, really bad...You have none of the markers, you know you're negative for this and you're negative for that and it's terrible. I was saying okay so what's the next step...and he was sort of looking at me...you could see him going, you don't understand what I'm saying. You could see that he thought it was an appalling situation and he couldn't understand why...I needed to burst into tears for him to understand that I understood what was going on."*  
[Patient]

Most patients interviewed for this study were predominantly positive about the healthcare professionals they had encountered and interacted with over the course of their journey. Particular praise was reserved for Consultant Medical Oncologists and the Oncology Nurse Specialists, with a strong sense of compassion being shown by them, and their patients typically treated with the appropriate dignity and respect. Where negative interactions with healthcare professionals took place, they were typically with peripheral staff that were not familiar with the individual patient's case.





Treatment Journey

# Each Patient's Treatment Journey Is Unique To Them



In most cases of lung cancer, the patient may have approximately one week to come to terms with their diagnosis before presenting to Oncology for their first formal appointment. Nurse Specialists observe that this short time gap can be of benefit and allows patients to process the information and prepare for next steps.

Nurse Specialists also observe a sense of relief for some patients once the treatment plan has been formulated and communicated, as this often removes a degree of uncertainty for the patient, particularly given most patients will have gone through an exhaustive series of tests at that stage.

*"Generally about a week... I think it's actually beneficial, it doesn't do patients any favours to rush them."*

[Nurse Specialist]

*"A lot of them are relieved. That they have a treatment plan and know their stage of diagnosis and they just want to know what's going on. They have a plan. They are not going for another test."* [Nurse Specialist]

The role that medical treatment can play will vary depending on each individual case of lung cancer and will be determined by the Oncology team in consultation with the patient. Nurse Specialists describe varying treatment goals by patient stage of disease. In this research, lung cancers at stages 3 and 4 were examined, although specific treatments and medications were not focused upon, as outlined previously.

Conventional treatment options for lung cancer include surgery, chemotherapy, and radiation. However, those with more advanced disease are unlikely to achieve a complete cure from these conventional treatment options, though they may significantly improve survival and provide symptom relief.

Immunotherapy is the use of medicines to stimulate a person's own immune system to recognise and destroy cancer cells more effectively. Immunotherapy can be used to treat some forms of non-small cell lung cancer and is resulting in the evolution of treatment goals. Targeted therapies are medicines that target specific molecules within a tumour, to slow down or block the growth of the cancer. Some targeted therapies have been developed to treat lung cancer, including medicines that target particular gene changes and proteins on the surface of tumour cells. Recent clinical studies of these innovative treatments are encouraging.

At stage 3, Nurse Specialists describe the potential for cure via treatment, while in stage 4 cases, the primary aim is to achieve stability of the disease and no disease progression. Regardless of disease stage, an overarching goal throughout treatment is to maintain the patient's quality of life and manage their symptoms.

*"At stage 4, it's about trying to get the cancer to sleep."* [Nurse Specialist]

*"I'd say even lung cancer treatments have probably expanded more than some other areas in recent times. Because of the advent of targeted therapies and immunotherapy which has become active. So I would say there's probably more changes in lung cancer treatment than some other areas."* [Nurse Specialist]



*“The other thing I really enjoy about the job is all this development of new treatments and things like the immunotherapy. It’s a whole exciting new era and we are making progress in terms of developing treatments.”*

[Nurse Specialist]

The patients in this research described various forms of treatment that they had experienced at different points in their journey. These included radiation therapy, chemotherapy, targeted therapy and immunotherapy. Many patients were required to take additional medications in combination with some of these treatment approaches, with steroids, opiates and anti-nausea medicines all commonly mentioned. There is a strong sense of trust throughout in the treatment approaches being recommended by the Oncology team.

Outside of the core treatments provided by the Oncology team, some patients may turn elsewhere for additional ways to get through their journey and manage their condition. The potential use of cannabis oil as a form of treatment and/or symptom relief is sometimes discussed among patients. Examples were also cited of patients using acupuncture, energy cupping, and a faith healer during their lung cancer journey. There is much debate around the merits of complementary treatments and it is important to seek the advice of a qualified healthcare professional at all times.



# Lung Cancer Treatment Presents Both Physical And Emotional Challenges

Given the severity of the condition and the complexity of medical interventions that are undergone, lung cancer treatment takes a significant toll on patients. During this research, patients described some of the challenging side effects that they had experienced and, while one cannot definitively say all were as a result of their lung cancer or its treatment, these are summarised below;

- Profound tiredness and fatigue, with patients often having to sleep during the day.
- Being confined to the bed, with a lack of mobility due to low energy levels.
- Significant pain, labelled “indefinable” by one patient.
- Vomiting and diarrhoea.
- Loss of appetite and loss of weight.
- Loss of hair, or in some cases loss of one’s eyelashes/eyebrows.
- Severe skin rashes, typically on the face or the chest.
- Runny nose.
- Ingrown toenails.
- Blurred or poor vision.

*“It’s like having a car with half an engine – there’s no power to keep you going.”*  
[Patient]

However, the challenges faced by patients while on treatment for lung cancer are not just physical by nature. Several other difficulties were described by patients as part of their treatment journey, including;

- Waiting for results of scans and tests is difficult and can be frustrating, e.g. having to wait for the results of a mutation analysis to determine the next stage of one’s journey.
- Inequality of access, e.g. based on whether or not one may have private health insurance.
- Confusion and error over appointments, e.g. blood tests that were not conducted when necessary or delays in the results of those tests being shared within the hospital.
- Practical difficulties when attending hospital, e.g. being unnecessarily sent around the hospital building or misdirected where to go for appointments, as well as the need to plan and arrange travel to/from hospital for treatment, particularly for those living significant distances away.
- Not being able to work or function as one did before while on or as a result of treatment, due to the physical difficulties described above. Indeed, for some patients, the difficulty was having to discipline oneself not to work (be it inside or outside of the home).
- Coping with the financial burden that may be present, sometimes from not being able to work, e.g. examples of patients encountering difficulties while applying for disability benefit.

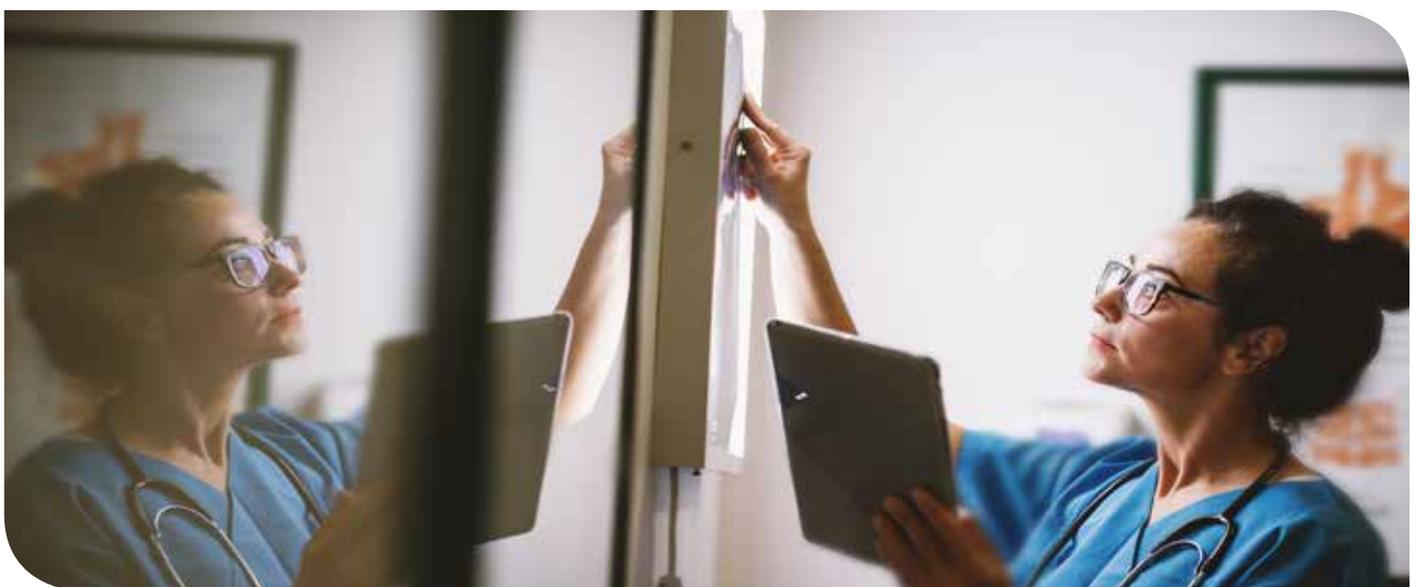
*“I applied for the disability but of course you don’t get that for about four months afterwards. Which is horrendous. I personally think anybody diagnosed with cancer should be given a medical card and either a disability payment or whatever... We couldn’t pay our rent for about three or four months and the landlords never once asked us for a penny of it.”* [Patient]

# The Nurse Specialist Plays A Wide-Ranging And Vital Role



Given the fact that Oncology Nurse Specialists were central to this research, it is important to acknowledge the breadth of their role, not only described by themselves but also echoed by the wholehearted praise they received from patients. The Nurse Specialist must play multiple parts in patient journeys, as described below;

- **Continuity:** For a patient who may be dealing with multiple healthcare professionals throughout their journey, the Nurse Specialist becomes relied upon as a continuous, consistent point of contact.
- **Educator:** Central to their role is to educate the patient about all aspects of lung cancer and the treatments they will be receiving.
- **Communicator:** The Nurse Specialist must tailor their approach to communication based on differing levels of health literacy, which refers to the patient's ability to understand the health information they receive, as well as the knowledge to understand their options and make informed decisions about their own health.
- **Contact:** As was evidenced by the fact that some Nurse Specialists fielded phone calls from patients even during their interviews, they will always reassure patients that they are available, often via a 24/7 service.
- **Adviser:** The Nurse Specialist listens to patient feedback about their treatments and may subsequently advise the Medical Oncologist where appropriate, e.g. recognising side effects when they arise.
- **Planner:** They are also responsible for all of the practical requirements necessary for a smooth and efficient appointment, for example ensuring blood tests are conducted and returned, as well as monitoring the patient's height and weight and helping to manage their prescriptions.
- **Co-ordinator:** As outlined earlier, patients can sometimes encounter challenges during their journey and the Nurse Specialist will help the patient to navigate the health system, as well as organising and directing them towards ancillary support services when necessary.
- **Problem-solver:** In short, the Nurse Specialist is always there to help when issues arise.
- **Support:** Above all else, the Nurse Specialists were widely praised by patients for simply being caring, compassionate and showing understanding, being a rock of support for patients on their difficult journey.





It is important to note that Nurse Specialists face several challenges themselves in their delivery of service. Broader health system issues such as human resource deficits can mean that they may have inadequate time to spend with patients to effectively carry out their role, or be unable to offer the patient a hospital bed due to capacity constraints.

*“We are the trouble shooters.”*

[Nurse Specialist]

Nurse Specialists also described the difficult cases where they are managing patients whose disease is progressing, which can be made all the more challenging when some of these patients have initially responded well to treatment. Delivering bad news that the patient’s disease has progressed or is no longer responding to treatment can be especially difficult if the patient is actually feeling relatively well.

Patient expectations must also be managed, e.g. when a patient hears about a new treatment that is not suitable for their particular strain of disease, or patients requesting to go forward for clinical trials that they are not in fact appropriate candidates for. Nurse Specialists must also sensitively deal with palliative cases who are no longer fit for treatment and explain the rationale for that decision to both the patient and their loved ones.

Despite these challenges, all Nurse Specialists agree that their job is a rewarding one. With recent advances in treatment options, they are now seeing patients living longer on more tolerable medications. They also enjoy the one-to-one interactions and the chance to get to know their patients and build strong relationships with them. Despite the seriousness of lung cancer, plentiful examples were given of positive craic, banter and laughter when dealing with patients, which is of mutual benefit to both parties.



# The Provision Of Information And Support Is Vital For Patients

Most lung cancer patients want to be fully informed about their condition and the treatments they are undertaking. They are typically given a range of printed materials from their healthcare team and are also referred to the hospital's lung cancer co-ordinator for support.

---

***"I'd made a decision early on that I wasn't going to spend my time googling up medical stuff online. But I did want to get core information."***

[Patient]

---

The written information that is provided is generally considered to be helpful by patients. Nurse Specialists recommend that any such booklets should be short, concise and not overwhelming, perhaps mindful of varying levels of health literacy.

Even if advised not to, most patients will inevitably go online to look up information about lung cancer once their diagnosis has been confirmed. Nurse Specialists may also direct patients towards certain websites that are appropriate to their needs.

MSD Ireland and Ipsos MRBI have recently published additional research\* on the trust the public have in online healthcare information which reveals the following;

- The approach any individual takes to searching for this information varies considerably. Online searches are far from linear and standardised, with the choice and sequencing of which sites to enter ultimately at the user's discretion. Moreover, the competence of the individual to interpret and make sense of the information they do find will also differ.
- A standardised approach to assessing the veracity of health content on the internet does not appear to exist. A verified trust mark to help users determine the validity of the information they review is of interest to many. However, the practicalities of implementing and managing such a system would require a significant undertaking, with many unanswered questions remaining.
- The public are open to guidance when searching for health information sources, whether online or in traditional printed format. The role of healthcare professionals is key in providing this guidance, with patients more likely to place value on materials directly recommended to them by an experienced practitioner.

---

***"Most of the time, people are glad to actually get some written information."***

[Nurse Specialist]

---

This research supports the view that the public are open to guidance and that information that is provided is generally welcomed. However, it is important that any information materials provided are evidence based and are there to supplement the one-to-one support, and that they are not a substitute for honest, direct dialogue, delivered compassionately.

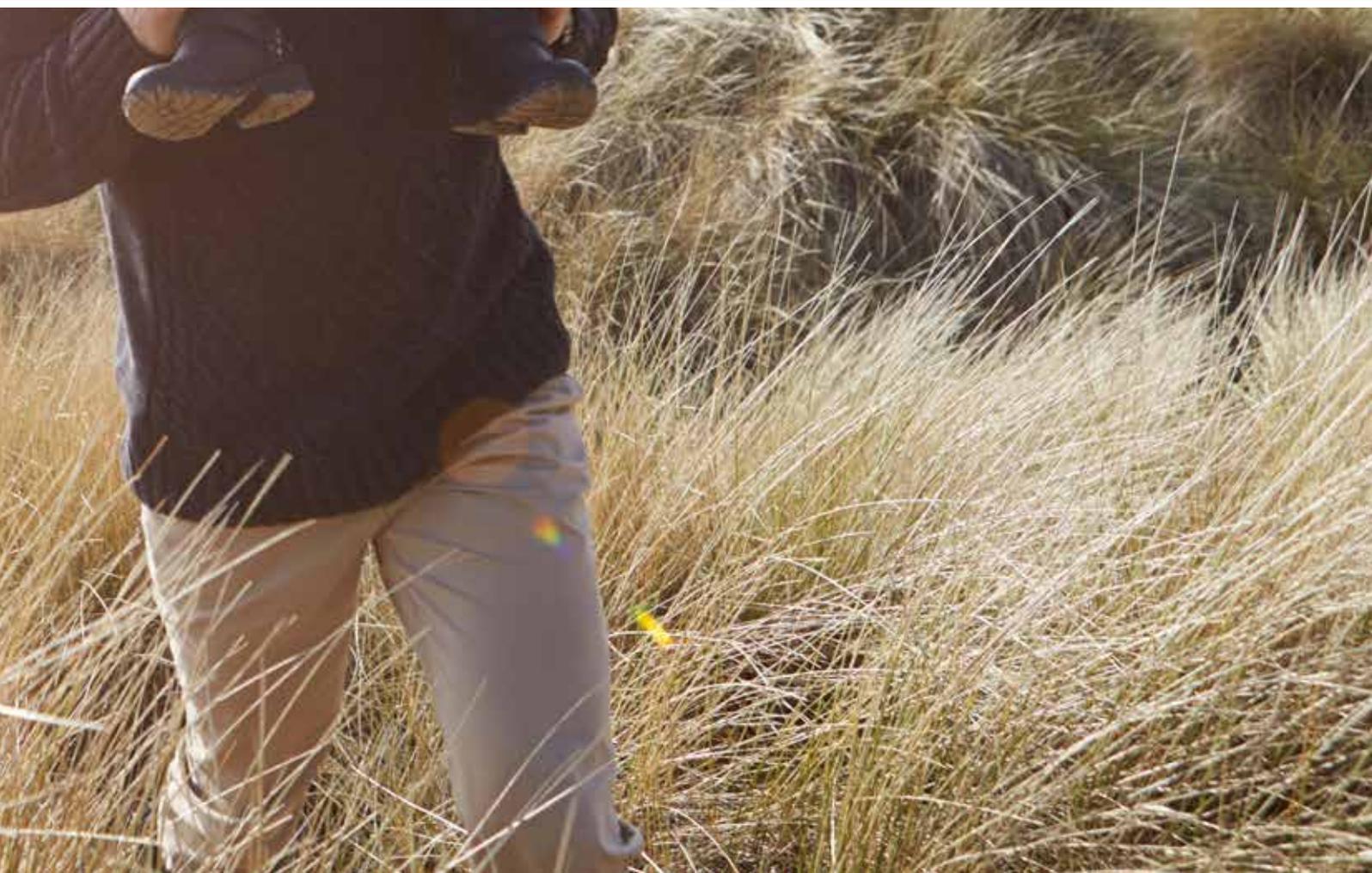
---

[\*Source: The Right Click – Exploring Trust in Online Healthcare Information (MSD Ireland /Ipsos MRBI), <http://www.msd-ireland.com/about-us/58/my-healthcare,-my-future>]





Living With Lung Cancer



# There Is No Set Formula For How To Cope With Lung Cancer



What is clear from this research is that no two cases of lung cancer are the same and that patients will react and behave differently throughout their own unique journey. Each person will cope with their diagnosis and treatment in their own way.

---

***“I’d never worry the kids, but I’d tell them what’s going on. But I’ve been hiding an awful lot of my pain.”*** [Patient]

---

Some patients do not show their emotions externally, preferring to remain strong and reassure family (especially children), yet internally they are likely to be in difficulty by their own admission. However, their strength and determination are very apparent. In accepting their prognosis, most patients simply want to live for as long as possible.

Patients do not tend to manage their journey alone. Partners, family and friends are frequently cited as being tremendously supportive. That support can be delivered in different ways, in some cases through every step of the journey while others can be supportive in a more remote, understated way, almost as a distraction. Lung cancer does not have to dominate every conversation. In fact, some patients are appreciative when their loved ones do not constantly talk about it.

---

***“I know my prognosis is crap. But I don’t think they can be any more specific than that.”*** [Patient]

---

The acceptance of one’s diagnosis and learning to live with lung cancer is a difficult but important milestone for patients. Most admit this is challenging. As one patient put it, it requires *“time, toughness and treatment”*. For some, it is about accepting that their condition is not curable, but treatable. Others may never be fully accepting of their condition.

Confirmation of the treatment plan can help with this, though delays in pre-treatment testing can add to anxiety levels. Another particular challenge is the uncertainty about whether or not one will respond to a particular treatment. Furthermore, patients must be made aware that even after seemingly successful treatment, their cancer may return.

---

***“Living with the fact that cancer can recur... it’s the acceptance of that.”***

[Nurse Specialist]

---



***“A couple of friends were very, very good. My partner has been incredible.”***

[Patient]

# Optimism & Pessimism

It is encouraging to note that some lung cancer patients, including those interviewed in this study, survive beyond the expected timelines they are given.

This can lead to a degree of optimism, which is described by patients not as a sense of false hope, but rather one of positivity that they are getting more time than had been envisaged. A more pessimistic patient, meanwhile, may believe they will get less time than have been told and then can be surprised with their outcome.

*“You think it’s like when people go to jail, they get four years and they only do two. So that was going through my head, I’ve twelve to eighteen months, so really that’s six to twelve months.”* [Patient]

Some patients will make preparatory steps for their death, e.g. giving away belongings, preparing a will, planning their funeral. For some, this is part of their acceptance of their condition and helps them to remain in control.

Any positive responses to therapy, such as a result showing shrinkage of the tumour or a lack of disease progression, are met with tremendous satisfaction by the patient. They can provide a degree of hope, though most are aware that the course of their disease remains unpredictable.

Nurse Specialists emphasise that there is reason for optimism as treatment options improve.

*“So should we be combining chemo and immunotherapy or chemo and these targeted therapies? It’s evolving very quickly and you know it’s up to us healthcare professionals to keep on top of it...  
...Because I’ve been working in oncology many years, I’ve been there since the birth of immunotherapy per se for lung cancer and it’s very exciting. For many years there was just chemo and you know you did what you could.  
But now we are seeing better results. People are living longer with lung cancer.”* [Nurse Specialist]



*“I would ask, how long will I get?  
And they would say, who knows?”*  
[Patient]

# First-Hand Advice From Lung Cancer Patients

To conclude our research, patients were asked what advice they would provide to others who are diagnosed with lung cancer. The positive sentiments revealed the resilience of these patients and their words, illustrated below, are a testament to the strength they display throughout their journey.



To paraphrase the words of one patient and their partner, life does not have to stop when one has cancer, it is often the hope that keeps you going.

*"Keep on asking questions, keep on pushing for the best treatment, take it when it's going..."*

*Life doesn't stop when you have cancer...you have to keep going...accept it for what it is.*

*You've won the worst lottery in the world but there's always hope, there's treatment.*

*And you're going to have really bad days. Just keep going.*

*You have to face up to the fact that this is a killer disease. We know cancer is the boss here.*

*You've got to grasp that reality and then park it. It's lying in the long grass.*

*But we just deal with it. Hope keeps you going." [Patient & their partner]*



## Conclusions & Recommendations





# Conclusions & Recommendations

## *Though smoking is a primary risk factor, lung cancer can happen to non-smokers too*

While a lung cancer diagnosis may not be entirely unexpected for those who have smoked long-term, it can be a shock for younger, non-smoking, relatively healthy cases, a cohort that appear to be proportionately increasing according to Nurse Specialists. The stigma around lung cancer remains intrinsically linked to smoking and this perception affects both smokers and non-smokers alike.

## *Awareness of symptoms needs to increase among the public and GPs to facilitate referral and diagnosis*

Descriptions of initial symptoms are consistent, in particular a seemingly innocuous but persistent and increasingly severe cough. Campaigns to highlight the need to investigate such symptoms are to be welcomed. The advice from patients is to be persistent in one's pursuit of a definitive diagnosis and not to accept any uncertainty.

GPs play a vital role in the early pick-up of potential lung cancer cases, with timely referral for X-ray being a critical first step in investigations. GPs must be encouraged to pursue this action, regardless of whether or not the patient is a smoker or has a family history of cancer.

The potential seriousness of early symptomology can be missed by both patients and healthcare professionals. The holistic picture of the presenting case may not always be pieced together, which can lead to anger and difficulty in acceptance among some patients who feel they could have been diagnosed earlier. However, Nurse Specialists also note that lung cancer can be more challenging to diagnose than other more symptomatic cancers, particularly in the absence of a lung cancer screening programme.

## *Patients should expect to experience a rollercoaster of emotions when their diagnosis is confirmed*

The patient will go through a range of highly charged emotions at the time of diagnosis, in particular shock, anger, fear and a sense of vulnerability. It is also possible that a strange sense of surreal detachment may envelop the patient as they seek to remain calm, often coping by displaying strength while those around them struggle with the news. Ultimately, reactions are down to individual circumstance and personality type and are therefore unpredictable.

## *Healthcare professionals must be compassionate, honest and balanced in their communications*

Communication is a critical success factor in the patient's journey, particularly at diagnosis. While undoubtedly this is extremely difficult news for a healthcare professional to deliver to a patient, examples of poor communication practices are in evidence and it appears the information is best delivered by an experienced, senior clinician in a calm, direct, compassionate manner.

Nurse Specialists can sometimes observe a sense of relief for the patient post-diagnosis, when the unknown has become known and a treatment plan is being formulated. Treatment goals vary by stage of disease, with Stage 3 cases striving for curative treatment if possible and Stage 4 cases aiming for disease stability. Quality of life, symptom management and specifically pain relief are important goals for all cases.



### ***The Nurse Specialist is respected and valued, becoming the cornerstone of support for patients***

The Nurse Specialist plays a pivotal, wide-ranging role for the patient, becoming a continuous cornerstone for the duration of their journey. However, they often face numerous challenges in dealing with a lack of resources and capacity while managing patient expectations (particularly as their disease progresses).

### ***The lung cancer journey is unique and deeply personal to each patient***

Though many patients receive the same treatments, the specifics of each person's journey and how they cope and respond to medications is unique to them. Patients place a strong sense of trust in healthcare professionals that they will endeavour to provide the best possible treatment plan for the patient and the majority of medical staff are held in very high regard by their lung cancer patients.

### ***Patients will require a strong support network to cope with physical, mental and emotional challenges***

The side effects experienced while on the array of treatments that may be required can take a significant toll on patients, not only physically (which can be profound) but also mentally, be it the stress of travel, financial concerns particularly if they can no longer work, appointment errors, or waiting for results and treatment decisions. Furthermore, the major life adaptation that may be required (for example no longer being able to work) can result in a challenging period of adjustment. The supportive role of family and close friends is cited as invaluable.

### ***Access to relevant, trusted information is valued by patients and should always be proactively provided***

Most patients welcome the provision of information from their healthcare professional, whether on the disease itself or on their treatments, though its value is dependent on the patient's health literacy and interest in engaging with such information. Nurse Specialists will also direct patients towards appropriate external support services. Details of a variety of patient support resources are available on [www.mariekeating.ie](http://www.mariekeating.ie), including details on services and courses such as; *Ask The Nurse Service*, *Survive & Thrive* and *Positive Living*.

### ***Deficits in services and resources across the healthcare system can result in gaps for patients***

Nurse Specialists identify a number of unmet needs for patients, including their own lack of resources to cope with capacity, a lack of adequate ancillary services for patients, delays in accessing new treatments and transport challenges for patients travelling to and from the hospital.

### ***While guidance is available, there is no rulebook for how best to cope with lung cancer***

Ultimately, this research demonstrates that lung cancer is a unique, personal challenge which does not follow a set formula. Every individual will cope differently depending on their own experience, personality, circumstances and support network.



### *Reaching a state of acceptance of one's diagnosis is a critical first step*

Patients believe that a critical factor in moving forward following diagnosis of lung cancer is the acceptance of that diagnosis, with confirmation of a treatment plan being central to this. A positive response to treatment can be the boost the patient needs to continue their journey with determination, but there must also be an acceptance that set-backs will happen. Meeting other people who have been through a similar path of treatment, feelings and emotions can be very helpful to individuals and create a sense of belonging and togetherness.

### *Patients must take control of their illness, not give up hope and keep fighting for their lives*

The advice of patients is to be positive and persistent while accepting their diagnosis; to ask questions, talk to others and challenge where necessary; to be determined and keep fighting for their lives; to keep oneself healthy; and to remember that there is always a degree of hope.

### *Access to new treatments such as immunotherapy and targeted therapy is vital for these patients*

The sense of hope is echoed by Nurse Specialists who acknowledge the advent of new therapies such as immunotherapy and targeted therapy as offering lung cancer patients more treatment options. Recent clinical studies of these innovative treatments are encouraging.

### *Future research with stakeholders across the journey could further enhance our understanding*

This study is not meant to be an exhaustive examination of the journey from every perspective, as it is qualitative in nature and focuses on patients and Nurse Specialists. There is scope to conduct further phases of research interviews with other stakeholders (e.g. General Practitioners, Consultant Oncologists, support service providers), as well as with more patients, to delve deeper still into the journey.

## Recommendations for Policy Makers

- Campaigns to raise awareness of the early symptoms of lung cancer, among both smokers and non-smokers.
- Emotional and psychological supports to be made available to patients at the time of diagnosis.
- Development of communications protocols and guidelines for healthcare professionals who communicate a diagnosis of lung cancer.
- Ensure proper resourcing of the Nurse Specialist role, so all lung cancer patients have access to a Nurse Specialist.
- Improve access to innovative treatments.
- Provision of relevant, trusted information about lung cancer in a format suitable to the patient's needs.



# Acknowledgments



---

The Marie Keating Foundation, MSD Ireland and Ipsos MRBI would like to acknowledge the participation and valuable contributions made by the following during this research:

- The patients and their families that took the time to share their stories with such openness and honesty.
  - The Oncology Nurse Specialists that provided invaluable input both during and beyond their interviews.
  - Dr. Anne-Marie Baird, School of Medicine, Trinity College Dublin.
  - ARC Cancer Support Centres.
  - Purple House Cancer Support, Co. Wicklow.
  - All healthcare professionals and patient organisations who assisted with recruitment for this study.
-



# About Marie Keating Foundation

---

It is 21 years since the Marie Keating Foundation was set up, following the death of Marie Keating from breast cancer in 1998. After losing their mother, the Keating family promised that they would do everything they could to bring an end to cancer.

The Marie Keating Foundation helps men and women prevent cancer, detect it at its earliest stages and supports them through cancer diagnosis, treatment and survivorship. The organisation raises awareness about the signs and symptoms of cancer and educates men and women throughout Ireland about cancer prevention and the importance of early detection.

The Marie Keating Foundation is now a leading voice in cancer awareness and support for both men and women in Ireland. The Foundation's mission is 'to make cancer less frightening by enlightening' and its aim is 'to achieve a world free from the fear of cancer'.

The Marie Keating Foundation provides information on all common cancers, including breast cancer, cervical cancer, ovarian cancer, lung cancer, skin cancer, prostate cancer, testicular cancer, bowel cancer and bladder cancer. It provides practical support to cancer patients and their families throughout the cancer journey and has a range of survivorship support services for the growing number of cancer survivors in Ireland.

The organisation has best-of-class corporate governance structures having achieved the 'Triple Lock' standard for best practice governance in the charity sector.

For more information about the Foundation's cancer awareness and support services, please refer to [www.mariekeating.ie](http://www.mariekeating.ie).

---

# About Ipsos MRBI

---

Ipsos is a global independent market research company ranking third worldwide among research firms. At Ipsos, we are passionately curious about people, markets, brands and society. We make our changing world easier and faster to navigate, and inspire clients to make smarter decisions. Ipsos is represented in Ireland by Ipsos MRBI, Ireland's longest established research firm.

With a heritage stretching back over fifty years, Ipsos MRBI is renowned for delivering high quality, insight-driven, actionable research. We employ 35 full time employees, who are supported by a staff of over 200 experienced interviewers nationwide.

Ipsos MRBI interviewers abide by strict fieldwork quality standards set by the ESOMAR International Code of Marketing and Social Research Practice and AIMRO (Association of Irish Market Research Organisations). We are dedicated to ensuring quality throughout all elements of our research, and in order to demonstrate this we became the first research agency in Ireland to be certified to ISO quality standards.

---

---

MSD Ireland is one of the country's leading healthcare companies, having first established here over 50 years ago.

We currently employ approximately 2,100 employees, across five sites in Ballydine, Co Tipperary, Brinny, Co Cork, Carlow and Dublin and, in addition, operate substantial Human Health and Animal Health businesses. In total to date, we have invested \$2.5 billion in our Irish operations and our annual turnover ranks us as one of Ireland's top 20 companies.

At MSD, we have and always will be...Inventing for Life. These three powerful words reflect our commitment to inventing new medicines and vaccines that save lives by preventing and fighting disease. MSD has dedicated researchers trained in many different scientific disciplines who work tirelessly to find cures for significant diseases that still afflict millions around the world and we will continue on this path.

At MSD Ireland we firmly believe that the most important thing we make is a difference – to patients, to our employees, to our communities and to the Irish healthcare landscape generally. MSD Ireland is 100% committed to putting the patient at the heart of everything we do. Significantly, our Irish sites manufacture approximately half of MSD's top twenty products, saving and enhancing lives in over sixty countries around the world.

---

# Notes



# 'Time, Toughness & Treatment'

Understanding the Experiences of People Living with Lung Cancer



Marie Keating  
FOUNDATION

Marie Keating Foundation  
Unit 9,  
Millbank Business Park,  
Lucan,  
Co. Dublin

 +353 (0)1 628 3726

 [www.mariekeating.ie](http://www.mariekeating.ie)

 Ipsos MRBI

Ipsos MRBI  
Block 3, Blackrock Business Park  
Carysfort Avenue  
Blackrock  
Co. Dublin  
A94 D5D7

 +353 (0)1 4389000

 [www.ipsos.com/en-ie](http://www.ipsos.com/en-ie)



**MSD**

INVENTING FOR LIFE

MSD Ireland  
Red Oak North  
South County Business Park  
Leopardstown  
Dublin 18  
D18 X5K7

 +353 (0)1 299 8700

 [www.msd-ireland.com](http://www.msd-ireland.com)