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# Irish Cancer Society Pre-Budget Submission

June 2024

# Irish Cancer Society

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# **Executive Summary**

Budget 202	5 Key Ask	Budgetary
Invest in the National Cano	cer Strategy	<ul> <li>An additional the National Car</li> <li>An assessmer this extra €20 m full implementat</li> <li>End the recru funding to fill cr date workforce</li> </ul>
Priority Areas	Relevant Department	Budgetary Ask
Prevention	Health	<ul> <li>E-cigarettes:</li> <li>e-cigarette flavou and social media r</li> <li>Tobacco cess increase excise du line with the tobac</li> <li>Genetic servi recommendations Genomic Medicine Workforce Plan.</li> <li>Fund dedicated protected theatree</li> <li>HPV vaccinat Brennan HPV Cato who missed out on</li> <li>Dedicated func- people of the ben uptake.</li> <li>Sunscreen: Re available in public</li> </ul>



# Ask

I €20 million in 2025 in new recurrent funding for ancer Strategy.

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nding for raising awareness among parents and young nefits of HPV vaccination focusing on areas with lower

educe taxation on sunscreen and make it freely spaces.

Priority Areas	Relevant Department	Budgetary Asks
Early	Health	Diagnostic Tests:
Detection		• Train, recruit and retain sufficient staff to meet diagnostic targets, including in endoscopy, colonoscopy, colposcopy and radiology.
		• Invest in hospital infrastructure to protect diagnostic pathways (e.g. procedure rooms, day ward space, up-to-date radiology and other testing equipment, etc.) and ensure those scheduled for diagnostic tests are seen within the recommended timeframe.
		Cancer Screening:
		Allocate funding to the National Screening Service to:
		• Expand the age range for BreastCheck to 45 - 74 years of age.
		<ul> <li>Expand the age range for BowelScreen to 50 - 74, (€2m).</li> </ul>
		• Ensure BowelScreen reaches the 60% uptake target.
		<ul> <li>Plan for further expansion of our existing screening programmes, and piloting of new programmes in lung, prostate and gastric cancer, as recommended by the European Council.</li> </ul>
		<ul> <li>Invest in communications and awareness raising activities to ensure high uptake of screening among all communities.</li> </ul>
		<ul> <li>Ring-fence funding to ensure underserved groups, including people with disabilities, attend screening programmes. Communications and accessibility needs in particular should be addressed.</li> </ul>
		• Fund the implementation of a pilot/implementation study on lung cancer screening (LCS), using community-based, low-dose computed tomography (LDCT). The implementation study should also include smoking cessation support.
Children,	Health	Dedicated funding to the NCCP to develop CAYA referral guidelines.
Adolescent, Young Adults		Co-develop a GP education and awareness programme on the early detection of CAYA cancers for GPs, with the Irish Cancer Society and ICGP.
		The provision of a travel abroad scheme to cover non-medical expenses of travelling abroad for medical care.
	Social	The provision of a specific CAYA allowance.
	Protection	The provision of an exceptional needs payment/additional needs payment without means testing for CAYA cancer applicants.

Priority Areas	Relevant Department	Budgetary Asks
Timely	Health	Invest in workfore
access to		<ul> <li>Ensure safe and suff</li> </ul>
treatment		<ul> <li>Address the challeng services, through adea mechanisms for recrui conditions.</li> </ul>
		• Invest in infrastructu to enable protected p inpatient beds and the in the National Cancer people getting cancer
		New medicines:
		Increase the budget fo
		• Ringfence funds to in recommended in the <i>I</i> the NCCP and NCPE, a indicative timelines for
		Clinical trials:
		<ul> <li>Fund protected time staff.</li> </ul>
		<ul> <li>Improve data protect participation in cancel</li> </ul>
		• Ring-fence regular, 1 research and infrastru
		• Ensure that HSE inco directly invested into a clinical trials governan
		Digital Health:
		• Provide sufficient fur of electronic health re IT staff in all hospitals

### rce capacity:

ficient staffing levels in cancer care;

nges to recruitment and retention of staff in cancer equate training places across all disciplines, improved uiting from overseas and improvements in working

cure (i.e. dedicated physical space and equipment pathways for treatment, including day ward space, neatres) to meet the target treatment times set out er Strategy and annual increases in the number of er.

for new medicines.

implement the improvements in the approval process Mazars review, including increased staffing for an application tracker, greater transparency and or the approval of medicines.

e for clinicians and adequate research and support

ection and other regulatory processes, to improve er research and trials.

flexible, and sustained investment in clinical trials ucture.

come from commercially funded studies can be clinical trial operations at the discretion of local nce structures, including funding clinical trials staff.

unding to develop and implement the national rollout ecords across the health system, including sufficient and the HSE.

Priority Areas	Relevant Department	Budgetary Asks
Living Well	Finance	Legislate for a 'right to be forgotten' for cancer survivors, so they do not have to disclose their cancer diagnosis after 5 years, with independent oversight and penalties for companies who breach this right.
	Social Protection	Broaden the Partial Capacity Benefit criteria to increase security for those with a previous cancer diagnosis seeking to return to work.
		Introduce a new statutory payment for employees and self-employed people with chronic illness to attend medical appointments rather than being forced to take unpaid leave.
		Fund the Lymphoedema and Lipoedema model of care.
	Health	Review and fund the appropriate number of professionals to meet the needs of cancer patients and survivors, including dieticians, physiotherapists, occupational therapists, speech, and language therapists and medical social workers through the public health service in their local communities.
		Ensure cancer survivors can access assessment and treatment for long-term and late effects such as pain, fatigue, depression, incontinence, and sexual dysfunction.
		Funding to ensure the full implementation of the Model of Care for Psycho-Oncology services for patients aged 0-24 years and their families.
		Fund equitable universal state allowances for hairpieces and post- mastectomy products (including prostheses and specialised bra(s)) at the highest rates currently available.
		Ensure the funding of cancer survivorship programmes, to allow cancer patients to transition from cancer treatment back to "normal" life, with easy and direct pathways to re-enter cancer services if required.
	Children, Equality, Disability, Integration and Youth	<ul> <li>Leave our Leave:</li> <li>Change the Maternity Protection (Amendment) Act 2004 to allow women with cancer diagnoses to defer their maternity leave.</li> </ul>

Priority Areas	Relevant Department	Budgetary Asks
End of Life	Health	<ul> <li>Increase Governm Nursing service so t the comfort of their</li> <li>Ensure greater ac counties in Ireland e accessing such a vit</li> </ul>
Financial Costs of Cancer	Health	<ul> <li>Car parking charges</li> <li>car parking charges</li> <li>Automatic med patients upon diagr</li> </ul>
	Social Protection	Energy hardshi Benefits Package, Fu and electricity credi remainder of their li
	Health	<ul> <li>Drugs Payment per month, as per th</li> <li>Prescription ch medical card holder</li> </ul>
	Social Protection	Domiciliary Car Allowance eligibility

ment support for the Irish Cancer Society Night that more people can spend their final nights in r own homes.

ccessibility of palliative care services across all ensuring that no community is excluded from tal service.

arges: Provide funding to hospitals to abolish s for cancer patients.

dical cards: Provide medical cards to all cancer nosis, until their treatment is finished.

**ip:** Automatic entitlement to the Household Fuel Allowance, Additional Needs Payment, lits for cancer patients in palliative care for the life.

**t Scheme:** Reduce the threshold to at least €72 he 2017 Sláintecare Report.

harges: Abolish prescription charges for all rs.

re Allowance: Expand the Domiciliary Care criteria from 16 to 18 years of age.



Averil Power CEO, Irish Cancer Society

# Foreword

One in two of us will be diagnosed with cancer in our lifetimes. When we are, we deserve the best possible chance of surviving the disease. Sadly, people with cancer in Ireland are not being given that chance at present.

In the latest year for which comparable data is available, Ireland's cancer mortality rate was the third highest in Western Europe. Our mortality rate is the 13th highest of 27 EU states.

Ireland is a leader in many areas. We should not be a laggard in cancer care. People with cancer, their loved ones, and the staff who care for them deserve better.

The National Cancer Strategy, published in 2017, sets out a roadmap to worldclass cancer care in Ireland. However, it has only received proper funding in two of the last seven budgets. As a result, people with cancer are being left waiting. Waiting for time-critical tests. Waiting for essential treatment. Waiting for the support they need to rebuild their lives after cancer.

Budget 2025 must priortise the National Cancer Strategy, with ringfenced new recurrent development funding for the National Cancer Control Programme of at least €20 million. It should also include a commitment to multiannual funding for the Strategy going forward, to enable effective planning for improvements in the coming years.

Funding must also be provided for the other recommendations in this submission which require action from several government departments. These include measures to address the cost of cancer, such as the abolition of hospital parking fees, an automatic entitlement to the medical card, enhanced access to the domicillary care allowance, and a statutory 'right to be forgotten' for cancer survivors.

With the number of people getting cancer in Ireland expected to double by 2040, cancer is a societal issue that is only set to grow. Dedicated funding for cancer care is not a short-term cost.

It's a strategic investment in public health that will save the State money in the longterm. Diagnostic delays, for example, have exponential costs. A melanoma diagnosed at Stage 1A is 25 times less costly to manage than one diagnosed at Stage 4.

Investing in cancer prevention, care and survivorship is not just the right thing to do. It is fiscally prudent and should be a priority for Government as a whole.

veil Tower

CEO, Irish Cancer Society

# Message from the Chair of the National Cancer Strategy and Presidents of ISMO and ISRO

As the Chair of the National Cancer Strategy and Presidents of the two main representative groups for cancer doctors in Ireland, we are deeply concerned about the impact lack of investment in the National Cancer Strategy is having on people with cancer in Ireland.

The strategy has the potential to significantly improve Ireland's cancer outcomes through investment in cancer prevention, detection, treatment and survivorship supports.

However, as a result of inadequate funding, its ambition has not been fully delivered.

Screening has not been expanded as planned.

Target waiting times for cancer tests are not being met.

Cancer surgeries are frequently delayed due to shortages in staffing, beds and theatre space.

Investment in infrastructure has been lacking, despite increasing infection control issues and rising cancer incidence.

Radiotherapy services are operating significantly below capacity.

We are falling far short of the modest target of 6% of cancer patients participating in clinical trials.

Access to new medicines is much slower. here than in other European countries.

Our healthcare staff do everything they can to minimise the impact of these deficits on patients. However, it is simply not possible to provide optimal care or patient outcomes in these conditions.

We urge Government to commit to providing at least €20 million in ringfenced new recurrent development funding in 2025, and each year thereafter, to ensure full delivery of the strategy. We also support the other recommendations in this submission, which would help prevent people from getting cancer and improve outcomes for those who do.



Prof John Kennedy Chair of the National Cancer Strategy



**Prof Michaela Higgins** President, Irish Society of Medical Oncology



**Prof John Armstrong** President, Irish Society of Radiation Oncology

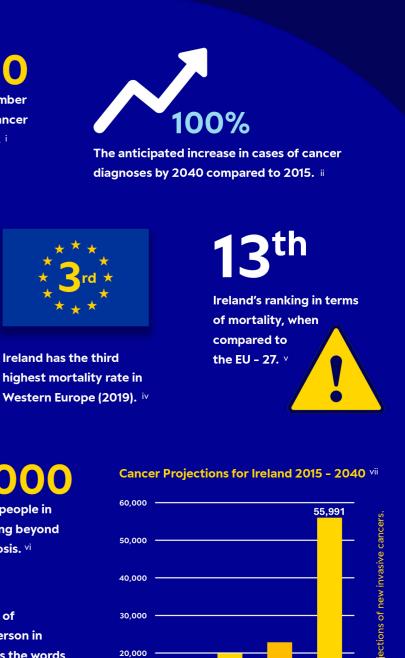
# **Cancer by Numbers**

42,000 The approximate number of people who get cancer in Ireland every year. 🗉





The number of cancer deaths in Ireland in 2023.



2010

2000

2020

2040



215,000 The number of people in

Ireland now living beyond a cancer diagnosis. vi



The number of minutes a person in Ireland hears the words "You've got cancer".

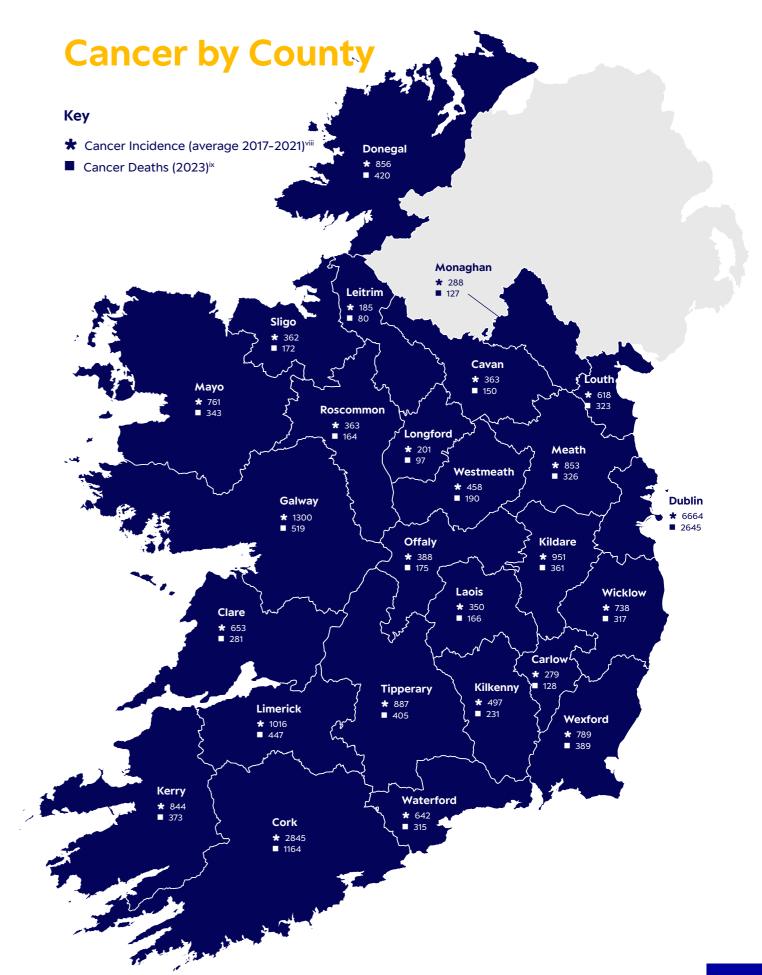
10.000

### 12



# **National Cancer Strategy**





# Funding: Required vs. Delivered

# **Priority**

# Sustained, predictable, multi-year funding for the National Cancer Strategy.

The current National Cancer Strategy (2017-2026)<sup>x</sup> sets out a framework to build on previous advancements and create conditions to improve the quality of life for people affected by cancer.

It includes, but is not limited to, activities focusing on:

**Prevention,** e.g. smoking rates.

Catching cancer early, e.g. cancer screening services, access to a GP, access to diagnostics, information on detection, etc.

**Treatment,** e.g. accessibility and availability of treatment options.

Reducing inequalities in outcomes.

According to the HSE, the NCCP's annual budget for implementation of the National Cancer Strategy should have increased incrementally over the past 8 years to be €110m higher in 2024 than in 2016. Instead, it is only €65m higher. The cumulative increased investment over the last 8 years should have been €491m but has only been €313m. Therefore, the Strategy has been underfunded by almost €180m to date.

2024 saw no new development funding awarded whatsoever. Of the 23 KPIs set out in the Strategy, only one was deemed fully met in 2022 – the target uptake rate for BreastCheck.<sup>xii</sup> There has been no public update on progress in 2023. As a result, it is not possible to assess how the recommendations have progressed.





# Risk

Given the Government's failure to provide any new recurrent development funding for the National Cancer Strategy in 2023 or 2024, the impact of COVID-19 on Ireland's cancer services and the recruitment embargo, Ireland's cancer outcomes are at risk of stagnating or going backwards.

# Action

Sustained, predictable, multi-year development funding for the National Cancer Strategy is vital to ensure its full implementation.



# Budget 2025 Asks



- An assessment of the funding needs of cancer services, above this €20 million minimum additional annual funding level, to ensure full implementation of the National Cancer Strategy by 2026.
- End the recruitment embargo by allocating the necessary funding to fill crucial healthcare sector posts based on up-to-date workforce plans.

# **Prevention** | At a Glance

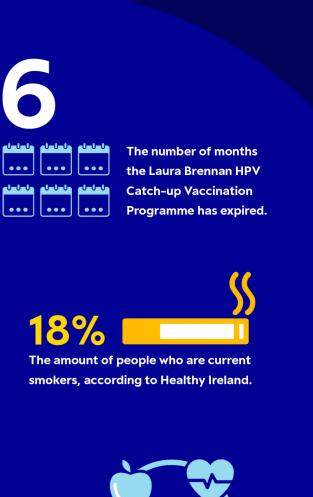
# 90%

The vaccination target for all girls specifically by 2030, to reach the WHO target of cervical cancer elimination by 2040.





7 in 10 The number of people in Ireland who think sunscreen is too expensive.





The rate of cancers preventable through various lifestyle changes.

# **Prevention**

An estimated 40% of cancers are preventable through lifestyle changes such as not smoking, reducing alcohol intake, losing weight, exercising, and reducing exposure to the sun and air pollution.<sup>xiii</sup>

# e-Cigarettes

# Risk

There is an alarming rise in use of e-cigarettes by children and young people.

The World Health Organisation (WHO) reports on the highly addictive nature of nicotine found in most e-cigarettes and its negative effect on brain development.<sup>xiv</sup>

Recent research from the Royal College of Surgeons in Ireland indicates that future cancers are likely to emerge due to longterm exposure to vapes.<sup>xv</sup>

**16 - 20**%

Findings from the 2023 Healthy Ireland survey found that 20% of females and 16% of males aged 15-24 use e-cigarettes either daily or occasionally.<sup>xvii</sup>

# Action

Implement stronger restrictions and a domestic tax on nicotine inhaling products.

The WHO recently called on governments to treat e-cigarettes and vape products similarly to tobacco products. This includes increasing taxation on such products. Ireland needs to follow other EU member states and introduce a domestic tax on nicotine inhaling products.<sup>xviii</sup>

# Budget 2025 Ask

Tax e-cigarettes and introduce restrictions on e-cigarette flavours, packaging, point of sale display, use in public areas and social media marketing.

# **Reducing smoking rates**

## Risk

Tobacco Free Ireland, the national strategy for a tobacco-free Ireland by 2025, seeks to reduce the smoking rate to less than 5%.<sup>xix</sup>

However, the 2023 Healthy Ireland survey reports 18% of the population to be current smokers (14% daily and 4% occasional).<sup>xx</sup>

The impact of smoking-related diseases causes a considerable burden on the healthcare system with an estimated annual cost to the health service of €460 million. In comparison, costs for providing support to stop smoking are relatively small.<sup>xxi</sup>

Evidence shows that taxation and pricing are the most effective measures to reduce tobacco consumption and harms.<sup>xxii</sup> To complement these measures, sufficient QUIT supports and public awareness initiatives are crucial.

# Action

Ensure adequate funding for the expansion of QUIT support services. This should include targeted QUIT initiatives, along with hospital cessation services to support cancer patients, as well as services to help users of nicotine inhaling products to quit.



# Budget 2025 Ask

Ø

Expand investment in QUIT support services and increase excise duty on cigarettes and roll-your-own tobacco products in line with the tobacco tax escalator and inflation.

# **Genetic Services**

# Risk

# Ireland's cancer genetic services are significantly underdeveloped.

Around 5-10% of cancers are clearly linked to an inherited genetic change.<sup>xxiii</sup> Improvements in our understanding of hereditary cancers have the potential to prevent cancer and strengthen patient outcomes through more precise diagnosis and personalised treatment.

However, patients with potential inherited risk are waiting too long to access public genetic clinics. Such delays cause considerable stress and anxiety to those affected. Routine referrals on the public system can have a waiting time on average of 18+ months.<sup>xxiv</sup> While some patients can pay to attend private services for testing, others can't afford to do so.

In addition to testing, there are also delays in accessing preventative procedures, surveillance measures and reconstruction surgery (if relevant).<sup>xxv</sup> Some of the reasons behind this includes insufficient staffing



The number of genetic counsellors in the Cancer Genetics Department in St James's Hospital is 80% below international comparators. <sup>xxvi</sup> for genetic testing services and a lack of ringfenced downstream capacity, including protected surgery time for preventative surgeries. Cancer genetics services need resourcing in line with increased demand. Workforce challenges highlighted by staff in cancer genetics departments include the absence of training programmes for genetic counsellors in Ireland and the issues caused by a lack of a HSE grade code.<sup>xxvii</sup>

# Action

Investment across cancer genetic services to ensure timely access to genetic counselling, testing, preventative procedures and surveillance measures.

# Budget 2025 Asks

Fully resource the implementation of the recommendations of the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland and the National Genetics and Genomics Workforce Plan.

Fund dedicated time for surveillance and treatment services, including protected theatre time and ring-fenced diagnostic imaging.

# **HPV Vaccination Programme**



Risk

Efforts to eliminate cervical cancer by 2040 must include vaccination for young adults who were not vaccinated as teenagers.

In the 2022/23 academic year, 80% of females and 76.6% of males received the HPV vaccination as first year students in second level schools. Such uptake rates vary across CHOs, for example 66.8% in CHO 9 compared to 84.9% in CHO 6.xxviii

The Laura Brennan HPV Catch-Up Vaccination Programme was launched in December 2022 offering free HPV vaccines to students in second-level education who were previously eligible but had not received it.<sup>xxix</sup> In 2023, HPV vaccinations were offered to females aged 24 or younger and males aged 21 or younger.

This Programme ended on the 31st December 2023. The Irish Cancer Society is concerned that the Government have not continued to fund the Laura Brennan HPV Catch-Up Vaccination Programme. It is an important initiative, which will bring benefits in the long term and promote the reduction of HPV-related cancers.

As per targets set by the World Health Organisation, Ireland needs a 90% vaccination rate for all girls by 2030.<sup>xxx</sup>



# Action

An extension of the Laura Brennan HPV Catch-Up Vaccination Programme to all those under 25 who missed out on the HPV vaccination at school.

# Budget 2025 Asks

Fund the extension and
expansion of the Laura Brennan
HPV Catch-Up Vaccination
Programme to all those under
25 who missed out on the HPV
vaccination at school.

Dedicated funding for raising awareness among parents and young people of the benefits of HPV vaccination, focusing on areas with lower uptake.

# **Skin Cancer**

# Risk

Sunscreen products are out of reach for many due to cost.

Skin cancer is the most common cancer in Ireland with over 13,000 cases diagnosed each year.<sup>xxxi</sup>

The National Cancer Registry of Ireland expects the number of skin cancer cases to significantly increase by 2040.<sup>xxxii</sup>

Skin cancer is largely preventable by protecting skin from UV radiation. The sun emits such UV radiation, along with artificial sources, including sunbeds.

Research commissioned by the Irish Cancer Society reports that seven in 10 people say suncream is too expensive, and one in 10 say they do not wear it because they can't afford it.<sup>xxxiii</sup>

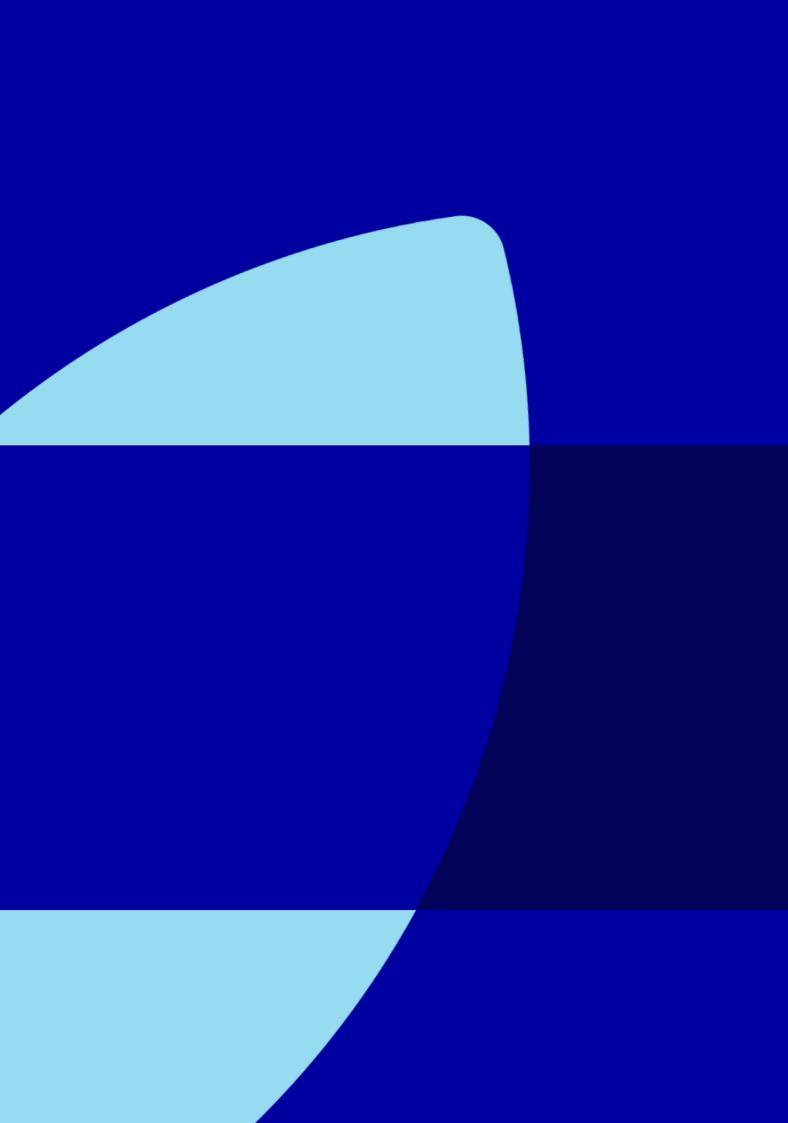
No person should be exposed to the harsh effects of sun exposure simply because they cannot afford the price of sunscreen.

# Budget 2025 Ask

Reduce taxation on sunscreen products and make it freely available in public spaces.



Introduce practical measures to improve access to sunscreen products.



# **Early Detection**

The earlier cancer is caught the better. Currently, many patients are not getting timely access to the tests they need to detect cancer, impacting access to vital treatments. Treatment delayed is treatment denied.

# **Diagnostic Tests**

# Risk

Too many patients are not accessing their diagnostic tests in the recommended timeframe.

Without investment in early detection patients will pay the price for delayed diagnosis with poorer survival outcomes and quality of life. Early diagnosis translates to greater cost savings to the State.

The cancer care pathway in Ireland is beset by delays in access for a variety of reasons. Some of these diagnostic services are protected pathways dedicated to diagnosing cancer, meaning less competition for resources with other services. Others, however, are competing with resources across different disease areas with great demand, including endoscopy and diagnostic imaging.

Long waiting times invariably translate to inequality in the healthcare service. Patients without private health insurance often cannot afford to access diagnostic tests privately and, therefore, wait for longer.xxxv

€122,985

Melanoma is more than 25 times more expensive to treat at Stage 4 (€122,985) than at Stage 1A (€4,269).xxxiv



The number of days a patient should wait for a diagnostic test, according to Sláintecare. xxxvi

276.004 Total number of people waiting for a diagnostic imaging test by March 2024. XXXVIII





# 164,500

Total number of people waiting for a diagnostic imaging test for over 3 months by March 2024. xxxvii



# 1.133

Number of patients waiting more than 4 weeks for an urgent colonoscopy. xxxix

# Action

Invest in workforce capacity and hospital infrastructure to ensure timely diagnostics for everyone within the recommended timeframes.

According to the National Cancer Strategy, Ireland should increase the proportion of cancers diagnosed early by at least 10% and also reduce the proportion of cancers diagnosed in Emergency Departments.

The Sláintecare policy states that a person should wait no more than 10 days for a diagnostic test.<sup>xii</sup> This target should not be accepted as out of reach. The State must be sure to make this a lived reality for all.

# Budget 2025 Asks

Train, recruit and retain sufficient staff to meet diagnostic targets, including in endoscopy, colonoscopy, colposcopy and radiology.

 Invest in hospital infrastructure to protect diagnostic pathways (e.g. procedure rooms, day ward space, up-to-date radiology and other testing equipment, etc.) and ensure those scheduled for diagnostic tests are seen within the recommended timeframe.



# **Cancer Screening**

# Risk

Cancer screening programmes will not reach all eligible people, particularly members of under-represented groups, or have the ability to expand to new groups.

Cancer screening saves lives by identifying cancer, and in some cases pre-cancerous changes, in people who have not noticed any symptoms. Screening works. More cancers are caught at Stage 1 or 2 via screening in the eligible age groups compared to the number detected outside of screening.

# Stage at diagnosis for screened vs. non-screened groups xiii

Screened Detected Stage 1/2	
Bowel cancer	6 in 10
Breast cancer	8 in 10
Cervical cancer	9 in 10
Not screened Detected Stage 1/2	
Bowel cancer	4 in 10
Breast cancer 5 in 10	
Cervical cancer 7 in 10	

A range of socio-demographic inequalities can create barriers across the cancer pathway, including in access to screening.

For instance, men participate in bowel cancer screening less than women; Travellers tend to participate less in both bowel and breast cancer screening; people with lower educational attainment participate less across cervical and breast cancer screening programmes.<sup>xliii</sup>



People with disabilities have also highlighted challenges in accessing screening programmes, including the costs and logistics involved with travelling longer distances to participate in screening, communications/information which was not suitable to their needs, and a lack of accommodations/accessibility at screening sites.<sup>xliv</sup>

# Lung Cancer Screening

Each year, roughly 2,600 people are diagnosed with lung cancer in Ireland.<sup>xtvii</sup> Lung cancer is among the most common cancers and is the leading cause of cancer death in Ireland.<sup>xtvii</sup> Unfortunately, too many lung cancers are diagnosed at Stages 3 and 4; with 1 in 4 diagnosed via emergency presentation.<sup>xtix</sup> We must make every effort to turn the tide.

# Action

It is imperative to boost funding in screening programmes to expand the services. Such funding should be allocated to ensure greater workforce capacity for implementing screening and downstream services (surveillance, diagnostics, treatment, etc.). Resources should also be targeted to promote and raise awareness of screening and its benefits amongst underserved groups.

BowelScreen should start from age 50, and the Irish Cancer Society has submitted a proposal to the National Screening Advisory Council to ensure more people get access. The National Cancer Strategy uptake target of 45% must be extended to 60%, in line with strategic commitments.<sup>xlv</sup> Similarly, BreastCheck should expand to reach women from age 45 in line with European Council Recommendations.<sup>xlvi</sup>

### Lung Cancer Screening

Prevention efforts are vital to support people to quit smoking and reduce their risk of cancer. Equally important is making use of scientific developments to catch cancer amongst current and former smokers at the earliest possible stage.

Lung cancer screening has been studied across Europe and the United States, resulting in earlier detection and a reduction in lung cancer deaths.<sup>1</sup>

The European Council made a recommendation to Governments to assess the use of lung cancer screening through implementation studies, to strengthen efforts towards early detection.<sup>11</sup>

We urge the Government to invest in lung cancer screening to save lives.



# **Budget 2025 Asks**

Allocate funding to the National Screening Service to:

Expand the age range for
 BreastCheck to 45 - 74 years of age.

► Expand the age range for BowelScreen to 50 – 74 (€2m).

Ensure BowelScreen reaches the 60% uptake target.

Plan for further expansion of our existing screening programmes, and piloting of new programmes in lung, prostate and gastric cancer, as recommended by the European Council.

Invest in communications and awareness raising activities to support the equitable uptake of screening across all underserved communities. Ring-fence funding to enhance the accessibility of screening programmes to underserved groups, including people with disabilities, in particular to address communications / information and accommodations / accessibility needs.

Fund the implementation of a pilot/implementation study on lung cancer screening (LCS), using community-based, low-dose computed tomography (LDCT). The implementation study should also include smoking cessation support.

# **CAYA** (Children, Adolescents & Young Adults)

# **Cancer in Young People**

# Risk

In Ireland, approximately 337 young people aged 0-24 years are diagnosed with cancer each year.<sup>III</sup>

Childhood cancer remains the number one cause of death in young people<sup>liii</sup> and brings a heavy burden of intensive treatment and profound psychosocial impacts on the entire family.<sup>liv</sup>

Following a child's cancer diagnosis, a family will lose over €1,200 in income each month. At the same time, new costs emerge such as medication, mental health supports and the cost of attending appointments, educational supports, etc.<sup>IV</sup>

Earlier detection of CAYA cancers can improve both survival and quality of life. However, CAYA cancers look and act differently to cancers in adults. Therefore, it is essential that GPs are equipped to recognise signs and symptoms of CAYA cancers and have clear guidelines on when to refer child and young people for cancer tests. In the absence of this, there is a risk of delayed diagnoses.

# Action

It is important that the Government supports families caring for a child with cancer, alleviating the costs so families are not subject to financial pressure.

The National Cancer Control Programme (NCCP) must have the resources to develop GP referral guidelines, and build-out GP education via an e-learning programme, as well as better public awareness of CAYA cancer symptoms.

# Budget 2025 Asks

Dedicated funding to the NCCP to develop CAYA referral guidelines.

Co-fund a GP education and awareness programme on the early detection of CAYA cancers for GPs, with the Irish Cancer Society and ICGP.



The provision of a specific CAYA allowance.

The provision of a travel abroad scheme to cover non-medical expenses of travelling abroad for medical care.



The provision of an exceptional needs payment/additional needs payment without means testing for CAYA cancer applicants.

# **Treatment** | At a Glance



Almost 1 in 4 Breast cancer patients did not get their surgery on time in 2022.  $^{ix}$ 

# **Timely access to treatment**

Cancer patients in Ireland should have access to the right care, in the right place, at the right time.<sup>Ixi</sup>

# **Delays in Treatment**

# Risk

# Delays in accessing treatment can put outcomes at risk.

A significant proportion of cancer patients are waiting longer than the targets set out in the National Cancer Strategy to get their treatment. Such delays are evident in radiation therapy and surgery, in particular.

Some radiotherapy machines are lying idle due to a 30% shortfall in the number of radiation therapists, while others are past their useful life and often out of service.<sup>lxii</sup>

Delays in accessing cancer treatments causes huge anxiety for patients and can also have a negative impact on their cancer outcomes and quality of life. Insufficient staffing and infrastructure mean that recommended timeframes to access treatment are not being met.

# Action

Ensure adequate capacity to meet the demand for cancer treatment, including investment in staffing, infrastructure and facilities to ensure survival gains into the future.



# Budget 2025 Asks

# Invest in workforce capacity to:

Ensure safe and sufficient staffing levels in cancer care;

Address the challenges to recruitment and retention of staff in cancer services, through adequate training places across all disciplines, improved mechanisms for recruiting from overseas and improvements in working conditions. Invest in infrastructure (i.e. dedicated physical space and equipment to enable protected pathways for treatment, including day ward space, inpatient beds and theatres) to meet the target treatment times set out in the National Cancer Strategy and annual increases in the number of people getting cancer.



# **New Medicines**

# Risk

# Cancer patients are missing out on timely access to new effective medicines.

Access to new medicines is significantly slower in Ireland than in other EU countries. Inequality between public and private patients is also increasing, as some cancer drugs are available to those with private health insurance but not public patients.<sup>[xiii</sup>

The human cost of these delays on cancer patients can be considerable – particularly when there is no alternative treatment pathway.

# LESS THAN HALF

Less than half (45%) of drugs undergoing the reimbursement and pricing decision-making process in Ireland are completed within a year; only 3 in 5 (62%) are completed within 2 years.<sup>bdiv</sup>

# Action

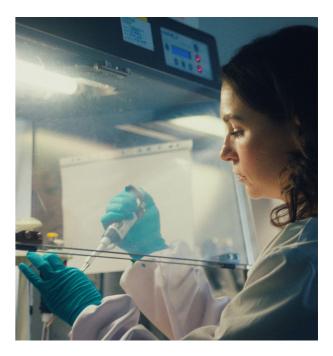
Invest to ensure Irish cancer patients are not waiting longer than the EU average for access to new medicines.

# Budget 2025 Asks

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Increase the budget for new medicines:

Ringfence funds to implement the improvements in the approval process recommended in the Mazars review<sup>IXV</sup>, including increased staffing for the NCCP and NCPE, an application tracker, greater transparency and indicative timelines for the approval of medicines.



# **Clinical Trials**

# Risk

Low participation in clinical trials means Irish cancer patients are missing out on new and innovative treatments.

Ireland's cancer research environment lags behind that of other countries and the accruals to cancer clinical trials fall far short of the already modest 6% target.

At the time the National Cancer Strategy was developed, 3% of cancer patients were participating in trials and the target was to increase this to 6%.<sup>kvi</sup> Instead, trial participation has decreased significantly in recent years. There has been a 54% decline in clinical trial accrual (90% reduction in accrual to radiotherapy trials) compared to 2019. Lack of staffing due to the pandemic was one of the reasons cited for the decline, demonstrating the need for workforce capacity/availability for clinical trials. Yet, 3 in 5 people in Ireland have stated that they would be willing to participate in a clinical trial.<sup>kvii</sup>

# Action

Invest in clinical trials to improve cancer outcomes. Investment in cancer research is essential to find new and better ways of preventing, detecting and treating cancer. Cancer patients have better outcomes in research active hospitals.<sup>Izviii</sup>

In addition to increased funding, there is an urgent need for reform of the regulatory process for clinical trials in Ireland.

# Budget 2025 Asks

 Fund protected time for clinicians and adequate research and support staff.

Improve data protection and other regulatory processes, to improve participation in cancer research and trials.

Ring-fence regular, flexible, and sustained investment in clinical trials research and infrastructure.

Ensure that HSE income from commercially funded studies can be directly invested into clinical trial operations at the discretion of local clinical trials governance structures, including funding clinical trials staff.

# **Digital Health**

### Risk

A 2022 OECD economic survey highlights Ireland's weakness in the area of digital health.<sup>Ixix</sup>

Our current system does not lend itself to the collection and provision of timely, accurate and robust data, which are essential for informing decision-making and best utilising resources across departments. The health service is being held back by inefficient, often paper-based interactions.

A Royal College of Physicians of Ireland report on the impact of COVID on cancer care, highlighted the importance of integrated digital health structures, such as electronic health records, for planning across the health care system.<sup>bx</sup>

# Action

Patients should have access to their own healthcare information. eHealth infrastructures will contribute towards an enabling environment for patients accessing the healthcare system and, for instance, participating in clinical trials.

There are strong e-health commitments in the Programme for Government, Sláintecare plans and the eHealth Strategy for Ireland.<sup>bxi</sup>



# **Budget 2025 Asks**

Provide sufficient funding to develop and implement the national rollout of electronic health records across the health system, including sufficient IT staff in all hospitals and the HSE.

# Life with/beyond cancer

# Risk

Approximately 215,000 people in Ireland are living beyond a cancer diagnosis, <sup>laxii</sup> many of whom are living with unmet need.<sup>lxxiii</sup>

### Lymphoedema services

Regional access to lymphoedema services is inconsistent with funding varying across sites.<sup>bxiv</sup> Patients have reached out to our Support Line flagging issues with local access to services and the significant wait times to access hospital services on the public system.

International studies show the €13.6 million it costs to treat patients with cellulitis related to lymphoedema could be reduced by over 87% if comprehensive lymphoedema services are introduced.<sup>kxxv</sup>

# Hairpieces and post-mastectomy products

Currently allowances for cancer patients towards hairpieces and post-mastectomy products are means tested and vary depending on where you live, creating geographic inequity. When a person is diagnosed with cancer, they need affordable access to vital specialised supports such as postmastectomy products (PMP), including prostheses, specialist bras and hairpieces. Currently grant levels for these products vary between different CHOs across the country.

# Other survivorship supports

Some people may need support with the emotional and social impact of cancer and would benefit from access to psychooncology services. Others, need access to a range of other survivorship services that can be difficult to access through the public health service, such as dieticians and speech and language therapists. Treatment side effects and late effects can also mean many people are unable to return to full-time work and require flexibility and ongoing financial support.<sup>boxvi</sup>

Furthermore, cancer survivors often struggle to access mortgage protection and other insurance products for many years after their treatment ends. This has a huge impact on their quality of life and ability to put their cancer experience behind them.

# Action

Invest in supports to ensure that people live well beyond cancer. Such supports include dietetics, lymphoedema, social protection supports, psycho-oncology supports, and the list goes on.

Broader social protection supports will mean that people returning to work after a diagnosis can have flexibility to attend medical appointments and return to work in a way which is appropriate to them.

We also need to follow several EU countries that have introduced 'right to be forgotten' laws providing that, after a specified

timeframe, cancer survivors do not have to declare their diagnosis when applying for financial products.

In relation to CAYA, a survivorship service for CAYA cancer survivors, including lifelong clinical and psychosocial support is needed; access to functional assessments, including education plans and guidance counselling for CAYA cancer survivors should be funded and tailored supports for starting/returning to work as a CAYA cancer survivor are required.

### **Budget 2025 Asks**

### Department of Finance

Legislate for a 'right to be forgotten' for cancer survivors, so they do not have to disclose their cancer diagnosis after 5 years, with independent oversight and penalties for companies who breach this right.

### Department of Social Protection

Broaden the Partial Capacity Benefit criteria to increase security for those with a previous cancer diagnosis seeking to return to work.

Introduce a new statutory payment for employees and self-employed people with chronic illness to attend medical appointments rather than being forced to take unpaid leave.

### Department of Health

Fund the Lymphoedema and Lipoedema model of care.

Review and fund the appropriate number of professionals to meet the needs of cancer patients and survivors, including dieticians, physiotherapists, occupational therapists, speech, and language therapists and medical social

assessment and treatment for longfatigue, depression, incontinence, and sexual dysfunction.

Model of Care for Psycho-Oncology

allowances for hairpieces and postmastectomy products (including

survivorship programmes, to allow cancer patients to transition from cancer treatment back to "normal" re-enter cancer services if required.



# **Leave our Leave**

# Risk

# Approximately 60 women per year go through a cancer diagnosis whilst pregnant or postpartum.

These women are unable to defer their maternity leave when ill, so all or almost all, of their maternity leave, is spent receiving life-saving treatment denying them time to spend with their newborn baby. Men can defer their paternity leave if they are sick, but women are denied this right.

# Action

The Government has indicated that it will amend legislation to allow women battling cancer to defer their maternity leave until they finish their treatment. But as of June 2024, no draft legislation or heads of bill has been published.

# Budget 2025 Ask

Change the Maternity Protection (Amendment) Act 2004 to allow women with cancer diagnoses to defer their maternity leave.



LEAVE OUR LEAVE!

#LeaveOurLeave

# LEAVE OUR LEAVE!

a garage and a second

#LeaveOurLeave

# Irish 😽 Cancer Society Night Nurse

# **End of Life**

# **Palliative care services**

# Risk

Every year over 9,000 Irish people die from cancer.<sup>bxvii</sup> Three-quarters of the population would prefer to die at home;<sup>bxviii</sup> yet only 1 in 4 people with cancer die at home, consistent with the national average across all disease groups.<sup>bxxix</sup>

Conversations around death and dying are complex and nuanced, and therefore deserve thoughtful consideration.

Dying at home is not always possible for a range of reasons. The Irish Cancer Society believes that the equitable, local (or at home) provision of quality palliative care, free at the point of access, should be available for all who need it.

Such a vital service must include access to quality psycho-oncological and practical support for people at the end of their life and their loved ones.

# Action

Ensure equitable, local (or at home) provision of quality palliative care, free at the point of access is available to all who need it.<sup>Ixxx</sup>

A national plan for the provision of equitable bereavement support services for families who have lost a young person to cancer should be completed.

# Budget 2025 Asks

- Increase Government support for the Irish Cancer Society
   Night Nursing service so that more people can spend their final nights in the comfort of their own homes.
- Ensure greater accessibility of palliative care services across all counties in Ireland so that no community is excluded from accessing such a vital service.



# **Cost of Cancer** | At a Glance



€64 - the average monthly cost of hospital car parking to cancer patients. <sup>Ixxxi</sup>



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The number of palliative care nurses who reported patients were struggling to pay energy bills. boxiii

€4,776 The estimated average cost to families over the course of a year in expenses associated with



The average drop in household income following a cancer diagnosis. <sup>boxii</sup>



The number of pages a cancer patient undergoing chemotherapy must submit as part of a medical card application.





People in the general public felt they must prioritise other costs over their healthcare, most notably food shopping and utility bills. <sup>boxxv</sup>



# **Financial Costs of Cancer**

From the point of diagnosis, the financial cost of cancer quickly takes its toll when patients are struggling to deal with huge additional expenses while also experiencing a significant drop in income. Such costs have only worsened due to the rising cost of living.

Findings from the Real Cost of Cancer 2019<sup>Ixxxvi</sup> highlights the significant monthly expenses faced by cancer patients and their families. The average cost to someone dealing with cancer is €756 a month. This can rise in some cases to over €1,000.

# Findings: The Real Cost of Cancer 2019

Monthly Expenses	€ Cost
Getting to hospital appointments (petrol, car parking, sustenance)	€291
Physiotherapy or other specialist medical care	€113
Prescription medication	€111
GP visits	€81
Dietary supplements	€59
Over the counter medication	€53
Specialist dressings	€40
One-off Expenses	€ Cost
Wigs, hair pieces, head coverings	€500
Specialist dental work and dental care	€622
New clothes	€276

# 1. Hospital car parking charges

# Challenge

Hospital car parking charges are causing additional stress and anxiety to cancer patients and their loved ones at a time when they are already vulnerable.

The Government has promised to reform hospital car parking charges since 2018. The current Programme for Government commits to "introduce a cap on the maximum daily charge for car parking for patients and visitors at all public hospitals, where possible. Introduce flexible passes in all public hospitals for patients and their families."Ixxxvii

In the years since, thousands of patients and their families have spent significant

> "It has put a huge strain on us financially, between extra diesel, food, heating bills plus hospital parking [...]"

> > - Respondent to Cost of Living Survey 2022

sums of money just to get to the hospital door to access lifesaving treatment.

As featured on RTÉ's "The Complaints Bureau" in April 2024, Tara Doonan, a cancer survivor was forced to spend €1000+ on car parking charges while receiving treatment in the Mater Hospital.<sup>Ixxxviii</sup>

# Action

There are huge disparities in charges across the different hospitals. Some have free parking available, some have concessions for cancer patients, while other cancer patients pay €3.20 or more per hour to park.<sup>Ixxxix</sup> No cancer patient, regardless of where they are getting treatment, should have to pay parking charges for their hospital appointments.

# Budget 2025 Ask

Provide funding to hospitals to abolish car parking charges for cancer patients.

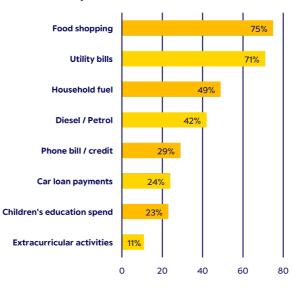
County	Car Parking Costs + Concessions (2023)
Carlow	-
Cavan	Concessions: Not universal; limited number (for long-term patients) at Cavan General Hospital
Clare	-
Cork	<b>Concessions:</b> between 50%-100% South Infirmary Victoria University Hospital; €5 weekly for patients getting radiation treatment & €5 daily for patients getting chemotherapy at Cork University Hospital; €5 daily charge for patient attending radiation or oncology at The Bon Secours. <b>No car park:</b> Mercy University Hospital.
Donegal	Free for cancer patients: Letterkenny University Hospital
Dublin	Free for cancer patients: St. Luke's Hospital, Rathgar. Concessions: Half price at St Vincent's University; €5 a day at St James's Hospital; available only after specified time period at Children's Health, Ireland (Crumlin). No free parking or concessions: Beaumont Hospital; Mater Hospital; Tallaght University Hospital; Connolly Hospital.
Galway	Free for cancer patients: Merlin Park University Hospital; limited availability of free parking at Portiuncula University Hospital. No free parking or concessions: Galway University Hospital.
Kerry	Free for cancer patients: University Hospital Kerry
Kildare	Free for cancer patients: Naas General Hospital
Kilkenny	Free for cancer patients: St Luke's General Hospital
Laois	No free parking or concessions: Midland Regional Hospital, Portlaoise
Leitrim	-
Limerick	Free for cancer patients: University Hospital Limerick
Longford	-
Louth	No free parking or concessions: Our Lady of Lourdes Hospital Drogheda
Мауо	Free for cancer patients: Mayo University Hospital
Meath	-
Monaghan	-
Offaly	Concessions: €1 per day for cancer patients, Midland Regional Hospital Tullamore
Roscommon	-
Sligo	Concessions: Sligo University Hospital (€7.50 weekly rate)
Tipperary	Free for cancer patients: South Tipperary General
Waterford	No free parking or concessions: University Hospital Waterford
Westmeath	No free parking or concessions: Midlands Regional Hospital Mullingar
Wexford	No information

# 2. Automatic medical cards

# Challenge

Cancer patients face a heavy burden of medical expenses, and an equally burdensome application process.

An Irish Cancer Society/Core Research survey from November 2022 showed that some people felt they were in a worse financial position compared to the year before. Unfortunately, it is possible that such financial anxiety has an adverse impact on people's health. Of this group, 1 in 5 people who had a cancer diagnosis did not attend a GP/hospital appointment in the past 6 months even if needed. Two in 5 carers avoided attending a GP/hospital over the same time period.<sup>xc</sup>



### Costs prioritised over healthcare xci

# Action

Provide every cancer patient with an automatic medical card following their diagnosis, until treatment is finished. Having an automatic entitlement to a medical card following a cancer diagnosis would remove the burdensome application process and alleviate some of the expenses associated with cancer, including visiting a GP and getting prescribed medicines.

Additionally, when applying for a medical card, there are over 18 pages to complete. When undergoing treatment or during a cancer journey, filling out long tedious forms and identifying specific information sources puts yet another burden at a time when a cancer patient is already vulnerable. Automatic entitlement would remove this significant administrative burden.

# Budget 2025 Ask

Provide medical cards to all cancer patients upon diagnosis, until their treatment is finished.

# 3. Energy hardship amongst cancer patients in palliative care

# Challenge

People receiving palliative care and their carers are more vulnerable to the cold.

Many are struggling to heat their homes due to high energy costs. Palliative home care nurses identified housing issues such as damp, mould, condensation, and draughts.xcii

A survey of palliative home care nurses, commissioned by the Irish Cancer Society, showed that:xciii

- Almost 1 in 3 nurses reported that a person they cared for, or their family, initiated a conversation about energy hardship.
- 3 in 5 nurses reported households' difficulty in paying bills (e.g. utilities, mortgage, rent).
- 2 in 3 nurses reported households' difficulty affording home heating.

# Action

Provide investment to help people at end-of-life receive broader State supports to help them feel more comfortable and supported at home.

# Budget 2025 Ask

Automatic entitlement to the Household Benefits Package, Fuel Allowance and Additional Needs Payment, and electricity credits for cancer patients in palliative care for the remainder of their life.

"The saddest observation [...] is a family member who questioned whether they did the right thing in bringing a loved one home because the family member could not adequately support the heating requirements of that home."xciv

> – Anna Drynan-Gale Irish Cancer Society Night Nurse



Energy Hardship for People with Palliative Care Needs at Home: Understanding Issues and Promoting Actions Executive Summary Irish Cancer Society



# 4. Drugs Payment Scheme

# Challenge

Cancer patients face the disproportionate financial burden of prescribed medicines or medical and surgical appliances.

As it stands, the Drugs Payment Scheme (DPS) means that the costs of approved prescribed drugs and medicines, along with relevant medical equipment does not exceed €80 per month.

# Action

Lowering the scheme threshold to reduce the financial burden on patients.

Research findings shows that overall, 1 in 4 people in the general public felt they must prioritise other costs over their healthcare, most notably food shopping and utility bills.

The Irish Cancer Society believes the DPS threshold should be reduced to relieve some of the financial pressure placed on cancer patients and their families.



# Budget 2025 Ask

Reduce the Drugs Payment
 Scheme threshold to at least
 €72 per month, as per the 2017
 Sláintecare Report.<sup>xcv</sup>

# **5. Prescription Charges**



Those most at risk of being economically vulnerable are put under undue financial strain.

Medical card holders under 70 are charged €1.50 for each item on prescription from a pharmacy up to a maximum of €15 per month per person/family.

Those over 70 pay a prescription charge of €1 per item, up to a maximum of €10 per person/family.<sup>xcvi</sup>

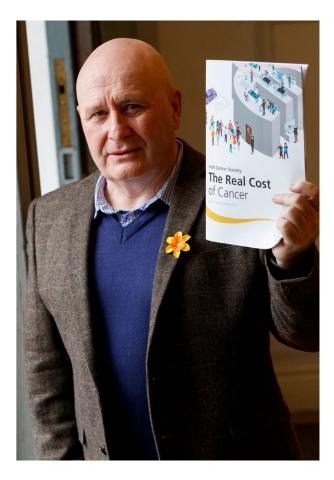
# Action

Reduce the financial burden on economically vulnerable cancer patients.

Government must honour commitments to reduce the financial burden on economically vulnerable patients, and to remove barriers so that everyone can access the medicine they need.

# Budget 2025 Ask

Abolish prescription charges for all medical card holders.



# 6. Domiciliary Care Allowance

# Challenge

# Families of a child with cancer face undue financial hardship.

Domiciliary Care Allowance (DCA) is a monthly payment for families caring for a child with a severe disability. The rate of payment stands at €340 per month.<sup>xcvii</sup>

This payment helps to meet the increased expenses associated with caring for a child with cancer. Families use this payment as a source of supplementary income while they cannot work and care for their child on a full-time basis.

The current policy means that when the young person turns 16, they are no longer entitled to the DCA. They can instead apply for Disability Allowance on their own behalf, which amounts to €54 per week at the full rate and €27 at the half rate.xcviii

# Action

Ensuring that families are not left financially worse off by ending this payment once their child turns 16.

# **Budget 2025 Ask**

Expand the Domiciliary Care Allowance eligibility criteria from 16 to 18 years of age.



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