Lung Cancer

Action Plan
2019

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Overview

In 2019, almost 2,500[1] men and women in Ireland will receive a lung cancer diagnosis, and unfortunately more than 1,800 men and women will die[2] from this largely preventable cancer.

Lung cancer is the leading cause of cancer deaths in Ireland in both sexes - it accounts for 19% of all cancer deaths in women and 23% in men[3].

Incidence of lung cancer are on the rise - female lung cancer is projected to increase by 105% between 2015 and 2045, by 131%[4] in men, and by 119% for females and males combined.

Typically lung cancer is diagnosed at a late stage in Ireland, with 2 out of 3 lung cancers being diagnosed at Stage III or IV[5]. A late diagnosis reduces the chances of survival and greatly limits treatment options.

With the majority of lung cancers diagnosed late, survival rates are low. Five years after diagnosis 18% of lung cancer patients are alive in Ireland, and by 10 years, unfortunately, only 15% are still alive[6]. This is in contrast to 5 year survival rates of up to 92% in the earliest stages reported from international series[7].

In 2017, the Irish Cancer Society commissioned analysis from the National Cancer Registry of Ireland (NCRI) to establish the proportion of cancers diagnosed via emergency presentation (ED) for the years 2010-2015[8]. This was the first time this data has been available in Ireland.

The research found that 14% of all cancers diagnosed in Ireland during 2010-2015 were via emergency presentation[9].

Specifically, in relation to lung cancer it showed:

- Lung cancer had the fifth highest proportion of diagnosis by emergency presentation
- 26% of lung cancers were diagnosed via emergency presentation – over 600 cases a year
- Patients with lung cancer from the most deprived populations were 41% more likely to present as emergencies
- 71% (of those who presented in ED) of lung cancers occurred in people over 65
- 2 out of 3 lung cancers were diagnosed at a late stage

Further research from the National Cancer Registry of Ireland (NCRI) shows there is a deprivation gradient for lung cancer. Lung cancer incidence increases with deprivation index, with age-standardised rates about 60% higher in the most deprived compared with the least deprived fifth of the Irish population[10].

This same research indicated other lung cancer inequalities:

- A greater lung cancer incidence in urban areas
- A lower surgery rate for lung cancer in more deprived areas
- Lower survival rates from lung cancer and a higher proportion of late stage diagnosis in more deprived areas

The National Cancer Strategy 2017-2026[11] recognises the burden posed by lung cancer and sets out a number of targets in relation to improving lung cancer outcomes in Ireland over the course of the strategy – targeted multi-media public awareness campaigns; increasing the percentage of lung cancers diagnosed at Stage I and Stage II; and reducing the percentage of cancers diagnosed in ED.

While the Irish Cancer Society has been working on raising awareness of lung cancer, and providing services to lung cancer patients for many years, this is the first time we have published a cancer specific action plan.

We are focusing on lung cancer for our first 'cancer' action plan for a number of reasons. Lung cancer is often diagnosed late; it causes the most cancer deaths in Ireland; the number of cases is increasing, particularly amongst females; and it's a mainly preventable cancer. Additionally, it is now an opportune time to start considering lung cancer screening.

Most importantly, the Irish Cancer Society believes meaningful changes can be made to improve the earlier diagnosis of lung cancer, improve survivors' lives, and reduce lung cancer mortality significantly.

Prevention

Cigarette smoking is the leading cause of lung cancer. More than eight out of ten cases of lung cancer are linked to smoking[12][13]. Even light or occasional smoking and second hand smoking increases the risk of lung cancer. The risk of developing lung cancer is directly linked to the number of cigarettes smoked every day and the years spent smoking. People who quit smoking have a lower risk of lung cancer than if they had continued to smoke, but their risk is higher than the risk for people who never smoked. Quitting smoking at any age can lower the risk of lung cancer.

Ireland has a strong track record in tobacco control. Progress has been made through a comprehensive range of efforts across pricing, legislation, advertising and cessation services. Smoking prevalence has declined over the last thirty years. The estimated prevalence of daily smoking declined by 0.9% and 1.7% per year for men and women respectively[14]. 20% of the population are current smokers, 17% smoke daily and 3% smoke occasionally.[15]

Tobacco Free Ireland, the report of the Tobacco Policy Review Group, was endorsed by Government, and published in October 2013. This builds on existing tobacco control policies and legislation and sets a target for Ireland to be tobacco free (i.e. with a smoking prevalence rate of less than 5%) by 2025.

To achieve the target of the 2025 target of less than 5% smoking prevalence, we need almost 95,000 fewer people smoking a year between now and then[16].

The Irish Cancer Society is fully supportive of the goal of a Tobacco Free Ireland by 2025. Significant progress has been made to date that has been reflected in the recent drop in smoking prevalence from 22% to 20%[17]. However, there remains an urgent need for renewed leadership and commitment to realise the vison of a tobacco free Ireland.

The recent Healthy Ireland Survey (2018) indicated that smoking rates are higher in more disadvantaged areas (26%) than in more affluent areas (16%). There is consistent evidence that differences in smoking behaviour is a leading cause of inequalities in health across society.[18] Tobacco use perpetuates poverty, reduces social mobility and, as society becomes increasingly tobacco free, contributes to social exclusion. Innovative cessation programmes and smoking prevention solutions are required to ensure that the potential for a positive impact on health inequalities is maximised.

Supporting people to quit smoking is by far the most important intervention to prevent cancer and is also essential after the diagnosis of cancer to improve clinical outcomes. It has been estimated that smoking prevalence at the time of diagnosis have been estimated to vary from 45% to 75% and even though survival and quality of life are adversely affected by smoking, about one-third of cancer patients who smoked prior to their diagnosis continue to smoke[19,20]. Tailoring smoking cessation as part of disease management programs to the specific needs of cancer patients is likely to yield higher rates of long term quits, and result in improved disease outcomes. Therefore evidence-based smoking-cessation treatment should be an integral component of care for every person with cancer who smokes.

There is currently limited data on smoking prevalence by cancer type. There is a need to, collate accurate data, explore the barriers and facilitators of smoking cessation for cancer patients, learn about the mechanisms which help cancer patients to quit and support health professionals in providing smoking cessation advice to cancer patients.

The World Health Organisation has categorised radon as a carcinogen. In Ireland, up to 250 cases of lung cancer each year are linked to exposure to radon. Radon is a naturally occurring radioactive gas. It has no taste, colour or smell. It is formed in the ground by the radioactive decay of uranium which is present in all rocks and soils. It can only be measured with special detectors.

Radon can enter a building from the ground through small cracks in floors and through gaps around pipes or cables. Buildings in some parts of the country are more likely to have a radon problem. The Environmental Protection Agency (EPA) has provided an interactive map[21] to help people identify high radon areas. The EPA recommends testing homes for radon and using proven ways to lower high radon levels[22].

Other substances found at some workplaces that increase risk of lung cancer include asbestos, arsenic, diesel exhaust, and some forms of silica and chromium. For many of these substances, the risk of getting lung cancer is even higher for those who smoke. People exposed to large amounts of asbestos have a greater risk of developing mesothelioma, a type of cancer that starts in the pleura (the lining surrounding the lungs).

In recent years, government regulations have greatly reduced the use of asbestos in commercial and industrial products. It is still present in many homes and other older buildings, but it's not usually considered harmful as long as it's not released into the air by deterioration, demolition, or renovation. It is essential that that all stakeholders continue to support the work of the Health and Safety Authority to ensure that strong workplace regulations are in place and health and safety regulations are fully communicated and understood by all those who work with these substances in their workplace.[23]

The recently formed Cancer Prevention Network[24] provides an opportunity to bring those working in cancer prevention together to collaborate on targeted awareness campaigns and

disseminate research. This is a positive development and has the potential to support lung cancer prevention and early detection initiates.

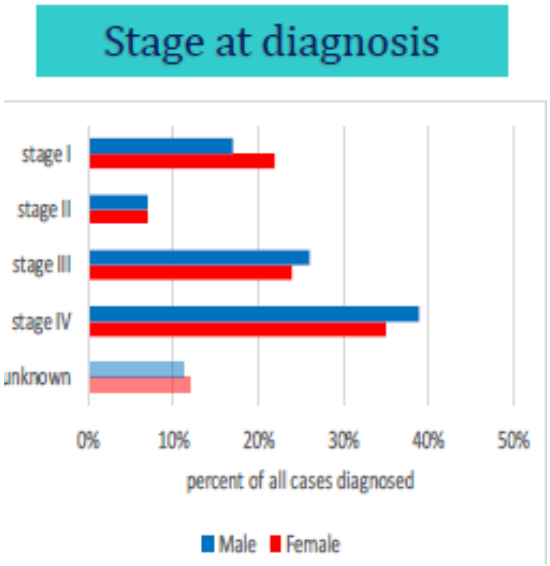
Recommendations:

- **The Department of Health with stakeholders, including the Irish Cancer Society fully implement the recommendations of the Tobacco Free Ireland Plan**
- **The Government supports additional investment in tobacco control and smoking cessation measures**
- **Collate data on smoking prevalence of lung cancer patients and develop a smoking cessation service tailored to cancer patients, and in particular lung cancer patients**
- **All national stakeholders support the work of the Environmental Protection Agency to ensure that the population are protected from the harmful effects of radiation and other carcinogenic substances**
- **All national stakeholders support the work of the HSA to raise awareness of the causes of occupational cancer and prevent exposure to carcinogens.**
- **Build the capacity of the Cancer Prevention network to increase public awareness with co-ordinated consistent messages**

Early Diagnosis

In order to reduce the high number of deaths from lung cancer we must improve on achieving an earlier diagnosis of lung cancer. In Ireland 2 out of 3 lung cancers are diagnosed at Stage III or IV[25] (see table below).

Table 1: Stage of Lung Cancer Diagnosis: Lung Cancer Factsheet 2017, NCRI.



As the majority of lung cancers are diagnosed at a late stage it has a very low survival prognosis. Amongst the most common cancers lung has the worst 10 year survival – 15% of lung cancer patients survive to 10 years in comparison to 89% of prostate patients who survive to 10 years post-treatment (See table 2).

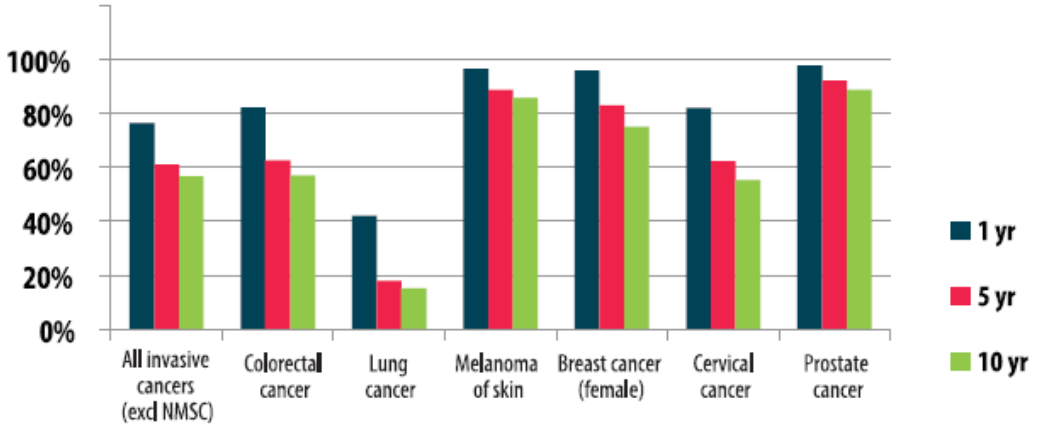


Table 2: One, five and ten year survival age standardised for most common cancers (2010-2014) [26].

The reasons for late diagnosis of lung cancer are complex. Symptoms are often very non-specific, tend to appear at a later stage and are similar to symptoms of other common smoking-related lung diseases. Patients may delay presentation because of the stigma associated with lung cancer and smoking, there is an element of denial[27]and a lack of awareness of signs and symptoms[28].

We know there are ways to encourage earlier diagnosis - through lung cancer screening or 'health checks' (see section below), public awareness campaigns, clinician education and better and earlier access to diagnostics.

The National Cancer Strategy has a number of targets to improve the earlier diagnosis of lung cancer including targeted public awareness campaigns to raise awareness of the signs and symptoms of lung cancer, and a key performance indicator (KPI) to increase the number of lung cancers diagnosed at Stage I and II by 10% between 2013 and 2020.

Despite lung cancer causing the most cancer deaths in Ireland and the high mortality rate associated with a lung cancer diagnosis, there is still little awareness of the major signs and symptoms of this cancer.

Research from the Global Lung Cancer Coalition (GLCC), in 2017, revealed that 27% of Irish people were unable to name any symptoms of lung cancer (Globally four out of ten people (42%) were unable to name any symptoms of lung cancer). Additionally, Irish Cancer Society research[29], from 2015, showed:

- Over a third of adults who experience three or more symptoms of lung cancer were unconcerned about being diagnosed with the disease
- 7 in 10 smokers claimed to have never spoken with a doctor or a pharmacist about lung health

- Over a fifth of adults (22%) and a third of smokers (32%) said they would not go to their doctor with any symptom as they would be afraid of what they would be told

These research findings indicate there is opportunity to raise awareness of the signs and symptoms of lung cancer among the Irish public, it is therefore imperative that targeted national awareness campaigns on lung cancer are prioritised. The National Cancer Strategy recommendation 7 states 'The NCCP and the HSE Health & Wellbeing Directorate, in partnership with the voluntary sector, will develop a rolling programme of targeted multi-media based public awareness and education campaigns, aimed at the early detection of specific cancers and with particular focus on at-risk populations.' As part of this initiative, targeted public awareness campaigns on signs and symptoms of lung cancer are required as a matter of urgency.

Work on this has recently commenced with the establishment of an inter-disciplinary Early Detection of Cancer steering group to advise on the priorities and format of public awareness and education campaigns. These are aimed at the early detection of specific cancers, with particular focus on at-risk populations. The group have prioritised lung cancer awareness and aim to deliver this campaign later in 2019.

Be Clear on Cancer Campaign – UK

Be Clear on Cancer is a campaign run by Public Health England to raise awareness of the signs and symptoms of cancer, and promote earlier diagnosis of cancer. The campaigns are conducted in conjunction with NHS England, CRUK and the Department of Health. Since 2010 this brand has been used to raise awareness of lung cancer signs and symptoms. Regional pilots were initially carried out in 2012 before a national campaign was run.

The campaign focused on a persistent cough lasting over 3 weeks and encouraged people to visit their GP. The message was targeted to over 50s. Results (May-Jun 2012) show there was an additional 700 lung cancers diagnosed in the months around activity, and 400 more people had their cancer diagnosed at an earlier stage. As well as this, there was a significant increase in the proportion of patients who received surgical resection as a first definitive treatment. A survey of the public indicated an increase in population awareness of a persistent cough as a symptom of lung cancer – from 54% pre-campaign to 65% post-campaign.[30]

Analysis from GP practices (2012)[31] showed a 62% increase in GP attendances for a persistent cough in the over 50s and urgent referrals for lung cancer saw a 32% increase (2012).

Ireland is in a good position to learn from the 'Be Clear on Cancer' campaign and Scotland's 'Detect Cancer Early'[32], which may be more relevant given our similar population and size, and rural/urban mix.

GPs, as a regular point of contact for patients, have a particular role to play in earlier diagnosis of cancer. On average patients attend their GP three times before a cancer diagnosis is made[33].

A GP might only see, on average, 7 cancer cases a year, only 1-2 of which will be lung cancer[34][35]. While we acknowledge they are already highly skilled in this area, further engagement on signs and symptoms of cancer will assist in earlier diagnosis.

In 2015, the Society surveyed GPs on their experience of accessing tests to diagnose cancer. In the survey, GPs listed "guaranteed direct access to diagnostic tests for cancer" and "establishment of rapid access clinics for all suspected cancers" as the top two factors which would most assist them in the early detection of cancer[36].

Rapid Access Clinics (RAC) for lung cancer offer direct and rapid access to assessment and diagnosis for suspected lung cancers. They are key to improving earlier detection of lung cancer. These clinics are supported by National GP referral guidelines and a standardised referral form and electronic referral system. The Rapid Access Lung Clinics have a target that 95% of patients referred to a RAC, in a designated cancer centre, receive an appointment within 10 days of receipt of that referral. This is also a Key Performance Indicator (KPI) of the National Cancer Strategy.

As you can see from the table adjacent these national targets are not currently being met across the board, and potentially this could lead to a delay in a lung cancer diagnosis. However, according to the NCCP, 95% of patients are seen within 15 days and over 99% are seen within 20 days.

Lung Rapid Access Clinics performance vs. KPI

Hospital	Metric	Dec '17	Jan '18	Feb '18	Mar '18	Apr '18	May '18	Jun '18	Jul '18	Aug '18	Sep '18	Oct '18	Nov '18	Total
Hospital A	%	95%	100%	100%	100%	100%	100%	96%	100%	100%	92%	100%	100%	99%
	N	19	34	23	21	39	24	24	23	17	24	30	20	298
Hospital B	%	83%	50%	50%	82%	81%	63%	34%	48%	78%	89%	89%	91%	67%
	N	24	44	44	40	26	35	47	27	37	18	27	34	403
Hospital C	%	100%	98%	98%	100%	97%	94%	85%	99%	96%	97%	93%	95%	96%
	N	46	60	66	54	62	52	48	68	50	39	45	56	646
Hospital D	%	95%	96%	100%	100%	100%	97%	100%	98%	95%	97%	95%	97%	98%
	N	22	56	44	45	47	37	44	47	38	29	56	35	500
Hospital E	%	59%	60%	58%	67%	52%	75%	55%	58%	65%	59%	48%	68%	60%
	N	46	60	45	39	50	48	60	50	46	58	56	62	620
Hospital F	%	100%	100%	100%	100%	100%	100%	100%	98%	100%	94%	100%	100%	99%
	N	28	38	40	28	33	39	24	41	29	33	36	29	398
Hospital G	%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
	N	28	36	42	23	41	41	36	43	45	66	69	80	550
Hospital H	%	100%	100%	93%	100%	96%	97%	93%	100%	100%	100%	95%	83%	96%
	N	10	27	27	26	26	32	30	15	16	27	19	30	285
National	**%**	**89%**	**86%**	**87%**	**93%**	**90%**	**90%**	**78%**	**88%**	**90%**	**89%**	**88%**	**91%**	**88%**
	N	**223**	**355**	**331**	**276**	**324**	**308**	**313**	**314**	**278**	**294**	**338**	**346**	**3700**

No Clinic /Not Applicable	Missing Data	≥95%	85-95%	<85%

While the target that 95% referrals to lung Rapid Access Clinics are seen within 10 days is still not being met, it is evident that improvements have been made over the past couple of years, following a period of underperformance which saw 78% of patients referred within 10 days in September 2017.

This follows the roll-out of improvement initiatives at Rapid Access Clinics, which sought to firstly identify and then address issues which resulted in unsatisfactory performance. These initiatives have been ongoing for 18 months, and at time of writing are 87% complete.

Recommendations:

- **The National Cancer Control Programme (NCCP) and the Department of Health, in conjunction, with stakeholders, including the Irish Cancer Society, Irish College of General Practitioners (ICGP), and Irish Pharmacy Union (IPU), run national, targeted public campaigns to raise awareness of signs and symptoms of lung cancer, and assist in earlier diagnosis of lung cancer.**

- **Improvement initiatives at Rapid Access Clinics continue and KPIs are rigorously monitored to ensure targets set out in the National Cancer Strategy are being met.**

Screening

We know that early diagnosis saves lives. Lung cancer CT screening has the potential to detect lung cancer at an early stage, and improve mortality. There are several studies completed and being carried out worldwide examining the effectiveness and benefits of lung cancer screening. These studies focus on using CT scans on high risk patients (smokers or ex-smokers) only.

In the UK some small regional pilot lung cancer screening programmes have been carried out, and the NHS are planning 10 pilot small scale regional lung screening programmes in the future[37]. In the US screening is now widely available – Medicare covers screening for eligible patients, as well as some private insurance companies.

Currently in Ireland there is no public lung cancer CT screening. Lung cancer screening is not addressed in the National Cancer Strategy.

Large scale UK (UKLS)[38], European (NELSON) [39] and US (NLST)[40] studies have all found screening to be beneficial[41].

The National Lung Screening Trial (NLST), in the US, found that the use of low dose CT in at-risk populations was associated with a significant reduction in lung cancer mortality[42].

Specifically, annual screening in smokers or recent former smokers aged 55 to 74 years was associated with a 20% decrease in the death rate from lung cancer.

A comprehensive literature survey by the Agency for Healthcare Research and Quality (AHRQ) on lung cancer screening, which synthesised data from 63 papers published between 2000 and 2012, supports screening for lung cancer[43][44]. Based on these findings, low dose CT screening has been recommended by the US Preventative Services Task Force, the American Cancer Society (ACS) since 2013, and a number of other medical organisations.

The UK Lung Cancer Screening Trial (UKLS)[45] identified 67% of participants at early stage of disease, and was shown to be cost-effective under NICE guidelines.

The second largest screening trial after NLST, the NELSON study, recently announced its initial findings on the benefits of CT lung cancer screening[46] (published full results are outstanding at this time). The NELSON study built on the learnings from previous trials to devise and apply a comprehensive trial design framework. The study, which included 15,792 participants, found a 26 per cent reduction in lung cancer deaths among asymptomatic men at high risk for lung

compared with no screening[47]. In the smaller subset of women who were screened there was a mortality reduction of up to 61 per cent.

These results show a greater mortality reduction than the NLST study, and have reinforced calls for European countries to now consider population based lung cancer screening.

In 2017, a European Union (EU) position statement on lung cancer screening was published, outlining the evidence for using low dose CT as a screening tool[48]. The report calls for an EU Expert Group on lung cancer screening to be set up by the EU Commission to support the implementation and suggest recommendations for the lung cancer screening policy by 2019/2020. The Irish Cancer Society is supportive of this call, will work with its European counterparts to see it acted on, and will ensure this becomes a priority for the Irish Government.

In the UK, two smaller regional pilot lung cancer programmes have been running for a number of years, one in Liverpool funded by the NHS and the other in Manchester, funded initially by Macmillan and now by Manchester Cancer. Both of these achieved earlier lung cancer diagnosis and demonstrated how to access 'hard to reach' groups. These offer a good opportunity for Ireland to learn from. Two other major research programmes have launched in England. The Yorkshire Lung Cancer Screening Trial (funded by Yorkshire Research who also funded a Leeds pilot [49]) was launched in November 2018 and a major research programme based in North East and North Central London and run by University College London began in December 2018.

Experience from UK suggests that smaller regional pilot programmes within a carefully defined target population and with proper evaluation may work the best. NHS England is now funding a small scale screening programme in west London and will shortly be funding 10 more small local pilots of what it is calling 'targeted screening'.

Lung Cancer Screening Pilot – Manchester

The Lung Health Check pilot was introduced in 2016 and was able to quadruple early diagnosis rates by offering breath testing and on-the-spot scans around shopping areas in some of the city's most deprived boroughs through mobile CT scanner units.

The scheme invited 2,500 people aged 55 to 74 with a history of smoking for CT scans in car parks, community hubs and shopping centres across Manchester. The scheme diagnosed one cancer case for every 33 patients screened. Critically, four out of five of these were at an early, more treatable stage.

The one-stop-shop Lung Health Check in the community is part of the £5.65 million Macmillan Cancer Improvement Partnership (MCIP) – and is designed to increase early diagnosis rates for lung disease in Manchester. The project is also part of NHS England's ACE programme.

The NHS is conducting a small pilot in London, and will shortly put a call out for 10 new smaller regional pilots.

Lung cancer CT screening has also been reported to have favourable cost implications compared with other cancer screening tools[50]. It has been recommended to include smoking cessation along with CT screening to improve cost-efficiency[51]. A cost-effectiveness study of the NLST trial showed a cost of less than $100,000 per QALY gained. This study showed that screening was more cost effective in certain population groups - in women, those with higher risk of lung cancer, and for current smokers[52].

In contrast, in breast and colon cancer screening where age and sex can be the determinants, the population groups need to be much more defined in lung cancer screening in order for it to be cost-effective. Additionally, an added advantage of CT screening is that it has the potential to identify other major tobacco-related diseases like cardiovascular disease and COPD.

Now that data from NELSON is available, we have to await the full paper publication to fully consider its findings. But the initial results have confirmed the benefits of lung cancer screening in high-risk individuals, first demonstrated in the NLST study. With NELSON there is now conclusive evidence for implementation of lung cancer screening in Europe. This evidence must be translated into action and supported by national Governments and the European Commission.
It is now time for the Department of Health, NCCP and the National Screening Service (NSS) to begin considering lung cancer screening as an option in Ireland, and identify possible challenges to future screening programmes.

The Irish Cancer Society believes that much of this work should be carried out by the promised National Screening Committee, as per the recommendations of the Scoping Inquiry into the CervicalCheck Screening Programme[53]. As part of its final report, the Inquiry recommended the establishment of an independent National Screening Committee. This committee would be responsible for considering population level screening programmes in Ireland, and would be specifically tasked with:

- Effectively implementing an agreed methodology for accepting applications to consider new or revised screening programmes;
- Agreeing and implementing a prioritisation process for the consideration of new or revised screening programmes;
- Developing and implementing a robust and transparent system to consider potential population-based screening programmes;
- Clearly communicating the recommendations and the reasoning to the Department of Health, stakeholders and the public on the outcomes of deliberations;
- Reviewing any advice routinely every three years, or beforehand, if significant new evidence becomes available.

The Government has committed to accepting all 50 of the report's recommendations, and the Minister for Health has confirmed he intends to establish a National Screening Committee by early 2019[54].We believe the Committee should, as a matter of priority, consider the introduction of a lung cancer screening programme.

We acknowledge that there are still a number of issues that need to be resolved before screening can commence. This includes:

- the identification of the appropriate high risk population groups;
- consideration of gender differences, and optimal screening intervals;
- agreement on quality standards and quality measures;
- examination of cost-effectiveness, how to minimise false positives, and how to integrate smoking cessation into a screening programme.

Other major considerations are health service capacity to undertake more lung CTs, governance, informed consent, open disclosure, recruitment, how to manage findings including positive results, false negatives and incidental findings.

To consider and address these issues, the Irish Cancer Society recommends that the Irish Government works with its European counterparts to champion the establishment by the European Commission of an EU Expert Group on Lung Cancer Screening.

According to research the Irish Cancer Society carried out with the ICGP in 2015, only 20% of GPs have direct access to chest CT scans. GPs reported an average waiting time for access to a chest CT in the public system was 62 days versus 5 days in the private system[55]. However, when you are referred through a lung RAC, you receive quicker access to CT scans. In order to introduce lung cancer screening in Ireland a number of actions would need to happen first:

- An increased CT capacity
- Establishment of access to diagnostic testing in community healthcare
- Making direct access to diagnostics for GPs available, in order to assist with the likely increased referrals

However, despite these potential issues, we believe it is time to start the conversation about lung cancer screening in Ireland.

Recommendations:

- **The NSS, NCCP and Department of Health should monitor lung cancer screening progress in other jurisdictions, review the research and consider a national lung CT screening programme in Ireland**
- **An action plan is put in place to ensure adequate health service resources and workforce capacity are there to support any increased referrals arising from screening**
- **Once constituted, the National Screening Committee, recommended in Dr. Gabriel Scally's Scoping Inquiry into the CervicalCheck Screening Programme, should give early consideration to the introduction of lung cancer screening[55]**
- **To consider and address these issues, the Irish Cancer Society recommends that the Irish Government works with its European counterparts to champion the establishment by the European Commission of an EU Expert Group on Lung Cancer Screening, and to support the development of guidelines for quality assurance on screening at a pan-European level**

Treatment

The development of lung cancer referral guidelines, Rapid Access Clinics, the centralisation of cancer services, advances in the accuracy of TNM staging and treatment modalities, supported by specialist MDT discussions, have all contributed to better treatment options for Irish lung cancer patients. More lives are being saved thanks to the creation of designated cancer centres. Five year survival rates for lung cancer patients are significantly higher in designated cancer centres at 29% in comparison to 7% for lung cancer patients in other public hospitals[57].

The majority of lung cancer patients are diagnosed at a later stage when radiotherapy and drug therapies are more suitable treatment options than surgery. A variety of radiotherapy techniques, chemotherapy and targeted therapy drugs have been developed to treat the disease. More recently, a range of immunotherapy drugs have become available to lung cancer patients. These drugs are better tolerated and result in significantly improved outcomes.

However these drugs are expensive. It is likely to be more cost effective to invest in early diagnosis and prevention of lung cancer rather than the increasing costs of systemic treatment required for later stage cancers. Lung cancer diagnosed earlier is more suitable for surgical interventions and less likely to require expensive drug therapies.

Considering the low rates of survival and the high morbidity, more coordinated research is urgently needed, covering all fields from basic to clinical research. There is a need for improved access to innovative drugs and increased numbers in clinical trials.

Lung cancer trials are, however, much harder to execute than breast and prostate cancer trials, for example, as the patient population is more vulnerable and this has resulted in chronic underfunding of lung cancer research compared to other cancer types. This is not just confined to Ireland, but is a global problem.

In 2016, the GLCC commissioned the Institute of Cancer Policy (UK)[58], to provide a comprehensive picture of the world lung cancer research landscape, which demonstrated that relative to the huge health, social, and economic burden associated with lung cancer, the level of global research output lags significantly behind that of research on other malignancies.

In terms of progressing MDT-led, consistent treatment in Ireland, the most important development in recent years has been the publication of the NCEC National Clinical Guidelines on Lung Cancer[59]. These provide guidelines on the identification, staging and treatment of lung cancer, and will help deliver consistent cancer care across the country.

The Society supports the NCEC Guidelines, and wishes to emphasise the importance of ensuring they are frequently monitored and updated.

A key cornerstone of modern cancer care is Multidisciplinary team (MDT) working[60]. The 2006 'A Strategy for Cancer Control in Ireland'[61] recommended that all cancer patients' cases be discussed at MDT level, and great progress has been made in this regard. The National Cancer Strategy 2017-2026 stated: *"MDT working has led to improved decision-making, more co-ordinated patient care and improvements in the overall quality of care."*

MDT care is particularly relevant in the case of lung cancer patients who may have more complex health needs, as well as psychosocial issues unique to their disease group (see section below on details for distress, stigma and extensive needs of lung cancer patients).

The Irish Cancer Society would like to see the development of the role of the MDT including nutritional and physiotherapy care services with particular focus on the Lung Cancer Nurse Specialist (Lung CNS) in the care of lung cancer patients[62]. The UK Lung Cancer Coalition document "The Ideal MDT" outlines the important and varied role of the lung CNS, as the preeminent link with patients and families, offering educational, emotional and psychological support throughout the cancer journey from presentation to palliative care. The UK National Lung Cancer Audit, (NLCA) states that the lung CNS plays an essential role in the evaluation of the patient and improves the carer's experience and recognises that every patient should have specialist nursing involvement[63]. The Mater hospital has the first specialist thoracic surgery ANP in place, these types of roles need to be replicated in other centres.

While great advances have been made here in developing lung cancer services in Ireland there are additional learnings from the UK, in their collection of lung cancer data. The UK National Lung Cancer Audit, (NLCA) began collecting national data in 2005 and collects data on lung cancer, surgical outcomes and an evaluation of lung cancer staffing and resources across the UK. NLCA has led to greater clarity of lung cancer services across the UK, helped drive improvements and led to more consistent care.

Given the success of NLCA in the UK, consideration should be given to whether Ireland needs to adopt something similar and begin to collect lung cancer data on a national, annual basis. There are examples of this happening on a small scale in Ireland.

There are local audits already available, for example, in 2015 the Mater University Hospital published a comprehensive guide to their lung cancer data a 'Lung Cancer Annual Report 2014'[64]. Similarly, St James's hospital have produced a ten year cancer audit report 2003 - 2012. A national audit could assist in driving improvements in lung cancer care and ultimately improve outcomes.

In the UK, the Lung Clinical Expert Group developed the Optimal Lung Cancer Pathway in 2017[65]. This could be considered in Ireland, but vast work and research is required on existing infrastructure and resources to facilitate this.

Survivorship

Fortunately deaths from lung cancer have decreased in the last 20 years, and survival rates are slowly increasing. However, the reality is that lung cancer still has a very low survival prognosis, as evidenced in the table below[66].

According to the latest National Cancer Registry of Ireland Annual Report 1994-2016[67], as of 2016 there were 173,000 cancer survivors in Ireland. Approximately 3% of these, 5,190, are lung cancer survivors.

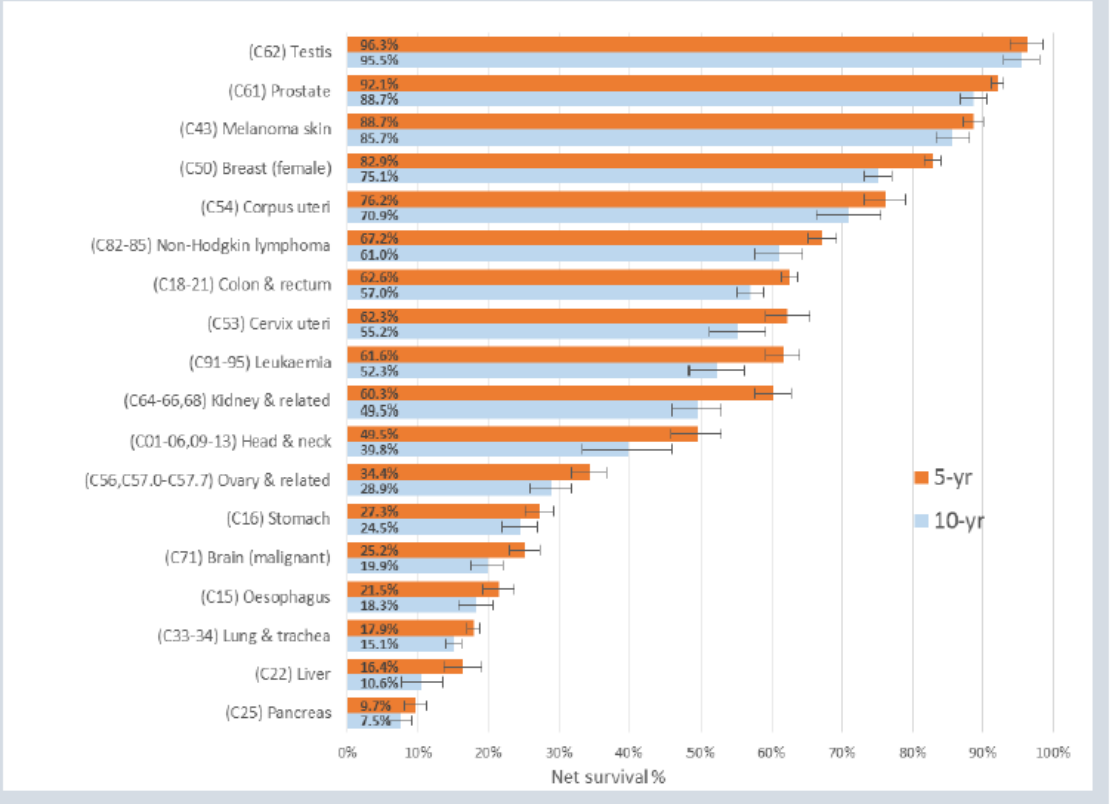
As well as improving survival rates, we need to look at the needs and management of lung cancer survivors.

Lung cancer patients are often diagnosed late; can have co-morbidities; experience a myriad of symptoms and treatment side effects; there is a stigma and distress unique to this cancer; it causes the most cancer deaths; and has low survival rates. For these reasons lung cancer patients experience particularly high levels of distress.

The National Cancer Strategy recognises the importance of survivorship needs. One key recommendation is that the NCCP, in conjunction with the ICGP, cancer centres, Irish Cancer Society and cancer support centres will conduct a cancer survivorship needs assessment to ascertain the most suitable model of survivorship healthcare. This is due to be completed in 2019 and will contribute to the development of a model of care to support those living with and beyond cancer.

However, the needs of lung cancer survivors can be very complex, and the Irish Cancer Society is asking for the development of specific care plans for this group of patients.

Figure 6-1. Estimates of 5-year and 10-year net survival (age-standardised) for invasive cancers in Ireland, 2010-2014



We know that lung cancer patients suffer much more distress than patients diagnosed with other cancers. Research shows that approximately 25%-30% of all newly diagnosed cancer patients experience elevated levels of emotional distress. A landmark study in 2001[68] examined the prevalence of psychological distress by cancer and found considerable variation.

Of the patients surveyed, 43% of lung cancer patients experienced elevated levels of distress in comparison to 32% of breast cancer patients, 31% of bowel cancer patients and 30% of prostate cancer patients.

A 2010 study showed nearly 40% of lung cancer patients reported levels of distress and depressive symptomatology that meet clinical cut-offs. Many of these patients expressed interest in treatments that could improve quality of life like - treatment of fatigue, information about their disease or treatment, and psychological counselling or support[69].

Further research found that lung cancer patients score highly on distress levels due to poor prognosis and self-attribution due to smoking[70]. In particular, the stigma and association with tobacco causes lung cancer patients distress[71][72]. Research from GLCC in 2017 found 20% of people in Republic of Ireland agreed that they have less sympathy for people with lung cancer than other forms of cancer[73].

Some of the reasons listed below contribute to the high level of distress seen in lung cancer patients:

- Diagnosed with a high mortality cancer
- Diagnosed at an advanced stage with a poor prognosis
- Post –treatment side effects
- Co-morbidities / Debilitating symptoms
- Nihilistic attitude among the public / the media / healthcare professionals
- Stigma, shame and blame
- Less likely to avail of supportive services

We welcome the appointment of a National Clinical Lead for Psycho-Oncology and support the full implementation of the hub and spoke model recommended in the National Cancer Strategy. This model includes distress screening and provision of appropriate psychosocial support as standard of care. However for the reasons outlined above, the Irish Cancer Society also recommends the development of survivorship care plans, specifically for this patient cohort.

As well as dealing with their emotional distress and physical side effects, there are other needs particular to lung cancer patients like increasing physical activity and smoking cessation. Smoking cessation is particularly important as it can lead to better treatment efficacy, fewer side-effects, less risk of recurrence and less risk of developing other smoking-related health problems[74].

The Irish Cancer Society has commissioned research to better understand the needs of lung cancer patients and their carers, to see what supports and services may assist them. This research will be complete later in 2019 and will be helpful in developing tailored care plans for lung cancer survivors.

The Society is also funding research examining the effect that surgery has on physical fitness and quality of life in patients with lung cancer. The research will examine if exercise training can improve physical fitness, recovery, and quality of life before and after surgery.

Recommendations:

- **The development of a comprehensive care plan for lung cancer patients addressing their emotional and physical needs be considered by the NCCP, in addition to the planned model of care for cancer survivors**
- **Examine the research findings of the Irish Cancer Society Lung Cancer Needs Assessment and implement appropriate actions**
- **Further research is required into the unique psycho-social issues that lung cancer presents**

Palliative Care

Given that the mortality rates for lung cancer are high and lung cancer patients have particular psychosocial needs, palliative care has a special and important role in lung cancer care. Palliative care can assist supporting patients in the management of symptoms and psychosocial support.

Palliative care has the potential to improve the quality of care and reduce the use of medical services[75]. To have a meaningful effect on patients' quality of life and end-of-life care, palliative care services must be provided earlier in the course of the disease, and in conjunction with cancer-directed treatments.

Research has shown that among patients with metastatic non-small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival[76].

It is recommended by in the NCEC Lung Guidelines that "All patients with advanced stage lung cancer should have their palliative care needs assessed[77]."

The National Cancer Strategy 2016-2027 recommends that "designated cancer centres will have a sufficient complement of specialist palliative care professionals, including psycho-oncologists, to meet the needs of patients and families".

It also contains a target that 90% of patients with Stage IV disease will receive a specialist palliative care assessment by 2019. Finally it is a recommendation that all staff should have training in carrying out a palliative care needs assessment and making referrals to specialist palliative care when necessary[78].

Recommendations:

- **To ensure lung cancer patients get access to palliative care services as early as possible to ensure best possible outcomes**
- **To ensure the KPI target in the National Cancer Strategy is reached by 2019**

Conclusion

Lung cancer causes the most cancer deaths in Ireland. Due to historical smoking trends, lung cancer cases are due to increase into the future.

In order to increase lung cancer survival into the future and reduce Ireland's high mortality from lung cancer we need to begin to act now to reverse these trends.

This paper has outlined how achievable goals – like the development of national awareness campaigns on the signs and symptoms of lung cancer, serious consideration for the development of lung cancer screening programmes, promoting the benefits to be had from early diagnosis, and ultimately the introduction of a national lung cancer screening programme, or a comprehensive survivorship care plan for lung cancer patients could make meaningful and significant change to lung cancer patients in a short time frame.

We need the Government, the NCCP, the NSS , and organisations like the Irish Cancer Society to come together to take urgent action and implement concrete measures that will improve the earlier diagnosis of lung, and other cancers in Ireland, during the lifetime of National Cancer Strategy 2017-2026.

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