

Cut the Costs

for cancer patients



Irish Cancer Society

Pre-Budget Submission 2023

& CAYA Pre-Budget Submission 2023

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Cut the Costs

Over many years, patients have told the Irish Cancer Society that the cost of cancer causes immense anxiety and distress during the most physically and financially vulnerable point of their lives. Now the spiralling cost of living has made this intolerable reality worse. Budget 2023 provides an opportunity to make a huge difference to people's lives, and that's why we are asking for you to support our **Cut the Costs** Pre-Budget Submission to Government.

Cancer patients don't only face costs such as medication, GP visits, specialist dressings, travel, wigs and additional dental care, they also have to bear the burden of statutory charges like in-patient fees when they get chemotherapy. All these costs are on top of reduced incomes while they go through treatment, and without the security of being automatically entitled to a medical card. Now more than ever, the State must do more to protect patients and their loved ones from the financial impact of a cancer diagnosis.

The Irish Cancer Society is appealing to Government to prioritise the needs of cancer patients in Budget 2023. There are approximately 200,000 cancer survivors living in the country, with a further 45,000 new diagnoses to be made next year. Never has this awful disease affected more people and never has Government action on costs been more necessary.

The extent of the costs faced by families affected by cancer is not limited to finances though. There are deep concerns being expressed to the Irish Cancer Society around the timely availability of healthcare, particularly diagnostics. The impact of late presentations and delayed diagnosis has already been observed by clinicians, so it's absolutely vital that services can be provided within reasonable timeframes to those who need them.

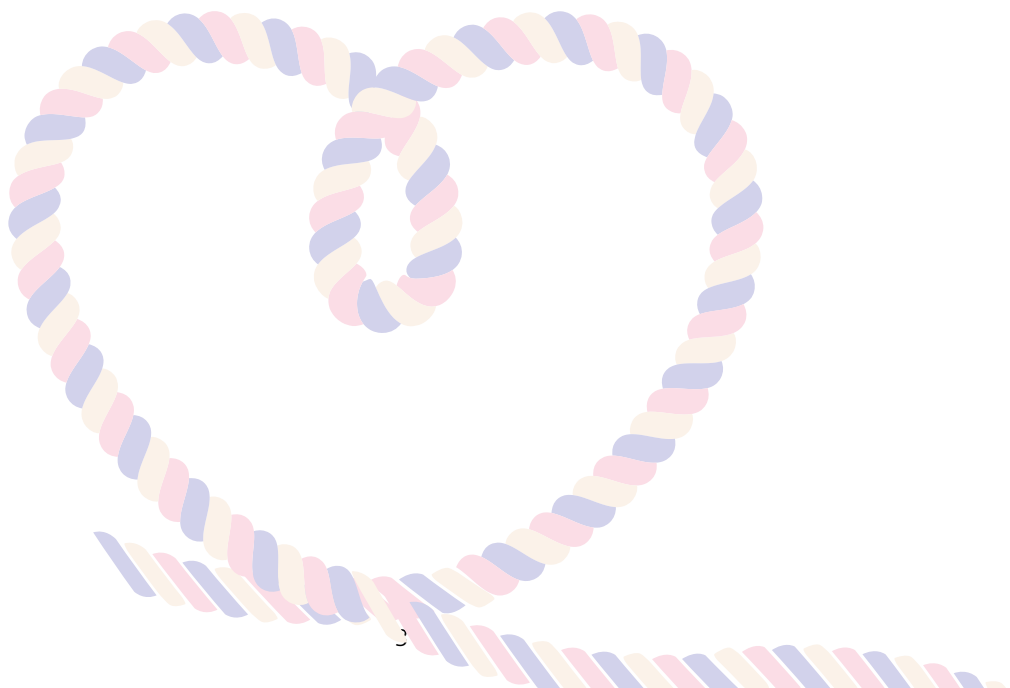
Despite emerging from the worst of the pandemic, the anticipated "catch-up" phenomenon, driven by late presentations, has now manifested itself in our healthcare services. The National Cancer Registry of Ireland has estimated that approximately 10 - 14% fewer cancers were diagnosed in 2020, with 2021 figures still unavailable. We still do not know if all those cancers have been detected yet, or if people are still at home managing their symptoms, or somewhere on a waiting list with an undiagnosed cancer.

The Minister for Health has released a significant amount of funding to cancer services since he took up office and this has been widely welcomed. The funding will be directed at reducing waiting lists, expanding services and building up the cancer workforce. However, the systematic issues that are the root cause of many barriers to real change need to be tackled too and with great urgency.

Budget 2023 must rise to meet the cost of living crisis, which is most acutely affecting cancer patients and their families.

It must continue to invest in an ambitious National Cancer Strategy that is some way off being realised at its midway point. And it must deliver comprehensive, easily accessible care through investment in infrastructure, staffing and clinical advancements, as well as sufficiently resourcing prevention programmes to reduce the rising cancer incidence rate.

The Irish Cancer Society urges all members of Government, the Oireachtas and public servants to support our Pre-Budget Submission so we can provide better care and lasting care across Ireland.



Our Three Priorities

Alleviating the financial and
psychological burden of cancer

Supporting cancer services
post-pandemic

Prevention &
Future Proofing

The impact of cancer extends beyond physical and clinical needs. Now more than ever, the State must do more to protect patients from the financial implications of a cancer diagnosis.

Our Budget 2023 recommendations in this section include vital, practical measures to address the huge financial and social impact of cancer. We are calling on the Government to:

- Abolish inpatient charges, at an estimated cost of €30 million; end the practice of debt collectors' pursuit of cancer patients;
- Invest €5.1 million in public hospitals to reduce the cost of car parking charges for patients;
- Provide medical cards to all cancer patients upon diagnosis, until their treatment is finished;
- Abolish prescription charges for medical card holders;
- Maintain the Drug Payment Scheme cap at €80 per month at an estimated cost €21.1 million and €72 per month for single-headed households at an estimated cost of €5.2 million;
- Expand the Household Benefits Package to include those with a cancer diagnosis;
- Broaden the eligibility criteria for Partial Capacity Benefit, to increase security for patients and survivors seeking to return to work;
- Fulfil the commitment to deliver publicly funded fertility treatment in Budget 2023.
- Complete the funding of psycho-oncology posts across the designated cancer centres in Ireland.

We urge the Government to provide €45 million in new funding for cancer services, across the following areas:

- Provide €15 million in funding to alleviate the diagnostic backlog caused by COVID-19;
- Fund the National Cancer Strategy to the sum of €30 million.

Some of this funding must be allocated towards the following:

- Fully resourcing the Programme for Government commitments on eHealth;
- Providing a funding stream for a dedicated cancer infrastructure;
- Investment in sufficient healthcare staffing;

- Ensuring comprehensive, sufficiently resourced national screening services;
- A commitment to sustained, ring-fenced State investment in clinical trials;
- Funding the development of a world-class cancer genetics service.

The full resourcing of the following must be prioritised in Budget 2023 for:

- Lymphoedema Model of Care and National Lymphoedema Clinical Guidelines;
- A permanent funding stream for endoscopy services;
- The funding of Sláintecare.

4 out of 10 cancer cases can be prevented.

The more investment spent on prevention measures now, the less the cancer burden will be on the State going forward.

We believe the following actions can save lives for future generations by potentially eliminating a number of invasive cancers:

- Increasing the excise duty on a packet of cigarettes and roll-your-own tobacco products, and providing greater supports to smokers to help them quit;
- Funding the HPV catch-up programme for all those who missed out on receiving the vaccine in secondary school, and those up to the age of 25, including males;
- Full funding for the National Skin Cancer Prevention Plan;
- Funding radon testing kits; covering remediation costs in high risk areas;
- Investing 20% of the transport capital budget, €360 million, into walking and cycling infrastructure;

Alleviating the financial and psychological burden of cancer

Quote

“Over three in five of those working have had their income reduced as a result of their cancer diagnosis with annual income reducing by over €18,323, equating to about €1,527 per month”

Real Cost of Cancer Report

We need to show as much concern for the quality of life and the well-being of cancer survivors and patients, as we do with treatment and survival rates.

As more people than ever are either surviving cancer or living well with cancer, Government 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 significant costs associated with cancer are made clear in our ‘Real Cost of Cancer’ Reportⁱ, which shows that cancer patients face increased expenditure of €756 per month, on average, at a

time when they face a loss in income of over €1,500. Meanwhile, the estimated annual cost of childhood cancer to families is €15,300. For those without a medical card or private health insurance, the cost of statutory charges levied during treatment can be crippling.

Taking account of the rapidly rising cost of living, that burden has increased recently. Figures published from the Central Statistics Office shows the annual rate of inflation rose to 7.8% in May, the largest annual increase in 38 years.ⁱⁱ

Within this context, we urge the government to take action to address the impact this is having on already hard-pressed people and families living with a cancer diagnosis. Now more than ever, instead of focusing on their well-being and recovery, patients and their families are worried about getting by.

Although the medical card system provides a financial lifeline for so many households, including those affected by cancer, poorer households are still disproportionately likely to experience financial hardship.ⁱⁱⁱ

More must be done by Government to protect cancer patients from the financial implications of a diagnosis. Our Budget 2023 recommendations in this section include vital, practical measures to address the huge financial and social impact of cancer.

Implementing these proposals would be a clear message to those living with cancer, and their loved ones, that the Government are listening to their concerns and are committed to easing the significant financial burden their diagnosis places on them.

Changes like abolishing inpatient charges levied on patients without a medical card or private health insurance for cancer treatment sessions, maintaining the Drugs Payment Scheme threshold at €80 per month and honouring the Government’s commitment to introduce caps on hospital parking charges and flexible passes, are targeted fiscal measures with the specific purpose of aiding a vulnerable group, which will not act to exacerbate inflation.





Providing medical cards to all cancer patients upon diagnosis, eliminating prescription charges for medical card holders, and extending the Partial Capacity Benefit so that patients and survivors can be supported when returning to work, are reasonable measures that will support patients at their most vulnerable. As per the National Cancer Strategy^{iv}, we need to ensure psycho-oncology services are fully resourced in all designated cancer centres, so patients get the access to the psychological supports they need.

Additional supports with regard to expanding the Housing Benefits Package would also be hugely welcome, given the very real risk of many facing cancer slipping into energy poverty.

1.1 Abolish inpatient charges, at an estimated cost of €30 million; end the practice of debt collectors' pursuit of cancer patients

Inpatient charges typically include outpatient charges, emergency department charges, in-patient charges and long-term stay charges. They are paid by patients without a medical card and private health insurance who need an overnight stay in a public hospital or receive treatments in day ward.

As stated under the Health (Amendment) Act 2013, inpatient charges cost €80 per hospital visit, and are capped at 10 visits or €800 in a consecutive twelve-month period for people without a medical card or private health insurance.

As most courses of chemotherapy and radiotherapy require more than 10 visits, the majority of patients will pay the maximum charge of €800. Under the current Act, the HSE has a statutory obligation to levy and collect these charges and hospitals have the discretion to operate payment plans where appropriate.^v While the €800 cap limits the financial impact slightly, these charges can be crippling for families struggling to make ends meet while also trying to cope with the impact of cancer on their lives. In cases of "excessive hardship", hospitals can waive the charge, but there are no clear guidelines on this.

The Irish Cancer Society believes that these charges are unfair on patients who are going through what can be the most physically, emotionally and financially draining period of their lives. We know the impact the costs associated with cancer has on people's everyday lives, and most of these costs will never be reclaimed. Such





financial burden is discriminatory and disproportionately affects those most economically vulnerable.

Quote

"I was already fighting cancer with a new baby, I didn't need the additional fear of debt collectors knocking at my door."

Marie Moran, breast cancer survivor

The announcement from the Minister of Health's office of the intent to abolish inpatient charges in 2023 is much welcomed and an issue that the Irish Cancer Society have advocated on since publishing the first 'Real Cost of Cancer' report in 2015.

For Budget 2023, the Irish Cancer Society are asking the Government to abolish inpatient charges, at an estimated cost of €30 million.^{vi}

Under the HSE's National Financial Regulations on Hospital Acute Charges and Debtors (NFR-25), hospitals are required to refer an unpaid debt to a collection agency 47 days after an invoice has been issued for hospital charges, if it hasn't yet been paid.^{vii}

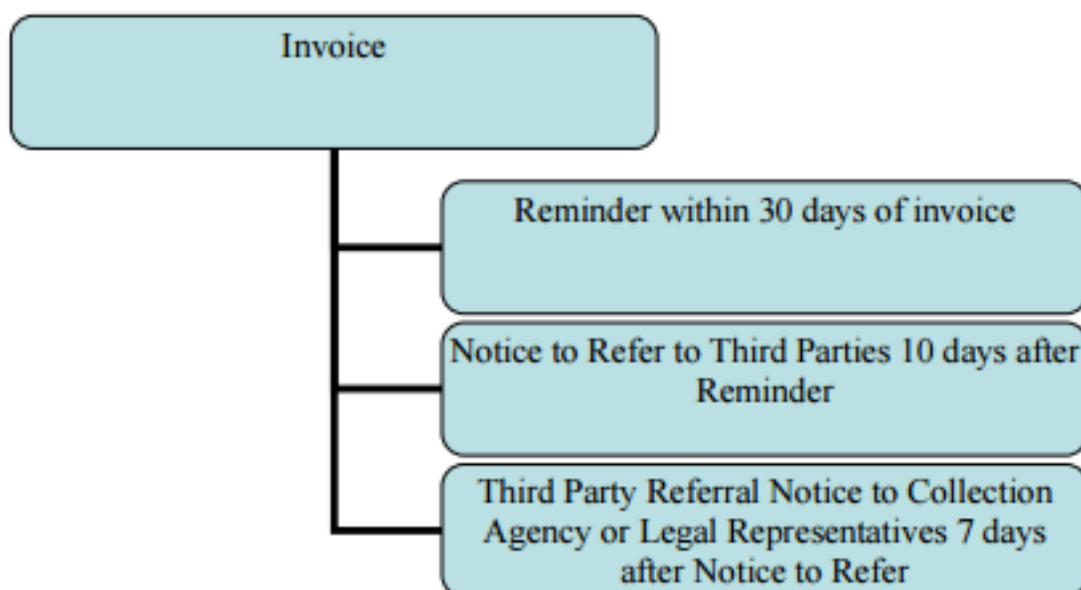
The last thing cancer patients and their families need is the added stress and fear of being hounded by debt collectors, sometimes for as little as €80. Such vulnerable patients should not have to deal with communication from debt collection agencies.

Guidance must be issued to the HSE on how to collect charges from very ill patients, and advise that this method of collecting payment must not be applied in the case of someone with cancer.

The HSE's use of debt collectors to pursue cancer patients for this money is an unfair practice on top of an unfair charge.

Along with the abolition of in-patient charges, **the Irish Cancer Society are calling for an end to debt collectors' pursuit of cancer patients.**

25.10.1. Figure 1 below sets out the standard follow-up routine to apply to those accounts not subject to health insurance direct payment arrangement.



HSE procedure for 'Charges collectible from the non-insured' per NFR-25^{viii}



1.2 Invest €5.1 million in public hospitals to reduce the cost of car parking charges for patients

'The Real Cost of Cancer' report^{ix} published by the Irish Cancer Society in 2019, revealed that 4 in 5 cancer patients incurred parking costs, at an average of €64 per month.

Such charges are not what one first thinks about when they first hear the words "you have cancer", but they can quickly take their toll when patients are struggling to deal with huge additional outgoings and a significant drop in income. This is especially true for those who are required to travel long distances for treatment and appointments, which require significant expenses on child minding, travel and accommodation before reaching the hospital.

Quote

"During that time, my wife came to visit me five days a week. It cost her almost €1,200 in parking charges alone in that time. That's a lot of money"

Gerry Carroll, Cancer Survivor

While car parking charges may be a key source of income for some hospitals, the Irish Cancer Society do not believe they should be used as a revenue-raising tool.

The Irish Cancer Society requests that the HSE work with hospitals to find alternative revenue sources than the excessive car parking rates charged to already hard-pressed cancer patients.

Following a 2018 review of car parking charges, the HSE signed off on a plan to cap daily parking charges at €10. The plan was signed off by the HSE directorate in January 2019 but has never been published. This has resulted in an inconsistent approach towards car parking charges across the country, leading to a wide range of charges levied on patients. Our Lady of Lourdes Hospital in Drogheda, for example, charges up to €25 per day.

The Programme for Government pledges to "introduce a cap on the maximum daily charge for car parking for patients and visitors at all public hospitals, where possible", in addition to a pledge to "introduce flexible passes in all public hospitals for patients and their families" but the Government has not yet established a timeline for implementation.

The Irish Cancer Society call on Government to honour its commitment to cap car parking charges for patients and set out defined timelines as when they will deliver on such. This will require a commitment of €5.1 million to replace this revenue source for public hospitals.*



1.3 Provide medical cards to all cancer patients upon diagnosis until treatment has finished

Research conducted by the Irish Cancer Society in 2019^x found that almost 1 in 10 cancer patients (9%) had neither a medical card nor private health insurance. For these individuals, treatment and its associated costs can be financially crippling. Just under half of research respondents (47%) had a medical card.^{xi}

Cancer patients can face massive increased expenditure on items such as wigs, new supportive clothing, medications, supplements, modifications to the home, and increased home heating, to name just a few.

The Irish Cancer Society believes that the double blow of increased costs and loss of income needs to be taken into account when considering what cancer patients can reasonably bear. There needs to be a greater appreciation of the huge financial strain of having cancer. **This is the case more than ever, with recent increased living costs and rising inflation.**

Almost 4 in 10 people in Ireland who returned to work after a cancer diagnosis did so before they were ready.^{xii} Of these, half did so because of financial need. **Medical costs are a significant cost for cancer patients and the wider provision of medical cards would alleviate some of the financial difficulty of a cancer diagnosis.**

While we welcome the Government's extension of medical cards to patients with a terminal diagnosis of less than 24 months, wider provision of medical cards for cancer patients would provide more protection to some of society's most vulnerable by ensuring that no patient has to choose between purchasing their medication and providing for their families.

In Budget 2023, the Irish Cancer Society is asking the Government to provide medical cards to all cancer patients upon diagnosis, until their treatment is finished.

1.4 Abolish prescription charges for medical card holders

For those with medical cards, a charge of €1.50 applies to prescribed medicines, up to a maximum of €15 per month per person or family. This prescription charge is reduced to €1 per item for people aged over 70, up to a maximum of €10 per month per person or family.

Before 1 November 2020, charges were €0.50 higher, with a monthly limit of €20 (or €15 for over 70s). While the Irish Cancer Society welcomes reductions to prescription charges in recent budgets, the financial burden of such charges are considerable to medical card holders, often those most economically disadvantaged within society.

The World Health Organisation^{xiii} highlight the need for exempting medical card holders from prescription charges. Without exemptions from such, those from lower income households and regular users of health care, the incidence of catastrophic health spending is likely to remain high among the poorest quintile.

In this time of financial uncertainty, rising inflation and significant increases in the cost of living, the additional economic burden a cancer diagnosis brings is felt by patients and their loved ones.

The State must honour such commitments to reduce the financial burden on economically vulnerable patients, and to ensure that everyone can access the medicine they need.

To move closer towards 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.

In light of this, the Irish Cancer Society is asking the Government to abolish prescription charges as part of Budget 2023 to reduce the financial burden on economically vulnerable patients.



1.5 Maintain the Drugs Payment Scheme cap to a maximum payment of €80 per month, and a maximum payment of €72 a month for single-headed households

As it currently stands, the Drugs Payment Scheme means that no individual will pay more than €80 per calendar month for approved medicines and appliances.^{xiv} No means test is required to avail of the scheme and a medical card is not needed in order to qualify for it.

Budget 2022 provided for a reduction in the Drug Payment Scheme monthly threshold from €114 to €100. In February 2022, the Government announced a further reduction to €80 as part of their measures to offset the burden associated with the increased cost of living. **The Irish Cancer Society welcomed this positive reduction to the monthly threshold and hopes that it will be made permanent, at the estimated cost of €21.1 million per year to the State.**

For cancer patients, maintaining this threshold reduction will make a considerable difference in ensuring families can afford basic necessities and household items.

We urge the government to adopt the commitment outlined in the 2017 Sláintecare Report^{xv} recommending that the Drugs Payment Scheme threshold for single headed households be reduced to €72 per month alleviating the disproportionate burden faced to the cost of €5.23 million.

Quote

"All the extra costs especially the petrol and extra heating costs. I used my credit card which has resulted in me maxing out my card."

Real Cost of Cancer Report

1.6 Expand the Household Benefits Package to include those with a cancer diagnosis

Findings from the 'Real Cost of Cancer'^{xvi} study reported that 49% of those surveyed experience higher heating and electricity bills during their cancer diagnosis.

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

Significant price hikes have added an estimated €540 to customers' gas and electricity bills since the autumn of 2020.^{xvii} Electricity bills have increased by 41% since last year, gas bills by 57% and home heating oil by 102.5%.^{xviii} Such price hikes are more likely to affect lower income households disproportionately, as they spend a greater proportion of their income on utility bills.

This rise in energy prices have a considerable impact on cancer patients who already face higher energy expenses, as they spend more time at home, as well as feeling the cold more during treatment.

Although the rise in energy bills is not an isolated issue for household finances, providing greater allowances towards covering electricity or gas costs would be a considerable step towards preventing instances of fuel poverty among those with cancer and their families.

The Households Benefits Package provides allowances towards household running costs, including electricity or gas costs. The package is generally available to people living in the State aged 66 years or over who are in receipt of a social welfare type payment or who satisfy a means test. The package is also available to some people under the age of 66, who are in receipt of certain social welfare payments with only one Household Benefits package payable per household.

The Irish Cancer Society is asking the Government to expand the Households Benefits Package to include all cancer patients upon diagnosis, until their treatment is finished.



1.7 Broaden the eligibility criteria for Partial Capacity Benefit, to increase security for patients and survivors seeking to return to work

In February 2021, the Irish Cancer Society published research conducted by the Economic and Social Research Institute (ESRI) on 'Returning to employment following a diagnosis of cancer'.^{xix}

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.

We in 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.^{xx}

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 2023, the Irish Cancer Society is asking the Department of Social Protection to broaden the eligibility criteria for Partial Capacity Benefit, to increase security for patients and survivors 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.

In addition, we are asking Government to introduce a new statutory payment for employees and self-employed people with chronic illness to attend medical appointments where they have had to take unpaid leave to attend appointments during work time.

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.





1.8 Fund fertility treatment for cancer patients and survivors

Fertility preservation is an important consideration for adult patients as it provides cancer patients at risk of infertility due to treatment with an opportunity to have children.

Currently, fertility preservation for the general population is not available through the Irish public health service; however, there is a free service for adult cancer patients through Sims IVF, funded by the HSE.

Following a referral, a person can be seen at a fertility clinic within 24-48 hours of their cancer diagnosis to ensure that there are no unnecessary delays to cancer treatment. Following a consultation/counselling, a person can choose to freeze their sperm, eggs or embryos. These samples will be stored, free of charge, for 10 years. Generally, Sims IVF treats 2-4 males and 2-3 females per week for onco-fertility preservation.

When it comes to fertility treatments, like IVF, there is no publicly funded service for the general population, or for people with serious illnesses like cancer.

The Irish Cancer Society welcome the announcement made by Minister Stephen Donnelly on plans to fund IVF fertility treatment for public patients from 2023.

Ireland is the only state in the EU that does not offer publicly funded IVF treatment despite an announcement in 2017 that a €1-million-euro fund would be rolled out in 2019, and a further announcement of a €2 million euro fund that would be implemented in 2021.^{xxi} The European Atlas of Fertility Treatment Policies^{xxii} ranked Ireland as “exceptionally poor” in their comparative study on fertility services and related policies across Europe.

An IVF cycle costs between €4,000 to €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 of

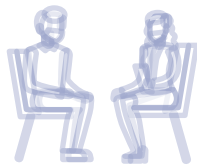
being treated in a clinic that is not geographically close to their home can also be significant.

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 fertility treatments that may have no proven medical efficacy.

The Irish Cancer Society welcomes the progression of the Health (Assisted Human Reproduction) Bill 2022 and calls for cross-party political support to ensure the long awaited commitment to implementing publicly funded fertility treatment is fulfilled with a defined timeline on when this will take place.

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^{xxiii} to deliver publicly funded fertility treatment in Budget 2023.



1.9 Fund the establishment of psycho-oncology services across Ireland

Psycho-oncology is a multi-disciplinary speciality focusing on the psychological and mental health care of people affected by cancer, their carers and families.

It recognises that cancer symptoms, treatments, and treatment side effects can have major adverse effects on the quality of life of the person with cancer and on those in their close social network. Unaddressed psychological obstacles can impact adherence to treatment protocols, rehabilitation programmes and ultimately on clinical outcomes.^{xxiv}

Specialist psycho-oncology teams can offer timely and appropriate intervention for patients to understand what cancer diagnosis means in their lives.

The psychological care of patients experiencing cancer is considered an integral part of quality cancer care^{xxv}, with up to half of cancer patients reporting distress and up to a third needing referral to a Psycho-Oncology service.^{xxvi}

In 2021, the Irish Cancer Society Support Line received 1020 calls relating to unmet psychological needs inquiries, 61 of which related to specifically to the lack of access to psycho-oncology services within the hospital setting.

The National Cancer Strategy 2017–2026^{xxvii} makes clear recommendations in relation to the development of Psycho-Oncology services in Ireland. Recommendation 30 states that: “Each designated cancer centre will establish a dedicated service to address the psychosocial needs of patients with cancer and their families. This will operate through a hub and spoke model, utilising the MDT (multi-disciplinary team) approach, to provide equitable patient access.”

A National Clinical Lead for Psycho-Oncology was appointed in December 2018, with a model of care published in September 2020.^{xxviii}

In Budget 2022, the Irish Cancer Society called for funding for the remaining posts so that psycho-oncology services can be fully established in the 8 designated cancer centres.

Over 2020 – 2021, each of the eight designated cancer centres (Mater, Beaumont, St. James’s Hospital, St. Vincent’s Hospital, Cork University Hospital, Galway University Hospital, University Hospital Limerick, University Hospital Waterford), as well as Children’s Hospital Ireland at Crumlin and Saint Luke’s Radiation Oncology Network, Rathgar now have a multi-disciplinary team in situ.^{xxix}

The Irish Cancer Society calls for the Government to recruit and fund all final outstanding psycho-oncology services posts in 2023.



Supporting cancer services post-pandemic

The COVID-19 pandemic has negatively impacted the public health system in a number of ways.

Although cancer services were somewhat protected, rising rates of infection meant that many hospitals and intensive care units were deeply affected by the inflow of people with COVID-19, resulting in the postponement of elective procedures. Anxiety around COVID-19 meant that many were reluctant to seek medical advice when needed. Waiting lists were impacted, particularly for routine care, likely due to staffing capacity and the need to social distance. Staffing, too, was affected as healthcare staff became ill, or were redeployed to other areas of the healthcare system, impacting workforce numbers.

Moving forward post-pandemic, the impact of late presentations and delayed diagnosis has manifested itself in our healthcare services. It is essential that our vision for cancer care ensures timely access to services at all stages of the cancer care pathway for all people, from screening to survivorship. For as long as bottlenecks exist in any part of the healthcare system, timely and equitable access to quality care and optimum outcomes for all people cannot be guaranteed.

Diagnosing cancer at its earliest possible stage is a crucial first step to achieving higher survival rates and improving the quality of life of people living with cancer.

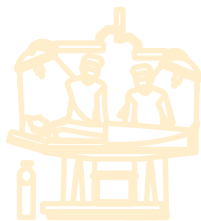
The early diagnosis of cancer is associated with significant cost savings for the State. Although there is an absence of specific Irish data, a study undertaken

by Cancer Research UK found that, if all areas in England diagnosed colon, ovarian, rectal and lung cancer as early as the best performing regions, this could save the National Health Service (NHS) over £44 million in treatment costs benefitting over 11,000 patients each year.^{xxx}

We need to take this opportunity to ensure cancer services are stronger and more sustainable than ever before. There are opportunities to improve services for cancer patients, survivors and their families now, and into the future.

In order to ensure this happens, €45 million in new funding for cancer services must be provided in 2023.





2.1 Allocate €15 million in funding to address the impact of system backlogs and future demand on cancer services

By now, we are well aware of the significant challenges COVID-19 created for the Irish healthcare system and the impact it will continue to have for years to come. Throughout the pandemic, patients postponed doctors' visits, screening programmes were paused, and acute services were reconfigured to reduce footfall in hospitals.

Patients and clinicians are now seeing the impact of COVID-19 and the cyberattack at all stages of the cancer pathway, from screening to surgery, diagnostics to treatment. The issue of delayed diagnosis has been widely reported, with data published by the European Cancer Organisation stating that one million cancers may have gone undiagnosed across Europe as a result of the impact of the pandemic on cancer care.^{xxxvi}

There are a number of reasons as to this surge in undiagnosed cases, including the suspension of screening appointments, a drop in GP attendance rates and a reduction in referrals to Rapid Access Clinics (RACs) for breast, lung and prostate cancer in the early stages of the COVID-19 public health crisis.

For instance, colonoscopies help doctors detect bowel cancer, which is one of Ireland's most common cancers. At the end of 2019, 253 new people were waiting over four weeks for an urgent colonoscopy^{xxxvii}; but by the end of 2021 the number was 4,000^{xxxviii}. At the end of May 2022, 7,267 of 13,196 (55%) people were on the NTPF "active" in-patient day case waiting list for colonoscopy for over 13 weeks, meaning they have not yet received an appointment time.

Waiting times for scheduled appointments and procedures have been adversely affected by the COVID-19 pandemic. By year-end, new attendances in 2020 at rapid access clinics (RACs) for investigation of patients with suspected cancer were at 88% of 2019 figures.^{xxxix}

The most significant concern is that the longer cancer is left untreated, the more likely it is to be fatal. For example, delays in routine radiology services are causing

knock-on delays to treatment with the number of patients receiving radiation oncology between January and November 2021 stands at 85% of 2019 activity.^{xxxv}

The latest available figures show 15,674 people referred for a routine colonoscopy had been waiting longer than 13 weeks as of the end of March. Such delays can lead to cancer being diagnosed at a later stage of the disease, when treatment options are limited, and the prognosis is worse. The indirect consequences of such strain include a 10-14% reduction in cancer diagnoses in 2020^{xxxvi}, in addition to deferred tests and treatment delay.^{xxxvii} 'Missing' cancers are now entering the health system, and causing additional strain on services.

This can have a considerable impact on the quality of life, as well as the mental health of those waiting for cancer care.

Quote

'We are now increasingly seeing the knock-on effects of the Covid pandemic for people with other diseases including cancer. Some patients are now presenting for the first time with very large and advanced bowel tumours, in some instances through the emergency department, and some have clearly been unwell for some time'

Professor Glen Doherty, consultant gastroenterologist at St Vincent's Hospital in Dublin

Continued and sustained action is required by Government to manage the impact of such delays in presentation and diagnosis on the system going forward.

The Irish Cancer Society believe that approximately €15 million in new funding will be required in 2023 to alleviate the backlog of cancer diagnosis and prevent poorer survival rates.



2.2 Invest in the implementation of the National Cancer Strategy

Cancer incidence in Ireland is set to double in Ireland by 2045.^{xxxviii}

Despite technological and organisational advances in the provision of cancer care in Ireland, underinvestment before the pandemic meant that key performance indicators (KPIs) set out in the National Cancer Strategy were not being met, impacting on scope and quality of service provision. The ambition and vision which guided the most successful aspects of Ireland's approach to the COVID-19 must be applied to the implementation of the National Cancer Strategy, 2017-2026.

Budget's 2021 and 2022^{xxxix} saw an additional €40 million allocated to the implementation of the National Cancer Strategy, which was welcomed by the Irish Cancer Society. This increased funding was assigned to improve access to diagnostics, further the development of radiation and surgical oncology, expand the integration of psycho-social pathways for patients and to improve the quality of life of those living with and beyond cancer.

Five years on and halfway through the Strategy, significant spending is required to accelerate the recommendations to ensure key targets are met.

Many of the issues that face cancer services today are amplifications of problems that pre-dated the publication of the National Cancer Strategy. To illustrate this, one can consider the percentage of patients seen within the National Cancer Control Programme's (NCCP) target surgery timeframes pre-pandemic. At that time, these targets were met for 80% for breast cancers, 78% of pancreatic cancers and 59% of lung cancers. The target is 90% and the deadline to meet this target passed in 2017.

The National Cancer Strategy Implementation Report and Key Performance Indicators for 2021 were yet to be released at the time of writing. The most recent Performance Reports published by the HSE date back to the July - September 2021 period. This underscores the woeful lack of real-time health data in Ireland, which makes it impossible to make insightful, informed and targeted policy decisions.

At the time of writing, the National Cancer Strategy Implementation Report and Key Performance Indicators for 2021 were yet to be released. However, a snapshot of the National Cancer Strategy indicators that have yet to meet their targets, and for which the deadline has already passed, include:

Objectives	Key Performance Indicators	Progress known to date
Reduce waiting times for surgery	90% of patients seen within NCCP target surgery timeframes for defined cancers.	The target was scheduled to be met in 2017. However, according to the latest known data update from National Cancer Strategy Implementation Report 2020, 77% of breast and 55% lung cancer patients were seen within NCCP target surgery timeframes (January-June 2020). ¹
Achieve the radiotherapy treatment target	90% of patients commencing treatment within 15 working days of being deemed ready for treatment.	The target was scheduled to be met in 2017. However, according to the HSE National Service Plan 2022, projected outturn for 2021 was 74.7%. ²
Rapid access clinic attendance for breast referrals (urgent only)	95% attendances within 2 weeks of referral.	2021 data shows 55.8% attendance (14,152 of a target of 25,363). ³
Rapid access prostate clinic attendance	90% attendance within 10 working days of receiving a referral.	2021 data shows 66.4% attendance (2,405 of a target of 3623). ⁴
Rapid access lung clinic attendance	95% attendance within 10 working days of receiving a referral.	2021 data shows 89.6% attendance (3,285 of a target of 3667). ⁵

1 As per the National Cancer Strategy Implementation Report 2020. Available at: <https://www.gov.ie/en/publication/bd03f-national-cancer-strategy-implementation-report-2020/>

2 As per the HSE National Service Plan 2022. Available at: <https://www.hse.ie/eng/services/publications/serviceplans/hse-national-service-plan-2022.pdf>

3 Available at: https://www.oireachtas.ie/en/debates/question/2022-02-22/689/#pq_689

4 Available at: <https://www.oireachtas.ie/en/debates/question/2022-02-22/687/>

5 Available at: https://www.oireachtas.ie/en/debates/question/2022-02-22/685/#pq_685



2.3 Fully resource Programme for Government commitments on eHealth

Advances in technology have transformed how cancer is diagnosed and treated, improving patient outcomes and efficiencies in cancer care. Digitalisation across many healthcare systems has led to more integrated, effective systems and processes.

The Irish Cancer Society welcomes the announcement from Government that the Cabinet has received approval to develop the Health Information Bill, a positive step towards the development of an integrated health service.

Digitalisation is a significant need in the reform of the HSE. To ensure that the healthcare system's approach is agile and responsive to emerging trends, the timely collection and validation of data is essential to ensure accountability. A key issue that COVID-19 has highlighted is the need for a digitalised system to replace paper-based ones, allowing for responsiveness and flexibility within the system, reduced errors and the improvement of virtual access to patient records.^{xi}

A real-time publicly available electronic health database with the adequate staff capacity and financial resourcing to ensure that data can be validated and updated swiftly, is required. As is often the case with cancer treatment, patients will move between individual centres for specialist care. In such instances, data is logged across separate systems. The current approach of siloed access to health data across services, presents considerable challenges in capturing a real-time view of cancer activity across the country. This lack of holistic view greatly hinders efficient service planning and timely responses to unexpected challenges that arise.

Electronic healthcare records (EHR) containing digitally stored medical information on patients, have been established in several EU countries including Germany and the Netherlands. A similarly high rate exists in the United Kingdom.^{xxv}

The National Cancer Strategy 2017-2026 commits to achieving a 95% target to "expand electronic referrals for all GP cancer referrals" by the end of 2022. The interim figure of 75% by the end of 2019 indicates how behind we are in achieving such targets.

The continued focus and investment in technology is fundamental in building resistance against unexpected future challenges, to effectively track cancer-related activity, improve cancer services and ensure the demands of the growing population are accommodated for.

Learning from the 2021 cyber-attack on the HSE, a fully resourced cyber security strategy should accompany these measures to ensure the safety and security of all people interacting with the healthcare system and in fully addressing privacy matters.

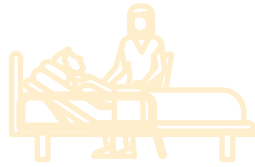
The Programme for Government makes a number of commitments on health data, including:

- Investing in a modern eHealth and ICT infrastructure, in line with Project Ireland 2040 and the eHealth Strategy for Ireland;
- Rolling out the Individual Health Identifier (IHI) programme, ensuring that patient information is accessible across different services to improve patient safety; and
- Implementing an Electronic Health Record (EHR) system in the new Children's Hospital and preparing to roll it out nationwide.

The pandemic has accelerated the development of some aspects of eHealth, such as ePrescriptions and online consultations. IHI was widely utilised as part of the roll out of the national vaccination programme. Such momentum in establishing IHI's should continue to expand the use of IHI's were across the health care system.^{xiii}

The Irish Cancer Society welcome the progress in the rollout of the National Cancer Information System (NCIS) with Beaumont Hospital and St James's Hospital going live in December 2021. NCIS is a single, national computerised system that records and stores information relevant to a patient's health care, including medical history, cancer diagnosis and treatment options.

The Irish Cancer Society is calling for commitments on eHealth and the rollout of the National Cancer Information System to the remaining designated cancer centres nationwide to be treated as a priority and resourced in full, in Budget 2023.



2.4 Provide a new funding stream for dedicated cancer infrastructure

Recent years have demonstrated the fragility of our cancer services, highlighting the need for cancer specific diagnostic pathways and dedicated cancer infrastructure to future-proof our services and deliver lasting care for all who need it.

Cancer services compete with demands for urgent care in other areas of the health system. At the root of this problem is the fact that in Ireland, 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 need and diagnosis of different illnesses and diseases. This means that when a crisis occurs, resources that could be preserved for cancer patients are reallocated for use elsewhere.

We have seen examples of this right across the cancer pathway, with surgeries/resections particularly impacted during the pandemic. Between January and November 2021, the number of patients undergoing surgical oncology was estimated at 80% of 2019 activity.^{xliii}

Life-saving and often time sensitive cancer surgery should not be competing for theatre time against other life-saving, unscheduled care. Even pre-COVID-19, elective surgery rates were typically reduced by 15% or more because of the winter surge. This led to significant health, practical and emotional consequences for patients. The arrival of COVID-19 therefore underscored what we already knew – acute services and elective care should not be drawn from the same pool of resources. So while the recent funding will certainly be part of the solution, we need to look into the future and find a way forward that ensures patients have timely access to cancer care, as well as planning for the inevitable growth in cancer numbers.

We have noted earlier in this document in the context of the National Cancer Strategy, these specific challenges, however additional funding for dedicated cancer infrastructure is required. The reality is, without investment in physical and human capital, the delivery of the Strategy will be extremely challenging.

To address this there is a need to examine the expected future demand across cancer services into the future. The Irish Cancer Society suggests an action plan for cancer infrastructure is required, taking into account the number of dedicated theatres for cancer surgery, beds, diagnostic tests and day wards.

Quote

“The time to act is now, otherwise the current pandemic will inevitably lead to a cancer epidemic for citizens across Europe”

Professor Mark Lawler

Rising incidence rates of cancer into the future, due to the ageing and growing population, as well as delayed diagnoses due to the pandemic and cyber-attack, result in a need to examine the exact requirements for service provision going forward.

The Irish Cancer Society are calling for a new funding stream set aside for the building of effective and dedicated cancer infrastructure.



2.5 Invest in sufficient healthcare staffing

Demographic change, the increasing complexity of care and rising expectations and demands from patients are putting huge pressures on healthcare staff.^{xliv} This is an issue across community care services, in addition to diagnostic and acute hospital care.

The Irish Cancer Society welcomes the increase in university places for the undergraduate programme in radiography, from approximately 45 to 100 per year.^{xlv} Announcements from Minister Harris on the increase of numbers of medicine places by 200 by 2025 are also welcome.^{xlvi} This must be matched by measures from the State to ensure there are adequate internship places for medical students as they proceed with their training.

While this is a positive step, wider staff retention and pay issues must be addressed.

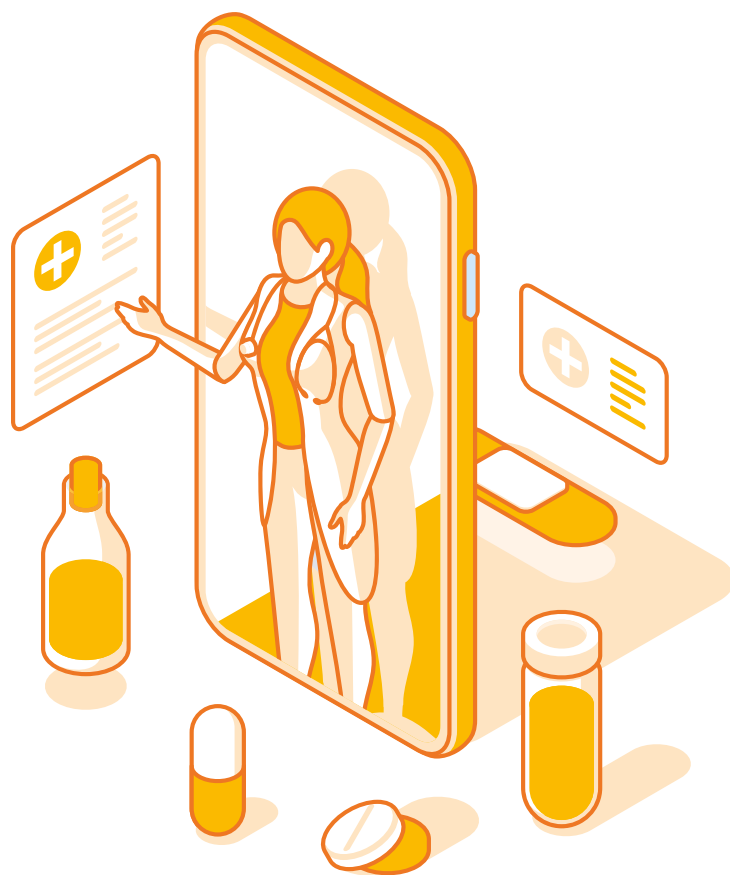
Recent figures presented by the Irish Medical Organisation show that 402 doctors have emigrated to Australia alone to date in 2022, up from 272 in 2019, noting working conditions for junior doctors/non-consultant hospital doctors (NCHDs) as a considerable contributing factor.^{xlvii}

Research from Brugha et al report (2020) how national retention measures have failed to effectively address stressful working conditions and issues regarding unsatisfactory training. As a result, the benefits of increased domestic production of doctors have not been realised and Ireland's compliance with the cornerstone principle of the World Health Organization Global Code 'train and retain' have been undermined through the largescale emigration of doctors.^{xlviii}

Initiatives by training bodies and employers to improve training experiences and working conditions will have limited effect in the absence of sufficient political will and resources to ensure an effective response to Ireland's medical workforce crisis.^{xlix}

As per the Sláintecare Report of 2017 and echoed in the Programme for Government, to recruit "additional frontline community staff, including public health nurses and allied health professionals, such as occupational therapists, physiotherapists, dementia advisers and speech and language therapists".

The Irish Cancer Society call for designated funding in Budget 2023 for the comprehensive resourcing of the healthcare system to plan and meet current and future demands.





2.6 Ensure comprehensive, sufficiently resourced national screening services

Screening is a vital tool in detecting pre-cancer or early-stage cancer in asymptomatic individuals, so that timely diagnosis and early treatment can be offered.

Ireland has three cancer related population-based screening programmes, under the management of the National Screening Service - BreastCheck, CervicalCheck and BowelScreen.

BreastCheck

BreastCheck is the national breast screening programme with the aim of finding breast cancer early and to provide treatment of breast cancer to those who show no symptoms of the disease. The programme offers a mammogram to all women between the ages of 50 and 69 free of charge every 2 years.

Due to COVID-19, some people's invitation for breast screening was delayed by approximately one year.

Data from the National Screening Service shows a 52.0% uptake rate of the 13,236 invited to attend screening during the first quarter of 2021ⁱ in comparison to the same period in 2019 where 62,151 invites were sent out with an uptake rate of 73.7%.ⁱⁱ

The HSE National Service Plan outlines the intention to maximise the update of the BreastCheck screening programme through targeted communication and promotion, developing and integrating an upgrade to the Client and Radiology Information System and by increasing resourcing within BreastCheck units (over the course of 2022). **The Irish Cancer Society call for the provision of adequate resourcing to improve screening uptake and ensure the programme is equipped to deliver screening every 2 years upon the completion of the current 3-year round.**

Adequate resourcing must be provided to ensure such plans are carried out and to ensure that the uptake rates for BreastCheck are improved.

Further to such changes to the BreastCheck programme, it is important that the Screening Service has guaranteed

downstream hospital capacity available to it for follow-on appointments. This should include the significant expansion and resourcing of symptomatic services so that they are equipped to meet current and future demand.

CervicalCheck

CervicalCheck is the national cervical screening programme targeted at those with a cervix who have been sexually active and aged between 25 to 65 years old.

As highlighted in the most recent National Cancer Registry of Ireland (NCRI) Reportⁱⁱⁱ, the rate of cervical cancer is continuing to fall, reflecting the positive impact of the screening programme.

However, inadequate screening participation between the ages of 50-to-64 years has been identified as a significant risk factor for cervical cancer for women in their 60s and 70s.ⁱⁱⁱⁱ Women are six times more likely to develop cervical cancer if not screened between the ages of 50 and 64.

Therefore, it is extremely important that women over the age of 50 engage with the cervical screening programme, as this will reduce their risk of developing cervical cancer and its associated mortality and morbidity in later life. **The Irish Cancer Society is calling on Government to increase their efforts to ensure that cervical screening is accessible, acceptable, and available to everyone who would benefit from it. Targeted communication aimed at groups with lower uptake levels is essential to improve screening rates.**

The most recent figures from CervicalCheck demonstrate a five-year coverage rate of 78.5% (ending 31st March 2020). The programme's national target is 80%.^{lv} Such figures indicate that, a significant proportion of the eligible population, approximately 1 in 5 eligible people, do not attend.

In a submission to the National Screening Advisory Committee, the Irish Cancer Society propose the addition of a self-sampling HPV test to the CervicalCheck programme, in an attempt to boost the number of people availing of the CervicalCheck programme. In line with its approach for the elimination of cervical cancer, the WHO recommends the use of self-sampling as an approach to HPV testing.^{lv} HPV self-sampling, which women can



undertake at home, is now an option and greater use of this tool could undoubtedly help to improve access to screening programmes and improve uptake.

Such changes to the CervicalCheck programme would need to anticipate the increase in response to testing through self-sampling to ensure that the requisite colposcopy capacity and resourcing for the National Cervical Screening Lab (NCSL) for the CervicalCheck programme was available for any necessary follow up.

For Budget 2023, the Irish Cancer Society are calling for CervicalCheck to pilot fund self-sampling tests for those eligible for the cervical screening programme to ensure as many people are tested as possible. 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.

BowelScreen

BowelScreen is the National Bowel Screening Programme, which offers free bowel screening to people aged 60 to 69 every 2 years.^{lvi} Bowel screening looks to detect and remove polyps. Polyps are small growths that are not cancer but, if not removed, might turn into cancer over time - approximately ten years. If polyps are found, they can be removed easily.^{lvii}

Approximately 2,800 people^{lviii} are diagnosed with bowel cancer in Ireland annually. Approximately 300 of such cases are people screened by BowelScreen.

Over 3,000 people have pre-cancerous growths (known as polyps) removed every year, which can prevent cancer from actually developing in the first instance.^{lix}

Around 1,000 men and women die of bowel cancer each year in Ireland, and this number is expected to increase significantly over the next 10 years, according to the HSE.^{lx}

Research findings reveal that a fifth (19%) of those surveyed stated their fear of the screening process. National Screening Service figures show that only 44.5% of the 43,623 people invited to return a faecal immunochemical test (FIT) kit had done so.^{lxi}

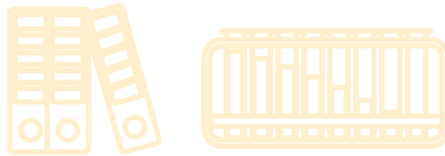
The main reasons for not taking part included 'embarrassment' and 'not knowing they were eligible'.^{lxii}

It is essential that the Government invest in specific campaigns to target those afraid to get screened for bowel cancer, emphasising its importance in the first instance and of repeated screening every 2 years.

The target set out in the National Cancer Strategy 2017-2021^{lxiii} that "the HSE will ensure that the appropriate endoscopy capacity is provided in hospitals to allow for the expansion of BowelScreen to all aged 55-74 by end-2021" has elapsed. For the second time, the extension of the bowel screening age range has been pushed out (the first being 2014). Time and time again, limited capacity in downstream services like colonoscopy mean that timelines continue to slip.

The Irish Cancer Society is calling for commitment from Government so that Bowel Cancer-Screening programmes will continue to expand in line with Government policy. We urge the State to further examine the feasibility of expanding the screening age even further to begin at 50 years of age. When the age range is extended, the National Screening Advisory Committee (NSAC) must examine how best to enhance colonoscopy capacity in the event that uptake improves.

We also ask Government to 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.



2.7 Commit to sustained, ring-fenced State investment in clinical trials

Clinical trials are used to determine whether new drugs or treatments are both safe and effective.

The aim of clinical trials for cancer treatments is to find new and better treatments and to help to improve outcomes in cancer patients.

Cancer trials aim to find better ways to:

- Detect cancer
- Treat cancer
- Prevent cancer from reoccurring
- Improve the comfort and quality of life for people with cancer^{lxiv}

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.

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 euro was saved in the cost of cancer drugs.^{lxv}

This is yet another example of a pro-active measure that can be funded by government to ease the burden on tomorrow's health system by improving patient outcomes today.

In 2019, a significant reduction was made to Cancer Trials Ireland's grant provided from the Department of Health through the Health Research Board, which means that several important clinical trials could not open.^{lxvi} Fewer opportunities were therefore created to recruit patients, to improve outcome and to drive the highest standards of care.

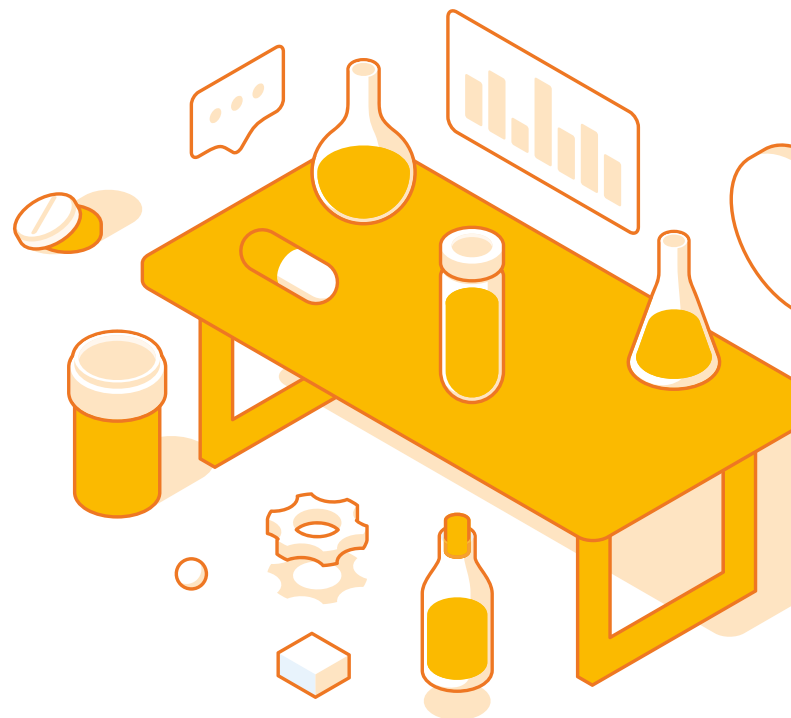
On a per capita basis, Ireland falls far behind the levels of trial activity seen with many European counterparts.^{lxvii} Recruitment, too, generally takes longer (by approximately 2 months) in Ireland than other EU

countries of similar population size, such as Denmark and Finland.^{lxviii}

A recent nationwide survey conducted on behalf of Cancer Trials Ireland showed that 60 per cent of people would be willing to take part in a clinical trial – up from 48 per cent in 2020. Such willingness needs to be reinforced with funding and opportunities to participate.^{lxix}

Clinical trials and research of this nature provide the opportunity for patients to contribute to scientific advances. The government must show political willingness to close the research gap, broadening investment in cancer research, to ensure the best possible outcome.

The Irish Cancer Society calls for sustained, regular investment in clinical trials research and infrastructure to ensure designated research funding offer cancer patients the best chance of survival.





2.8 Fund the development of a world-class cancer genetics service

Cancer is caused by certain changes to genes (genetic mutations) that control the way our cells work, most especially how cells grow and divide.

Some of these changes are inherited or familial genetic mutations, which are changes that are passed down through families from one generation to the next. These type of changes may increase a person's risk of developing cancer, and are known to play a major role in about 5-10% of all cancers (including breast, colorectal and ovarian cancers).

Cancer genetic services can:

- help an individual understand whether an inherited health condition may affect them, their children or other family members;
- show if the individual is at higher risk of getting certain health conditions, including some types of cancer;
- guide doctors in deciding what treatments best suit the person diagnosed with certain types of cancer.^{lxx}

Genetic testing has the possibility of reducing cancer cases, as well as the number of deaths.

Global advances in genetic testing, preventative treatment and personalised medicine offer great hope. Investment in, and equitable access to, these services has been proven to save lives and improve quality of life for people with a higher genetic risk of getting cancer.

The need for investment in such services has been highlighted by the European Commission, in its Beating Cancer Plan^{lxxi}, and highlighted in the National Cancer Strategy.^{lxxii} The launch of the 'Genomic for Public Health' project by European Commission to support member states emphasises willingness on an EU and global scale to capitalise on the rapid evolution of genomics in cancer prevention, diagnosis and treatment.^{lxxiii}

However, cancer genetic services in Ireland are underdeveloped and under resourced. A report prepared for the Irish Cancer Society^{lxxiv} demonstrates how Ireland

lags far behind other countries in this area and the consequences of such for individuals and their families.

As of the 9th March 2022, 2,225 patients were waiting for a cancer genetics appointment in St James's Hospital, with waiting times stretching from 15 to 18 months. With staffing levels under additional pressure during the pandemic, limited theatre time, along with the complex surgical expertise required, caused elective surgical services to be curtailed.^{lxxv}

In addition, notable findings include 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.^{lxxvi}

The Irish Cancer Society welcome the development of the HSE National Genetic and Genomic Steering Group. The Government must significantly increase the resources provided to genetic services to ensure that the National Genetic and Genomic Strategy for Ireland and implementation plan produced by the Steering Group receive adequate funding.

The work of this group will consider issues like the shortage of trained genetic specialists, substantial knowledge gaps in the clinical workforce and a lack of genetic/genomic literacy across healthcare professionals and the public. It will provide a model for coordination and integration between clinicians, and review the needs for a centralised national body with responsibility for genetic services and the establishment of future services, with appropriate governance structures, policies, procedure, and protocols.

This will assist with the following:

- Implementing a hub and spoke model with genetics expertise within the dispersed oncology system;
- Build and further develop the genetics workforce and capability by increasing cancer genetics diagnostics capability and expertise in Ireland;
- Establishing a streamlined genetics pathway which optimises online data collection and processing of data ensuring that follow-up counselling and health promoting interventions for individuals with positive mutations is optimised



Ensuring the full financial resourcing and implementation of the National Cancer Strategy 2017–2026^{lxxvii} recommendations around genetic services is key in reducing genetic testing wait times and to best optimise the health benefit advancements in this area. The challenge remains to ensure timely and appropriate implementation of all such recommendations.

In Budget 2023, the Irish Cancer Society ask that new funding is allocated to develop a world-class cancer genetics service. This will contribute towards cancer being caught earlier, the understanding of how cancers will develop, and ultimately the reduction in cancer deaths.

2.9 Fund the Lymphoedema Model of Care and National Lymphoedema Clinical Guidelines

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.^{lxxviii}

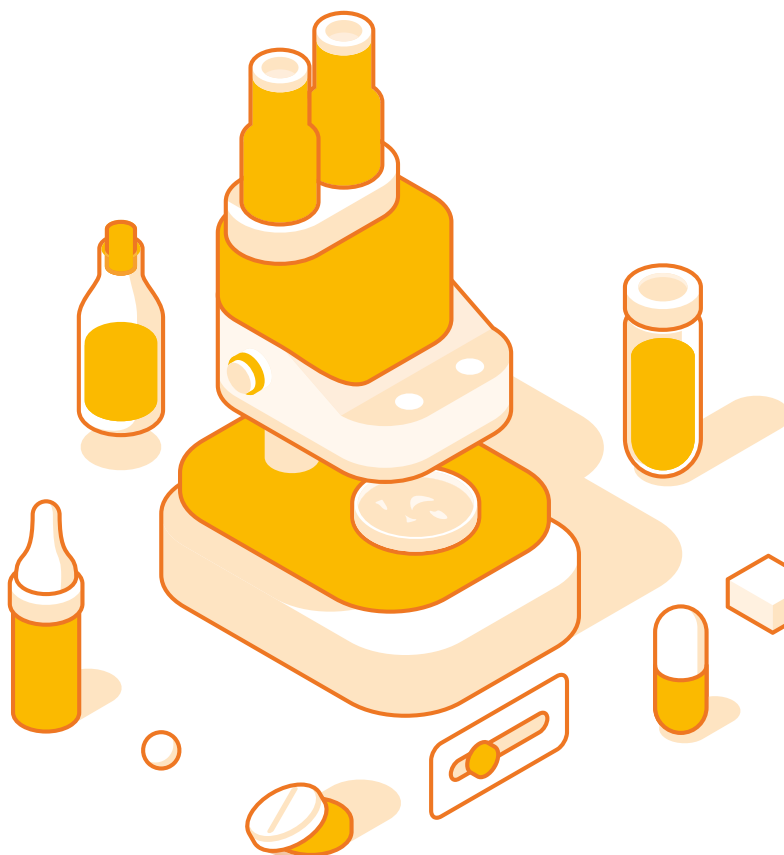
Approximately 12,500 people in Ireland have lymphoedema, which is incurable and lifelong, as well as having a significant impact on the quality of life of patients and their families. A proposed model of care, published in 2018, sets out plans to deliver a comprehensive service for patients to deliver.^{lxxix}

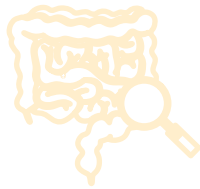
The HSE initiated the implementation of the Model of Care for Lymphoedema and Lipoedema through two proof of concept services - one for a primary care specialist lymphoedema service in Laois/Offaly (Community Healthcare Organisation 8 area) and the other for early detection in acute services (Mater Hospital).

The Minister for Health advised^{lxxx} that the National Lymphoedema Clinical Guidelines were being developed and due to be completed in mid-2021. This timeline has now elapsed. 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% if comprehensive lymphoedema services were introduced.^{lxxxi}

The need for lymphoedema services will continue to rise due to an ageing population, increase in obesity and increased cancer diagnosis and survival.

The Irish Cancer Society is once again calling for funding to ensure that the full implementation of the model of care proceeds as soon as possible, to ensure the adequate provision of lymphoedema services.





2.10 Provide €11 million towards endoscopy services

An endoscopy is a minimally invasive procedure used to observe an internal organ or tissue in detail. There are a number of such 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.

The HSE National Services Plan for 2022, includes an objective to “implement sustainable improvements to acute endoscopy waiting lists”.^{lxviii}

Some €263m, of the €350m fund made available via the 2022 Waiting List Action Plan^{lxvii}, was allocated to the HSE and National Treatment Purchase Fund (NTPF) to source additional outpatient (OPD), endoscopy (GI Scopes), diagnostics and inpatient day case (IPDC) activity.

The Irish Cancer Society welcome this allocation of funding. However, the reality is that in 2020, GI endoscopic biopsy rates were 80% of 2019 levels (30,350 fewer biopsies)^{lxix} and significant issues remain across the country when it comes to accessing such services with 28,535 patients waiting to receive an endoscopy appointment.^{lxx} Meanwhile, while use of the National Treatment Purchase Fund does ensure long waiters receive the diagnostics they require, it is often high-volume, low-complexity work, and an over-reliance on the private sector to prop up endoscopy services is unsustainable, and undermines the principles of Sláintecare.

In Budget 2023, we are still calling on such measures to be introduced. Endoscopic procedures ensure the early diagnosis of cancers and other morbidities, ultimately saving lives. The impact of such delays is that patients are presenting with large, more advanced cancers, many through A&E departments. More must be done to ensure sufficient funding is allocated to endoscopy services across the country.

Quote

‘Some progress has been made in recent budgets, but Government needs to provide a sustained funding stream for new posts in endoscopy services to meet demand and to support innovative new services like capsule colonoscopy and the use of faecal immunochemical tests [which can pick up early signs of cancer] for patients with low risk symptoms.’

Rachel Morrogh, April 2022



2.11 Fully resource Sláintecare

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.

A Eurofound survey published in 2021 highlighted that of the people who had reported an unmet need for a medical examination or treatment, 14% stated not being able to afford it as a very important contributing factor.^{lxxxvii} An Irish Cancer Society survey carried out in 2020, found that more than 8 in 10 people agreed that creating a health care system based on need and not ability to pay was important to them. This survey also found that 3 in 4 believe that the Government should prioritise spending on healthcare free at the point of access, rather than by reducing taxes.

The Sláintecare report of 2017 recommends 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 front-loading 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.

Five years on from the publication of the original Sláintecare report, progress has been slow in its implementation.

While the most recent available Sláintecare Progress Report highlights areas where the initiative was on track, there are many important areas, which have met significant challenges, such as actions to deliver a multi-annual plan on reducing waiting lists and eHealth. For instance, at the end of April 2022, almost 900,000 people were on a waiting list in the healthcare system.

^{lxxxviii}

The Irish Cancer Society believes that the funding towards the implementation of the Sláintecare report must be significantly increased to ensure the delivery of a system of universal healthcare based on need and not the ability to pay. The public healthcare system is in crisis. In this context, we are calling on the government to provide additional funding in 2023 to make Sláintecare a reality.



Prevention and Future Proofing

The number of patients diagnosed with cancer every year is rising as the Irish population grows and life expectancy increases.

Smoking, alcohol, physical inactivity, excessive sun exposure, and sexually transmitted viruses such as HPV are all major risk factors for cancer.

Cancer prevention is a cornerstone of the National Cancer Strategy^{bookix} as it offers the most cost-effective, long-term approach for cancer control. The sustained efforts of those involved in primary cancer prevention are key to ensure the reduction of cancer incidence rates.^{xc}

Once again, the Irish Cancer Society are calling for an increase in excise duty on cigarettes, funding for cessation programmes to support smokers to quit, the expansion of the catch up programme for HPV-caused cancers, an increase in funding for the National Skin Cancer Prevention Plan and continued budget allocation towards national walking and cycling infrastructure.

Cancer, its prevention, diagnosis and treatment will continue to dominate the public health and public policy agenda for many years to come. The more money spent on such measures now, the less the cancer burden will be on the State going forward.^{xcj}

The Government must do all they can to tackle the root causes of cancer, ease the cancer burden on the healthcare system and ultimately save lives.

3.1 Increase excise duty on cigarettes and roll-your-own products; invest in helping smokers to quit

Lung cancer was the leading cause of cancer death between 2016-2018,^{xcii} with an average of 1,880 deaths per year. It is the second most common cancer among women and the third most common in men.^{xciii}

A report commissioned by the Department of Health, titled "An assessment of the economic cost of smoking in Ireland"^{xciv} notes a minimum of 41 health conditions with a causal relationship with smoking. The World Health Organization European Region report^{xcv} directly links 85% of deaths from lung cancer to tobacco use. In the Irish context, smoking (including passive smoking) is the biggest contributor to cancer in Ireland, responsible for 13% of all cancer (excluding non-melanoma skin cancer).^{xcvi}

As outlined in the National Cancer Strategy,^{xcvii} smoking is the most significant modifiable lifestyle or environmental risk. The European Code Against Cancer^{xcviii} notes cigarette smoking as the single largest preventable cause of cancer in the EU.

This is why the Irish Cancer Society has, for decades, advocated for measures that will reduce cigarette smoking.

We commend the work of Tobacco Free Ireland in their efforts to reduce smoking rates in Ireland. Since 2007, smoking prevalence has declined from 29% to 18% in 2021. Successive governments have introduced key policies such as the indoor workplace smoking ban, plain packaging, advertising restrictions as well as increases in tobacco taxation.

Despite such efforts, the ambitious target of a smoking rate of 5% or less by 2025 is a long way off. For Budget 2023, the Irish Cancer Society is urging the Government to adopt well-evidenced, cost-effective policies that





support people to stop smoking so that the target can be reached as quickly as possible. The latest data from Healthy Ireland show a slight increase to 18% after the 2018 interim target of 17% had previously been met.^{xcix}

As evidenced by the World Health Organisation^c and others^{ci}, raising prices through taxation is the most effective way to reduce tobacco use and the harm associated with smoking. Higher taxes cause many smokers to quit and prevent others from starting in the first place, significantly impacting children and adolescents.^{cii}

The more expensive cigarettes become, the more motivation there is for a smoker to think about quitting.

As part of Budget 2023, the Irish Cancer Society calls for an increase on the excise duty charged on a pack of 20 cigarettes by €1.92.

This would see an increase in the price of a packet of cigarettes, from €15 to €16.92 in 2023, reflecting an increase of 5% in line with a tobacco tax escalator, and the rise in inflation.*

Such implementation will show the intent by Government to fulfil its commitment to “increase the excise duty on tobacco in the years ahead to further discourage smoking”.^{ciii}

Secondly, we are calling for excise duty increases on roll-your-own (RYO) cigarettes, to ensure their tax is equivalent to that on cigarettes, in an attempt to deter smokers from switching to such products.

‘Roll your own’ (RYO) tobacco is taxed at a lower rate than manufactured cigarettes in many countries. This is the case in Ireland with the excise duty on RYO tobacco remaining substantially lower.

Studies show that a reduction in the use of one tobacco product will be offset by increased use of other tobacco products (such as RYO) if the prices of these products are not also increased.^{civ}

A study commissioned by the HSE^v, showed that the age group with the highest prevalence of roll-your-

own cigarettes were those under the age of 25 (45%). Almost half of those smoking RYO (46%) were from the DE Group, representing those from lower income households.

This stresses the importance of implementing any tax increases to all tobacco products, so that the price differentials are minimised. This will ensure the maximum public health benefit such as reduced consumption, preventing uptake among young people, and promoting cessation.^{cvi}

Rather than giving up smoking completely, some smokers choose RYO products as a cheaper alternative.

We welcome the increased investment of €3 million per year as outlined in the new HSE Programme Plan (2022-2025) in ‘stop smoking’ services nationally, along with a community-led programme to encourage people to quit.

In addition to such measures on the cost of tobacco products, the Irish Cancer Society believe more should be done by the State to help smokers quit.

The socioeconomic differences in smoking prevalence worldwide is well established.^{cvi} Those on lower incomes are carrying more of the burden of disease from tobacco. This is also the case for Ireland with prevalence higher in lower socio-economic groups (SEGs)^{cvi}, contributing to the significant gradient in mortality rates by SEG.^{cix}

Targeted supports should be provided by the State as those from lower income households are disproportionately impacted by tobacco addiction.

Excise receipts from tobacco in 2021 were projected to amount to over €1.3 billion^{cx}, yet in 2021, the HSE’s spending on measures to tackle tobacco use amounted to little over €15.6 million.^{cx} The Irish Cancer Society argue that the revenue collected from tobacco should be used effectively in order to fund cessation service and prevention measures.

* This figure is based on a 7.8% annual rise in inflation as measured by the Consumer Price Index for May 2022 and based on the average retail price of a packet of 20 cigarettes following Budget 2022.



The Department of Health-commissioned the report “An Assessment of the Economic Cost of Smoking in Ireland”, published in 2016, estimated the annual cost to the health service as €460 million, and the total annual costs to the state as €10.7 billion.^{cxii}

In comparison to the financial impact on the State, costs for providing nicotine replacement therapy (NRT)/stop smoking medications to all who engage with the QUIT services are relatively small. The average price in 2019 was €188/person for the recommended 12-week course of medication NRT/Stop smoking medication.^{cxiii}

A 2017 Assessment from HIQA Health Technology^{cxiv} of smoking cessation interventions found that the most effective smoking cessation intervention is the use of a combination of the prescription drug varenicline and nicotine replacement therapy. Professional smoking cessation services, along with the use of NRT increase the chances of success in quitting by up to four times.^{cxv}

Currently in Ireland, those who hold a medical card can avail of free NRT/Stop Smoking medications under the General Medical Services scheme. This includes a requirement to attend GP services and re-attend every 2 weeks for a further script causing delay in access for the client, as well as further pressure on already stretched GP services. NRT is not covered by the Drug Payments Scheme providing an additional barrier in accessibility.

Given the social and financial impacts of smoking, there is a strong budgetary case for reimbursing Nicotine Replacement Therapy and other smoking cessation supports. The Healthy Ireland survey of 2020 showed a decline of 15% from those surveyed in the previous year, of those who saw their GP in their attempt to quit smoking.^{cxvi} The government must do more to remove any financial barriers linked to helping smokers give up.

Funding for medication for those enrolled in cessation programmes totals €813,570, a meagre total in comparison to the costs of smoking on the health service.

The Irish Cancer Society also call on the Government to consider including NRT under the zero rate under the exclusion list for the VAT Directive.

3.2 Fund the HPV catch-up programme

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

There are over 100 types of HPV with only certain types considered high risk increasing the likelihood of cancer. For example, types 16 and 18 can cause cervical cancer and type 16 is common with anal cancer. HPV has also been strongly linked to a number of other cancers including cancers of the mouth and throat, vulva, vagina and penis. Most cervical cancers and anal cancers are caused by the HPV virus.

In Ireland, there are an estimated 406 HPV-related cancers every year. Over 6,500 of those with a cervix need hospital treatment for pre-cancer of the cervix and approximately 90 people die annually from cervical cancer.^{cxvii}

The World Health Organization’s new global strategy for the elimination of cervical cancer (launched in November 2020)^{cxviii}, together with Europe’s Beating Cancer Plan^{cxix} (February 2021), the EU Cancer Mission^{cxx} and the EU4Health Programme^{cxxi}, together provide a major opportunity to tackle decisively all the cancers caused by HPV.

The World Health Organization’s (WHO) objective^{cxxii} is to vaccinate at least 90% of the EU target population of girls and to increase significantly the vaccination of boys by 2030, as outlined in Europe’s Beating Cancer plan.^{cxxiii}

In Ireland, the HPV vaccine is offered free of charge to all students in their 1st year of secondary school. The recommended vaccine ages are chosen in order to give each child the best possible protection against vaccine preventable diseases. If possible, this is before a person becomes sexually active and therefore first exposed to HPV infection.



The National Immunisation Office have advised that the latest available figures of HPV vaccine uptake rates show a projected 76% uptake for dose 1 and 65% uptake for dose 2 in the 2020/2021 academic year.^{xxxiv}

We believe the government can do more to increase the vaccine uptake, reducing more people's risk of cancer in the future.

The Irish Cancer Society believes that the elimination of HPV-caused cancer is within our grasp. The European Cancer Organisation's 'Viral Protection: Achieving the Possible. A Four Step Plan for Eliminating HPV Cancers in Europe'.^{xxxv} The recommended steps, which Ireland is making significant progress on, include:

1. Universal HPV vaccination for adolescents and optimal levels of uptake.
2. National organised population-based cervical cancer screening programmes using HPV testing systems and with higher levels of uptake.
3. Cancer treatments consistently and equitably offered in line with best practice guidelines and care and support that maximises patients' quality of life.
4. Action to improve public and professional awareness and education about HPV in order to improve vaccination and screening uptake.

Currently, anyone not in first year of secondary school or age equivalent in special schools or who are home schooled who wish to get the HPV vaccine must go to their GP or sexual health clinic and pay privately for the vaccine and its administration. As the private cost of the vaccine is anywhere up to €800, it is not affordable for most.

We welcome the Government announcement on the HPV vaccination catch-up programme. The catch-up programme will see schoolchildren, who missed out on HPV vaccination, as well as women under the age of 25 being prioritised for vaccination, as recommended by the National Immunisation Advisory Committee. 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 the value of vaccines.

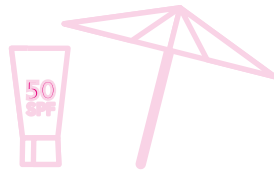
Further to this announcement, we appeal for funding to the HSE to develop an implementation

plan as speedily as possible so that those who may have missed out can soon benefit from vaccinations. The Irish Cancer Society also call for a focus on the need for males under the age of 25 to be included in the catch-up programme.

Such an approach would mirror that of the UK whereby if you are eligible and miss the HPV vaccine offered in year 8 in secondary school, it is available for free on the National Health Service (NHS) up until your 25th birthday.^{xxxvi}

In Budget 2023, we are asking the Government to prioritise the rollout of this catch-up programme for all those who missed out on receiving the HPV vaccine in secondary school and up to the age of 25, as well as funding allocation for the HSE to operationalise the policy. Clear targets for each of the next few years need to be published along with the resourcing of a public information campaign.





3.3 Fund the National Skin Cancer Prevention Plan

Skin cancer is the most common form of cancer in Ireland. With over 13,000 cases diagnosed each year, it accounts for over one-third of all cancers diagnosed annually.

Skin cancer is generally classified into two groups: melanoma and non-melanoma skin cancer (NMSC). Although it is the less diagnosed skin cancer, melanoma is associated with significant ill-health and is much more likely to spread to other parts of the body, which can be fatal. Non-melanoma skin cancer (NMSC), the most common form, includes basal cell carcinoma and squamous cell carcinoma, is a less aggressive, slower progressing cancer.^{xxxvii}

As the majority of those living in Ireland have fair skin, the type which burns most easily, the risk of ultraviolet (UV) damage, as well as skin cancer is high among the general population.^{xxxviii}

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.^{xxxix}

Cases of melanoma, the most dangerous form of malignant skin cancer, have been steadily rising in Ireland, which is a significant cause for concern. The most recent NCRI Report^{xxx} noted the continued increase in incidence and mortality rates of melanoma skin cancer among females between 1994 – 2019.

Research by the World Cancer Research Fund (WCRF)^{xxxi} ranks Ireland as the 12th highest nation in the world, and 10th in Europe, for detection of melanoma worldwide, with 16.3 cases per 100,000 people.

Cases of skin cancer have doubled in the last ten years and are projected to more than double again by 2025.

xxxii

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 a population level more must be done to reduce instances of skin cancer.

The aim of the National Skin Cancer Prevention Plan 2019-2022^{xxxiii} is to develop and implement evidence-based strategies, which will increase awareness and adoption of skin cancer prevention behaviours through cross-sectoral collaboration. We need to ensure that the Department of Health, as well as the HSE and such relevant partner organisations, have the funds needed to implement the plan so that the rising skin cancer incidence rates can be effectively addressed. Such funding will ensure the operationalisation of the National Skin Cancer Prevention Plan can be rolled out effectively, as well as education initiatives and campaigns.

Since the launch of the National Skin Cancer Prevention Plan in July 2019, circa €538,000 has been spent on its implementation. This includes investment from the HSE National Cancer Control Programme, Healthy Ireland and Sláintecare.^{xxxiv}

The Irish Cancer Society is calling for full funding to be provided to the National Skin Cancer Prevention Plan.





3.4 Fund radon testing kits; cover remediation costs in high risk areas

The radioactive gas radon is the main cause of lung cancer in non-smokers in Ireland, causing 350 cases every year.

Radon is a naturally occurring gas released by the decay of uranium in rocks and soils. Long-term exposure to high levels of radon can cause damage to DNA in the lungs, increasing the risk of cancer. The risk from radon is 25 greater for those who smoke (in addition to the risk of smoking itself) than for lifelong non-smokers exposed to the same levels of radon.

A recent report highlighting the radon risk map for the country shows 170,000 homes located in high-radon locations, an increase of 45,000 homes since 2002, with the burden of risk particularly high in the Munster and Connaught areas.

The Environmental Protection Agency advise that homeowners test for the presence of radon, which involves leaving detectors in place for at least three months to capture an accurate analysis.

For most homes, a radon extraction fan will draw the radon from underneath the ground and out into the atmosphere, costing in the realm of €1,000 – 2,000. Increased ventilation will also improve radon levels.^{xxxv}

In Budget 2023, we are calling on the Government to cover the cost of radon testing kits, as well as providing a grant in high-risk areas.

3.5 Continue to allocate 20% of the transport capital budget to walking and cycling

A commitment of €1.8 billion in funding over the lifetime of the Government in the Programme for Government and in Budget 2022 demonstrated significant ambition to provide the necessary infrastructure to enable everyone in society to walk and cycle.

The Irish Cancer Society welcomed the announcement in January 2021 that funding would be allocated for up to 248 new jobs, across local authorities and Regional Cycling Design Offices, to expand walking and cycling facilities all over the country, by improving infrastructure and increasing participation.^{xxxvi}

Integrating exercise into everyday lives is a key way to lower the risk of developing cancer, cardio-vascular disease, and other adverse health outcomes. It also makes it much easier to maintain healthy habits and reduce the risk of developing cancer.^{xxxvii}

Making walking and cycling facilities safer and more accessible will ensure greater take up by members of the public, encouraging active travel as well as contributing towards tackling climate change.

In addition, walking and cycling for daily travel is considered the most affordable, feasible, and dependable way for people to get the additional exercise they need.^{xxxviii}

The Irish Cancer Society is once again calling for 20% of the transport capital budget, €360 million, to be invested in walking and cycling infrastructure, so we can continue to make Ireland a place where it is safe and convenient to make the healthy transport choice.







Irish Cancer Society

CAYA Pre-Budget Submission 2023

Supporting Children, Adolescents and
Young Adults (CAYA) with Cancer



“Supporting young people, supporting families”

Contents

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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 devastating illness. Cancer at this age is all-consuming and impacts just young people but their entire families. Many struggle to cope financially and need extra supports, so they can focus their time 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 Irelandⁱ.

Table 1: Annual average numbers of childhood / adolescent / young adult cancers diagnosedⁱⁱ

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

The survival rates of childhood cancer in particular have improved dramatically with improved clinical care; since the 1960s mortality rates have been decreasing on average 2.6% per year for boys and 2.9% per year for girlsⁱⁱⁱ. 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 following them into adulthood. Unfortunately, this is not currently 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 lifespan of every young person with cancer; from early detection, through to treatment, survivorship care, and in end of life care.



Our Main Asks

Provide financial **supports for families**

1

Close the **Care Gap**

2

A Extend the Domiciliary Care Allowance to 16 and 17 year olds - €30 million

B Provide a State Allowance for families to cover the financial impact of childhood cancer

C Waive or significantly reduce hospital car parking charges for families attending appointments

D Provide lifelong medical cards for young people with cancer

E Provide a fund for families who require cancer treatment abroad

A Continue to invest in cancer care innovation for young people through research

B Fully fund the psycho-oncology model of care for young people with cancer and their families

C Fund the implementation of the NCCP Adolescents and Young Adults (AYA) Framework

D Invest in the expansion of the genomics division of cancer care in young people - €1.4 million

Promote quality of life initiatives **in young cancer survivors**

A Invest in long-term supports for young people going back to school or work after cancer

B Fund practical supports to AYA cancer survivors returning to work

C Fund initiatives addressing the survivorship needs of young people surviving cancer

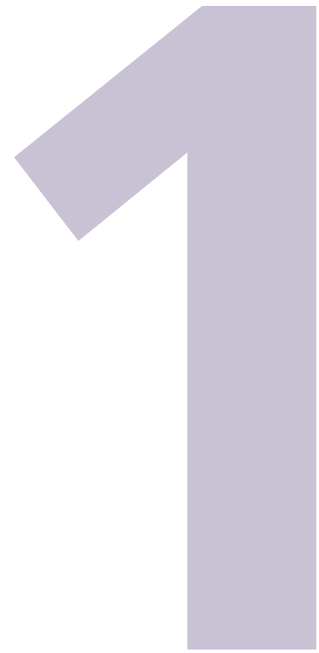
Fully fund palliative care and end **of life care for young people**

A Fully fund the Paediatric Palliative Care Model

B Fund bereavement support for families with children who have died of cancer.



Provide financial supports for families



The current State supports for families do not cover the costs they face after a devastating cancer diagnosis. Families face a double burden; at the same time they see an often dramatic decrease in household income, they experience significant new expenses relating to caring for their sick child. The cost of living crisis has hit these particular families hard; any income they receive is going straight to managing the staggering expenses of attending hospital appointments, let alone the day-to-day expenses every family in Ireland is struggling to pay due to inflation. It is important that the State steps in to ensure this situation doesn't continue, and we are asking the Government to take action to meet the needs of families.

The Real Cost of Childhood and Adolescent Cancer Report

The Irish Cancer Society published the first research of its kind on the financial impacts of childhood cancer on families in Ireland. The Real Cost of Childhood and Adolescent cancer report shows the stark reality families face when a child is diagnosed with cancer^{iv}.

- Four in 5 of all parent/guardian respondents reported a reduction in personal income as a result of their child's diagnosis.
- Four in 5 of all parent/guardian respondents reported an increase in costs (an average of €4,178, median of €2,250). This includes medications, wigs, fabric supports and play therapy.

- Appointment-related costs for cancer care (chemotherapy, follow-up care etc.) were on average €989, median €398 per month.
- Treatment for childhood/adolescent cancer can lead to late effects in cancer survivors which require additional care in adulthood, with increased medical costs and an impact on their work and education.

Current financial supports from the Irish State available for families, including the Carer's Allowance, medical cards and the Domiciliary Care Allowance, can offset some of the costs they encounter when a childhood cancer diagnosis impacts their family. It is important to note, however, that these allowances are often means-tested, and not all allowances are available to every family who applies for them. The double-impact of loss of income and increased costs often leaves family in debt and struggling to make ends meet while caring for their sick child.

Quote

"No long term financial plan - I live one day at a time, week to week, constantly budgeting... No retirement plan - No savings - all used up..."

Respondent in the Real Cost of Childhood and Adolescent Cancer Report.

There are several ways the Government can take action:



A) Extend the Domiciliary Care Allowance to 16 and 17 year olds - €30 million^v

"[...] carers allowance and Domiciliary Allowance was such a life saver for us alongside private fundraising our family did to help us survive financially."

Respondent in the Real Cost of Childhood and Adolescent Cancer Report.

The Domiciliary Care Allowance (DCA) is often the first State support families apply for when their child is in hospital with cancer. It provides welcome relief to parents or guardians who have to reduce their working hours or give up their job to stay in hospital while their child is receiving treatment. The payment is cut off once a young person turns 16. This often comes as a shock to families; the expenses haven't stopped mounting, so why should this lifeline payment be suddenly cut off? Young people often remain in the care of their families, and become adults at the age of 18.

We are asking the Government to extend the DCA to 16 and 17 year olds.

Including 16 and 17 year olds in the DCA scheme would require a €30 million investment from the Government; this is one of the key steps to provide some financial security to these families.

B) Provide a state allowance for families to cover the financial impact of childhood cancer

We welcome the recent extension of the Domiciliary Care Allowance to 6 months for children in hospital; families tell us this is the payment they first apply for, so this change brings some relief. However, allowances such as the Domiciliary Care Allowance and carer's allowance do not cover the expenses families experience following a childhood cancer diagnosis; these welfare supports are a small safety net, but do not cover the costs of reduced income and increasing expenses associated with childhood cancer treatment. The Irish Cancer Society offer a once-off, non means-tested payment of €3,000 to every family with a childhood cancer diagnosis; and is a safety net for many, although is just a contribution to the families facing ever-increasing expenses.

These facts are laid bare in our report on the Real Cost of Childhood and Adolescent Cancer; families pay over and above what is expected to support their child as they go through treatment, and face life-changing financial issues. Families often rely on fundraising, and go into debt to cover expenses; saving and planning for the future does not happen when immediate costs are so high. Cancer is a prolonged and significant life-threatening illness for young people; frequent and prolonged hospital stays makes cancer a costly disease for families to cope with.

According to our research, the annual average drop in income for families is €1,275 a month. If families receive both the Domiciliary Care Allowance and the Carer's Allowance, these supports would cover this drop in income. However, families who have finished cancer treatment also reported additional monthly expenses of €1,990 associated with attending their child's medical appointments while they were in treatment^{vi}. This amounts to €23,880 a year in non-medical expenses to care for their sick child with cancer, which they cannot cover due to the coupled decrease in income. Families told us that their young person's cancer treatment lasted on average for 2 years and 4 months^{vii}. This research was completed in 2021; expenses such as accommodation, food and fuel have since increased, so these families are also being hit worse by the cost of living crisis every family in Ireland is currently experiencing^{viii}.

We are asking for the Government to create a State "Childhood and Adolescent Cancer Care allowance" that will cover the expenses incurred by families.

This allowance should not be means tested, and it should be automatically given to families upon a cancer diagnosis up to the age of 24, so families do not face a delay in receiving support. It could act as a supplemental payment to the Domiciliary Care Allowance to recognise the additional costs associated with cancer at a young age. An allowance of €1,500 per month would begin to cover some of these non-medical costs, and would allow families to get back on their feet during cancer treatment.

The costs in the table below outline expenditure reported by parents/guardians of children who were undergoing treatment for cancer at the time of the research, and expenditure reported by parents/guardians relating to children who had finished receiving treatment during the time they were undergoing treatment.

*The table represents responses from all 100 parents/guardians who participated in the "Real Cost of Childhood and Adolescent Cancer" survey and represents **monthly costs of attending hospital appointments for cancer treatment.***

	Child is currently receiving treatment for cancer	Average €	Median €	Child has finished receiving treatment	Average €	Median €
Travel costs going to and from appointments e.g. petrol, fares, taxis, etc	94%	279	120	97%	463	200
Parking costs while at appointments, etc	89%	66	30	91%	201	50
Cost of eating out while at appointments	94%	118	70	92%	365	200
Accommodation costs	28%	88	90	42%	503	175
Other travel-related costs associated with appointments (tolls, car servicing etc.)	6%	202	202	19%	458	180
None of these	0%	-	-	3%	-	-

C) Waive or significantly reduce car parking charges for families attending appointments

Quote

“Parking, this is probably the toughest thing. To get parking in the hospital you had to be there before 8am and then the parking is just so expensive. Think we spent €120 a month, petrol €150 a month.”

Respondent in the Real Cost of Childhood and Adolescent Cancer.

One of the most difficult and common expenses families face while a child is going through treatment is the cost of car parking.

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. Alongside CHI Crumlin, there are 16 hospitals in the National Children’s Cancer Service, and the vast majority offer concessions or free car parking for young cancer patients attending appointments. The Irish Cancer Society recognises these efforts, and we believe it is up to the government and the HSE to replace any lost income hospitals receive as a result.

Families where their child has finished treatment in our Real Cost of Childhood and Adolescent Cancer reported spending €201 per month (median €50 per month) on parking charges during their treatment^{xi}. The Programme for Government commits to price caps for patients in hospital car parks^x. While progress in this respect would be welcome, **we are calling on the Government to provide funding to waive or significantly reduce car parking charges to the families of the CAYA group who are going through cancer treatment.**

This waiver could be provided via the provision of parking discs to families attending hospital appointments for cancer treatment; the disc could be used hospital car parking for on-street parking, which is often the only option in city centres.

In 2019, there were over 11,000 day case episodes and 2,900 inpatient stays in the over 40 hospitals across the country treating people aged 0-18 with cancer^{xi}. Providing a waiver for these cases would ease the significant challenges these families face during cancer treatment.



D) Provide lifelong medical cards for young people with cancer

Quote

"I do believe survivors should be given life time medical cards to help financially."

Respondent, Real Cost of Childhood and Adolescent Cancer, 2021.

Being diagnosed with cancer at an early age means that there is a higher risk of illness and disabling events in adulthood. A major study showed that at age 45 years in comparison to the general population, survivors of childhood cancer have twice the burden of disease and 7 more chronic conditions, 2 of which are likely to be disabling, life-threatening, or fatal^{xiii}. Impacts are wide-ranging, and include delays in psychological development, and illness such as cancer reoccurrence, mental health issues, cardiac issues, increased risk of infection, and more visits to the hospital in comparison to the general population. These late effects are also higher in groups of socioeconomic disadvantage^{xiv}.

Current practice means that those diagnosed with cancer in childhood (0-18 years) within the last 5 years are entitled to a medical card^{xv}; this was introduced following the recommendation by the Clinical Advisory Group of the HSE to introduce this scheme, who were appointed following the Keane report on medical card eligibility in 2014. The medical card entitles these children and adolescents to free inpatient (in public hospitals), outpatient and GP services, as well as free prescription drugs (although a prescription charge applies up to a maximum of €15 per month)^{xvi}.

Families who contributed to our Real Cost of Childhood and Adolescent Cancer report were grateful for the medical card, as it covers many of the medical expenses associated with cancer treatment. Families recommended that access to the medical card is made easier for families, and that it does not expire; adult survivors of childhood cancer reported high costs of dealing with medical issues associated with their cancer

treatment. Despite cancer patients under 18 being eligible for a medical card within five years of diagnosis, uptake reported by the parents/guardians surveyed was lower than anticipated at only 6 in 10^{xvii}. This suggests a need for improved awareness of what is a vital lifeline for many.

A recognition of the lifelong impacts of CAYA cancers requires an extension of this time limit, and provision of lifelong medical cards to this group from diagnosis. CAYA cancer survivors face a range of challenges into adulthood that the general population will not.

We are calling on Government to provide lifelong medical cards for survivors of CAYA cancers.



E) Provide a fund for families who require cancer treatment abroad.

Statistic

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.^{xviii}

The Treatment Abroad Scheme provides a lifeline to families who must go abroad for lifesaving treatment for children and young people. It ensures that approved treatment is paid for, 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 accommodation, food and other expenses. Outside of the expenses covered by the Treatment Abroad Scheme and money received through charities or private fundraising, families reported still being €3,175 out of pocket on average, based on our Real Cost of Childhood and Adolescent Cancer report. Important to note that this is an average cost based on the survey responses from parents/guardians of children who had received a cancer diagnosis, and some people spend significantly more according to our research. 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^{xix}. While families can claim tax relief on some of these items, and voluntary organisations provide crucial funds and support for these families, the costs still represent a significant burden on families that are already struggling.

We are calling on the Government to introduce a new "travel abroad fund" to cover the non-medical expenses of these arduous and stressful journeys.

The cancer-specific fund would be administered by the NCCP, and would cover the accommodation and non-medical costs for families travelling abroad for care. In 2021, 18 families used the travel abroad scheme for people under 24 years old to access cancer treatment^{xx}; this fund would be of minimal cost to the State, but would make a huge difference to these struggling families.



Close the Care Gap



The progress in cancer care in young people has gained momentum over recent decades, with survivorship rates increasing every year through developments in medical care. Although young people's cancer survival rates are at an average of 80%^{xxi}, they live on with the higher burden of toxic effects from their treatment, with "late effects" such as impacts on their mental and physical health that bring profound changes to the rest of their lives. Doing everything we can so young cancer survivors can live normal lives is of profound importance.

A) Continue to invest in cancer care innovation for young people through research

As we have highlighted, survival rates have greatly improved; however, these rates are losing momentum, 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^{xxii}. 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 our young people.

The HSE Action Plan for Health Research 2019-2029^{xxiii} sets out an ambition to further develop the research capacity of the health service and improve outputs,

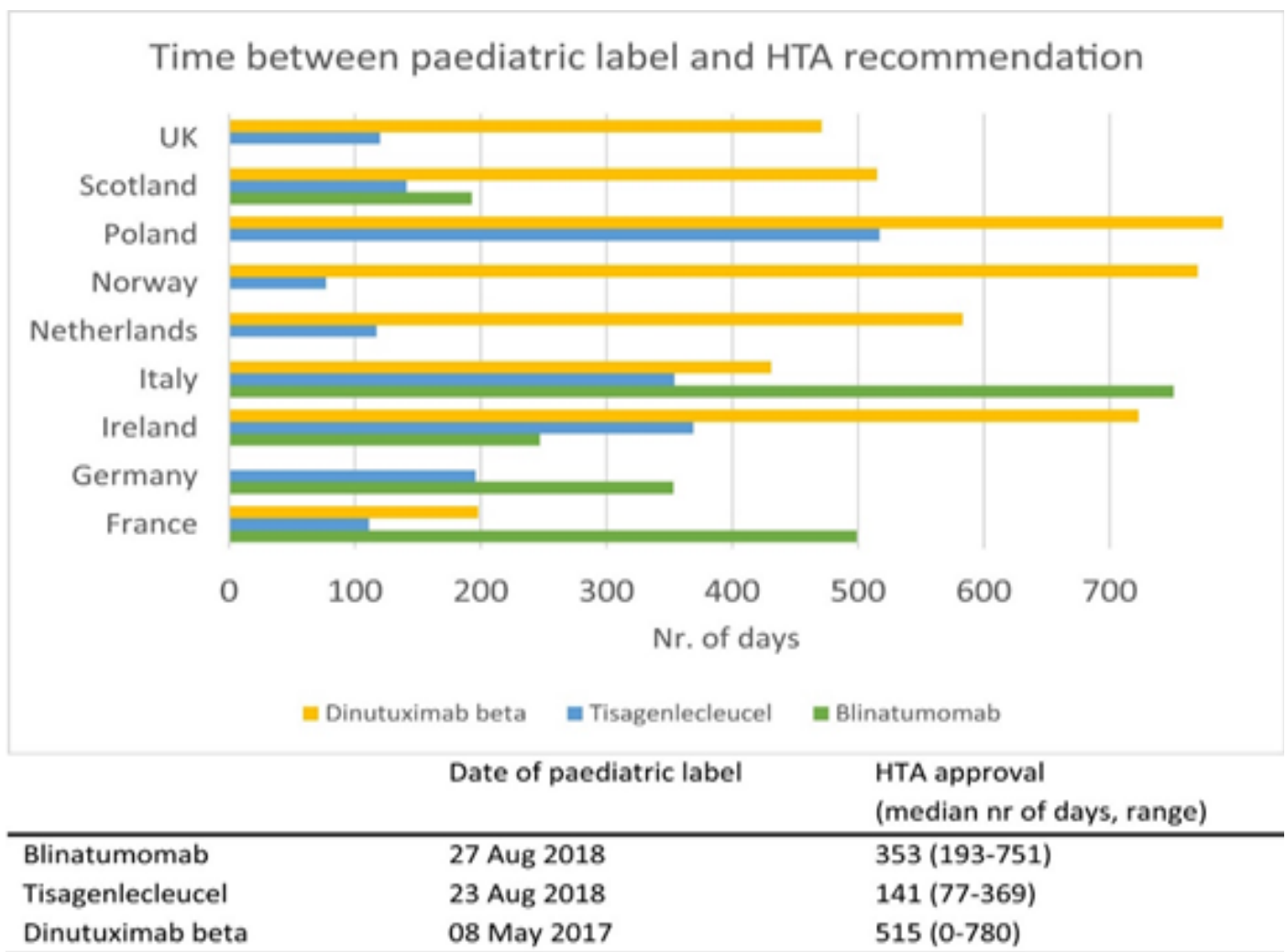
such as increased amounts of clinical trials being undertaken, which is the cornerstone of developments in CAYA cancer research. Building capacity in the health workforce to enable them to undertake groundbreaking research will only bring benefits for patients. Prof. Owen Smith, Consultant Paediatric 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^{xxiv}; further investment can develop Ireland's contributions in this growing field of cancer research

We are asking the Government to ring-fence funding to enable the CAYA cancer workforce to undertake impactful research.

There is a low output of market-driven research from the pharmaceutical industry in cancer drugs to treat childhood cancers specifically; **we call on the government to incentivise medicine development in childhood cancers.** Investing in the development of international research platforms to further our knowledge on curative treatment for childhood cancer is needed^{xxv}. Young cancer patients experience unacceptable delays to accessing the cancer drugs they need for their treatment in Ireland^{xxvi}; collaboration and cohesion with other EU countries is needed so we don't fall behind in the progress being made². A recent study shows that for access to some drugs for paediatric oncology, it took the Irish health authorities over 18 months to approve the reimbursement of these drugs for use after they are recommended by the EU HTA body^{xxvii}.

2 The ACCELERATE project is an excellent example of efforts to accelerate innovation and international collaboration on childhood and adolescent cancer. <https://www.accelerate-platform.org/>

Fig. 1 Comparison table of EU member State approvals of medicines for use in paediatric oncology and health technology assessment (HTA) recommendation on an EU level^{xxviii}.



UK: refers to England and Wales

B) Fully fund the psycho-oncology model of care for young people with cancer and their families

“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

The Society is aware that a Paediatric Psycho-Oncology Model of Care is in development to meet the specific needs of children and adolescents living with cancer.^{xxix} 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.^{xxx} For instance,

siblings of a child/adolescent who has had cancer may have unmet psychological need.^{xxxi} Parents of children and adolescents with cancer have to make sacrifices, and in some instances they can experience economic, occupational and marital difficulties.^{xxxii}

The effects of a childhood cancer diagnosis and treatment often follow a person and their family into adulthood.^{xxxiii} Parents can continue to carry their stress and anxiety including fear over their child’s health throughout their lifetime.^{xxxiv} The psychological effects of a childhood cancer diagnosis can be delayed for a number of years.^{xxxv} Survivors can endure anxiety linked to their health and experience higher rates of psychological challenges,^{xxxvi} prescriptions for anti-depressants, and hospitalisation for mental disorder, compared to the general population.^{xxxvii}

People who live with cancer and who have their psychological needs met have better health outcomes.^{xxxviii} However, current provision of mental health services in Ireland is insufficient,^{xxxix} and the National Children’s Cancer Service (NCCS) does not meet international standards of psychosocial care^{xl}. To address these shortcomings, recent research has recommended that additional staff are required for key posts in haematopoietic stem cell transplantation, in the late effects clinic and a senior neuropsychologist for people impacted by cancer.^{xli} 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 2023 we are asking Government to fund a CAYA specific public psycho-oncology support service.

These services should also be available to survivors of CA cancer 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.

C) Fund the implementation phase of the NCCP Adolescents and Young Adults (AYA) Framework involving the creation of specific, age appropriate care in the National Children's Hospital and in shared care centres.

Quote

"It is now widely accepted internationally that traditional models of cancer care do not adequately meet the needs of the AYA population."

National Cancer Strategy, 2017-2026

Quote

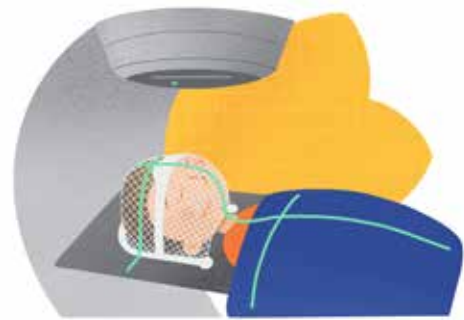
"I believe this Framework report offers the best possible overarching future vision for AYA cancer for the Republic of Ireland based around the National Cancer Strategy recommendations"

Prof. Owen Smith, CAYA Clinical Lead, NCCP Framework for the Care and Support of Adolescents and Young Adults (AYA) with Cancer in Ireland 2021-2026

The NCCP AYA Framework is a landmark proposal to change the entire cancer care pathway for young people aged 16-24^{xliii}. This particular group "falls between the two stools" of paediatric and adult cancer care, leaving them left out of the crucial developments taking place in cancer research and supports.

We call on the Government to provide continuous core funding to the implementation of the NCCP Adolescents and Young Adults (AYA) Framework; this involves hiring an experienced workforce and creating a dedicated research infrastructure to reduce the inequalities faced by this group, and to provide the tailored age-appropriate care they need. This young age group may start their cancer treatment in the National

Children's Cancer Service, and then face a difficult transition into adult services; the AYA framework is needed to make sure they are no longer the "lost tribe" of cancer patients, and receive the required age-appropriate care and support services, through the designated share care centres.



D) Invest in the expansion of the genomics division of cancer care in young people - €1.4 million

It is the vision of the Irish Cancer Society that every young person has genomics care as a core part of cancer care at diagnosis. Mapping of the cancer type and the genetics of the young person can ensure individualized treatment plans will be developed, including in immunotherapy. The recently introduced CAR-T cell therapy is a fantastic development in this area^{xliii}, and the Irish Cancer Society has funded a post in CHI Crumlin to develop the cancer genetics service.

We ask the Government to fund the national genomics service for young children with cancer.

An investment of €1.4 million over 5 years would allow every young cancer patient have their tumour DNA and their own DNA sequenced, so individualised, targeted immunotherapy can be the backbone of their cancer treatment. This 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.

Promote quality of life initiatives in young cancer survivors

Survivorship care is increasingly becoming more of a focus in the CAYA cancer community. Now recovery rates are at an all-time high, structures need to be in place to provide long-term support, so survivors don't face inequality in comparison to their peers who have not gone through cancer.

Survivors can face many different long-term effects as a result of cancer treatment, such as pain, cognitive impairment, anxiety, depression and fatigue. These can affect the cancer survivor, as well as their family, in many ways, from social isolation, mental health issues, and psychosocial issues^{xliv}. These cause long-term impacts on the opportunities available to cancer survivors; support needs to be consistently provided on a long-term basis, so survivors can thrive into adulthood.

A) Invest in long-term supports for young people going back to school after cancer

The psychosocial impacts of young cancer survivors can be profound, and can impact their socioeconomic standing in regards to their education level and career prospects^{xlv}.

The educational performance of young cancer survivors can be impacted by^{xlvi}:

- 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, for example, hearing loss, difficulty with peer relationships.

The education provision for young cancer patients is provided by a school in CHI Crumlin; however, schooling for adolescents and young adults treated in other hospitals isn't usually provided^{xlvii}. 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^{xlviii}. Cancer survivors often need to have supports in place to continue through to education; their eligibility can be difficult to assess, as cancer survivors are not in the specific criteria for supports, particularly for supports in higher education^{xlix}.

We are asking the government to provide automatic eligibility for young cancer survivors into the Disability Access Route to Education (DARE) scheme, as well as the provision of individual education plans for each student.

Specific support such as special needs assistants and/or assistive technology and adaptations should be consistently applied to the people that need them; assessing cancer survivors for their needs should also be provided rapidly and free-of-charge.

B) Fund practical supports to AYA cancer survivors returning to work

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. Our recommendations for government from our “Return to Work” report include starting a pilot scheme to support the reintegration of cancer survivors returning to work; the specific needs of young cancer survivors must be taken into account for this scheme to be a success. Balancing the needs of workers and employers is required in these cases, and upcoming legislation on work life balance must take into account the needs of young cancer survivors when reintegrating into work.

We are asking the Government to fund pilots promoting young cancer survivors’ reintegration to work following cancer treatment.



C) Fund initiatives addressing the survivorship needs of young people surviving cancer

Quote

“We should no longer focus on ‘how long’ people live after diagnosis, but rather on ‘how well and how long’ they live.”

EU Beating Cancer Plan

As survival rates for many CAYA cancers are over 80%, we are seeing a huge increase in the demand for supports after cancer treatment, as they plan for their futures. Following the landmark research on the Needs Assessment of Childhood Cancer Survivors^{li} from the NCCP, further research is now taking place to understand what supports families require; the Government needs to commit to funding these essential supports. Inequalities are high in childhood cancer survivors in comparison with their peers without cancer^{lii} so these initiatives are required to advance the quality of life in survivors and get them back on their feet following cancer treatment.

We ask the Government to fund survivorship supports for young cancer survivors to reduce inequalities for this group.

Promising research on the needs of young cancer survivors is in progress, for example, the Irish Cancer Society has funded a research project by Dr. Suzanne Guerin on the experience of marginalised groups within the adolescents and young adult population diagnosed with cancer. We need consistent government funding to enable the implementation of evidence-based recommendations and to provide the best standard of survivorship supports and follow up care. Tailored long term follow up care is required for each survivor of investment in strong co-ordination in care, as well as support during their transition into adulthood, will bring about lasting improvements in the quality of life of survivors.

Fund the Paediatric Palliative Care Model and End of Life Care



Even though most young people with cancer are given a positive prognosis and there is a range of different treatment options available, we must not forget that not every young person makes it through cancer. The geographic spread of palliative care services available make it challenging to provide tailored paediatric oncology palliative care to this group as they approach the end of their lives. Facing their most difficult challenge in their lives, families need to have the full complement of supports and options available to them at this phase in their journey.

A) Fund the Palliative Care Models for young people with cancer

We welcome the additional funding the Minister for Health has committed to providing palliative care in the community to children with life-limiting conditions; more consistent and predictable funding is now required to provide the optimal care these families deserve as they approach the end of life.

We support the recommendations of the Governance and Operations report for paediatric palliative care from the HSE; 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 access to age-



appropriate services in a timely manner; families also need to have the option of having end of life care at home if they choose also. Gaps are identified in the 2016 review of paediatric palliative care services, and include 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^{liv}. The charity sector provides essential palliative care supports to families, such as the Irish Cancer Society's Night Nursing, psychosocial supports and symptom management, and core funding is required to rollout equitable provision of these services nationally^{lv}.

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^{lvi}.

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^{lvii}.

We are calling on the Government to fund and resource age-appropriate palliative care models and fully fund national respite services.

B) Fund bereavement support for family with children who have died of cancer

Support from healthcare professionals in the hospital, such as medical social workers provide essential support to families when they lose a loved one to cancer. Community bereavement supports are available; however these are limited and 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^{lviii}. Alongside practical supports of dealing with a bereavement, emotional supports need to be available and accessible to anyone who needs them. This is a matter of urgency for families who have to deal with the premature death of a loved one.

We are calling on the Government to fund sustainable bereavement supports for families who have lost a young person to cancer.

The budgetary asks of the Irish Cancer Society's 2023 CAYA Pre-budget submission are supported by the following voluntary organisations:



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Pre-Budget Submission 2023

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