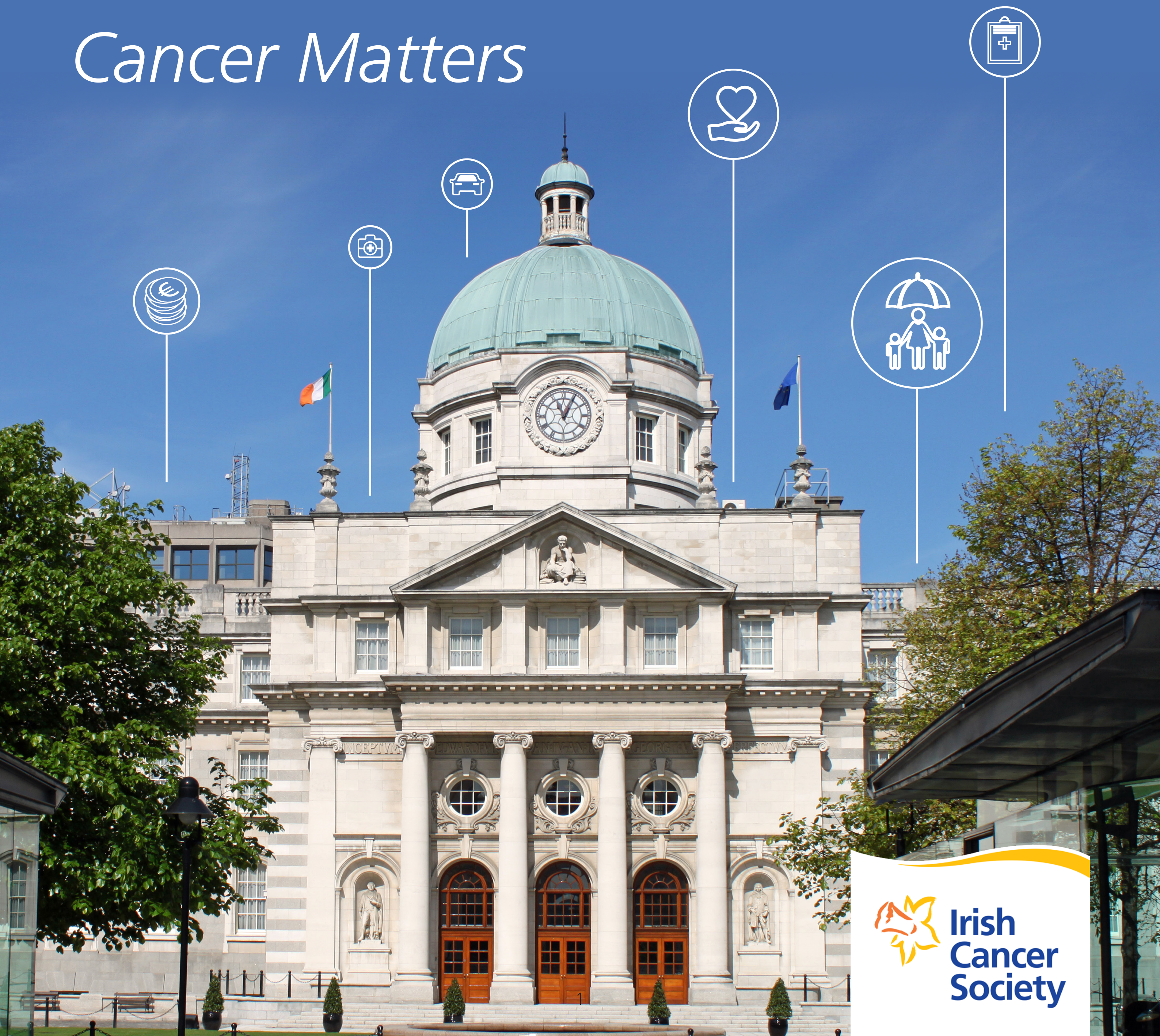
Irish Cancer Society

Pre-Budget Submission 2024

& CAYA Pre-Budget Submission 2024

Cancer Matters



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Submission Summary

Pre-Budget 2024 Asks

1. Cancer Prevention

Ask	Government Department
Tobacco cessation • Increase the excise duty on a packet of cigarettes and roll-your-own tobacco products by 5% in line with the tobacco tax escalator and again in line with inflation (7.7% - end of March 2023). • Allocate more funding towards targeted QUIT campaigns and support initiatives towards populations most likely to smoke. • Introduce a €500 tobacco retailer licensing fee. • Develop education and awareness campaigns on the dangers associated with e-cigarette use. • Introduce an environmental levy on all tobacco products sold.	Health
National Skin Cancer Prevention Plan • Abolish the standard rate of 23% on sun cream and Sun Protection Factor (SPF) 30+ products to introduce a 0% VAT rate. • Prioritise the full funding of the National Skin Cancer Prevention Plan 2023-2026. • Provide adequate resourcing for Environmental Health Officers, responsible for ensuring sunbed operators comply with current legislation.	Health
HPV vaccination programme • Funding to expand the catch-up programme to everyone up to the age of 25, in accordance with NIAC's 2022 recommendation. • Sufficient resourcing of a public information campaign to ensure greater take-up of the vaccine.	Health
Radon testing • Ensure that the next phase of the National Radon Control Strategy (2024) includes designated State funding for financial supports towards radon testing and remediation works.	Communications, Climate Action and Environment
Genetic services & supports • Ensure the full financial resourcing and implementation of the National Cancer Strategy 2017-2026 recommendations around genetic services, reducing genetic testing wait times and best optimise the health benefit advancements in this area. • Ensure that the National Genetics and Genomics Workforce Plan, once finalised, can tap into dedicated multi-annual funding mechanisms for its implementation, starting with a significant funding injection in 2024. • Publish, and provide specific funding for, the BRCA Model of Care. • Linked to the Genetics and Genomics Strategy and BRCA Model of Care, fund dedicated time for downstream staff time in diagnostic/surveillance and treatment services. • Ring-fenced funding to implement a hub and spoke model with genetics expertise within the dispersed oncology system.	Health

2. Timely access to diagnostics

Ask	Government Department
Access to primary, emergency care and diagnostic services (€15m) • Fund services to ensure that timely and appropriate diagnostics is available to everyone who needs it. • Fund services to ensure that they are sufficiently staffed, with access to the necessary infrastructure and equipment, in order to take action on waiting list times. • Fund the roll out of FIT testing to triage people on long colonoscopy waiting lists. • Fund research to examine best practice and innovations towards reducing waiting time, e.g. the use of pill cams.	Health
Screening services **BowelScreen** • Fund the roll out of the BowelScreen programme to people aged 55-74 as outlined in the initial BowelScreen plan, and then to people aged 50-74 pending a recommendation by HIQA. • Invest more in impactful campaigns to target those eligible for bowel cancer screening, emphasising its importance in the first instance and of repeated screening every 2 years. • Consider how population-based screening can be enhanced by the provision of regular screenings for those most at risk of bowel cancer, taking into account family history, genetic mutations etc., by working with other partners within the healthcare system. • Create greater awareness of the registration process for BowelScreen among the general population, in that the target population are not automatically on the register. • Ensure that the National Screening Service (NSS) has guaranteed downstream hospital capacity for follow-on appointments that doesn’t affect symptomatic services.	Health
BreastCheck • Fund recruitment drives for radiographers to ensure that BreastCheck has necessary staffing capacity. • Further examine the feasibility of expanding the screening age to begin at 45 years of age, as per the European Council proposal, for the age bracket to be extended to women aged between 45 and 74 years and to consider specific diagnostic measures for women with particularly dense breasts.[i] • Examine how best to enhance staffing capacity for BreastCheck when the age range is extended. The National Screening Service (NSS) should have guaranteed downstream hospital capacity for follow-on appointments that does not impact the delivery of symptomatic care. • Invest in specific campaigns to target those eligible who are not participating in BreastCheck, emphasising its importance in the first instance and of repeated screening every 2 years.	Health
CervicalCheck • Increase the uptake rate amongst communities that currently have low acceptance rates. For example, targeted communications campaigns aimed at groups with lower uptake levels are essential to improve screening rates. • Pilot fund self-sampling tests for those eligible for the cervical screening programme to ensure as many people are tested as possible. • Ensure sufficient capacity in line with the expansion of the current screening service.	Health

3. Treating cancer

Ask	Government Department
Regional accessibility of cancer care • Provide necessary investment in regional cancer services across the country to ensure cancer outcomes are equalised. • Fund a national modelling exercise to anticipate future demand and need for services beyond the current National Cancer Strategy. • Appoint a design team urgently to support the cancer centre at UHG.	Health
Cancer pathway (Cost: €15m) **1. Surgery** • Develop a plan to increase surgical capacity to meet the significant increase in demand on surgical oncology over the next 20 years. The NCRI estimates it will be at least a 75% increase in demand. • Provide additional bed capacity in ICU so that more cancer patients can get timely cancer surgery.; • Increase surgical oncologists' access to operating theatres. • Build additional theatres so that more cancer surgery can take place and protect time for cancer surgery to take place. • Enable adequate surgical capacity for preventative surgeries to take place when the patient makes the decision to proceed. • Chart a new course for cancer surgeries so that cancer patients are not competing for theatre time with trauma and ED patients. **2. Radiation therapy** • Allocate funding towards the recommendations from an ongoing consultation exercise with radiation therapists, the HSE and the Department of Health and other relevant stakeholders throughout 2024. • Develop and fund a national plan that increases capacity in radiation therapy annually to meet the significant increase in patient demand expected over the coming years. • Ensure a ring-fenced budget for procurement of machinery to enable machines to be replaced and updated as needed. • Approve posts for out-of-hours support staff for radiotherapy practice. **3. Chemotherapy** • Develop recruitment and retention strategies for oncology nurses and haematology professionals in the day ward. • Fund the physical expansion of oncology day wards, to increase patient capacity (alongside increase in staffing capacity). • Fund oncology services in the community setting without delay.	Health
Access to medicines • Establishment and running of the Implementation Working Group. • Development and implementation of an application tracker. • Oversight/governance for compliance with indicative timelines for approval of medicines. • Greater resourcing for staffing at the NCPE and NCCP as outlined in the Mazars review.[ii]	Health
Investment in the following would bolster cancer services:	
National Cancer Strategy (Cost: €20m for new development funding.) • Ring fence multi-year funding dedicated to implementing all outstanding recommendations from the Strategy to 2026. • Evaluate NCCP progress to date and prioritise action items not yet progressed. • Begin planing for the next strategic cycle in 2026.	Health
Clinical trials • Provide sustained, regular investment in clinical trials research and infrastructure. • Streamline the national clinical trial regulation processes. • Ensure dedicated, protected research time is provided for health care professionals to lead more investigator-led clinical trials in Ireland. • Deliver strategies to improve the recruitment and retention of clinical trials staff and researchers. • Develop communication initiatives to improve knowledge and awareness of cancer clinical trials in the wider public.	Health
Staffing • Invest in workforce planning across different specialties, including GPs, radiology capacity, radiation therapy in addition to other hospital staff roles along the cancer pathway.	Health
eHealth • Provide sufficient funding to develop and implement the national rollout of the electronic health record (EHR) across the health system. • Provide funding for extra staff, including towards extra IT staff within the HSE to assist in the progression towards the rollout of electronic health records nationally. • Prioritise additional support for digital infrastructure.[iii]	Health
Lymphoedema services (Cost: €8m) • Fully fund the Lymphoedema and Lipoedema model of care.	Health
Sláintecare • Fully fund the implementation of the Sláintecare report.	Health

4. The Cost of Cancer

Ask	Government Department
Cancer during pregnancy & maternity leave (Cost: €3m+) The Government must allocate €2.6 million annually to develop a fund which would cover: • An illness benefit payment for new mothers/birthing parents duringthe time of their treatment for cancer. • A fund for employers from which to draw down to cover costs associated with sick pay cover where a new mother has had to postpone maternity leave. • Further allocate €500,000 in research grants to examine the needs of expectant parents who were diagnosed with cancer, with specific priority on expectant/new mothers and the development of recommendations around services required to accommodate their psychosocial needs.	Children, Equality, Disability, Integration and Youth
Car Parking • Abolish car parking charges across all public hospitals for cancer patients. • Develop defined timelines from Government as to when it will be delivered.	Health
Medical cards • Provide medical cards to all cancer patients upon diagnosis, until their treatment is finished.	Health
Prescription charges • Abolish prescription charges as part of Budget 2024 to reduce the financial burden on economically vulnerable patients.	Health
Drugs Payment Scheme (Cost: €12.5m per annum) • Reduce the Drugs Payment Scheme threshold to a maximum of €72 permonth.	Health
Household Benefits Package (Cost: est. €25m[iv*]) • Expand the Household Benefits Package criteria to include all cancer patients upon diagnosis, until their treatment is finished.	Health
Partial Capacity Benefit & extra supports to attend medical appointments • Broadening of 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.	Social Protection
Bras, wigs & prosthesis allowances • Ensure the development of a standardised, equitable approach to accessing post-mastectomy products and hairpieces for those diagnosed with cancer.	Social Protection
Fertility Cost • Ensure timely access to publicly available fertility treatment to people living beyond cancer. • Include people living beyond cancer specifically in the national eligibility framework so they may avail of publicly funded IVF treatment.[v]	Health

Introduction

Cancer affects us all. It robs us of the little things, the big days and the special moments. It kills more people in Ireland than any other disease,[vi] and yet there is a sense of optimism that runs through the backbone of this country that by working together more lives can be saved.

Each of us has a role in achieving that vision. Whether it be shaking a bucket on Daffodil Day, discovering new treatments or becoming aware of the signs and symptoms of cancer, there is always more that can be done.

Politicians and the Government play a critical and central role in ensuring more people survive cancer. Although significant actions have been taken in recent years, we ask the simple question: ‘But is it enough’?

We think that the figures in this submission speak for themselves.

This year, the Irish Cancer Society is publishing our Pre-Budget Submission whilst also acknowledging that there is still a risk that the impact of the pandemic could affect the number of cancers diagnosed in 2021. If that were found to be the case it would be cause for serious concern, as it would be the second year in a row of missed cancers.

We have some key areas that we hope the Government will invest in as part of Budget 2024. These areas cover Cancer Prevention, Timely Access to Diagnostics, Treating Cancer and the Cost of Cancer.

The Irish Cancer Society hopes every politician will support our call for:

- Significant additional investment in cancer services and the cancer workforce so that everyone can be offered timely tests and treatment.
- 0% VAT on sunscreen.
- The abolition of car parking charges in public hospitals.
- Funding so that mothers with cancer can defer maternity leave until they have finished treatment.

The impact of cancer on families across the country is being felt all the more acutely this year. Costs are being compounded by the cost-of-living crisis, some people are being diagnosed with more advanced cancers and the health service is buckling under increased and sustained pressure. The Irish Cancer Society believes that Budget 2024 is an opportunity to positively impact the future and that this Pre-Budget Submission charts a course towards that.

Cancer is not just a Department of Health, HSE or National Cancer Control Programme issue. Cancer is a disease that needs the attention of every member of Government and every elected representative.

Until the answer to the question, ‘But is it enough’ is yes, then every chance to do more must be grasped.


Irish Cancer Society
The Real Cost of Cancer


CUT THE COSTS
FOR CANCER PATIENTS
Irish Cancer Society

1 Prevention

Research shows that with the right support, information and services, 4 in 10 cancers could be prevented.[viii] Yet, spending on prevention amounted to 3.3% of health expenditure in 2020,[ix] illustrating the spending dynamic between healthcare and sick care.

The saying goes that prevention is better than cure. Given former Taoiseach, Micheál Martin's, warning of the 'frightening' wave of future cancer cases as a result of the pandemic, more needs to be done to reduce the scale of what lies ahead.[vii] Efforts to reduce the demand on health services needs to be prioritised alongside measures that increase capacity and supply of cancer care, which we address later in this submission.

To some degree, health and health behaviours are linked to a variety of structural factors that are beyond a person's control, including a person's background, education, location, ethnicity or income. We believe that, with the right support, informed health choices could be made easier for people and help reduce the cancer gap between privileged and disadvantaged communities.

People who suffer from inequalities in health are particularly at risk of preventable cancers and need specific support. If those supports are put in place, the potential for saving lives is enormous.

We also know that family history and hereditary factors can influence cancer risk. Genetics services play an important role in learning about and managing inherited cancer risk, providing an opportunity for timely interventions to reduce the potential for a cancer diagnosis with heightened risk.

To support effective prevention and risk-management interventions, Government need to provide the infrastructure, the resources, the legislation and the support to offer everyone the best chance of living a life free from cancer.

Our Budget 2024 recommendations include essential, concrete measures which, if adopted, would be central to preventing cancer in the first instance or catching it early.

Tobacco cessation

Relevant Department: Department of Health

Smoking causes harm

> **“Every week, over 100 people die and over 1,000 people are hospitalised in Ireland from smoking-related illness.”**[x]
>
> *– Health Service Executive, 2022*

The Irish Cancer Society has, for decades, advocated for measures that will reduce cigarette smoking and its harms.

Despite great strides being made in this area over recent years, with a decline in smoking rates from 29% in 2007 to 18% in 2022, the prevalence rate has not declined since 2019.[xi] A person’s likelihood of smoking is linked to employment status, education level and age.[xii]

The socioeconomic differences in smoking prevalence worldwide are well established.[xiii] Those on lower incomes are carrying a heavier burden of tobacco-related disease. This is also the case for Ireland with prevalence higher in lower socio-economic groups (SEGs)[xiv], contributing to the significant gradient in mortality rates by SEG.[xv] In particular, smoking rates remain higher for those who are unemployed (39%) versus those in employment (19%). They also remain somewhat higher among those who have not completed the Leaving Certificate (21%) compared with those with a Leaving Certificate or higher (17%).[xvi]

The latest Healthy Ireland Survey (2022)[xvii] showed a 4-point increase in the proportion of 25-34-year-olds who smoke (24%) compared to 20% in the 2021 survey. Considerable sustained efforts must be made to turn the tide on smoking especially as more young people are reporting they are smoking occasionally.

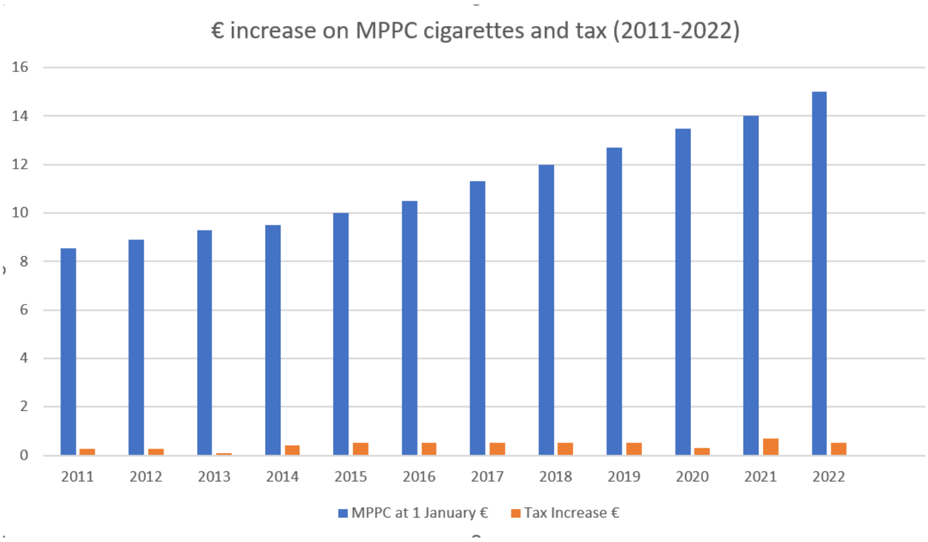
The impact of smoking-related diseases causes a considerable burden on the healthcare system with an estimated annual cost to the health service of **€460 million**, and the total annual costs as **€10.7 billion**.[xviii] In comparison, costs for providing support to stop smoking are relatively small[xix] and, as per the Department of Health commissioned HIQA report, are highly cost effective.

Taxation and pricing are the most effective measures to reduce tobacco consumption and harms.[xx] To complement these measures, public awareness against the dangers of tobacco is essential, as well as, ensuring sufficient supports are in place to help smokers quit.

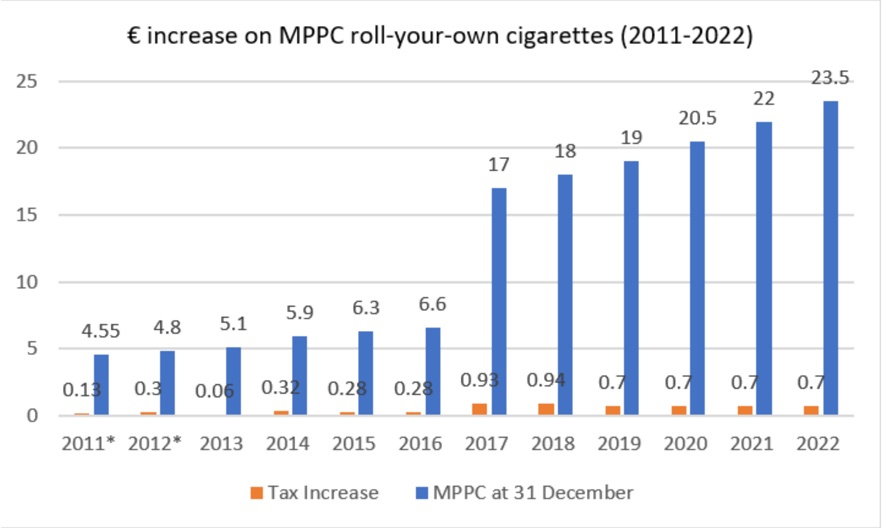
Price increases and smoking cessation supports

The Irish Cancer Society is calling for an increase in the price of a packet of cigarettes from €15.80 to €17.87 reflecting an increase of 5% in line with the tobacco tax escalator and the rise in inflation[1].

The price of a pack of 20 cigarettes has been continuously increasing over the past decade or so, from €8.90 on 31 December 2011 to €15.80 at the end of 2022 for the most popular price category (MPPC). The table below shows annual increases in the retail price and tax increase between 2011 and 2022 for a 20-pack of cigarettes.[xxi]



Similarly, we are calling for excise duty increases on roll-your-own (RYO) cigarettes, to ensure their tax is equivalent to that on cigarettes, to deter smokers from switching to such products. The table below shows annual increases in the retail price and tax increase between 2011 and 2022 for roll-your-own cigarettes.[xxii]



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[1] In mid-April 2023, the inflation rate was reported at 7.7%, as per CSO figures from March 2023

Revenue produced a Ready Reckoner, which provided an overview of expected tax revenue by defined increases in the price of cigarettes and Roll-Your-Own tobacco.

Revenue Ready Reckoner – Post Budget 2023 (reproduced by the Irish Cancer Society)[xxiii]

Cigarettes (per pack of 20)	
Increase by 5c	**€5 million**
Increase by 10c	**€11 million**
Increase by 25c	**€26 million**
Increase by 50c	**€52 million**
Increase by €1	**€103 million**
Roll Your Own (fine cut) tobacco	
Additional 50% on 5c increase	**€0.1 million**
Additional 50% on 10c increase	**€0.4 million**
Additional 50% on 25c increase	**€1.1 million**
Additional 50% on 50c increase	**€1.9 million**
Additional 50% on €1 increase	**€3.8 million**

Any tax revenue collected from tobacco should be used to ensure that quit supports are adequately funded. Provisional Tobacco Products Tax (TPT) receipts for 2022 are an estimated €1,160,600.[xxiv]

The Irish Cancer Society welcomes the announcement that nicotine replacement therapies (NRT) are now free from local stop smoking clinics as part of the HSE Quit service. This is another positive step to ensure that those who need access to NRT can do so.

Further to this, the State must ensure that targeted supports are in place and enough information is provided about how and where to go to do so for those who need it. Unfortunately, just under a fifth (18%) of smokers who saw their GP during the past 12 months discussed ways of quitting smoking – a decline from 38% in 2019.[xxv] While the reasons behind this are likely multi-factorial, the figure needs to increase if the smoking rate is to continue to decline. All primary care providers need to be resourced to undertake brief intervention and smoking cessation conversations with their patients.

Alongside the health implications of tobacco use, cigarette butts pose a serious litter problem on a global scale. Tobacco manufacturers should bear financial responsibility for the safe and effective disposal of waste associated with the product.

e-Cigarettes

Findings from the Healthy Ireland Survey Report indicate that e-cigarette use is highest among those aged under 25 with 6% in this age group currently using them.[xxvi]

As the presence of e-cigarette use becomes increasingly prevalent across society, we must apply the same focus used to tackle cigarette-related harms to this area, particularly on the younger generation's consumption.

The European Schools Project on Alcohol and Other Drugs (ESPAD)[xxvii] reports that more students report using e-cigarettes in 2019 than in 2015, and the use of e-cigarettes among students is now more common than cigarette smoking. Almost 4 in 10 students (39%) had tried e-cigarettes and almost 1 in 5 (18%) were current users, making both ever-use and current use of e-cigarettes higher than use of combustible cigarettes (32% had tried smoking, 14% current users, with 5% reporting daily smoking). Furthermore, a Health Research Board Evidence Review[xxviii] in 2020 reported that adolescents who use e-cigarettes are three to five times more likely to start smoking tobacco cigarettes compared to those who never used e-cigarettes.

It is welcome news that the HSE has developed new units of learning for the SPHE Junior Cycle curriculum, which contain lessons on e-cigarettes and nicotine delivery systems, however currently there is no allocated funding or planned mass media campaign to provide population-wide education and awareness on the use of e-cigarettes or similar products. Considering the prevalence of such e-cigarettes, a broader focus on this area is essential.[xxix]

For Budget 2024, the Irish Cancer Society urges the Government to adopt well-evidenced, cost-effective policies that support people to stop smoking.

Asks:

- Increase the excise duty on a packet of cigarettes and roll-your-own tobacco products by 5% in line with the tobacco tax escalator and again in line with inflation (7.7% – end of March 2023).
- Allocate more funding towards targeted QUIT campaigns and support initiatives towards populations most likely to smoke.
- Introduce a €500 tobacco retailer licensing fee.
- Develop education and awareness campaigns on the dangers associated with e-cigarette use.
- Introduce an environmental levy on all tobacco products sold.

National Skin Cancer Prevention Plan

Relevant Department: Department of Health

Skin cancer is the most common cancer in Ireland, with an average of 12,668 new cases (melanoma and non-melanoma skin cancer combined) diagnosed each year from 2018-2020. It is also one of the most preventable cancers.[xxx]

National Cancer Registry of Ireland (NCRI) projections suggest that the average number of cases diagnosed each year may double between 2015 and 2045.[xxxi] It is of great importance that prevention and early diagnosis are prioritised to minimise the financial burden of melanoma skin cancer in Ireland.[xxxii]

Managing melanoma diagnosed at stage IV is over 25 times more costly than managing melanoma diagnosed at stage IA (€122,985 versus €4,269).[xxxiii]

Skin cancer is largely preventable by protecting skin from UV radiation. UV is emitted naturally from the sun and comes from artificial sources, such as sunbeds. Excessive exposure to solar radiation can cause DNA damage in the skin, which over time, can cause the cells to start growing out of control. Exposure to such UV radiation is particularly harmful during childhood.[xxxiv]

Although individual behavioural changes can make a considerable impact (including covering skin as much as possible, applying high UVA/UVB protection, wearing a hat, sunglasses and seeking shade) at Government level, more can be done to reduce instances of skin cancer.

We must ensure that the Department of Health, as well as the HSE and other relevant partner organisations, have the funds needed to implement the National Skin Cancer Prevention Plan 2023-2026 effectively so that rising skin cancer incidence rates can be effectively addressed. Such funding will ensure the Plan, as well as education initiatives and campaigns, can be rolled out effectively.

The Irish Cancer Society supports the HSE's National Cancer Control Programme and Healthy Ireland's SunSmart campaign. A key tenet of the campaign is to 'Slop on broad-spectrum (UVA/UVB) sunscreen' before going out into the sun, and to reapply often.[xxxv] To support greater use of sunscreen as a key part of safe practices in the sun, a joint-up response is required to make it more widely accessible. No person should be exposed to the harsh effects of sun exposure simply because they cannot afford the current price. Value Added Tax (VAT) on suncream is levied at the standard rate of 23% in Ireland; we call for the abolition of VAT on suncream and sun blocker products.

Another area which requires more focus from Government is sunbeds. In 2019, the Irish Cancer Society conducted a sunbed mystery shopper survey which revealed that although it is illegal for under 18s to use sunbeds, 2 out of 5 operators offering sunbed sessions did not ask an underage person their age, 2 in 5 did not ask for identification and 1 in 3 booked in appointments for minors.[xxxvi] More resourcing to enforce the legislation needs to be prioritised by the State to ensure minors are protected from the dangers of sunbed exposure.

Asks:

- Abolish the standard rate of 23% on sunscreen products of SPF 30+ to introduce a 0% VAT rate.
- Prioritise the full funding of the National Skin Cancer Prevention Plan 2023-2026.
- Provide adequate resourcing for Environmental Health Officers, responsible for ensuring sunbed operators comply with current legislation.

HPV vaccination plan

Relevant Department: Department of Health

Human Papilloma Virus (HPV) is a family of very common viruses passed on during skin-to-skin contact, particularly sexual activity and including oral sex.

There are over 100 types of human papillomavirus (HPV), some types carry a risk of cancer.[xxxvii]

Most people will get HPV infection in their lifetime. Usually the body's immune system finds the HPV virus and resolves 9 out of 10 infections within two years.

The vaccine has been shown to reduce the risk of cervical cancer, in particular where a person received the HPV vaccine in early adolescence.[xxxix]

In Ireland, the HPV vaccine is offered free of charge to all students in their 1st year of secondary school. This recommended vaccine age is chosen to give the child the best protection possible against vaccine preventable diseases and therefore first exposed to HPV infection. While the uptake rate has increased from 2020/21 to 2021/22, as outlined in the table below, we believe there is an opportunity to do more to increase the vaccine uptake.

HPV is responsible for 1 in 20 cancers worldwide, and 406 cancers every year in Ireland.[xxxviii]

Academic year	Dose 1	Dose 2
2020/21[xl]	**76%**	**65%**
2021/22[xli]	**78.4%**	**69.4%**

In 2022, the National Immunisation Advisory Committee (NIAC) recommended that as-yet unvaccinated females and males (aged 9-24) should be eligible for dose 1 of the HPV vaccination. Specifically, the catch-up programme was recommended for females and males aged 15-24, prioritising people still in post-primary education.[xlii]

The HPV vaccine protects against the types of HPV that cause 9 out of 10 cervical cancers.

The Irish Cancer Society strongly welcomed the establishment of the Laura Brennan HPV catch-up programme that offers free HPV vaccines to all boys and girls in second level education who were previously eligible to receive the HPV vaccine and who have not yet, for whatever reason, received it. Young women, up to the age of 25, who have now left secondary school, and who did not receive the vaccine, are also eligible to receive the vaccine as part of the catch-up programme. We call on Government to fund the Laura Brennan HPV catch-up programme (awareness raising and vaccine intervention) for all people, including males up to age 25. Furthermore, expanding the HPV vaccine roll out to everyone free of charge up until the age of 25 would mirror the approach of the UK.[xliii]

This catch-up programme is particularly vital given the disruption caused to public health schemes by the pandemic, as well as a greater public acceptance and appreciation of vaccines.

The Irish Cancer Society believes that the elimination of HPV-caused cancer is within our grasp. In Budget 2024, we call for:

Asks:

- Funding to expand the catch-up programme to everyone up to the age of 25, in accordance with NIAC's 2022 recommendation.
- Sufficient resourcing of a public information campaign to ensure greater take-up of the vaccine.

Radon testing

Relevant Department: Department of Housing, Local Environment and Heritage

Each year, radon is linked to roughly 350 cases of lung cancer in Ireland.[xliv]

Radon gas is naturally occurring as a result of decay of soil and rocks. Radon particles can be inhaled and are dangerous to human health where radon is present in an enclosed space.

Lacking any taste, colour or smell, only radon detectors can pick up the presence of radon.[xlv]

An interactive radon risk map, published and updated by the Environmental Protection Agency (EPA) and Trinity College Dublin, shows 170,000 homes located in high radon locations. Compared to the 2002 analysis, 45,000 more homes were impacted in 2022.[xlvi]

Currently there are no financial supports in place for radon testing or remediation work; as such those living in high-risk areas must cover the cost of testing themselves.[xlvii]

For most homes, a radon extraction fan will draw the radon from underneath the ground and out into the atmosphere, which could cost between €1,000 – 2,000.[xlviii] A 26-watt radon extraction fan could cost approximately €100 a year to run.[xlix]

The Irish Cancer Society believes that Government commitment in this area would go a long way in protecting the general public from the dangers associated with radon testing.

Asks:

- Ensure that the next phase of the National Radon Control Strategy (2024) includes designated State funding for financial supports towards radon testing and remediation works.

Genetic services and supports

Relevant Department: Department of Health

Inherited gene variants are responsible for an estimated 5-10% of cancers.[l]

Genetic testing helps people understand their inherited risk of developing cancer. Access to genetics and genomics services could help people to recognise this risk and take action appropriate to them, as well as support treatment plans.[li]

Genetic testing can also help to reduce the burden of cancer in our population through prevention and early detection. We can also reduce the burden of cancer care through targeted therapy approaches.[lii]

For all the benefits of genetics testing for detecting and managing cancer risk, cancer genetic services in Ireland are underdeveloped and under resourced. A report prepared for the Irish Cancer Society in 2021 by Hegarty et al. on the unmet need in cancer genetic services demonstrates how Ireland lags far behind other countries in this area and the consequences of such for individuals and their families.[liii]

Notable findings from the research show how some of the patients surveyed had to wait for up to two years for genetic counselling.

> In addition, patients found to be at a high risk reported that after receiving their results, they had to wait two years for risk-reducing procedures and reconstructive surgery as a result.[liv]

In 2023, the latest available data show that 2,955 people are waiting for a genetics appointment at St. James's Hospital across three waiting lists (urgent, ASAP, routine).[lv] People are still waiting on average up to 2 years for an appointment on the routine waiting list.[lvi] The St James's Hospital Cancer Genetics Team works hard to support their patients, and they will need additional resources to support them in their work.

The Irish Cancer Society acknowledges and welcomes the progress made in genetics services in recent years. For instance, Children's Health Ireland (CHI) at Crumlin significantly reduced the number of people who were on a waiting list for more than 6 months.[lvii] It is important that this momentum is maintained into the future, which will require resources to be consistent with need.

To further the role of genetics in healthcare, the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland was published in 2022. The Strategy highlighted a range of areas for further developing genetics as part of the healthcare landscape. It outlines how €2.7 million in funding has been secured for implementing the Strategy in 2023, intended for the establishment of a National Office and funding some frontline roles. It is vital that additional funding is allocated with the purpose of pushing forward the Strategy's agenda to embed genetics and genomics healthcare in the system. Moving forward, the workforce, capacity, diagnostic capabilities, and infrastructure must be developed further.

We also welcome the recruitment of key roles, including the National Lead in Genomics, as well as recruitment within genetics services. The Irish Cancer Society looks forward to continued investment in genetics and genomics services as core components of cancer risk detection and management.

Asks:

- Ensure the full financial resourcing and implementation of the National Cancer Strategy 2017-2026 recommendations around genetic services, reducing genetic testing wait times and to best optimise the health benefit advancements in this area.
- Ensure that the National Genetics and Genomics Workforce Plan, once finalised, can tap into dedicated multi-annual funding mechanisms for its implementation, starting with a significant funding injection in 2024.
- Publish, and provide specific funding for, the BRCA Model of Care.
- Linked to the Genetics and Genomics Strategy and BRCA Model of Care, fund dedicated time for downstream staff time in diagnostic/surveillance and treatment services. Such ring-fenced time would mean allocating MRI and mammography appointment slots for the sole use of genetics services to give timely access to patients attending the genetics services, it would also mean protecting theatre and staff time for surgery only for patients in the genetics services to avoid direct competition with symptomatic services.
- Ring-fence funding to implement a hub and spoke model with genetics expertise within the dispersed oncology system.

2 Timely access to diagnostics

Diagnosing cancer is a race against the clock to ensure the best possible outcomes. The earlier cancer is caught the better – this is why timely access to diagnostics is incredibly important.

The early diagnosis of cancer is associated with significant cost savings for the State. A financial analysis conducted for Cancer Research UK demonstrated costs savings of up to £44 million if all regions in England had the same staging pattern as the best performing regions for four cancer types (lung, colon, rectal, ovarian). The same analysis demonstrated that over 11,000 patients would also benefit from early detection.[lviii]

> **"Our concern is that people may be delaying seeking medical advice because of the crisis across the health service, and when this is added to wait-times for diagnostic tests for those who do present with symptoms, there may be delayed diagnoses of cancer."**
>
> *– Rachel Morrogh, Director of Advocacy and External Affairs, Irish Cancer Society*

Delayed diagnoses costs lives. The National Cancer Registry Ireland (NCRI) outlined the impact of the pandemic on cancer detection rates, where an estimated shortfall of 2,600 cancers were registered in 2020. This is a major concern. For instance, there was a drop in detected versus expected cases for screened cancers including colorectal (18% less than expected), cervical (31% less than expected) and breast (23% less than expected) cancers.[lix] The Irish Cancer Society has previously warned that the number of cancers diagnosed in 2021 could fall short of the numbers projected. The impact of the pandemic continues to have long-lasting negative consequences for those with cancer and the Irish Cancer Society is using the opportunity of publishing this Pre-Budget Submission to once again make the case to Government that GPs, diagnostic services and treatment pathways need very significant and sustained investment to expand to meet demand and stop cancer outcomes from slipping backwards.

Ireland has come a long way in enhancing survival rates. It is important that such progress is continued. Unfortunately, many backlogs in services have worsened due to the COVID-19 crisis because they were under-funded and under-resourced for many years before the pandemic hit. The Irish Cancer Society is grateful for the efforts taken to date by the Minister for Health, the NCCP and the wider health service to mitigate the impact of the pandemic on diagnostic services and we have welcomed the funding provided by central Government to expedite these efforts. Despite the numbers of long-waiters being reduced, patients using public healthcare still wait far too long for tests that detect cancer and this has a direct impact on outcomes. In April 2023, Minister Donnelly made further efforts in this regard and proposed a policy to refer patients into hospitals, rather than to individual consultants. The Irish Cancer Society calls for the implementation of such a policy.[lx]

Early detection occurs on a spectrum, from screening services for breast, colorectal and cervical cancers, to GP services and subsequently to diagnostics services. Such services and their appropriate resourcing is essential for supporting better health and quality of life outcomes and lower treatment costs.

Access to primary and emergency care

Relevant Department: Department of Health

Public confidence in the healthcare system is mixed. Early results from our most recent research shows that around half of the population does not agree that health services are open (45%) or accessible (51%) to people when they need them.[lxi] People must trust that the right care is accessible to them when they begin to notice any signs and symptoms of cancer. More resourcing in primary care interventions and the early detection of cancer needs to be prioritised to avoid the health service solely focussing on urgent or emergency cases.

GP attendance

In Ireland, primary care is often the first port of call for an individual with symptoms of cancer, and is an important resource in catching cancer early, as well as in prevention activities.

Irish Cancer Society research from January 2023 shows that almost 3 in 10 people have put off going to a GP or hospital because of health service pressures in the last 3 months.[lxii]

The issue is that GP services, and wider primary care provision, is struggling to meet demand and we hear regularly from the public that they can wait a number of weeks for a routine appointment. The IMO estimates that 10% of people do not have a GP and this is a clear barrier to getting in-person medical advice for symptoms of cancer.

The staffing issues associated with GP services are highlighted in Section 3 "Treating Cancer".

Emergency department

Unfortunately, an all too common route to diagnosis is via emergency departments (EDs). As has been reported repeatedly in 2023, EDs are currently overwhelmed despite additional resources being provided to ease the pressure on capacity and on the ED staff.

> We know from previous research that 14% of invasive cancers are diagnosed in emergency departments.[lxiii]

It is likely that many of these cancers are diagnosed as a consequence of receiving care for another illness, symptom or health concern and that this group of people tend to be diagnosed with cancer at a late stage. Sadly, a person living in a more deprived area is 50% more likely to have their cancer detected in an emergency situation compared to people from more affluent areas.[lxiv]

Access to diagnostic services

Radiology Services

Relevant Department: Department of Health

Radiology is used for diagnosing and learning about a person's cancer. As such, ensuring timely access to a radiology appointment is incredibly important.

The current Sláintecare policy outlines that a person should wait no more than 10 days for a diagnostic test.[lxv]

Unfortunately, we understand that this target is a distant goal.

We believe that there are over 200,000 people waiting for a radiology appointment (like CT, MRI, ultrasound) – with almost 3 in 5 people waiting more than 3 months for an appointment.

It seems that those with red flag symptoms and those who are already diagnosed with cancer get access to radiology within acceptable timeframes, but those who have symptoms that are classified as routine or non-urgent, are left to wait too long.

For example, the Irish Cancer Society was recently made aware of a woman for whom back pain was her only symptom and was classified as routine. She was later diagnosed with metastatic cancer, illustrating that timely access to diagnostics is necessary for everyone referred for investigation.

The most significant concern is that the longer cancer is left undiagnosed and untreated, the more likely it is to be fatal.

When people engage with the health system, they should be confident they can access timely care. Unfortunately, people are waiting much longer than they should to access diagnostics and, as a consequence, the best chance to survive and have a good quality of life.

Radiology must be placed in diagnostic centres, which should be established, and removed from acute settings as a matter of priority.

Endoscopy capacity

Relevant Department: Department of Health

An endoscopy is a minimally invasive procedure used to observe an internal organ or tissue in detail. There are several procedures, including colonoscopy (examination of the lining of the large bowel), sigmoidoscopy (examination of the inside of the rectum and sigmoid colon), and upper endoscopy (examination of the lining of the upper part of the gastrointestinal (GI) tract which includes the oesophagus, stomach and duodenum), among others. Endoscopic procedures can detect gastrointestinal and colorectal cancers.

A colonoscopy is a procedure used to diagnose colorectal cancer. People are generally triaged as urgent and routine, depending on their symptoms. Like any triaging, some people can be categorised as routine, but actually have atypical symptoms and require treatment.

As with radiology tests that detect cancer, too many people are waiting longer than the recommended time for a colonoscopy.

The current target waiting timeframe for a routine colonoscopy is that 65% of people are seen within 13 weeks following their referral. The HSE National Services Plan 2023[lxvi] show that this target was missed in 2022, with 54% of people on waiting lists accessing a colonoscopy or an Oesophago-Gastro Duodenoscopy (OGD) within the recommended timeframe.

At the end of April 2023, almost 45,000 people were on the National Treatment Purchase Fund waiting list to access a colonoscopy via the private health system. Of these, 6 in 10 (58%) were waiting longer than the recommended time for their appointment.[lxvii] There has been no improvement in the number of people waiting longer than the recommended timeframe for a colonoscopy since January 2022.[lxviii]

'Missed' cancers are now entering the health system with a significant delay, causing additional strain on services. On top of this we know that the rates of diagnosis are not at the level projected – they remain lower. Cancer hasn't gone away. These undiagnosed cancers are out there but we simply don't know where. Urgent solutions are needed to address the issue.

Initiatives that would ease endoscopy backlogs include:

- A pilot is underway in the Saolta Group to offer FIT tests (the same test used by the BowelScreen programme) to people waiting for routine colonoscopy. This is designed to assess a person's need for urgent colonoscopy.[lxix] Almost 3 in 5 (58%) people have participated in the FIT test when invited, and of those 3 in 20 had a positive FIT result and needed a colonoscopy. It is expected that the pilot will be extended to another 5 sites and the Irish Cancer Society greatly supports this initiative.[lxx]
- Pill cams, or capsule colonoscopies, should be explored in feasibility and effectiveness for use in the Irish context.
- Adequately resource endoscopy services to meet the level of demand for routine and urgent colonoscopies to ensure that no person is put at risk for later diagnosis due to a delayed colonoscopy.

Government needs to do much more to ensure that timely and appropriate care is available to everyone who needs it. Patients still face unacceptably long delays, and our health service is under-resourced to meet the pressures that are already emerging from the growing number of people being diagnosed with cancer.

Asks:

- Fund services to ensure that timely and appropriate diagnostics are available to everyone who needs access.
- Fund services to ensure that they are sufficiently staffed, with access to the necessary infrastructure and equipment, in order to take action on waiting list times.
- Fund the roll out of FIT testing to triage people on long colonoscopy waiting lists.
- Fund research to examine best practice and innovations towards reducing waiting times, e.g. use of pill cams.

Costs:

- €15 million

Screening services

Screening programmes are important tools in the early detection of cancer. Enhancing attendance, ensuring accessibility and focusing on underrepresented groups with lower uptake rates must be key funding priorities.

One key step towards meeting some of these objectives is considering and accommodating the specific needs of the population. In recent years, the launch of Regional Traveller Health Units demonstrated positive outcomes when obstacles facing underserved communities in accessing healthcare are targeted.[lxxi]

In April 2023, the National Screening Service released a strategic plan for the years 2023-2027. The Strategy outlines objectives to reduce inequalities, improve population health, and enhance patient experience and involvement across the screening services.[lxxii]

> **"Screening is a valuable tool that helps to catch cancers at the earliest possible stage when treatment works best, so it is incredibly important that our screening services can return to a level of service that is at or above pre-pandemic levels"**[lxxiii]
>
> *– Averil Power, CEO, Irish Cancer Society.*

Cancer screening is an essential tool for the early detection of cancers. Targeted resourcing of our national screening services to increase uptake is a matter of priority in cancer control.

Table 1: Screening targets: National Cancer Strategy KPIs vs. actual uptake

	Target	**2019**[lxxiv]	**2020**[lxxv]	**2021**[lxxvi]	**2022**[lxxvii]
BreastCheck	70%	**72.5%** 170,955 people	**58.6%** 56,270 people *114,685 fewer people screened*	**77.1%** 127,288 people	**75%**
CervicalCheck	80%	**79.1%** 206,252	**77.5%** 143,028 *63,224 fewer people screened*	**72.6%** 318,486	**73%**
BowelScreen	45%	**42.5%** 122,726	**43.5%** 49,889 *72,837 fewer people screened*	**51%** 91,529	**40%**

BowelScreen (ages 60-69)

Relevant Department: Department of Health

Colorectal (bowel) cancer is the second most common of all cancers in men and the third most common among women in Ireland. This cancer affects the lower part of the digestive system.

Bowel cancer screening is used to detect cancer and pre-cancers in people who have no symptoms. Screening helps to detect and manage bowel cancer at an early stage when there is a much better chance of treating it successfully.

BowelScreen is the national bowel screening programme, which is currently available to people aged 60 to 69. Eligible people are invited to take a FIT (Faecal Immunochemical Test) at home and return it in the post.[lxxviii]

The Irish Cancer Society has long been a supporter of the BowelScreen programme, having donated €1 million in 2009 to contribute to the introduction of BowelScreen in Ireland.[lxxix] **We would like to see the programme develop further as a key component in detecting pre-cancers and cancer at the earliest possible opportunity.**

Bowel screening works. Over 6 in 10 screening detected bowel cancers are caught at Stage 1 or 2 compared to almost 4 in 10 non-screening detected cancers.[lxxx]

The current Government policy is to expand BowelScreen to people aged 55-74. The success of BowelScreen in detecting cancers at an early stage is more than sufficient rationale to expand the BowelScreen programme to other age groups. The Irish Cancer Society calls for BowelScreen to be available to all people aged 50-75, in line with international evidence and European Council recommendations.[lxxxiii] At the same time, the Irish Cancer Society welcome the HSE's plans to begin screening of people aged 59 this year.[lxxxv]

Given that over 1 in 4 cases of colorectal cancer (CRC) are detected in people aged 50-59 and 70-74, and 1 in 4 cases were detected in people aged 60-69, it is important that such a significant cohort can access this service.[lxxxv]

However, in expanding out the BowelScreen programme to new age cohorts, it is important not to overlook the fact that BowelScreen is not meeting its target uptake rate of 45%.[lxxxvi] To counteract the missed target, there must be an increased and sustained focus on raising awareness of the importance of BowelScreen among all eligible candidates and in seeking greater capacity within the healthcare system to ensure target population expansion and an increased target uptake rate.

For each of the years 2018 - 2022, BowelScreen participants accounted for between 4-5% of the total number of colonoscopies nationally. In line with the expansion of the BowelScreen age, endoscopy capacity must broaden accordingly to ensure that referral for further testing, post-screening, can occur in a timely manner.[lxxxvii]

An estimated 2,600 people are diagnosed with bowel cancer in Ireland every year.[lxxxv] When caught at the earliest possible stage, over 9 in 10 people survive to 5 years; unfortunately, at Stage IV, 1 in 10 people will survive 5 years.[lxxxii]

Asks:

- Fund the roll-out of the BowelScreen programme to people aged 55-74 as outlined in the initial BowelScreen plan, and then to people aged 50-74, pending a recommendation by HIQA.
- Invest more in impactful campaigns to target those eligible for bowel cancer screening, emphasising its importance in the first instance and of repeated screening every 2 years.
- Consider how population-based screening can be enhanced by the provision of regular screenings for those most at risk of bowel cancer, taking into account factors such as family history and genetic mutations, by working with other partners within the healthcare system.
- Create greater awareness of the registration process for BowelScreen among the general population, in that the target population are not automatically on the register.
- Ensure that the National Screening Service (NSS) has guaranteed downstream hospital capacity for follow-on appointments that doesn't affect symptomatic services.

BreastCheck (ages 50-69)

Relevant Department: Department of Health

Breast cancer is a common cancer in Ireland. More than 3,500 women and approximately 35 men are diagnosed with breast cancer every year. This could rise to 4,650 per year in 2045.[lxxxviii] When diagnosed at Stage I and II, survival to 5 years is over 90%.[lxxxix]

BreastCheck is the national breast screening programme for the early detection and treatment of breast cancer in women who show no symptoms of the disease. Women aged 50-69 are invited for a mammogram under BreastCheck every 2 years.[xc]

The current screening round is 3 years, compared to the usual 2 years. The recently launched National Screening Service Strategy outlines that screening will return to 2-year rounds in late 2023 – a welcome plan.[xci]

Some disparities exist in screening uptake. For instance, women from the highest education group (72%) attend breast screening at a higher rate than women from the lowest education group (56%).[xcii] A slightly smaller gap exists in uptake between women in urban areas (68%) compared to those in rural areas (65%).[xciii]

The National Screening Advisory Committee (NSAC) have asked that HIQA look at the evidence to expand eligibility of BreastCheck from age 45 to 49 and 70 to 74 years.

Asks:

- Fund recruitment drives for radiographers to ensure that BreastCheck has necessary staffing capacity.
- Further examine the feasibility of expanding the screening age to begin at 45 years of age, as per the European Council proposal for the age bracket to be extended to women aged between 45 and 74 years, and to consider specific diagnostic measures for women with particularly dense breasts.[xciv]
- Examine how best to enhance staffing capacity for BreastCheck when the age range is extended. The National Screening Service (NSS) should have guaranteed downstream hospital capacity for follow-on appointments that does not impact the delivery of symptomatic care.
- Invest in specific campaigns to target those eligible who are not participating in BreastCheck, emphasising its importance in the first instance and of repeated screening every 2 years.

CervicalCheck (ages 25-65)

Relevant Department: Department of Health

About 300 women are diagnosed with cervical cancer each year in Ireland.[xcv] If caught at Stage I, over 9 in 10 people will survive; unfortunately, survival reduces significantly with each subsequent stage.[xcvi] Fortunately, screening is available to identify people at-risk or with signs of cervical cancer.

CervicalCheck is the national cervical screening programme, which offers cervical screening tests to all women and people with a cervix who have been sexually active and aged between 25 to 65 (approximately 1.3 million individuals). The programme is responsible for the call, recall and management of the eligible participants through the screening pathway, as well as ensuring the follow-up of women referred for further care.[xcvii]

The aim of the programme is to reduce the number of people in Ireland who develop cervical cancer and, in tandem with the HPV vaccination programme, contribute to the elimination of cervical cancer in Ireland.[xcviii]

Unfortunately, disparities exist in CervicalCheck uptake rates in Ireland: women with a lower education level attend screening at a lower rate (29%) than women with a higher education level (69%).[c] Empowering people and communities to recognise and act on signs and symptoms of cancer, including through public awareness campaigns, is a critical step towards improving early diagnosis.

73% coverage rate for the CervicalCheck screening population vs. National Cancer Strategy targets of 80%.[xcix]

Self-sampling can be an effective and acceptable way to boost screening participation for those who do not wish to attend their GP for an initial screening exam.[ci] As per the European Council recommendations, kits allowing self-sampling should be considered to facilitate screening in non-clinical settings as a valuable strategy to reach underserved populations, where people do not follow up on their initial invitations to attend their GP for their CervicalCheck exam. In line with its approach for the elimination of cervical cancer, the World Health Organisation (WHO) recommends the use of self-sampling as an approach to HPV testing.[cii] The Irish Cancer Society made a submission to the National Screening Advisory Committee's first annual call recommending that self-sampling should be integrated into the CervicalCheck programme as an alternative test for people who do not wish to attend in person.

It is vital that any changes to the cervical screening programme complement the existing system, ensuring broader participation. For example, those who have abnormal markers on their test must then be brought into a GP clinic, or equivalent, for further testing. Primary care capacity must be considered in line with the expansion of the current screening service.

A new lab to process CervicalCheck samples opened at the Coombe but such services have currently been paused due to the need to finalise the accreditation process.[ciii] The Irish Cancer Society urges all efforts are directed towards a quick resolution to the issue. A workforce plan to support the transition of all testing of CervicalCheck samples to Ireland over the coming years, is needed.

Asks:

- Increase the uptake rate amongst communities that currently have low acceptance rates. For example, targeted communications campaigns aimed at groups with lower uptake levels are essential to improve screening rates.
- Pilot fund self-sampling tests for those eligible for the cervical screening programme to ensure as many people are tested as possible.
- Ensure sufficient capacity in line with the expansion of the current screening service.

3 Treating cancer

Ireland has made significant strides in cancer care since the 1990s. In about 30 years, survival has increased from 2 in 5 to 3 in 5.[civ]

We know that much of this success is due to many factors including the reorganisation of cancer services, centralisation of cancer surgery, new drugs, a decline in the rates of smoking and availability of cancer screening. To keep these hard won gains, such cancer services must be sustained and further developed. Into the future, more and more people will get a cancer diagnosis due to an ageing population, a growing population and exposure to modifiable risk-factors.

To do this, health services must at the very least keep pace with the demand for diagnostics and treatment.

The pandemic has had a considerable and negative impact on the number of cancers diagnosed. This is incredibly concerning to everyone in the cancer community, particularly in respect to cancers that have high mortality rates and tend to be diagnosed at a late stage, such as lung cancer. The fall in diagnoses puts even greater impetus to guarantee that patients can get timely access to treatment. Delays in accessing surgery, chemotherapy or radiotherapy of four weeks can affect mortality.[cv] Longer delays aggravate the risk.

“Our central concern is that in Ireland today, people are not being given the best chance of surviving cancer and having a good quality of life.”

“A cancer diagnosis is devastating and the prospect of treatment and the inevitable side-effects that follow is terrifying. And that is before the stress of delays, cancellations, financial barriers, crowded corridors, over-worked healthcare professionals and ultimately the worry that your care is not as good as it should be.”

– Averil Power, addressing members of the Joint Oireachtas Committee on Health.

Additionally, challenges with recruitment and sub-optimal retention rates within the healthcare system leads to further risk of not being able to optimise opportunities to progress cancer outcomes; or worse, slipping backwards.

We need to ensure that cancer services are stronger and more sustainable than ever before.

Our next step should be making sure 4 in 5 people survive, and in the longer term ensuring that nobody dies of cancer.

Regional accessibility of cancer care

Relevant Department: Department of Health

Healthcare staff are dedicated to providing high-quality care to their patients and are increasingly working in constrained environments. Investment in infrastructure and capacity must happen to support their efforts.

For example, University Hospital Galway (UHG) is a model four hospital, which serves approximately 1 million people in the region. Yet, the facilities cannot cater to the demand for services, including access to diagnostic tests and, as a consequence, access to timely care.[cvi] This invariably has a deep human impact on people with suspected cancer, and people treated for cancer, who rely on rapid access and who are competing for the access to hospital services.

Funding from the 2023 Capital Plan will be dedicated to commencing the project for a cancer centre at UHG, but a project design team should be appointed urgently to support the project.[cvii]

We acknowledge the investment in the new oncology unit at UHG, with plans to make the unit fully operational later in 2023.[cviii] The National Development Plan also outlines investment priorities around radiation oncology at Galway, Dublin Beaumont and St James's.[cix]

To deliver equal cancer outcomes across all regions in the future, planning should get underway to ensure services and supports beyond the current National Cancer Strategy cycle are planned for.

Throughout the remainder of this section on treatment for cancer, it is important to keep in mind the vital importance of fit-for-purpose infrastructure towards outcomes, such as survival and quality of life with and beyond cancer.

Asks:

We call on the Government to:

- Provide necessary investment in regional cancer services across the country to ensure cancer outcomes are equalised.
- Fund a national modelling exercise to anticipate future demand and need for services beyond the current National Cancer Strategy.
- Appoint a design team urgently to support the cancer centre at UHG.

Surgery

Relevant Department: Department of Health

When it comes to access to surgery, 90% of patients should be seen within the recommended timeframe, which varies by cancer type.

In 2021, this target was missed for breast (84%), lung (57%), prostate (47%) or pancreatic (49%) cancers.[cx]

One of the root causes of this problem is the fact that the infrastructure, staffing, and resources for diagnostics, surgery, support teams and even bed space often come from the same pool that the hospital system uses for intensive care patients, other acute medical needs and the diagnosis of different illnesses and diseases.

Life-saving and often time sensitive cancer surgery should not be competing for theatre time against other life-saving, unscheduled care in other areas of the health system. Even pre-COVID-19, elective surgery rates were typically reduced by 15% or more because of the winter surge.

This results in significant health, practical, financial and emotional consequences for patients.

We need to look towards the future and find a way forward that ensures every patient has timely access to cancer care, no matter what Cancer Centre they attend, the type of cancer they have or the stage at which they're diagnosed. Alongside this, adequate provision of surgical capacity needs to be made for the inevitable growth in cancer numbers.

Lessons in maintaining scheduled surgical activity must be taken from the COVID-19 response so access to this treatment is protected. For instance, infrastructural and operational improvements are required to avoid service disruptions[cxi] where other competing priorities are present within the healthcare system.

Asks:

- Develop a plan to increase surgical capacity to meet the significant increase in demand on surgical oncology over the next 20 years. The NCRI estimates it will be at least a 75% increase in demand.
- Provide additional bed capacity in ICU so that more cancer patients can get timely cancer surgery.
- Increase surgical oncologists' access to operating theatres.
- Build additional theatres so that more cancer surgery can take place and protect time for cancer surgery to take place.
- Enable adequate surgical capacity for preventative surgeries to take place when the patient makes the decision to proceed.
- Chart a new course for cancer surgeries so that cancer patients are not competing for theatre time with trauma and ED patients.

Radiation therapy

Relevant Department: Department of Health

Radiotherapy is a safe treatment option, which targets and destroy tumour cells.

The projected number of people attending radiation therapy in 2045 (12,756) will grow by 77% compared to attendance in 2015 (7,221).[cxii] But these figures do not capture the actual demand for radiation therapy into the future; rather they are based on 2019 figures when 27% of men and 33% of women attended radiation therapy.[cxiii] The figures are in contrast to the National Cancer Control Programme anticipating that 60% of people with cancer will require radiation therapy.[cxiv]

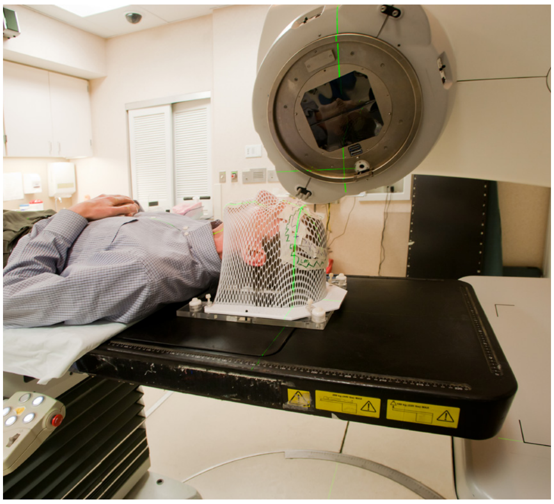
Unfortunately, many people are not getting timely access to this vital treatment. The national target aims for 9 in 10 people to start radical radiation therapy within 15 working days of being deemed ready to treat. Yet, this is far removed from the reality where only 7 in 10 cancer patients received radiotherapy on time (excluding palliative patients).[cxv] In other words, 3 in 10 cancer patients are not accessing this treatment on time. Unfortunately, the timeframe for meeting this target has been missed and there has been a decline in the proportion of patients getting timely access to radiation therapy in recent years (2017-2021).[cxvi] And timely access varies by cancer type: 6 in 10 people with prostate cancer started within the timeframe, and 7 in 10 people with breast cancer started within 12 weeks of their final surgery.[cxvii]

Such delays have a direct impact on patient outcomes, prognosis, earlier presentation of secondary cancers, among others.

There are many reasons behind this problem, including treatment machine closures and understaffing, which results in less treatment slots being available. To illustrate one aspect of the problem: there is a 30% shortfall in radiation therapists. The unfortunate consequence of this staffing deficit means around 4 machines are not in use, translating to approximately 120 missed appointments every day.[cxviii]

The reality of the situation is that access to radiation therapy services will only continue to fall behind demand for the treatment if these problems are not addressed.

And solutions to this problem exist. Urgent investment in the service in the short-term through investing in staff and career pathways is needed. At the same time, sustained planning and investment for the medium- to long-term viability of the service must also be actioned and sustained from this moment.



Asks:

- Allocate funding towards the recommendations from an ongoing consultation exercise with radiation therapists, the HSE and the Department of Health and other relevant stakeholders throughout 2024.
- Develop and fund a national plan that increase capacity in radiation therapy annually to meet the significant increase in patient demand expected over the coming years.
- Ensure a ring-fenced budget for procurement of machinery to enable machines to be replaced and updated as needed.
- Approve posts for out-of-hours support staff for radiotherapy practice.

Chemotherapy

Relevant Department: Department of Health

In 2015, 6,843 people accessed chemotherapy; by 2045, an anticipated 11,496 will need access to chemotherapy services.[cxxi] – a 68% increase.

Chemotherapy uses drugs to treat cancer by killing cancer cells, stopping the spread or growth of cancer and complementing radiotherapy. Immunotherapy treatment is designed to support the immune system with the aim of getting rid of cancer cells. The NCCP provides data on new systemic parenteral treatments (SPT) on day wards, which includes chemotherapy, immunotherapies, etc.

Nine in 10 cancer patients should have access to this treatment within 15 days of being ready to treat. It is important that the target is maintained or even exceeded to give people the best outcome possible.

Yet, timely access has been falling from almost 89.8% in 2019 to 86.6% in 2022 – a drop of 3.2 percentage points in 3 years.[cxix] The number of people attending for chemotherapy in 2019 (8,252) and 2022 (8,219) has remained relatively constant, though waiting times to access such treatment has increased over the years, suggesting that the service does not have the capacity to meet the demand.[cxx]

This is a worrying sign, particularly as the demand for chemotherapy will grow into the future.

Wave after wave of reports, strategies and policies have acknowledged the lack of capacity within the medical oncology service to meet current – and keep up with future – demand. The National Cancer Strategy, the leading cancer policy document, projected that people living with cancer who need systemic anti-cancer therapy (SACT) would grow faster than the number of new patients. Within this context, more medical oncology and haematology professionals would be required to meet the demand.[cxxii] The Strategy also called for a rolling capital investment plan.[cxxiii] The Irish Cancer Society believes such an investment plan should prioritise SACT services and timely access for patients. The National Development Plan 2021-2030 reiterates the Strategy's emphasis on improving units and day wards in medical oncology.[cxxiv] The Systemic Anti-Cancer Model of Care laid further emphasis on the importance of treating patients as close to their home as possible (for instance in Type 3 or 4 SACT services), and of ensuring that people waiting for SACT are managed effectively and that the key performance indicators are met.[cxxv]

Each of these plans have been drafted in response to a service which has been constrained for years. In 2017, the Midterm Capital Funding Review: NCCP Submission Cancer Day Ward Facilities for Systemic Anti-Cancer Therapy showed that day units were exceeding capacity by 20% and recommended a 70%-100% increase in capacity by 2025.[cxxvi]

Unfortunately, by the end of 2022, the statistics on timely access to chemotherapy and SACT services does not show progress in this regard. Almost a decade ago, the 2014 NCCP Oncology Medication Safety Review Report[cxxvii] highlighted that day ward facilities were not always appropriately organised, e.g. some space was not designed for the volume of people using services, patients waiting in corridors for appointments, some units would have less than a metre of space between patients.

The Irish Cancer Society believes that the Sláintecare vision for the right care in the right place at the right time[cxxviii] will not be achieved in relation to SACT services, where suboptimal facilities impact on availability of space and timeliness of access to care, without serious investment and course correction. **The time to build the workforce, capacity and infrastructure is now.** Capacity in day wards, including the recruitment of oncology nurses and a revision of the use of space, must be prioritised. Furthermore, oncology care in the community must be advanced.

Asks:

- Develop recruitment and retention strategies for oncology nurses in the day ward and haematology professionals.
- Fund the physical expansion of oncology day wards, to increase patient capacity (alongside increase in staffing capacity).
- Fund oncology services in the community setting without delay.

Access to medicines

Relevant Department: Department of Health

The medicines approval process in Ireland is a lengthy one. Roughly 7 out of every 20 (36%) drug reimbursement applications are completed by the HSE within one year.[cxxix] Recent findings from an EFPIA commissioned survey found that it took 673 days post-European Medicines Agency (EMA) authorisation for new cancer drugs to be made available to patients in Ireland. This is compared to Germany, where post-EMA authorisation, new cancer drugs can be made available in 102 days.[cxxx]

The Mazars review of the HSE reimbursement and pricing decisions process highlighted a number of recommendations, which would support governance and process through the allocation of resources. For instance, while expertise is available, more people working on the process are required.[cxxxi]

Such lag times in the approvals process have an inevitable impact on the care available to patients and their families. The Irish Cancer Society welcomes the Government's intention to work on the drugs reimbursement process, through indicative approval timelines and an application tracker. In particular we welcome the plan to establish an Implementation Working Group between the Department of Health and the HSE.[cxxxii] The Irish Cancer Society would like to be involved in this working group to put forward the needs and priorities of people affected by cancer.

Asks:

We ask the Government to fully fund the set up and implementation of measures designed to support the approvals process in Budget 2024:

- Establishment and running of the Implementation Working Group.
- Development and implementation of an application tracker.
- Oversight/governance for compliance with indicative timelines for approval of medicines.
- Greater resourcing for staffing at the NCPE and NCCP as outlined in the Mazars review.[cxxxiii]

Investment in the following would bolster cancer services:

National Cancer Strategy

Relevant Department: Department of Health

Appearing before the Oireachtas Health Committee, the Irish Cancer Society called for a renewed focus on the Cancer Strategy with "investment in bricks and mortar, beds and equipment, as well as empowering the National Cancer Control Programme and resourcing and retaining our incredible cancer workforce."

The reality is that the National Cancer Strategy is not progressing as it should be. For example, out of 23 key performance indicators (KPIs), 4 were deemed met at the end of 2021. Six were unmet. Others did not have the required data and some have not reached their deadline yet.

The strategy is an ambitious but realistic policy – it needs funding and it needs support and capacity from within the health system. We need to be future focused and understand what more is possible.

Continued focus and resourcing is needed to deliver sufficient diagnostic and treatment capacity to clear the COVID backlog and ensure all cancers are being picked up at an early stage when they are easier to treat. Funding services and recruiting a full cancer workforce is critical to ensuring survival rates don't go backwards.

The fact that official data from the first year of the pandemic in 2020 was only released at the end of 2022 highlights a major gap in our health services. Similarly, much of the data reported on dates from 2017.

The current iteration of the National Cancer Strategy will expire in 2026. Now is the time to assess and plan to build upon progress to date, prioritise action amongst items not yet achieved and develop objectives for the next 10-year cycle.

Sustained funding is vital to ensure the implementation of the current strategy to prepare for actions in the next strategic cycle. Multi-year funding and spending plans should be dedicated to implementing the Strategy to 2026, starting with an initial injection of €20 million in 2024.

Asks:

- Ring fence multi-year funding dedicated to implementing all outstanding recommendations from the Strategy to 2026, starting with an initial injection of €20 million in development funding in 2024.
- Evaluate NCCP progress to date and prioritise action items not yet progressed.
- Begin planing for the next strategic cycle in 2026.

Costs:

- €20 million for new development funding.

Clinical Trials

Relevant Department: Department of Health

Clinical trials are used to determine the safety and benefit of new approaches to treatment and care. In Ireland, clinical trials are led by patient need, giving access to new and innovative treatments, which would not otherwise be available outside of the trial.[cxxxiv]

The aim of clinical trials for people affected by cancer, and the reason why clinicians open trials, is to find new and more effective treatments and interventions, aimed at identifying new ways to improve the quality of life and outcomes. Such innovative treatments are made available without any cost to the participant, or to the State.

The availability of clinical trials for cancer patients enables access to the latest in breakthrough medical innovations, with the possibility of improving future cancer treatments, impacting the quality of life and survival rates. A key priority in the Irish Cancer Society Strategic Plan (2020-2025) is ensuring that Irish patients benefit from world-class cancer research and expertise. Central to this focus is fostering and cultivating clinical trial research to ensure that Irish cancer patients have access to excellent cancer treatment, research and leaders who will drive innovative, evidence-based improvements in patient care.

Cancer trials should be central to the treatment options available to people with cancer. As well as funding drug-based trials (so called IMP trials), the Irish Cancer Society also advocates to support the funding and development of non-drug based trials (non-IMP trials) in areas such as diagnostics, technology, radiotherapy, surgery, psycho-oncology, exercise, nutrition, side effect reduction and combinations of these.

Analysis commissioned by Cancer Trials Ireland estimates that the yield from State investment into cancer trials is double that which is invested, saving the State significant expense, e.g. in 2016 an estimated €6 million was saved in the cost of cancer drugs as these costs are typically covered by the trial sponsor.[cxxxv]

The National Cancer Strategy aimed to have 6% of patients on cancer therapeutic clinical trials by 2020.[cxxxvi] Despite such a low target, the accrual rate in 2017 indicated a 3% rate of participation.[cxxxvii] However, following on from the impact of the COVID-19 pandemic, this figure in recent years has now dropped even lower, with Cancer Trials Ireland reporting a 54% decline in clinical trial accrual, including a 90% reduction in accrual to radiography trials, persisting for over 18 months.[cxxxviii]

Flexibility in trial conduct, staff recruitment and retention, the need for harmonisation of processes, and research staff support in the context of remote working, were identified as priorities by the group.

Asks:

- Provide sustained, regular investment in clinical trials research and infrastructure.
- Streamline the national clinical trial regulation processes.
- Ensure dedicated, protected research time is provided for health care professionals to lead more investigator-led clinical trials in Ireland.
- Deliver strategies to improve the recruitment and retention of clinical trials staff and researchers.
- Develop communication initiatives to improve knowledge and awareness of cancer clinical trials in the wider public.

Staffing

Relevant Department: Department of Health

Healthcare staff are instrumental in delivering the early diagnosis and timely care patients need – in cancer care, their skills and expertise is invaluable.

Healthcare and frontline staff have been dedicated and hardworking in difficult circumstances. It is no secret that health professionals are reporting difficulties working within the system. A study released in 2020 highlighted how stressful working conditions and poor training in the Irish system have hindered retention measures.[cxxxix] The COVID-19 pandemic had a huge impact on healthcare workers, adding to their stress.[cxlvii]

There have been numerous announcements on the hiring of additional health care professionals, including 854 additional nursing posts announced by Minister Donnelly in May 2023 and an increase of 20,000 staff working for the health service since the COVID-19 pandemic began.[cxl] This is both welcome and necessary and we are grateful for this focus. However, unless there is an effective plan to retain trained medical and allied health professionals within the Irish system, the talent being recruited into the system will continue to exit at a considerable rate.

In 2022, Ireland trained an estimated 700 doctors. In that same year, 432 applied for visas and left for Australia.[cxli]

Doctors are emigrating. Junior doctors/non-consultant hospital doctors reported that working conditions, poor staff retention and their own wellbeing as motivating factors for emigrating.[cxlii]

Primary care is in crisis. Primary care is often the first port of call for symptoms of cancer, and is an important resource in catching cancer early, as well as in prevention activities. Due to current shortages, those with symptoms of cancer may face difficulty accessing their GP. The ICGP (Irish College of General Practitioners) has advised that 6,000 GPs will need to be in place by 2028 to meet existing demand and to accommodate for a growing population as well as GP retirements.[cxliii] The IMO reports that 1 in 10 people don't currently have a GP.[cxliv]

Early detection and diagnostic services need investment. For instance, there is a worldwide shortage of radiologists, and this has an impact on Irish services, including the BreastCheck programme. Many BreastCheck radiologists work across symptomatic or general radiology services, too[cxlv] – any plans to reduce the BreastCheck screening age and catch pre-cancers and early stage cancers in women before age 50 would need significant investment in staff recruitment.

Treatment services are understaffed. We already know that we have a staff shortage, and that this will only continue if we do not take the steps to remedy the situation, and to support the continuity of cancer care. There aren't enough radiation therapists: in Ireland, there is a 30% shortage.[cxlvi] Ireland has 0.6 radiation oncology professionals per 100,000 of the population compared to Australia's 1.3 and Canada's 1.5. There is 1 medical oncology professional for every 100,000 of the population in Ireland, in contrast to Australia's 1.9.[cxlvii] The OECD has noted areas for improvement in staffing the Irish healthcare workforce, highlighting the need for more specialists and advanced practitioners in surgical and radiation oncology, as well as research/clinical trials.[cxlviii]

Healthcare staff need a clear vision for the future of the health service, including how their prospects for progression and work/life balance will be achieved in order to remain in healthcare and to practice in Ireland. Many of these plans should be made in the short- to medium-term, which will lead to long-term benefits for staff and patients.

A thorough review of the cancer care workforce and a well-resourced strategic plan is required to ensure adequate capacity in the system. Such a review should start with accounting for the number of professionals working across different services and forecasting need alongside NCRI cancer incidence projections to 2045.

To ensure Ireland becomes internationally competitive, wider staff retention and pay issues must be addressed, along with those relating to accessing resources necessary to carry out work duties effectively. Incentives, such as opportunities to engage in research and training, as well as mapping out career progression pathways for doctors, nurses and allied health professional would be important.

To this end, enough places must be available at university level, as all as adequate training places throughout the pathway towards qualification, alongside bursaries to afford to move around the country to attend placements. To illustrate, a 2020 report highlighted that an additional 7-8 people must be admitted to higher specialist training to 2024/2025 for medical oncology.[cxlix] According to the Irish Hospital Consultants Association (ICHA) that amounts to a requirement for 73 new oncologists by 2028 in addition to the support staff needed to ensure those extra posts can deliver increased volumes of care.[cl]

To ensure Ireland becomes internationally competitive, wider staff retention and pay issues must be addressed, along with those relating to accessing resources necessary to carry out work duties effectively. Incentives, such as opportunities to engage in research and training, as well as mapping out career progression pathways for doctors, nurses and allied health professionals are essential.

Asks:

- Invest in workforce planning across different specialties, including GPs, radiology capacity, radiation therapy in addition to other hospital staff roles along the cancer pathway.

eHealth

Relevant Department: Department of Health

An Electronic Health Record (EHR) is a digital version of a patient's paper chart. EHRs are real-time, patient-centred records that make information available instantly and securely to the authorised user.

> **"The HSE's vision is that "E-health provides connected and complete digital patient records across all patient pathways and care settings."**[cli]

There are strong e-health commitments in the Programme for Government,[clii] Sláintecare plans[cliii] and the eHealth Strategy for Ireland.[cliv] A 2022 OECD economic survey highlights Ireland's weakness in the area of digital health.[clv]

The current system lacks access to timely, accurate and robust data essential for informing decision-making and best utilising resources across departments. The health service is being held back by inefficient, often paper-based interactions.

Reports released by the Royal College of Physicians on the impact of COVID on cancer care, highlight how the absence of integrated electronic health records across the health care system, along with the absence of near real-time complete data, prevented a comprehensive oversight of cancer related activity in Ireland during the pandemic.[clvi,clxvii]

> **"Is it not an awful indictment that there is more known about each one of our cars through the national car test database than there is about our public health?"**
>
> *– Cathal Crowe (Oireachtas Health Committee, 25th January 2023)*[clviii]

Following the pandemic, it is vital to take on board measures that would fundamentally improve how the healthcare system in Ireland operates.

Up-to-date data and information are integral parts of the healthcare system, essential for the delivery of high quality and effective health and social care.

Implementing technology and e-health solutions to accelerate the digitisation of our health service will allow for effective healthcare system planning. Such data can be used to improve services and in supporting research.

Effective healthcare system planning

Our technology and e-health systems must be radically overhauled to provide the solutions required in a modern healthcare system.

A national rollout of EHRs is one way to capture a patient's medical history across the health service. An Individual Health Identifier (IHI) is assigned to each person and linked to an EHR. This ensures that patient information is accessible, improving patient safety as it allows patients direct access to view and correct inaccurate information.

This would also overcome obstacles associated with having to transfer paper records from one area of a hospital to another, particularly when patients are receiving treatment across different hospitals among a range of services.

EHRs would also reduce the administrative burden on staff while identifying gaps in the system where additional services are required.

A recent report from Seamus O'Reilly et al. (2023) highlights how the availability of real-time high-quality data featuring statistics on all cancer types across the health care systems (public, private and voluntary) is imperative to improve cancer services and effectively track cancer-related activity. Suggestions of information to be captured includes, data on surgery, radiology and cancer genetics among others.[clix]

This would include harmonised diagnostic services between and within public and private hospitals to improve inter-hospital connectivity and integration of multidisciplinary patient care.[clx]

The Irish Cancer Society strongly welcomes the recent announcement from the Minister for Health on Cabinet approval for the General Scheme of a Health Information Bill. We hope legislation passes through the Houses of the Oireachtas in a timely manner so the roll out of IHIs can begin as soon as possible.

Health research perspective

As discussed in the Joint Oireachtas Committee on Health at the end of January 2023,[clxi] researchers need a national perspective to capture the full picture of a situation. Without national databases and national access to people's records and health, generalising scientific findings for analysis is not possible, affecting the ability for European and global comparability. A fully functioning eHealth system would allow for European and global comparison on averages and norms as to why patients have better outcomes in one region versus another.

The absence of electronic health records impacts on the research landscape as only certain data is available to researchers when looking at the national picture, causing difficulty in attracting clinical trial studies in Ireland.

As outlined above, the benefits to rolling out EHRs nationally are significant. Sustained investment is essential to ensure they provide ongoing clinical and administrative benefits to both patients and clinicians.

Asks:

- Provide sufficient funding to develop and implement the national rollout of electronic health records across the health system.
- Provide funding for extra staff, including towards extra IT staff within the HSE, to assist in the progression towards the rollout of electronic health records nationally.
- Prioritise additional support for digital infrastructure across cancer services.[clxii]

Sláintecare

Relevant Department: Department of Health

The premise behind Sláintecare offers real vision of a single-tier, publicly funded, integrated health care system that is accessible to all. Appropriate treatment must be available on a needs basis, rather than on the basis of means. There must be no restriction based on ability to afford healthcare.

It is important that the vision of universal healthcare is implemented, particularly to reorganise the demand on services. The Committee on the Future of Healthcare Sláintecare Report outlined scope for rethinking roles and making full use of the skill sets of health and social care professionals to alleviate pressures in the system and on waiting lists, in particular to bring some services, which are provided in hospitals, into the community and primary care.[clxiii]

The 2017 Sláintecare report[clxiv] recommended a transitional fund of €3 billion over the first six years of the strategy, equating to €500 million of investment per annum. Spending allocation must reflect the changes in demographics, increases in inflation and the frontloading nature of the fund. This involves a budget increase of 10%, year on year, to complete this phase of the plan in a comprehensive and protected manner.

While the most recently available Sláintecare Progress Report[clxv] highlights areas where the initiative was on track, there are many important areas, which have met significant challenges, such as actions to deliver a multiannual plan on reducing waiting lists and eHealth. For instance, in April 2023, 490,993 people were on hospital active waiting lists and waiting longer than recommended timeframe set out in the Sláintecare plan.[clxvi]

The 2017 Houses of the Oireachtas Sláintecare report recommended maximum wait times of no more than 12 weeks for an IPDC procedure or GI Scope and 10 weeks for a new outpatient (OPD) appointment. Across 2022, action was taken to offer people appointments, particularly those waiting longer than 12 months. For instance, 38.5% of people waiting longer than 18 months on an outpatient list, 22.6% of people waiting more than 12 months for an inpatient day case procedure and 86.5% waiting more than 12 months for a GI scope, were offered an appointment.[clxvii]

Asks:

- Fully fund the implementation of the Sláintecare report.

Lymphoedema services

Relevant Department: Department of Health

Approximately 12,500 people in Ireland have lymphoedema, which is incurable and lifelong, as well as having a significant impact on the quality of life of patients and their families.

Lymphoedema is a progressive, chronic disease that causes swelling of body tissue due to failure in the lymphatic system, a network of vessels and glands located throughout the body, and can affect people of all ages. It can be inherited or develop as secondary due to lymphatic damage as a result of cancer or its treatment, vascular disease, dependency, trauma or chronic infection.

Annually an estimated 1,451 patients are admitted to hospital with cellulitis related to lymphoedema. Average hospital stays of 11 days cost approximately €13.6 million to the Irish State. Based on international studies, this €13.6 million cost of treating these patients could be reduced by over 87% with the introduction of comprehensive lymphoedema services.[clxviii]

A proposed model of care, published in 2018, sets out plans to deliver a comprehensive service for patients to deliver.[clxix]

The HSE initiated the implementation of the Model of Care for Lymphoedema and Lipoedema through two proof of concept services – one for a primary care specialist lymphoedema service in Laois/Offaly (Community Healthcare Organisation 8 area) and the other for early detection in acute services (Mater Hospital). The first specialist lymphedema clinic opened in 2020 in Co. Clare. To date, 328 patients have been treated. A second clinic opened in Meath in May 2021, with 177 patients attending to date.

Further to the Model of Care, the National Lymphoedema Clinical Guidelines were published in Q4 2022 after a lengthy delay.[clxx]

The need for lymphoedema services will continue to rise due to an ageing population, increase in obesity and increased cancer diagnosis and survival rates. Clinical outcomes from the specialist centres in Clare and Meath have demonstrated "improved quality of life, improved access and high patient satisfaction." Patients reviewed after the first 6 months of treatment reported how their GP visits had reduced by 86% and public health nurses visits by 70%, reducing the pressure on primary health services locally. In addition, there was a drop in reported number of episodes of cellulitis from 49 to 3.[clxxi]

Funding for lymphoedema services is inconsistent and varies according to health care professional and site of services.[clxxii] As evidenced from the positive findings above, the State must ensure that the full roll out of the model of care is funded on a permanent basis.

Asks:

- Fully fund the Lymphoedema and Lipoedema model of care.

Costs:

- €8 million annually.

4

The Cost of Cancer

The Irish Cancer Society Support line received 30% more enquiries on financial issues in 2022 when compared to 2021.

After many years of campaigning to reduce the costs carried by cancer patients, the Irish Cancer Society welcomed the momentous announcement of the abolition of hospital in-patient charges and, consequently, the end of debt collectors' pursuit of cancer patients for such fees in Budget 2023.

Cancer takes a toll on a person and their family with many costs. From the moment of diagnosis, the quality of life and wellbeing of cancer patients and survivors must be prioritised, and this includes protecting their psychosocial and financial welfare.

Almost from the moment of diagnosis, cancer patients experience significant financial loss, for example a reduced household income.[clxxiii] At the same time, cancer patients and their families face massive increased expenditure on items such as medication, supplements, modifications to the home, additional heating costs while on treatment, car parking, wigs and new supportive clothing, to name just a few.

The cost of living crisis, too, has had an impact on people affected by cancer with over half worried about keeping up with paying bills amid rising expenses.[clxxiv, clxxv]

We want to see people supported beyond their cancer treatment and into survivorship, where many people face unexpected and sometimes costly challenges, including in returning to the workforce or starting a family. The number of cancer survivors in Ireland has grown by over 50% in 10 years to 207,000.[clxxvi] That is to say that 1 in 24 people are building their future post-cancer[clxxvii] and the Government can support them in moving forward.

We urge Government to take affirmative action to address the impact of rising living costs and increasing financial expenses is having on hard-pressed patients and their families. More supports to protect patients from the costs of having cancer are needed, including into survivorship.

Our Budget 2024 recommendations include vital, practical measures to address the huge financial and social impact of cancer.

Cancer during pregnancy and maternity leave

Relevant Department: Department of Children, Equality, Disability, Integration and Youth

Cancer can cast a shadow over life's precious moments. Each year, an estimated 60 women are diagnosed with cancer during pregnancy.

Little research has been conducted on the psychosocial impact of a diagnosis during pregnancy, and few supports have been mapped out. It is therefore important for research to examine this topic further and to identify interventions to support women with cancer during and after pregnancy.[clxxviii]

Sixty new mothers will undergo cancer treatment, which is gruelling, following the birth of their child(ren). Unfortunately, this treatment will take place during their maternity leave without any right to postpone it to take sick leave to complete their treatment before resuming maternity leave. Cancer treatment can take up most or all of the maternity leave allowance, leaving new mothers with no additional protected time to spend with their child.

> **"I thought I would be on illness benefit and keep my maternity leave for when I was no longer too ill to look after my baby fully. Because I had to go on illness benefit after my maternity leave ended I also couldn't postpone my 16 weeks unpaid leave either and lost that too."**
>
> *- Erica*

The Irish Cancer Society calls for the Government to amend legislation so new mothers with cancer have the option of postponing their maternity leave. To secure the legislative change, we ask Government to allow new mothers to postpone maternity leave to undergo their cancer treatment, which would require a financial commitment to secure sick pay during treatment, and a guarantee that the 12 final weeks of paid maternity leave can be postponed until treatment ends.

While Government is contemplating action on this, 1 new mother a week is foregoing maternity leave and living with the incalculable costs to family life. A small number of people are impacted, meaning the annual investment from Government into supporting them through this difficult time would be feasible.

Asks:

- We call on the Government to allocate €2.6 million annually to develop a fund, which would cover:
  - An illness benefit payment for new mothers/birthing parents during the time of their treatment for cancer.
  - A fund for employers from which to draw down in order to cover costs associated with sick pay cover where a new mother has had to postpone maternity leave.
- Furthermore, maternity leave benefits should be available to new mothers/birthing parents once maternity leave has been restarted, following the end of cancer treatment. Such options are available to new fathers: for instance, if a father is sick before paternity leave begins, he can postpone paternity leave until a recovery is made.[clxxix]
  - Further allocate €500,000 in research grants to examine the needs of expectant parents who were diagnosed with cancer, with specific priority on expectant/new mothers and the development of recommendations around services required to accommodate their psychosocial needs.

Car Parking

Relevant Department: Department of Health

The 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".

The Government has promised to reform hospital parking charges since 2018 but still the costs fall on those least able to afford them.

2016	Irish Cancer Society 'Park the Charges' report published.
2018	HSE to carry out a national review of hospital car parking charges. HSE finished review - never published.
2019	HSE implementation plan to the Department of Health.
2020	Programme for Government commitment to "introduce a cap on the maximum daily charge for car parking for patients and visitors at all public hospitals, where possible", and "introduce flexible passes in all public hospitals for patients and their families".
2022	Irish Cancer Society 'The Hidden Costs of Hospital Car Parking for Families' report published.

For over 7 years, the Irish Cancer Society has highlighted the need to protect cancer patients from financial burdens such as car parking. In the years since, thousands of patients and their families have had to spend significant sums of money just to get to the hospital door to access lifesaving treatment.

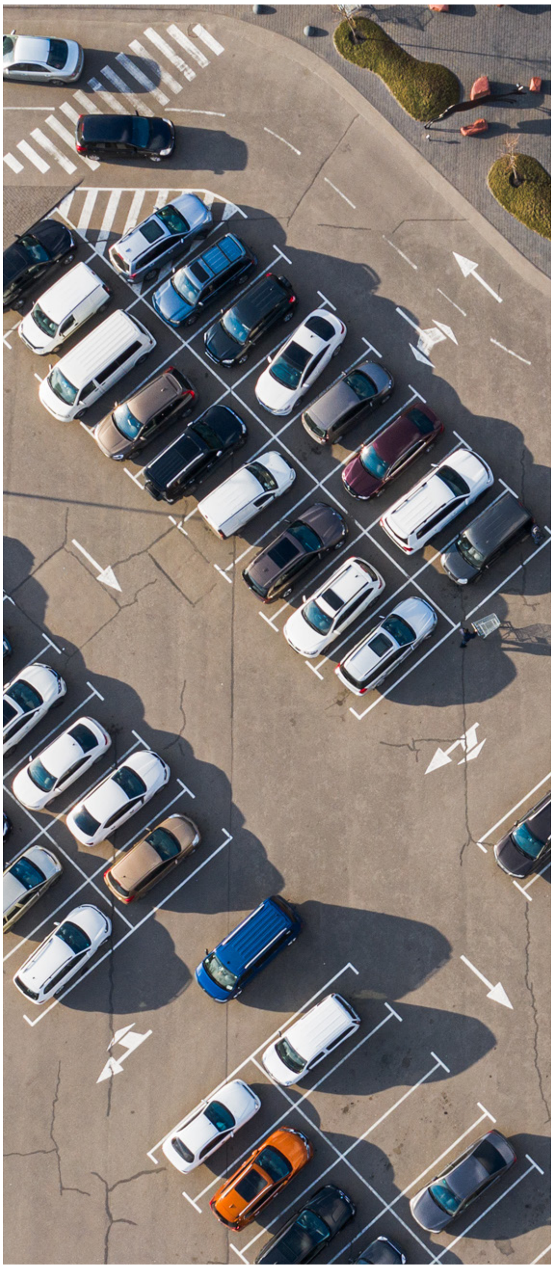
Parking charges mostly affects those with chronic conditions, who are least able to afford it, and impose not only financial, but also non-monetary costs, including time and stress. Costs, such as car parking charges, quickly take their toll when patients are struggling to deal with huge additional expenses, a drop in income, as well as significant expenses before reaching the hospital, such as childminding, accommodation and travel.

Statutory, voluntary and private hospitals in Ireland all arrange car parking differently with an inconsistent approach across hospital groups. Currently, 31 statutory hospitals provide parking to the public, 8 of which have free parking – Roscommon UH, Nenagh,

Ennis, Croom, University Maternity Hospital, Mallow General, Bantry General, St Luke's Radiation Oncology Network.

Car parking income at acute hospitals generated €5.1 million in 2021 and €7.4 million in 2022 (although 2022 figures are currently provisional).[clxxx]

Even where concessions are available for patients, they are often not well publicised which can lead to people paying for parking unnecessarily.



> **"I am self-employed and my ability to work was impacted while in treatment. I had to pay for up to five hours' parking at a time when I went into the hospital, which doesn't sound like a lot, but it is significant when you have countless appointments and other household expenses piling up. We had to dip into savings so that buffer is not there anymore. Even after treatment new expenses that you never considered can keep popping up"**
>
> *- Geraldine*

Hospital car parking challenges:

- **Inconsistent approach to car parking across hospital groups.**
- **Lack of centralised database for car parking charges or concessions.**
- **Lack of advertising where car-parking charges exist.**
- **No refunds if patients accidently overpay.**

The Irish Cancer Society does not believe that car parking charges should be used as a revenue-raising tool.

Alternative revenue sources should be used rather than the excessive car parking rates charged to already hard-pressed families.

Asks:

- Abolish car parking across all public hospitals for cancer patients.
- Develop defined delivery timelines by Government.

Medical cards

Relevant Department: Department of Health

The Irish Cancer Society/Core Research *Cost of Living* survey from November 2022 showed that 2 in 5 people had medical costs associated with their cancer diagnosis, averaging €202 per month. Of these people, 1 in 4 had costs for GP visits averaging €121.[clxxxi]

Medical costs are a significant expense for cancer patients and the wider provision of medical cards would alleviate some of the financial difficulty associated with a cancer diagnosis.

One in 5 people who had a cancer diagnosis did not attend a GP/hospital appointment in the past 6 months even if needed. The cost of living crisis is felt by carers of cancer patients, too. Two in 5 carers avoided attending a GP/hospital over the same time period.[clxxxii]

Having automatic entitlement to a medical card removes the expense associated with visiting a GP and for the majority of medicines prescribed and would alleviate expenses for cancer patients who need continued medical care.

The State must provide more protection to some of society's most vulnerable by ensuring that no patient has to choose between purchasing their medication or providing for their families.

Asks:

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

Prescription charges

Relevant Department: Department of Health

If you are a medical card holder, unless you qualify for an exemption, there is a charge for items on prescription.

If you are under the age of 70 years, there is a prescription charge of €1.50 for each item. This is up to a maximum of €15 per month, for each person or family.

If you are over 70 years of age, there is a €1 prescription charge for each item. This is up to a €10 maximum charge per month (for a person/family).[clxxxiii]

While the Irish Cancer Society welcomes reductions to prescription charges in recent budgets, the State must honour commitments to reduce the financial burden on economically vulnerable patients, and to ensure that everyone can access the medicine they need.

The Irish Cancer Society/Core Research Cost of Living survey shows that 40% of people affected by cancer had additional medical expenses associated with their cancer diagnosis, particularly over the counter medications (34%; €49) and prescription medication (23%; €110).[clxxxiv]

People from lower income households are disproportionately affected by what the WHO report by Johnston et al refer to as so-called catastrophic health spending, where out-of-pocket payments are greater than 40% of capacity to pay.[clxxxv] To alleviate the burden, medical cardholders should not have to pay prescription charges.[clxxxvi]

To make progress on a universal healthcare system, healthcare expenditure should be paid from the central exchequer and funded by progressive tax measures rather than regressive and counter-productive user charges.

Asks:

- Abolish prescription charges as part of Budget 2024 to reduce the financial burden on economically vulnerable patients.

Drugs Payment Scheme

Relevant Department: Department of Health

The Drugs Payment Scheme means that an individual or their family will not pay more than €80 each calendar month for approved prescribed medicines or medical and surgical appliances.

As per the 2017 Sláintecare Report[clxxxviii], it was recommended that the Drugs Payment Scheme threshold for single-headed households be reduced to €72 per month.

The Irish Cancer Society calls for this threshold reduction to alleviate the disproportionate financial burden experienced by this group.

Household Benefit Package

Relevant Department: Department of Social Protection

The Household Benefits Package (HBP) helps towards the costs of electricity or gas bills with one payable per household.

Findings from the Irish Cancer Society/Core Research Cost of Living survey showed that fuel, electricity and heating bills are the most common additional expenses faced by people affected by cancer.[clxxxix] More than half of patients surveyed were worried about keeping up with paying bills amid rising expenses and at a time when patients' income can take a huge hit.[cxc]

Such recurring expenses result in significant financial burden for those living with cancer, making managing household finances incredibly difficult.

Cancer patients would benefit greatly from contributions towards electricity or gas costs towards preventing instances of fuel poverty among those with cancer and their families.

> **"It has caused stress for me the carer and on the patient. Patient (husband) constantly cold as a result of chemo treatment. Heating constantly on. Very worrying if we can meet the bill?"**

Asks:

- Reduce to the Drugs Payment Scheme threshold to a maximum of €72 per month.

Costs:

- €12.5m per annum.*

* Minister for Health (18 April 2023) in response to parliamentary question (reference: 17048/23) asked by Deputy Neasa Hourigan. Available at: https://www.oireachtas.ie/en/debates/question/2023-04-18/1518/

Asks:

- Expand the Household Benefits Package criteria to include all cancer patients upon diagnosis, until their treatment is finished.

Costs:

- An estimated €25 million[cxci]

Partial Capacity Benefit & extra supports to attend medical appointments

Relevant Department: Department of Social Protection

In February 2021, the Irish Cancer Society commissioned the Economic and Social Research Institute (ESRI) to conduct research on 'Returning to employment following a diagnosis of cancer'.[cxcii]

Although this research revealed a broadly positive picture, with almost 7 in 10 patients and survivors stating their manager or organisation supported them in their return to work, almost half of people returning to work reported that their cancer diagnosis had a negative impact on their career. As more people than ever are either surviving cancer or living well with cancer, we must ensure that greater practical and financial supports are available to patients as they navigate one of the most stressful times of their lives.

The Irish Cancer Society published a number of recommendations for employers, trade union and representative groups, as well as Government, with measures on how to best assist employees returning to work post-cancer diagnosis.[cxciii]

Many people may wish to return to work post cancer diagnosis, although often chronic illness and its after-effects mean they will require flexibility and support to do so.

Following this, as part of Budget 2024, the Irish Cancer Society is asking the Department of Social Protection to broaden the eligibility criteria for Partial Capacity Benefit, to increase security for those with a previous cancer diagnosis seeking to return to work.

We believe that the eligibility criteria for Partial Capacity Benefit is too narrow, and that often people who would benefit cannot qualify for it. This form of top-up payment can help people return to work or self-employment with reduced hours and continue to receive a payment from the Department of Social Protection enabling a phased return to work.

COVID-19 has fundamentally changed the way we work in Ireland. Moving forward, we must ensure that support and flexibility continue to underpin our approach to assisting cancer patients and survivors in the workplace.

Asks:

- 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.

Bras, wigs and prosthesis allowances

Relevant Department: Department of Health

When a person is diagnosed with cancer, they need affordable access to vital specialised supports such as post-mastectomy products (PMP) and hairpieces (including wigs, scarves or turbans etc).

Post-mastectomy products (PMP) consist of post-mastectomy bras and prostheses. They are used following partial and full mastectomies.

As it stands, the provision of the contribution is on an annual basis for post-mastectomy bras and every second year for post mastectomy prostheses, from the HSE CHOs and/or appropriate HSE funded location.

Hairpieces are provided to cancer patients with short-term, cancer related hair loss on a once-off basis by the HSE via the CHOs. The average price of a synthetic wig ranges between €350 and €500. For human hair, it can vary between €600 and €1000 and beyond.

Currently, allowance amounts for both PMPs and wigs vary depending on CHO area, creating geographic financial inequity.

The State must ensure equitable access to PMP and hairpieces for all those who need it.

Asks:

- Ensure a standardised, equitable approach to accessing PMP and hairpieces allowances for those diagnosed with cancer.

Access to fertility services

Relevant Department: Department of Health

Planning and completing a family post-cancer treatment is a significant consideration in survivorship. Fertility preservation provides cancer patients – who are at risk of infertility due to treatment with an opportunity to have children.

Currently there is a free service for adult cancer patients through Sims IVF, funded by the HSE, which facilitates the freezing of sperm, eggs or embryos for 10 years at no cost to the service user.

However, fertility preservation is currently not available through the Irish public health service. Therefore, in order to use the saved sample in the pursuit of having a child, the cost must be covered out-of-pocket.

This means that many of those cancer patients who have frozen their sperm, eggs or embryos through public funding, in the hope of one day having children, can be hit with huge costs when they do decide to have children, excluding all but those who can afford very expensive fertility treatment.

People with infertility after cancer can often find themselves in a race against time to have a child. This makes them very vulnerable in a market that is highly commercialised but also to explore fertility treatments that may have no proven medical efficacy.

An IVF cycle costs approximately €5,000 - €6,000, depending on the clinic and treatment required. There is also the additional cost of transferring eggs, sperm or embryos that have been taken as part of fertility preservation to other fertility clinics. Meanwhile, the additional associated costs (direct and indirect) to the patient being treated in a clinic that is not geographically close to their home can also be significant.

An estimated 9,000 couples access private clinics in Ireland for IVF treatment, not including those who travel abroad.[cxciv]

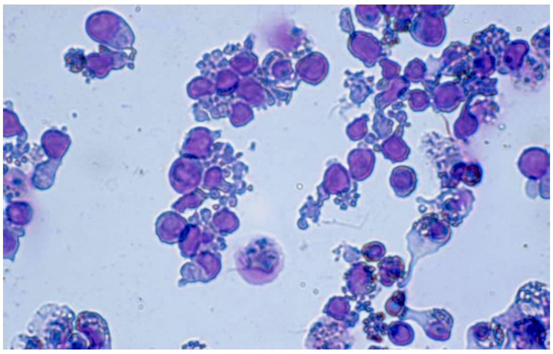
Ireland is the only State in the EU that does not offer publicly funded IVF treatment.

The European Atlas of Fertility Treatment Policies ranked Ireland as "exceptionally poor" in their comparative study on fertility services and related policies across Europe.[cxcv]

The Minister has announced that some funding will be made available to support access to advanced Assisted Human Reproduction (AHR) treatment via private providers from September 2023.

The announcement of the development of Regional Fertility Hubs is warmly welcomed by the Society. The hubs need to be rolled out as a matter of urgency to ensure that all patients have access to these vital public services.

The Irish Cancer Society believes that cancer patients, and others, have been waiting too long for equitable access to fertility treatment and is calling on Government to make good on its commitments[cxcvi] to deliver publicly funded fertility treatment by the end of 2023.



Asks:

- Ensure timely access to publicly available fertility treatment to people living beyond cancer.
- Include people living beyond cancer in the national eligibility framework so they may avail of publicly funded IVF treatment.

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Irish Cancer Society Pre-Budget Submission 2024 Part 2:

CAYA Pre-Budget Submission 2024

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Introduction

The devastating diagnosis of cancer at such an early stage in life means that children, adolescents and young adults (CAYA) face lifelong challenges; not just being in a hospital for weeks, but also dealing with the side effects of cancer treatment and returning to activities like school, work, and planning for their futures, as well as dealing with the psychological impacts of such a life-changing illness. Cancer at this age is all-consuming and impacts not only young people but their entire families. Many struggle to cope financially and need extra supports, so they can solely focus on caring for their loved ones.

In Ireland, over 360 young people aged 0-24 years are diagnosed with cancer each year. The table below gives an overview of the age breakdowns of diagnosis in this group. The five-year survival for childhood cancer is over 80% in Ireland[i].

Table 1: Annual average numbers of childhood /adolescent / young adult cancers diagnosed[ii]

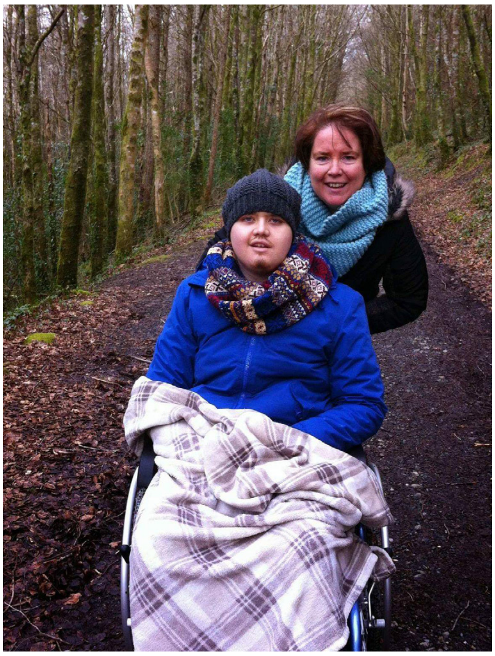
2018-2019 average annual cancer cases			
Age 0-15	Age 16-19	Age 20-24	**Total**
198	69	111	**378**

An estimated 1,000 CAYA patients are seen in the HSE for active and maintenance treatment each year, as well as surveillance following their treatment[iii]. Many more thousands are present in the community living as CAYA cancer survivors who are navigating the effects of their treatment into adulthood.

The survival rates of childhood cancer in particular have improved dramatically with improved clinical care; since the 1960's mortality rates have been decreasing on average 2.6% per year for boys and 2.9% per year for girls[iv]. While we continue to push for improvements in the treatment and early detection of CAYA cancers, we also need to cater to the long-term quality of life for the increasing population of survivors, who face long-term psychosocial and physical changes as a result of their cancer. Alongside pushing to increase the number of survivors, we need to focus on the long-term quality of life of survivors, as well as their family members.

The Irish Cancer Society wants to make sure that every single young person diagnosed with cancer survives, and that they are able to live long, healthy lives without the social, psychological and financial impacts of cancer. Unfortunately, this is currently not the case.

We are calling for significantly increased investment to ensure that Government does more to provide financial supports for families, and invests in cancer care throughout the entire lifecycle of every young person with cancer; from early detection, through to treatment, survivorship care, and in end of life care.



1

Financial Support for Families

Abolish Car parking charges

One of the most unjustifiable expenses is the charges families pay for car parking to attend cancer treatment for CAYA cancers. It is not the first expense that comes to mind, but it quickly takes a toll on families who are already struggling to make ends meet. The Irish Cancer Society are disheartened to hear of a proposed €10 daily charge for families that will be attending the National Children's Hospital, which is far beyond what families should be expected to pay.

Over 90% of families surveyed in the Real Cost of Childhood and Adolescent Cancer report told us they paid for parking to attend appointments for their child. Families where their child had finished treatment reported that they could spend on average €201 per month on parking charges when taking their child to cancer treatment. Charges vary across the country, with many families resorting to using on street car parking as hospitals have limited or no access to car parking spaces.

We are asking that a comprehensive solution is brought forward by Government to address the cost of car parking for CAYA cancer patients and their families.

The actions required include:

- The abolition of car parking charges for families who will be bringing their children to hospital for cancer treatment at the National Children's Hospital.
- The abolition of car parking charges for every cancer patient in the country.
- Ensuring existing concessions offered to cancer patients are highlighted via the HSE and hospital publications and websites.
- A waiver provided for cancer patients who must avail of on-street car parking for hospital appointments.
- The publication of the HSE hospital car parking guidelines that were prepared in 2019.

Extend the Domiciliary Care Allowance

The Domiciliary Care Allowance (DCA) is a payment designed for families caring for a child with a severe mental or physical disability. This payment is crucial for families caring for a child with cancer. The full-rate payment is €330 per week.

Current policy states that **provision of the Domiciliary Care Allowance ends once a young person turns 16.** The young person can then apply for the disability allowance on their own behalf. This is an unfair expectation to place on a young person with cancer; they are still a child, and are likely to remain in their parent's/guardian's care into adulthood.

Families use this payment as a source of income supplementation while they cannot work and care for their child on a full-time basis; no family should experience an abrupt end to this support at a vulnerable time. Families are also experiencing a wait time of 10 weeks for this payment to be processed . This payment helps to meet the increased expenses associated with caring for a child with cancer; ending this payment at 16 leaves families with even less money to face mounting medical and non-medical expenses. **When their child turns 17, families have the same mounting expenses, but are worse off by €17,160 a year.**

The Irish Cancer Society is asking for the Domiciliary Care Allowance to be extended to 16 and 17 year olds.

Create a Childhood, Adolescent and Young Adult Cancer Care Allowance - €6.5 million

Our 2021 report "The Real Cost of Childhood and Adolescent Cancer" lays bare the crippling financial impact of a cancer diagnosis in a young person on their family. The State entitlements, such as a medical card, domiciliary care allowance, carers allowance etc. covers some portion of the average €3,000 monthly hit on a family's income with increasing expenses and decreased income. Catastrophic healthcare spending leaves these families with a minimal safety net; the Irish Cancer Society provides a non-means tested grant to each young person diagnosed with cancer in Ireland, but this is not enough to meet the long-terms costs of cancer.

Alongside these mounting expenses, these families, like the rest of Ireland's population, face an increase in expenses with inflation; items affected are the typical expenses families face when bringing their children for appointments (petrol, food, accommodation), and when caring for their child at home (heating and electricity).

The Government needs to step in and provide the essential support families need to meet expenses. **The Irish Cancer Society is calling for €6.5 annual investment in a specific Childhood, Adolescent and Young Adult Cancer Care Allowance.** This would be a non-means tested payment for every person under 24yrs diagnosed with cancer. This is to meet the non-medical costs of treatment and acknowledge the unique financial burden faced by these families.

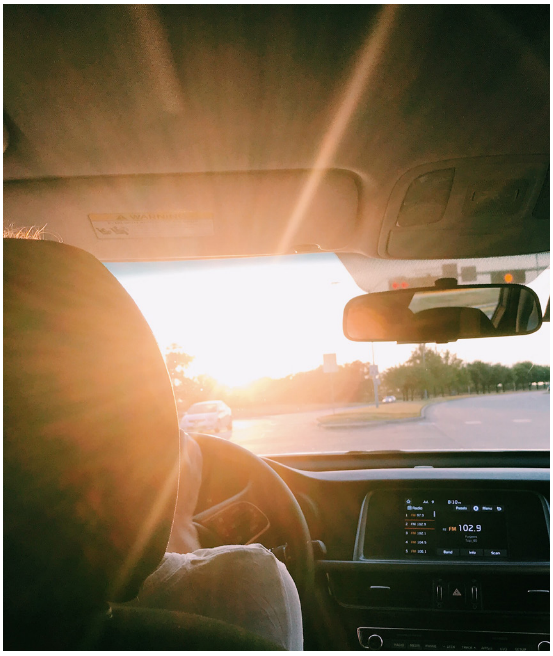
Cover the Costs of Travelling Abroad to Access Cancer Treatment - €450,000

The Real Cost of Childhood and Adolescent Cancer report: 1 in 5 survey respondents reported travelling abroad for their child's active treatment. Controlling for outliers, the average costs reported are €3,175 with median costs of €2,500[vii].

The Treatment Abroad Scheme provides a lifeline to families who must go abroad for cancer treatment such as proton beam therapy for children and young people. It ensures the treatment is paid for in certain conditions, and makes sure young people get the best possible treatment for their cancer, particularly for ultra-rare cancers where treatment in Ireland isn't available.

While this is welcome, it does not cover the expenses of hotel/apartment accommodation, food and other expenses that families face. The high costs often mean that families resort to taking out personal loans, or organising fundraisers, as they already struggle to deal with the expenses associated with cancer care. While families can claim tax relief on some of these items, and voluntary organisations provide crucial funds and support for these families, the costs are still a significant burden on families that are already struggling.

> **"It was all a huge shock and it just felt so far away from home to be getting treatment when they told us to go home and make sure our passports were in date."**
>
> *- Geraldine, mother of Childhood cancer survivor, who travelled with her daughter to Birmingham for chemotherapy.*



The Gavin Glynn Foundation, established in 2014, is dedicated to assisting families with the financial expenses and logistics associated with travelling abroad for CAYA cancer treatment. They estimate that it costs €15,000 per family for a typical cancer treatment abroad, e.g. a 6 week course of proton beam therapy. This includes the transport (flights, taxi transfers, car hire) accommodation and living expenses that are not covered by the State's Travel Abroad Scheme.

We are calling on the Government to introduce a new "Treatment Abroad Fund" to cover the non-medical expenses of travelling abroad for medical care. - €450,000

The cancer-specific fund would cover the accommodation and non-medical costs for families travelling abroad for care, and would require an investment of €450,000 from Government. In 2022, 19 families used the travel abroad scheme for people under 24 years old to access cancer treatment[ix][1]; this fund would be of minimal cost to the State, but would make a huge difference to these struggling families.

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[1] Figures from the Gavin Glynn Foundation show a higher number of families who have accessed cancer treatment via this scheme in 2022.

Remove means testing for the Exceptional Needs Payment/ Additional Needs Payment for CAYA Cancers

Social workers often highlight this payment as an additional once off, particularly as previous social welfare payments are not required. Applicants take place through a community welfare office long application form and means tested.

An investment of €600,000 is needed to cover this group of the number of CAYA cancer patients and survivors.

We are calling on the Government to extend the Additional Needs Payment to people with a cancer diagnosis to alleviate some of the financial burden.

The burdensome application procedure with a means test should be waived for this group and a cancer diagnosis should be the only qualifying criterion for accessing the payment for a family with CAYA cancer.

2

Cancer Treatment

CAYA Cancer Genomics - €1.4 million

It is the vision of the Irish Cancer Society that every young person has genomics care as a core part of the cancer care pathway. Mapping the genetic profile of the cancer type and the genetics of the young person can ensure individualised treatment plans will be developed, including in immunotherapy. The recently introduce CAR-T cell therapy is a fantastic development in this area[xix], and the Irish Cancer Society has funded a post in CHI Crumlin to develop the cancer genetics service. Having genomic sequencing available to every CAYA cancer patient would expand the treatment types available for these patients, so they are treated with less harsh chemotherapy and radiotherapy protocols and their long-term health is protected. It also ensures their siblings have genetic testing available, and that genetic counsellors would be in post to provide guidance and support to families in this area. Recent developments from the NCCP have ensured that children and adolescents have access to this pioneering service up to the age of 16. The opportunity to access this service as a standard of care should be expanded to the age of 24yrs, and requires Government investment to do so.

We are asking the Government to fund the expansion of the Genomics service for the CAYA group, from 16yrs to 24yrs of age.

Adolescent and Young Adult (AYA) Cancers

Ireland is a leader in creating a Strategy to meet the needs of the group diagnosed with AYA cancer. Adolescents and Young Adults (AYA's), aged 16-24yrs, are diagnosed with cancer at a pivotal time in their physical and psychological development, and their cancer care needs to address the challenges they face with tailored supports. For example, the AYA group can go through a transition period from paediatric to adult cancer services during treatment, which can be very challenging, and the lack of support at this time has been highlighted in Irish research[xxxiv].

> **"In the children's hospital, everything was amazing and I would always be offered anaesthetic for the most simple bone marrow biopsies, and I would never have to sign any consent forms. When I moved to the adult hospital, I was traumatised from all the bone marrow biopsies because I was awake for all of them, and that was a wake-up call."**
>
> *- Jessica, Teenage Cancer Survivor*

Ireland is a leader in creating a Strategy to meet the needs of this group. We are one of the three EU countries with a published AYA framework in place, and the HSE and National Cancer Control Programme have committed to making significant strides in the provision of holistic and equitable care, with the expertise and workforce in AYA cancers being centralised but made available across the country. The Framework for 2021-2024 sets out strong ambitions, and establishes a network of 4 cancer centres to be the AYA Cancer Service Network (AYACSN): CHI @ Crumlin, St. James's Hospital Dublin, Cork University Hospital and Galway University Hospital.

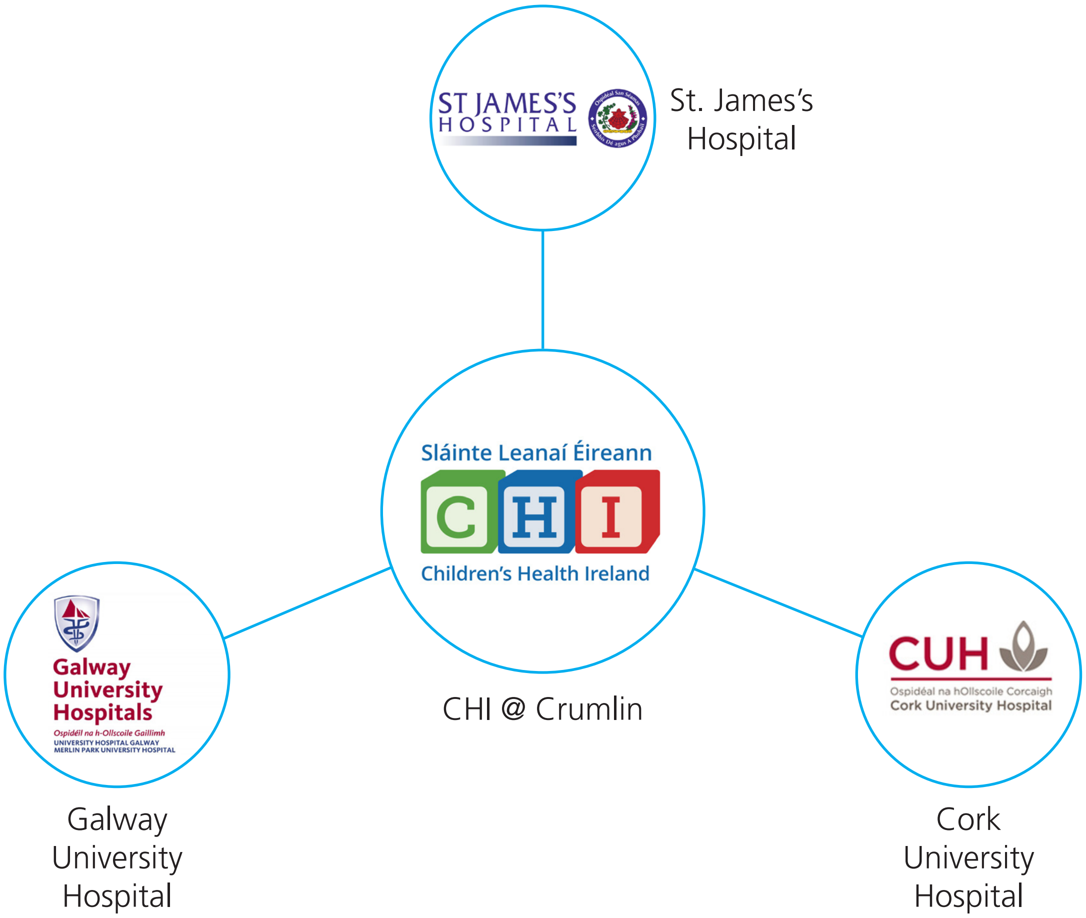


Figure 1 The AYA Cancer Service Network

We are approaching the midpoint of the lifetime of this framework, and a full workforce has yet to be established to create the AYACSN as a sustainable service for the AYA group. Good practice of AYA-specific care and supports exists, such as the pilot "hangout" for multidisciplinary supports for AYA cancer survivors in Dublin, however, the recruitment of staff and the provision of an age-appropriate services, particularly in psycho-oncology services, needs to be advanced as a matter of priority to achieve the vision of the NCCP's framework and ensure services are equitable across the country.

The Government needs to provide core funding for the AYA Cancer workforce recruitment and implementation of the NCCP Adolescents and Young Adults (AYA) Framework.

CAYA Psycho-Oncology Services

> **"Our biggest expense was counselling - the whole family needed counselling and we had to pay for most of it ourselves. At one stage we were paying €180 a week as 3 people were in counselling at the same time - so €720 a month. We had no idea our family would need so much counselling."**
>
> **"We could access everything but what we were offered for free wasn't anywhere near enough. My youngest child needed 20 sessions of play therapy."**
>
> *- Respondents from the Real Cost of Childhood and Adolescent Cancer*

A recent assessment of the needs of childhood cancer survivors in Ireland, from the perspective of patients, parents, guardians, and carers identified psychosocial support for survivors, siblings and parents as a key priority[xx].

The NCCP's Psycho-Oncology Model of Care has been published, and is designed to meet the specific needs of children and adolescents living with cancer[xxi]. At a time where families experience distress over their child's diagnosis and financial stress, it is important that psycho-oncology services are woven into the cancer care pathway as an integral component of treatment and survivorship.

When a child is diagnosed with cancer, the whole family is impacted. Family members of survivors can experience a psychological impact due to a childhood cancer diagnosis. While young cancer patients and survivors should have access to psychological support services from the moment of diagnosis, we argue that resources should be available to siblings and parents, too, to support them through this difficult time[xxii]. For instance, siblings of a child/adolescent who has had cancer may have unmet psychological need[xxiii]. Parents of children and adolescents with cancer have to make sacrifices, and in some instances they can experience economic, occupational and marital difficulties[xxiv].

The effects of a childhood cancer diagnosis and treatment often follow a person and their family into adulthood[xxv]. Parents can continue to carry their stress and anxiety including fear over their child's health throughout their lifetime[xxvi]. The psychological effects of a childhood cancer diagnosis can be delayed for a number of years[xxvii]. Survivors can endure anxiety linked to their health and experience higher rates of psychological challenges[xxviii], prescriptions for anti-depressants, and hospitalisation for mental disorder, compared to the general population[xxix].

People who live with cancer and who have their psychological needs met have better health outcomes[xxx]. However, current provision of mental health services in Ireland is insufficient[xxxi], and the National Children's Cancer Service (NCCS) does not meet international standards of psychosocial care[xxxii]. Community mental health supports are also under severe strain if young cancer survivors seek support through primary care, via the CAMHS service.

Psychological services and access to mental health evaluation must be available to survivors of childhood cancer over the course of their lifetime (from diagnosis into survivorship or, if required, end-of-life).

To better support children and adolescents living with cancer, their families, and survivors, in Budget 2024 we are asking Government to fund the implementation of the NCCP's CAYA Psycho-oncology model of care.

These services should also be available to survivors of CAYA cancers to ensure that children, adolescents, parents and families can access support from diagnosis and into survivorship. This funding should be used to adequately staff the service, for outreach, and to embed services within hospitals and the community.

Pathways to the Early Detection of CAYA Cancers

Early detection of cancer is a priority in the National Cancer Strategy; significant progress has been made in adult cancers, and we do not want people with CAYA cancers to be left behind in this progress.

GP Referral Guidelines and symptom awareness in the general public 2 of the top 5 factors which would assist in the early detection of cancer in primary care, according to a 2015 survey conducted by the ICGP[vii].

An editorial paper by Professor David Walker phrased the risk of CAYA cancer and GP diagnosis succinctly, saying "while the risk of the individual GP making a diagnosis of cancer is very low, the risk for each child is significant". It is estimated that a GP may see a case of CAYA cancer once every 5-10 years, however, the risk of CAYA cancer in childhood increases over time. A calculation of individual risk in a population shows that a child's cancer risk rises from being very low (1 in 4700) in the first year of life, rising rapidly until 5 years of age (1 in 1000), achieving a moderate risk by 15 years (1 in 450) and a substantial risk by 20 years (1 in 320). These risks are comparable to risk of other common childhood conditions such as diabetes, epilepsy, and bacterial meningitis[viii].

GP's are the frontline clinicians available to the CAYA cancer group when they first suspect cancer or attend an appointment with symptoms of cancer. GP's need to be equipped with robust training, guidelines, information and contact details of multi-disciplinary teams who can advise in these cases. This should be supported by a systematic review and evaluation system to ensure the diagnosis of CAYA cancers are optimal and the needs of each stakeholder involved are being met.

The creation of GP referral guidelines for CAYA cancers is the cornerstone requirement to promote the early detection of CAYA cancers. GP's must be supported in referring appropriately in the cases of suspicions of cancer with the help of expert clinicians in CAYA cancer and robust guidelines in the clinical care pathways available for this group.

We are asking the Government to invest in the creation of GP referral and support pathways in the early detection for CAYA cancers.

Access to Medicines

The process of introducing new anticancer medicines, particularly for childhood cancer, is a slow, arduous process. Individual national processes apply for approvals and drug reimbursement; the process in Ireland of a Health Technology Assessment (HTA) is overseen by the HSE, with variable timelines in making decisions on introducing drugs into Ireland.

Recent reports have shown that Ireland takes almost 1 year longer to approve anticancer drugs than the EU-15 average, despite having similar processes in place[ix]. The Irish Cancer Society is concerned with this delay and the impact this makes on people with cancer. Similar timelines are shown in specific drug approvals in Ireland for childhood cancer medicines[x], and the types of medicines can be more challenging to approve for this group[xi].

The Government has published the Mazars report on the evaluation of the drug reimbursement process in Ireland, and aim to increase transparency of the process[xii]; the Irish Cancer Society applauds this initiative. However, processes to accelerate the HTA process are badly needed, and evaluation and investment in the HTA approval mechanisms in place must be done to make sure we are meeting the needs of young people with cancer with access to innovative medicines as soon as possible. New treatments that can reduce the burden of disease, increase life expectancy and quality of life in young people with cancer means more time with friends and family and doing the things they love; improvements to the HTA process is a cost-saving exercise, and also worth doing to making the days count for young people and their families.

The Irish Cancer Society is asking the Government to fund the implementation of all recommendations of the Mazars report. The Irish Cancer Society would also ask for representation on the group that is to be established to oversee this work. Particular focus is required in the area of addressing the delays in the approval processes of anticancer medicines.

An illustrative analysis of 11 recently EMA-approved treatment-indications shows that time until reimbursement by the HSE together accounted for 2,600 years of potential life lost, of which 1,000 years in working-age patients resulting in an economic loss of €34 million.[xiii]

Ring-fence Investment in CAYA Cancer Research

Cancer research is vital towards improving our knowledge on early detection, treatment and survivorship and the patient experience. This is of particular importance in understanding how to develop and improve interventions of care, the patient experience and quality of life in survivorship. Childhood, adolescent and young adult cancers require complex and holistic interventions, from medical treatment to psychosocial programmes. To this end, research specific to the Irish context matters, and could have impact beyond our borders.

The Irish Cancer Society funds researchers looking into a range of pertinent questions in the CAYA research environment; more mainstreamed and targeted support must be an integrated component of healthcare practitioners' roles, in addition to appropriate incentives to encourage CAYA cancer professionals to engage in research.

As we have highlighted, survival rates have greatly improved; however, these rates are slowing down, and we need to find better cancer cures. The treatment and side effects of treatment cause lasting, often lifelong, physical and psychosocial changes to young people as they go into adulthood; long-term effects include heart problems, cancer re-occurrence, mental health issues, frequent hospital stays and infections[xiv]. Only cancer research can bring an end to this so it's imperative that Government provides sustainable funding for innovative research that will improve the lives of young people.

The National Cancer Strategy acknowledged the importance of protecting research time for new consultants and Advanced Nurse Practitioners. The latest available National Cancer Strategy Implementation Report (detailing progress for 2021) showed that COVID-19 slowed efforts to provide protected research time[xv]. The HSE Action Plan for Health Research 2019-2029[xvi] sets out an ambition to further develop the research capacity of the health service and improve outputs, such as increased amounts of clinical trials being undertaken, which is the cornerstone of developments in CAYA cancer research. Building capacity in the health workforce to enable them to undertake groundbreaking research will only bring benefits for patients. Prof. Owen Smith, Consultant Paediatric Haematologist and the NCCP's National Clinical Programme Lead for Children and Adolescent/Young Adults with cancer recently co-authored fundamental research in adolescents and young adults with cancer through SIOPE[xvii]; further investment can develop Ireland's contributions in this growing field of cancer research.

There are varied challenges to conducting clinical research in Ireland. For instance, adequate funding is a necessity; however, clinical research is not an integrated component of the Irish healthcare system, there is a lack of protected time for research activities in hospitals and there is a need for a charted career pathway for nurses and other professionals[xviii].

Each of these issues should be tackled in tandem, but resources will be necessary towards embedding a research culture within the healthcare system, and particularly where it relates to childhood and adolescent cancer treatment and survivorship.

We are asking the Government to ring-fence funding to enable the CAYA cancer workforce to undertake impactful research. Such action would include funding to protect time for clinical staff, foster incentives for clinical, allied health professionals and other staff to engage in research, as well as build Ireland's research portfolio. Such funding provides opportunities for more health and social care professionals at all career stages, across different disciplines, to participate in research activities to improve outcomes for CAYA living with and beyond cancer.

3

Living Well after CAYA Cancer

Fund lifelong clinical and psychosocial support for the surveillance of CAYA cancer survivors

> **“A few years after I finished treatment, it all sank in, what I had went through. Getting back to navigating your life – that was really difficult. You never fully go back to the way you were, it’s a new normal.”**
>
> *- Sarah O’Neill, AYA Cancer Survivor*

The need for a comprehensive survivorship service for the CAYA group cannot be overemphasised. The exemplary survival rate of over 80% on average in CAYA cancers ensures there is a growing number of CAYA cancer survivors in the community; a significant portion of this group will require ongoing support following medical discharge and cancer treatment has ceased.

The latest research from Gavin et. Al emphasises many aspects of survivorship care that needs to be prioritised from the young person’s perspective[xxxv]. This includes:

- Having a specific point of contact as a source of information and to co-ordinate discharge planning and multidisciplinary service provision
- A summary of their cancer treatment and information on potential side effects as a result of their treatment
- Support in transition care, such as the transition from children’s to adult services
- Additional supports to reintegrate back into school
- Timely, accessible information on the supports available to them in the community

European recommendations from expert groups have been established for the long term follow up CAYA cancer survivors to monitor the effects of cancer treatment into adulthood; it includes the requirement to monitor for diseases from bone and heart problems, cancer recurrence and fertility issues[xxxvi]. The recommendations are based on a person-centred approach for survivorship care with education and awareness promotion being crucial.

The Irish Cancer Society is asking the Government to fund the creation of a national survivorship service for CAYA cancer survivors which will include lifelong clinical and psychosocial support.

At present, there is no model for survivorship care in CAYA cancer survivors, and this needs to change. Care coordination and building a model that provides survivors with universal equitable access to supports is necessary and requires Government investment to progress.

Late effects from CAYA cancer treatment can include physical and psychological issues, as well as social isolation and premature mortality[xxxvii].

School supports for CAYA cancer survivors

The psychosocial impacts of young cancer survivors can be profound, and can impact their education level and career prospects[xxxviii]. The educational performance of young cancer survivors can be impacted by[xxxix]:

- School absenteeism – Through to treatment and with follow-up care, people can have approx. 5 years of irregular school attendance.
- Cognitive late effects of treatment can affect school performance.
- Changes to normal functioning as a result of treatment, e.g. hearing loss, difficulty with peer relationships, and difficulty focusing for long periods of time.

The education provision for young cancer patients is provided by a school in the ward in CHI @ Crumlin; however, schooling for adolescents and young adults treated in other hospitals isn't usually provided[xl]. Supports from schools can vary, as there is no guidance provided by the Department of Education, and families usually navigate the system of asking for supports by themselves[xli]. Cancer survivors often need to have supports in place to continue through to education; but access to these assessments can be a barrier, with some families being forced to avail of private services for these assessments.

The Irish Cancer Society are delighted to see the introduction of cancer into the disability access route to higher education (DARE) scheme; this makes the application process for CAYA cancer survivors far easier. This is one step into allowing young cancer survivors to reach their full potential after treatment.

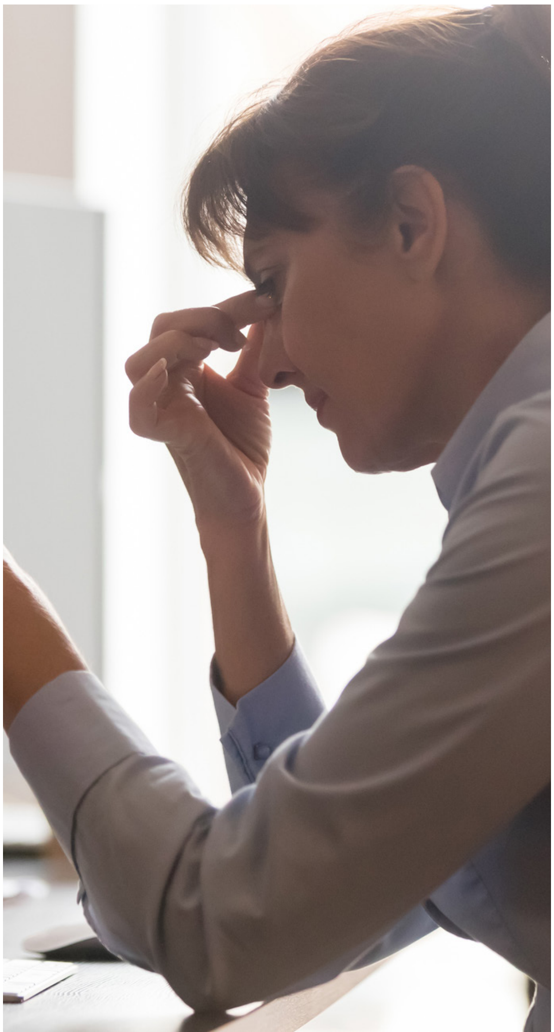
We are asking the Government to fund access to functional assessments, individual education plans, and guidance counselling for CAYA cancer survivors.

Specific support such as special needs assistants and/or assistive technology and adaptations should be consistently available for the people that need them, and assessments of their needs should be provided without delay and without a cost.

Return to work supports for CAYA Cancer survivors

Entering or returning to the workplace can be seen as an important marker of recovery from cancer. Flexibility and support is required to any young cancer survivor returning to work. The Irish Cancer Society's report "Returning to Work after a Cancer Diagnosis"[xlii] identifies many barriers that can make this transition challenging for cancer survivors. It is essential that young people, in particular, can start their career on the right track following cancer treatment, and know they can confidently pursue their goals in the world of work thanks to the supports that need to be put into place.

The Government needs to fund supports to support CAYA cancer survivors for starting/returning to work. This could include the provision of career guidance, the funding of a State-run pilot programme to support the reintegration into work after cancer, and flexibility from the Department of Social Protection on social entitlements, such as the partial capacity benefit.



4

End of Life

Provide equitable palliative care services

We support the recommendations of the Governance and Operations report for paediatric palliative care from the HSE published in 2020; the rollout of the workforce planning from this report needs to be accelerated, in order to ensure that young people and their families are not left in their community without any specialist care. Every child who needs palliative care should have timely access to age-appropriate services in their community. Gaps are identified in the 2016 review of paediatric palliative care services, and include; a lack of equitable access to palliative care depending on the region, a lack of training and workforce availability, and overstretched resources in providing palliative care services to young people and their families[xliv].

There is also a gap in the provision of age-appropriate palliative care to adolescents and young adults with cancer; the implementation of the AYA framework requires the funding for specific posts in palliative care for the AYA cohort, as well as training for staff in the provision of AYA care[xlv].

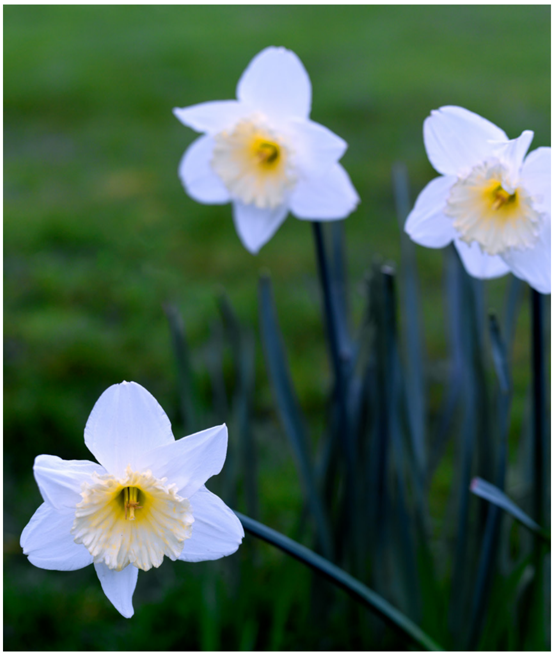
A large proportion of respite care is also provided to families via the charity sector; gaps in access to respite care needs to addressed urgently by the Government[xlvi].

We are asking the Government to continue to implement and accelerate the 2020 governance recommendations and paediatric palliative care model.

Provide and invest in bereavement supports for families affected by the premature deaths of young people with cancer.

Support from healthcare professionals in the hospital, such as medical social workers, is provided to families when they lose a loved one to cancer. Community bereavement supports are available, however, they are not distributed equitably across the country and they are not adequately sustained from public funding. The lack of bereavement services at such a crucial period has been highlighted in review of paediatric palliative care services[xlvii]. Alongside practical supports of dealing with a bereavement, timely access to emotional supports must be provided by the State. This is a matter of high importance for parents and siblings who have to cope with the premature death of a loved one from cancer.

We are calling on the Government to complete a national plan for the provision and funding of equitable bereavement support services for families who have lost a young person to cancer.



The budgetary asks of the Irish Cancer Society's CAYA Pre-Budget Submission 2024 are supported by the following voluntary organisations:

Childhood Cancer Ireland
ADVOCACY • AWARENESS • SUPPORT

The Gavin Glynn Foundation
SUPPORTING FAMILIES FIGHTING CHILDHOOD CANCER

CanTeen Ireland

Hand in Hand
Children's Cancer Charity

cancer fund for children

Our Priorities

1

Financial Support for Families

Our Budget asks:

- Abolish Car parking charges
- Extend the Domiciliary Care Allowance
- Create a Childhood, Adolescent and Young Adult Cancer Care Allowance
- Cover the Costs of Travelling Abroad to Access Cancer Treatment
- Remove means testing for the Exceptional Needs Payment/ Additional Needs Payment for CAYA Cancers

Our Priorities

2

CAYA Cancer Treatment

Our Budget asks:

○ CAYA Cancer Genomics

○ Adolescent and Young Adult (AYA) Cancers

○ CAYA Psycho-oncology services

○ Pathways to the Early Detection of CAYA Cancers

○ Access to Medicines

○ Ring-fence Investment in CAYA Cancer Research

Our Priorities

3

Living Well after CAYA Cancer

Our Budget asks:

○ Fund lifelong clinical and psychosocial support for the surveillance of CAYA cancer survivors

○ School supports for CAYA cancer survivors

○ Return to work supports for CAYA Cancer survivors

Our Priorities

4 End of Life

Our Budget asks:

○ Provide equitable palliative care services

○ Fund bereavement supports for communities affected by the premature deaths of young people with cancer

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