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Build To Last

Thousands of people have been affected by the impact of COVID-19 on cancer screening, diagnostics, treatment and follow-up appointments. That is before even factoring in the psychological impact on those receiving bad news or going through treatment alone, and the financial impact for patients, survivors and loved ones whose employment has been affected by the pandemic.

Systemic challenges in cancer and health services have been compounded by the joint impact of COVID-19 and the recent cyberattack. This has led to people presenting later to their GPs for fear of catching COVID in healthcare settings, people facing longer wait times for diagnosis, and delays in surgical intervention and treatment. All of this means that cancers are diagnosed and treated later, which ultimately costs more to patients and families in survival and quality of life. It also places an added financial burden on the state, with late diagnoses costing more to treat.

Cancer services were running to stand still before the pandemic, and despite unprecedented investment in Budget 2021, are struggling to recover.

Last year we called for investment to “Build Back Better”. Now, we are asking for a sustainable funding stream so we don’t just build back better, but “Build to Last”. The Irish Cancer Society urges all politicians to back our Pre Budget Submission which will build cancer services and care to last, and reduce future cancer burdens.

Additionally, supported by the Childhood Cancer Foundation, The Gavin Glynn Foundation, CanTeen and Hand in Hand, the Irish Cancer Society has for the first time developed a pre-Budget submission that addresses the distinct needs of children, adolescents and young adults (CAYA) and their families, “Supporting Children, Adolescents and Young Adults (CAYA) through the cancer pathway and beyond”. This standalone document has been included alongside our “Build to Last” submission to highlight to policy-makers the very specific challenges families of those with CAYA cancers face.



Our Three Priorities

There are three key priority areas that will support our call to Build to Last:

1. Provide €45 million in new funding for cancer services, on top of supporting improvements to the wider health sector.

In Budget 2022, to deal with the unprecedented challenges our cancer services, patients, families and healthcare workers face, we urge Government to provide €45 million in new funding for cancer services, broken down across:

- €15 million in recovery funding to address backlogs and future surges in services demand and;
- €30m towards the implementation of the National Cancer Strategy;

Some of this new funding must be targeted at:

- Providing a new funding stream for dedicated cancer infrastructure;
- Continuing to support the recovery of cancer screening programmes from the impact of the pandemic and cyber-attack
- Improving patient outcomes by funding clinical trials;
- Increasing investment to develop a world-class cancer genetics service.

Additionally, funding must be found to support improvements across the health service, including the full resourcing of:

- The Lymphoedema Model of Care and National Lymphoedema Clinical Guidelines
- Programme for Government commitments on eHealth;
- The Sláintecare Transition Fund and;
- Provide €11 million for staffing and innovative measures in endoscopy services.



2. Support patients, survivors and families at their most vulnerable

We at the Irish Cancer Society know from our daily conversations with patients, survivors, families and healthcare workers, and our detailed research on the financial and social impact of a cancer diagnosis, that the impact of cancer extends well beyond the physical and clinical.

In Budget 2022, to support cancer patients, survivors and their families to deal with the financial, social and psychological burden cancer can bring, we are calling on Government to:

- Provide €5 million to public hospitals to reduce the cost of car parking charges for patients;
- Reduce the Drugs Payment Scheme cap to a maximum payment of €100 a month, and a maximum payment of €72 a month for single-headed households;
- Provide €30.6 million to abolish Inpatient Charges;
- Abolish prescription charges for medical card holders;
- Provide medical cards to all cancer patients upon diagnosis until treatment has finished.
- Increase the number of patients and survivors returning to work who can access Partial Capacity Benefit;
- Fund new psycho-oncology posts;
- Fund fertility treatment for cancer patients and survivors.

3. Prioritise cancer prevention

We know that we cannot simply treat our way out of cancer. Between 30-40% of cancers are preventable. Smart, targeted investment, allied to revenue raising measures, can help in stopping cancer before it starts.

To help achieve this, we believe the following actions will save lives for future generations and potentially eliminate a number of invasive cancers:

- Fund the elimination of HPV-caused cancers and HPV catch-up plans;
- Increase excise duty on cigarettes by €1 a pack, and invest in helping smokers to quit;
- Allocate 20% of the transport capital budget to walking and cycling;
- Fund the National Skin Cancer Prevention Plan.



Provide €45 million in new funding for **cancer services, on top of supporting improvements to the wider health sector**



The COVID-19 pandemic and the May cyberattack have wrought untold damage on the provision of cancer services in Ireland, meaning that significant funding is required to restore services to pre-pandemic levels.

However, the Irish Cancer Society believes that setting the period before COVID-19 as a target for restoration of services is a low bar.

Before the COVID-19 pandemic, cancer services were crying out for more funding in areas like diagnostics, treatment, and human capital and digital infrastructure. These deficiencies have subsequently been laid bare by the hammer blows of COVID-19 and the cyberattack.

Budget 2021 provided €20 million for the implementation of the National Cancer Strategy, and €12 million to deal with the immediate impact of the pandemic on cancer services. This was very welcome, but sustained funding will be needed if we are to build services to last after the COVID-19 crisis.

We don't just need to rescue cancer services from the immediate crisis. We need to take this opportunity to make sure cancer services are stronger and more sustainable than before the pandemic, and that they offer the world-class options we all want for patients and survivors in our communities.

Underpinning all of this is the requirement to provide €45 million in new funding for cancer services in 2022.

1.1 Provide €15 million in recovery funding to address backlogs and future surges in cancer services demand

While COVID-19 and its impact was a shock to many, we are now well aware of the very significant challenges this virus has caused and have ample warning of the damage it will continue to cause for cancer services, and importantly, current and future patients for many years to come.

Experts in Ireland and abroad are warning of a coming surge in cancer cases. In May 2021, the European Cancer Organisation published data demonstrating that one million cancers may have gone undiagnosed across Europe.ⁱ In November 2020, the head of the National Cancer Control Programme estimated that 2,000 cancers had been missed in Ireland at that point, as a result of the pandemic.ⁱⁱ

A number of senior cancer doctors have outlined to the Irish Cancer Society their concerns at the increased numbers of people presenting to them with more

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advanced cancer. In a best-case scenario, we believe there were 10% fewer cancers diagnosed in 2020 than expected, but we anticipate this figure will be higher once the National Cancer Registry of Ireland (NCRI) publishes official data.



"We are now seeing patients present at much more advanced stages of cancer. They have had symptoms for much longer by the time they are diagnosed, often going on several months to a year rather than a few weeks or months that we would normally see, and are reluctant to go to their GPs for worrying symptoms of cancer, with some patients reluctant to undergo treatment due to perceived infection risk.



"This pandemic has highlighted the pre-existing weaknesses in our cancer services. We must put resources into catch-up screening programmes in order to reschedule missed or cancelled appointments, and patients need rapid access to diagnostic tests when they have symptoms and signs of cancer. Dedicated hospital wards and greater operating theatre access and ICU support for cancer surgery are needed along with more consultant cancer specialists in medical and radiation oncology."

-Dr Sinéad Brennan, Consultant Radiation Oncologist, St Luke's Hospital

'Missing' cancers are now entering the health system, and causing additional strain on services.

Patients and clinicians are seeing the impact of COVID and the cyberattack at all parts of the cancer pathway, from screening to surgery, diagnostics to treatment. Researchers from the Royal College of Physicians have noted COVID-19's disproportionate impact on cancer diagnostics, which "suggests that there is a cohort of people in the community who have not yet been diagnosed with cancer and who will subsequently present with more advanced disease, which will be more difficult to treat successfully".ⁱⁱⁱ

This is extremely concerning, because the longer cancer is left untreated, the more likely it is to be fatal. As recognised by Ireland's National Cancer Strategy, stage at diagnosis—the extent to which the cancer has grown and metastasized—is "probably the most important determinant of survival".^{iv}

To give just one example, 19 out of 20 people whose bowel cancer is diagnosed at Stage I survive; this falls dramatically to 1 out of every 10 people who receive a diagnosis at Stage IV.^v

There are multiple reasons that experts are predicting this coming surge:

- New screening appointments for breast, cervical and bowel cancer were entirely suspended for several months in 2020 and breast and bowel screening have continued to operate below capacity since then.
- Referrals to Rapid Access Clinics for breast, lung and prostate cancer dropped precipitously last year too.
- Fear of COVID-19 may have left many people unwilling to go seek medical advice. Irish Cancer Society research found that in 2020, 1 in 4 people were not attending a GP or hospital appointment in person even if they needed to.^{vi} Our most recent research, conducted in May 2021, showed

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that 1 in 6 people were still avoiding going to the doctor.

A recent HSE analysis found that there were 36,120 fewer elective cancer-related admissions in April to December 2020 than would have been expected based on admissions in the first three months of the year, a drop of 33.8%.^{vii}

Many of these challenges are being borne out in the serious delays we are witnessing in cancer diagnostics. At the end of May 2021, for example, 10,177 of 17,357 (58.6%) people were on the NTPF “active” in-patient day case waiting list for colonoscopy for over three months, compared to 11,676 of 18,871 (61.8%) people in May 2020. These figures demonstrate the impact of COVID-19 on waiting lists. To illustrate, in March 2020, 6,651 of 15,144 (43.9%) people were on the active waiting list for a colonoscopy, 726 of whom were waiting over 12 months. By May 2021, this number had grown 4-fold with 3,059 people waiting over 12 months.

Meanwhile, a number of clinicians have expressed deep concern at delays in routine radiology services, which is causing knock-on delays to treatment. Radiology is the use of medical imaging to diagnose certain cancers, through tests like Computed Tomography (CT) scans, X-rays, Ultrasounds and Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET). We understand staff shortages and older equipment are exacerbating these problems.

Delayed diagnoses mean that cancers might be picked up only when they have grown and spread. This means some diagnoses and their treatment and staging may be more serious than they otherwise would have been.

We believe real action is required now to stem the tide of oncoming cancer cases and ensure prompt diagnosis and world-class treatment.

We believe that circa €15 million in new funding will be required in 2022 to help prevent the poorer survival rates and later diagnoses caused by the knock-on effects of COVID-19.

1.2 Invest **€30m towards** **implementation of** **the National Cancer** **Strategy**

Moving beyond the current emergency situation, it is imperative that we draw the right lessons from the COVID-19 pandemic.

The Irish State’s response to the COVID-19 pandemic was very successful in many ways. The sheer scale and ambition of the healthcare system’s mobilisation against the virus showed that when we are presented with a clear set of objectives, we can deliver.

The ambition and vision which guided the most successful aspects of Ireland’s approach to COVID-19 must be applied to the implementation of the National Cancer Strategy, 2017-2026.

Cancer incidence in Ireland will potentially double by 2045. Despite technological and organisational advances in the provision of cancer care in Ireland, underinvestment before the pandemic meant key performance indicators (KPIs) set out in the Strategy were not being met, and services were effectively running to stand still.^{viii}

Only 2 of 10 KPIs in the National Cancer Strategy due to be met by the end of 2019 were on target.

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When the current Government entered office last year, Department of Health officials informed Minister Donnelly that of the €46 million in new funding needed to implement the Strategy between 2018 and 2020, only €6.3 million had been allocated.^{ix} For every €1 required, only 14 cent had been provided.

Thankfully, Budget 2021 saw an additional €20 million allocated to implement the National Cancer Strategy. The increased funding was spread between prevention measures, improved access to diagnostics, the further development of medical, radiation and surgical oncology and expanded services to support those living with and beyond cancer.^x

Funding above this level to the amount of €30m will be required in 2022 to:

- Begin development of a comprehensive cancer centre, facilitating excellence in cancer research, diagnostics, treatment and survivorship.
- Continue to make necessary improvements in radiotherapy services in support of the National Plan for Radiation Oncology (NPRO), which provides the strategic direction for the provision of radiotherapy services across Ireland and requires capital investment.
- Ensure that GPs have direct access to cancer diagnostics.
- Ensure Ireland is in the top quartile for five year survival among EU member states.
- Improve workforce capacity and infrastructure at hospitals providing cancer treatment to ensure treatments commence within target timeframes. A recent HSE report on demand for consultants and specialists showed there will be a need over the next seven years to increase the number of medical and radiation oncologists by 111% and 72% respectively^{xi}, or an average of 10 additional cancer specialists per year up to 2028 according to the IHCA^{xii}.
- Improve physical capacity, infrastructure and dedicated theatre time at hospitals providing

cancer treatment to ensure surgery and other treatments commence within target timeframes. The pandemic has exposed the lack of dedicated cancer infrastructure right across the cancer pathway from diagnosis to treatment, with a significant impact on surgery in particular.

1.3 Provide a new funding stream for dedicated cancer infrastructure

Against the backdrop of backlogs identified earlier in this section, we also see that cancer services are now competing 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 things like diagnostics, surgery, support teams and even bed space can come from the same pool that the hospital system uses for ICU 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 diverted.

We have seen examples of this right across the cancer pathway, with surgeries/resections particularly impacted during the pandemic. 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, delivery of the Strategy will be extremely challenging.

We need to support the development of infrastructure that provides best in class care and that effectively insulates cancer services from future crises.

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COVID-19 and the restrictions that came with it put huge strain on every aspect of patient care. Physical distancing requirements and staffing pressure presented huge challenges to the delivery of treatment, while surgeries were delayed or cancelled because of pressure on theatre time caused by an ICU system full to the brim.

To address this there is a need to examine the exact requirements for cancer services into the future based on rising incidence rates and the impact COVID and the cyberattack will have for years to come.

The Irish Cancer Society suggests an action plan for cancer infrastructure is required and needs to take account of dedicated theatres for cancer surgery, beds, diagnostic tests and day wards.

Ahead of Budget 2022, the Irish Cancer Society are calling for a new funding stream set aside for the building of effective and dedicated cancer infrastructure.



“One challenge is to increase the proportion of patients diagnosed at an earlier stage of their disease. If this can be achieved, for example, by improving access to diagnostics, by expansion of rapid access clinics, by improved education of the population and by greater uptake of available screening programmes, then not only will survival be improved, but significant efficiencies will be achieved in the health system.”

– Department of Health, ‘National Cancer Strategy, 2017-2026’^{xiii}.

1.4 Continue to support cancer screening services

Screening is a vital tool that allows for the early detection and treatment of pre-cancers and cancers before they become harder to treat.

Supporting a full and safe return of screening services to eligible populations must continue to be a priority for Government. Screening is an evidence-based and cost-effective way of reducing morbidity and cancer deaths in Ireland.

However, the State’s key cancer screening services—BreastCheck, CervicalCheck, and BowelScreen—have all been badly hit by the pandemic. To reduce spread of the virus, screening services had to operate at a reduced capacity or be paused completely for a period of time. Meanwhile many staff in the National Screening Service (NSS) were reassigned to other parts of the health service to support the national effort against COVID-19.

We do not yet know how many pre-cancers and cancers will have gone undetected due to the disruption to cancer screening last year. However, we do know that Breastcheck was 70% behind its 2020 target of completed screenings, BowelScreen was 60% behind target and CervicalCheck was 44% behind target.^{xiv}



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“Most years we pick up six cancers in every 1,000 women we screen. We’ve screened much less so there are hundreds of women we haven’t diagnosed. We know that and we are desperate to get back screening.”

– Professor Ann O’Doherty, Lead Clinical Director for BreastCheck, February 2021^{xv}

In Budget 2021, we welcomed the allocation of additional funding for screening programmes. This funding will assist in clearing screening backlogs, along with supporting the construction of a National Screening Service laboratory at the Coombe Hospital, as outlined in the 2021 HSE Capital Plan^{xvi}.

Ahead of 2022, the Irish Cancer Society is asking that the National Screening Service is supported with whatever resources it needs to recover from the impact of the pandemic. To mitigate any future impact on cancer screening, resources must be made available so that the ‘downstream’ services that are required by both the symptomatic and screening patient population, can meet demand from both referral points, without impacting on the available capacity of the other.

As such, in Budget 2022, the Irish Cancer Society is calling for the continued support from Government so cancer screening programmes can recover from the impact of the pandemic and the cyberattack. Over the longer term, additional capacity must be built in to ensure the diagnosis and treatment of the symptomatic patients does not affect the capacity available to screening services, and vice versa.

1.5 Improve patient outcomes by funding clinical trials

The availability of clinical trials offers patients hope that they can get access to the latest in breakthrough medical innovations. Where trials are appropriate, they can result in dramatic changes in survival chances and improvements in quality of life for patients, which, ultimately, is what we all hope for anyone who has been impacted by cancer.

The proportion of patients on clinical trials was targeted to double by 2020, yet no change in the 2017 rate of 3% accessing trials has been made to date. Cancer Trials Ireland figures suggest that the number of people recruited to clinical trials fell by 45% in the first three months of 2021 compared to the same period last year. As such, the number of people accessing cancer trials are in fact closer to 1%.

Based on information from Cancer Trials Ireland, fewer patients have been participating in clinical research, and there are fewer translational trials in progress. The number of accruals to academic trials between January to June 2020 compared to the same six-month period in 2019 fell by over 40%.

Additionally, children and adolescents (CA) with cancer, require access to cancer trials as set out in our joint submission with a range of childhood cancer charities, included within this document, “Supporting Childhood, Adolescent and Young Adults (CAYA) through the cancer pathway and beyond”. Plans to enhance children and adolescents access to clinical trials needs prioritisation and specific ring-fenced funding.

In Budget 2022:

- Cancer Trials Ireland requires sustainable and predictable funding to increase patient

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participation in clinical trials, which will ultimately lead to improved patient outcomes.

- It is also essential that clinicians and medical teams are offered protected time so they can do more research and that all is done to foster a culture of research in our hospitals.
- Investment in cancer research generally should be ring-fenced and commitments in the National Strategy prioritised.

That is why we are calling new investment to ensure research funding can be ring-fenced and patients offered the best chances of survival.

1.6 Increase investment to develop a world-class cancer genetics service

Cancer genetics services offer hope to reduce cancer cases and deaths.

Inherited genetic mutations play a major role in 5% to 10% of cancers, and genetic testing is an important tool in helping people to understand their risk for certain types of cancer including breast, colorectal, and ovarian cancers. Once you understand any genetic predisposition to cancer you may have, you are empowered with the knowledge required to take potentially life-saving decisions, such as risk-reducing surgery or chemoprevention.

Children, adolescents and adults alike would benefit from access to world-class genetic services.

Internationally, healthcare systems are moving to take advantage of our rapidly developing understanding of how our genetic make-up influences our cancer risk.

The European Commission, in its recently-published Beating Cancer Plan, announced a range of measures that will support Member States seeking to develop their capacity in this area, for example, the 'Genomic for Public Health' project.

Yet as other countries accelerate progress and their patients benefit from well-developed cancer genetics services and downstream pathways, Ireland lags behind. A recent report prepared for the Irish Cancer Society found that:



"It is apparent from engaging directly with service users that waiting lists exist at every point on the pathway for people who need genetic services. For those who may have a genetic risk of cancer, the wait times for access to testing alone (before counselling treatment, prophylactic surgery etc.) can be up to 2 years. Barriers to accessing cancer genetic services include costs of tests, long processing time for referrals to tests, restrictive referral criteria, and difficulty in accessing information on cancer genetic services."^{xviii}

– Professor Josephine Hegarty et al, 'The unmet need in cancer genetic services'

This creates an incredibly frustrating process for people who wish to be pro-active in reducing their risk of cancer. We are calling on the Government to recognise that Ireland has fallen behind international best practice.

We need significantly increased resources to be provided to genetic services if we are to catch up. This will facilitate:

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- The implementation of a hub and spoke model with genetics expertise within the dispersed oncology system;
- The provision of adequate psychological support for people on waiting lists and upon identification of genetic faults;
- An Action Plan to eradicate waiting lists for counselling and genetic testing;
- Building and development of the genetics workforce;
- An increase in cancer genetics diagnostics capability and expertise in Ireland to meet existing, increasing demands;
- Defined pathway for genetically positive individuals that includes timely access to evidence-based surveillance, screening, surgery and treatments as needed for individuals with specific mutations.

For Budget 2022, we are asking that new funding is allocated to develop a world-class cancer genetics service. This will allow us to catch cancer earlier, understand how cancers will develop, and reduce cancer deaths.



“Irish genetic services are two decades behind the UK”

– Genetic Counsellor interviewed as part of the ‘Unmet need in cancer genetic services’ report prepared for the Irish Cancer Society^{xix}



“ Genetic testing was not available to me at diagnosis. In those 13 months



waiting for a result I went through chemotherapy, a lumpectomy and radiotherapy on my breast, only for a double mastectomy to be required once the BRCA mutation was known. Had I known this earlier, my course of treatment could have been very different.

“I had to postpone a radiation treatment to go up to Dublin from Cork to do the genetic test, as it would have taken up to another 12 months in Cork, and then I waited over four months for the results. Once I received the news of the gene mutation, I had to navigate a path of risk-reducing surgeries. I researched and sought out a surgeon myself. There were no cross-discipline genetic service available to me to support this journey. I strongly feel there should be an urgency to improve these services.”

– Margaret Cuddigan, breast cancer patient

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1.7 Fund the implementation of the Lymphoedema Model of Care and National Lymphoedema Clinical Guidelines

Lymphoedema is a long-term (chronic) condition that causes swelling in the body's tissues. It can affect any part of the body, but usually develops in the arms or legs.

Lymphoedema is caused by a problem with the lymphatic system, a network of vessels and glands spread throughout the body. The main functions of the lymphatic system are helping fight infection and draining excess fluid from tissues.

There are 2 main types of lymphoedema:

- primary lymphoedema – caused by faulty genes that affect the development of the lymphatic system; it can develop at any age, but usually starts during infancy, adolescence, or early adulthood;
- secondary lymphoedema – caused by damage to the lymphatic system or problems with the movement and drainage of fluid in the lymphatic system; it can be the result of a cancer treatment, an infection, injury, inflammation of the limb, or a lack of limb movement.

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

A model of care, which was envisioned as serving as a blueprint for the development of a comprehensive lymphoedema service, which would make a significant difference in the quality of life of many people with lymphoedema, was published in 2018.

The HSE has begun 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), and National Lymphoedema Clinical Guidelines are due to be published shortly.

However, we believe that not enough progress has been made in progressing the model of care to date, and the pausing of lymphoedema services at the beginning of the pandemic due to redeployment of staff, further set back vital services for the thousands of people who need them.

As such, the Irish Cancer Society is calling for funding to ensure the long overdue full implementation of the model of care proceeds as soon as possible, along with the provision of resources for new National Lymphoedema Clinical Guidelines.



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1.8 Fully resource Programme for Government commitments on eHealth

The events of 2021 have exposed Ireland's extreme weakness in the area of digital health infrastructure. The cyberattack attack has revealed how important access to digital health records and other digitally-stored information are in ensuring world-class care for patients. Investing in eHealth and ICT infrastructure can help integrate different parts of the healthcare system to achieve better outcomes.

During the cyberattack, critical frontline services highlighted huge drops in referrals for critical conditions, demonstrating the fragility of our current system. For example, the Dermatology Department in St Vincent's Hospital raised concerns about a greater than 90% drop in skin cancer referrals since the cyberattack commenced.^{xx}

Ireland will now need to rebuild our digital health infrastructure from the ground up. This is a challenge, but also an opportunity.



back.”

“[Caring for patients after the cyberattack is] like working with your hands tied behind your

– *Dr Miriam O'Connor, consultant oncologist at University Hospital Waterford^{xxi}*

Even before the cyberattack, Ireland was a laggard in this area. eHealth initiatives such as developing an Electronic Health Record and using national health identification numbers can help ensure that worrying symptoms are not missed, that patients are empowered to access their medical records and manage their own care, and that doctors can access all the information they need to make the best possible decisions for each patient.

Yet healthcare remains one of the few areas of life in Ireland where information is not integrated and easily accessible across multiple systems.





“Electronic health records are set to become crucial tools in cancer prevention and care.

They will ensure that clinical information is shared efficiently between oncologists, radiologists and surgeons, enhancing the patients’ treatment and survival chances. Health records can also better capture the experiences and outcomes of oncology patients, painting a clearer picture than the 5% that participate in clinical trials. Combining health records... with other data sets, such as genomics, can provide even better insights into the efficacy of treatments and their optimisation.”

– European Commission, Europe’s Beating Cancer Plan^{xxii}

The Programme for Government makes a number of commitments in this area, 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 programme, ensuring that patient information is accessible across different services to improve patient safety; and
- Implementing an Electronic Health Record system in the new National Children’s Hospital and preparing to roll it out nationwide.

The Irish Cancer Society is calling for these commitments to be treated as a priority and resourced in full, in Budget 2022. As well as this, we want the Individual Health Identifier (IHI) to be rolled out across cancer services, including the screening services and the cancer registry as well as treatment services, so that data can be linked forwards and backwards. The IHI register is largely in place and people with cancer should be prioritised for the roll-out of the IHI.

1.9 Provide €11 million for staffing and innovative measures in endoscopy services

An example of the problems that exist in accessing downstream services, like diagnostics, which are funded separately to cancer services, is the area of endoscopy.

We welcomed the publication, in 2017, of the first ever national Action Plan on Endoscopy. Endoscopy is a nonsurgical procedure to examine the digestive tract. There are a number of endoscopic 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 esophagus, stomach and duodenum), among others.

Endoscopic procedures can detect gastrointestinal and colorectal cancers.

Recent years have seen growing demand for endoscopy services in Ireland, but capacity and staffing levels haven’t grown at the rate required to meet it, and this has seen growing waiting lists, worsened by the impact of COVID-19.

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Thankfully, in the HSE National Services Plan for 2021 and HSE Capital Plan for 2021, we have seen some progress with the:

- Creation of 39 new nursing roles^{xviii} which have enabled the:
 - Expansion of nurse-led non-invasive capsule endoscopy diagnostic services to provide planned surveillance and to manage low risk symptomatic patients¹;
 - Expansion of nurse-led endoscopy triage in endoscopy units nationwide
 - Use of less invasive clinical procedures for some GI endoscopy patients, including the use of faecal immunochemical test (FIT) for patients who are on waiting lists as well as using this test for newly referred patients;
- Planned replacement of the endoscopy unit in Cavan GH, provision for a third endoscopy suite at UH Galway, a new suite in Letterkenny and Bantry and additional endoscopy beds at Beaumont Hospital;

Despite this, significant challenges remain in taking action to meet and control demand, and ultimately ensure early diagnosis of cancers and other morbidities, and save lives.

To help achieve this, **in Budget 2022, the Irish Cancer Society is asking for Government to:**

- Agree a permanent funding stream for innovative measures recently introduced, such as capsule endoscopy services;
- Provide €8 million in funding in 2022 to resource 116 new full-time equivalent (FTE) posts to ensure all available capacity is effectively used.
- Provide €3 million in funding in 2022 to give GPs direct access to Faecal immunochemical tests (FIT) and urea breath testing in primary care for patients with low-risk symptoms. Both are rapid non-invasive procedures which may act to effectively triage patients, offering quicker access to appropriate tests and removing pressure from acute diagnostic services.



Provide €45 million in new funding for **cancer services, on top of supporting improvements to the wider health sector**



1.10 Fully resource the Sláintecare Transition Fund

The best—and only—way to secure the health of Ireland’s population into the long-term is to develop an affordable, robust, universal healthcare system. Patients must receive treatment promptly, and on the basis of need. There must be no restriction based on ability to afford healthcare.

This will not only protect against future shocks caused by pandemics of contagious diseases or the health effects of the climate and biodiversity emergencies; it will also help us deal with the rise in non-communicable diseases brought about by demographic changes.

In 2020, an Irish Cancer Society survey found that more than 8 in 10 people agreed that creating a health 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 reducing taxes.

Thankfully, there is already a plan available to bring about a better future for Ireland’s healthcare system. In May 2017, the Oireachtas Committee on the Future of Healthcare published its ‘Sláintecare Report’, an unprecedented cross-party effort to rethink the delivery of healthcare in Ireland.^{xxvii} The Report laid out a 10-year roadmap setting out how this transition could be made.

The Sláintecare report called for the provision of €3 billion in transitional funding over the first six years of the Strategy, to progress key structural projects that will reform our current health system and advance the Sláintecare vision.

The Irish Cancer Society believes that the Sláintecare transition fund should be resourced in full and that the Oireachtas report must be fully implemented to deliver a system of universal healthcare based on need and not the ability to pay. We are asking the Government to provide additional funding in 2022 to make this a reality.



Support patients, survivors and families at their most vulnerable

When we think about cancer, we have to think about its broader ramifications in people's lives, beyond the immediate health impact.

In 2019, the Irish Cancer Society published the 'Real Cost of Cancer' report.^{xxviii} This demonstrated the terrible financial burden of a cancer diagnosis, and the impact that the illness can have on all aspects of a person's life—not just their health.

The average cost to someone dealing with cancer is €756 a month. This can rise in some cases to over €1,000. At the same time, people are faced with a loss in income of over €1,500 a month on average. This is as a result of patients having to leave their job, take reduced hours, close their business or take significant time off work.^{xxix}

Our Budget 2022 recommendations in this section are practical and necessary measures to address the huge financial and social impact of a cancer diagnosis.

Changes like waiving car parking charges for cancer patients, reducing the Drug Payment Scheme cap, abolishing 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 all sensible measures that will support patients at their most vulnerable. Additionally, we also need to ensure psycho-oncology services are fully resourced in all 8 designated cancer centres, so patients get the access to the psychological supports they need.

Additionally, while this section focuses on the financial impact on those with an adult diagnosis of cancer, parents and guardians of children and adolescents with cancer also face significant financial burdens, including loss of income, transport and accommodation costs

and other new expenses on reduced income. The Irish Cancer Society's pre-budget submission dedicated to the needs of children, adolescents, young adults, survivors and their family "Supporting Childhood, Adolescent and Young Adults (CAYA) through the cancer pathway and beyond", and included in the second section of this document, sets out many of the challenges these families face, and the specific actions required to support them.

2.1 Provide €5 million to public hospitals to reduce the cost of car parking charges for patients

Research undertaken by the Irish Cancer Society in 2019 revealed that more than 4 in 5 cancer patients incur car parking charges at Irish hospitals, at an average of €64 per month.^{xxx} Cancer patients attending regular hospital appointments for chemotherapy, radiotherapy and other treatments can end up paying more money on hospital car parking than the cost of their treatment.

Car parking charges represent a massive financial burden to cancer patients. For the majority of patients, public transport or other forms of travel are not an option as they are medically vulnerable.

While car parking charges may be a key source of revenue for some hospitals, it is clear that excessive

rates are being charged. This puts unnecessary pressure on cancer patients and their families. The Irish Cancer Society would like the HSE to work with hospitals to find alternative revenue sources other than hard-pressed cancer patients.

“

“I stayed in hospital for 115 days and during that time, my wife Trish 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. If she was able to get free parking, or even a reduced rate, it would have been a great help to us.”



CASE STUDY – Gerry, a 59 year old Acute Myeloid Leukaemia survivor from Dublin faced huge costs for car parking while he was undergoing treatment.

In March 2018, Minister Simon Harris ordered a national review of hospital car parking charges, which we warmly welcomed after almost a year and half campaigning on this issue.

In November 2018, large extracts of a draft report on hospital car parking charges were published in a number of media outlets, and Minister Harris committed to their publication and implementation in 2019. It is estimated that implementation of these guidelines will cost in the region of €4- 5 million to fund.

However, there has been limited progress on this issue since that date.

The Irish Cancer Society welcomed the Programme for Government commitment to “introduce a cap on the maximum daily charge for car parking for patients and visitors at all public hospitals”, and to “introduce flexible passes in all public hospitals for patients and their families”.^{xxxi}

For Budget 2022, we urge the Government to deliver on this commitment, and relieve cancer patients of this huge source of financial stress. This will require a commitment of €5 million to replace this revenue source for hospitals.

2.2 Reduce the Drugs Payment Scheme cap to a maximum payment of €100 a month, and a maximum payment of €72 a month for single-headed households

The Drugs Payment Scheme means that no individual will pay more than €114 per calendar month for approved medicines and appliances. The Scheme has no means test, and is available to individuals without a medical card. Given that many patients’ medicine costs would otherwise far exceed €114 a month, the Scheme can provide some financial relief.

Support patients,
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However, the cap for the scheme is still significantly higher than it was in 2008, when no patient paid more than €90 per month for medicines. This means that cancer patients in receipt of the Drugs Payment Scheme in 2021 pay €288 more per annum for medicines than someone in 2008 paid.

We know that for cancer patients, each additional expenditure adds up and can make the difference in being able to afford basic items like food and household utilities.

For Budget 2022, the Irish Cancer Society is asking the Government to reduce to the Drugs Payment Scheme threshold, so that patients pay a maximum of €100 per month.

In addition, we are asking the Government to consider the particular burden on households where the patient is the sole provider. **The 2017 Sláintecare report recommended that the Drugs Payment Scheme threshold for single headed households be reduced to €72 per month.**^{xxxii} This would particularly assist single people and lone parent households facing the burden of a chronic disease. We urge the Government to adopt this commitment for Budget 2022.

2.3 Provide €30.6 million to abolish Inpatient Charges

Inpatient charges are incurred by patients without a medical card or private health insurance, at a cost of €80 per visit, or up to €800 per year. Inpatient charges are incurred by those who need an overnight stay in a public hospital, but also by those receiving day treatment such as chemotherapy and radiotherapy.

This affects cancer patients significantly because every time they need to go for treatment, they pay €80.

This is up to a maximum of €800 for 10 visits over a 12-month period.

In cases of “excessive hardship”, hospitals can waive the charge, but there are no clear guidelines on this. Meanwhile, we know that if patients don’t—or can’t—pay the charges within 47 days, their case can be referred by the hospital to debt collection agencies. This is a frightening prospect for many cancer patients at a vulnerable time in their lives.

The Irish Cancer Society believes that these charges are discriminatory, and disproportionately affect patients going through what can be the most physically, emotionally and financially draining period of one’s life. We know the impact that costs associated with cancer have on people’s everyday lives, and most of these costs will never be reclaimed.

For Budget 2021, we are asking the Government to abolish inpatient charges, at an estimated cost of €30.6 million.^{xxxiii}

2.4 Abolish prescription charges for medical card holders

Prescription Charges are levied on medical card holders at a rate of €1.50 per item, up to a maximum of €15 per month per person or family. There is a reduced rate of €1 per item for those over 70, up to a maximum of €10 a month per person or family.

These charges were introduced in 2013, and peaked at a rate of €2.50 per item from 2014. Despite welcome reductions in recent budgets, a cancer patient with a medical card in 2021 still has to pay up to €150 more per year than a cancer patient in 2013 would have.



While the amount brought in to the State's coffers by these charges is relatively small in the context of overall expenditure on the health system, they represent a huge burden to medical card holders, who are generally the most economically disadvantaged people in society.

Indeed, there is evidence that these charges are actively undermining healthcare in Ireland. Research undertaken by Core Research on behalf of the Irish Cancer Society in 2020 found that:

- 4 in 10 medical card holders rationed their medication because they couldn't afford prescription charges; and
- 4 in 10 medical card holders chose to pay for household necessities ahead of prescription charges.^{xxxiv}

This is further evidenced by a 2020 World Health Organisation report, 'Can people afford to pay for health care?: New evidence on financial protection in Ireland'.^{xxxv} The report notes that "Even relatively low user charges can lead to financial hardship for very poor households and, at the same time, present a financial barrier to access." The authors state that "unmet need for prescribed medicines in Ireland is on average more than twice as high as the EU average and, within Ireland, more than twice as high among the least educated than the most educated people". On this basis, the report recommends exempting medical card holders from paying prescription charges.^{xxxvi}

The Irish Cancer Society believes that no cancer patient should be forced to choose between putting food on the table and paying for medication to treat the side effects of their cancer. Prescription charges are a continuous financial burden for those living beyond cancer; a monthly reminder of the financial hardship that a cancer diagnosis brings to individuals in Ireland even after treatment.

If we truly wish to move towards a universal healthcare system, healthcare expenditure should be paid from the central exchequer and funded by progressive

tax measures. User charges are regressive, counter-productive, and belong to a past era of austerity.

In light of this, the Irish Cancer Society is asking the Government to abolish prescription charges as part of Budget 2022, in order to reduce the financial burden on economically vulnerable patients, and to ensure that everyone can access the medicine they need.



"Without exemptions from prescription charges for poor and regular users of health care, the incidence of catastrophic health spending is likely to remain high among the poorest quintile."

– Johnston et al, 'Can people afford to pay for health care?: New evidence on financial protection in Ireland' (2021)^{xxxvii}

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

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



Medical cards provide a financial lifeline for so many cancer patients. Cancer patients can face massive increased expenditure on items like wigs, new supportive clothing, medications, supplements, modifications to the home, and increased home heating, to name just a few.



“People with cancer experience high rates of financial hardship and in many cases, catastrophe, which is increasing over time as cancer care becomes more expensive... Severe financial distress after a cancer diagnosis may increase the likelihood of death, even after apparently effective treatment.”

– World Health Organisation, ‘Report on Cancer: Setting priorities, investing wisely and providing care for all’ (2020)

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.

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 putting food on the table for their children.

We welcome the Government’s recent extension of medical cards to patients with a terminal diagnosis of less than 24 months.

For Budget 2022, the Irish Cancer Society is asking the Government to provide medical cards to all cancer patients upon diagnosis, until their treatment is finished.



“I was only 34 years old when I was diagnosed, less than two years married with a 5 month old baby. We struggled very much as I got full pay for the first 3 months from work and then half pay for another 3 months and then nothing but I wasn’t entitled to the medical card until I was on unpaid leave. We found it extremely costly with medication, hospital visits, etc. and I’d also to put my son into full time childcare as I wasn’t able to look after him. I felt we’d no support.”

Case study – Sinead

2.6 Increase the number of patients and survivors returning to work who can access Partial Capacity Benefit

More people than ever are either surviving cancer or living well with cancer. Many of those people may wish to return to work once they are able, although often their chronic illness and its after-effects mean they will require flexibility and support to do so.

Support patients, survivors and families at their most vulnerable



Earlier this year, the Irish Cancer Society published research conducted by the Economic and Social Research Institute (ESRI) on 'Returning to employment following a diagnosis of cancer'.^{xi}

While this research revealed a broadly positive picture, with almost 7 in 10 patients and survivors saying their manager or organisation supported them in their return to work, almost half of people returning to work after a cancer diagnosis reported that their diagnosis had a negative impact on their career.

The Irish Cancer Society believes that all patients should feel supported in their return to work after a diagnosis, and their quality of life, finances and career prospects should not be affected by their illness.



"There is a key role for Government in ensuring that there are adequate financial supports in place to allow those diagnosed with cancer to return to employment only when they are ready. Such supports should seek to facilitate the return to work on a phased and flexible basis."

– Connolly et al, 'Returning to employment following a diagnosis of cancer'

There is a clear benefit for the State and for broader society in cancer patients returning to work. A key commitment of the Programme for Government is a "jobs-led recovery", getting people back to work after the massive disruption of the COVID-19 pandemic.

The COVID-19 pandemic has revealed our ability to innovate and adapt, to empathize and support. Government and employers adapted to support workers during one of the most challenging times in recent history, and we note a number of recent

legislative and policy developments around working from home, the right to disconnect and sick leave.

In this light, we must recognise that cancer patients and other people dealing with chronic illness require flexibility and practical support if they are to return to work. We presented a number of recommendations on how this could be achieved in February 2021.^{xii}

In Budget 2022, we are seeking a widening of eligibility criteria on Partial Capacity Benefit—the social welfare scheme which allows a person to return to work or self-employment and continue to receive a payment from the Department of Social Protection. We believe that the eligibility criteria for Partial Capacity Benefit are too narrow, and that often people who would benefit from it cannot qualify for it. This form of top-up payment can help people whose illness means they must work reduced hours and take home less pay. In this way, the payment can enable a phased return to work.

For Budget 2022, 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.

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.

2.7 Fund new psycho-oncology posts

Psycho-oncology, a multi-disciplinary speciality focusing on the mental health care of people affected by cancer, their carers and families, is a key tool in the response to cancer. Cancer can be a psychologically intense



experience, and it is so important that everyone receives the supports they need going through it.

The Irish Cancer Society Nurseline receives a significant number of calls relating to unmet psychological needs inquiries (867 in 2019 and 724 between January and October 2020).

In 2017, Recommendation 30 of the National Cancer Strategy stated 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 [Multidisciplinary Team] approach, to provide equitable patient access.”^{xliii}

Some promising steps have been taken to implement this commitment. A National Clinical Lead for Psycho-Oncology was appointed in December 2018, and a new model of care was published in September 2020.^{xliii}

However, despite the best efforts of the National Cancer Control Programme, healthcare professionals and other stakeholders, limited progress on the actual roll-out of the model was made until funding was provided in Budget 2021.

The Irish Cancer Society received notification in July 2021 that 19 new posts in psycho-oncology were going to be funded, supporting services in 10 hospitals around the country. This is very welcome news indeed, and will mean that cancer patients finally begin to receive the dedicated psychological supports they need as they go through one of the most difficult experiences of their lives. It is important that the remaining posts are also filled.

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

Children and adolescents (CA) living with and beyond cancer, and their families, also need timely access to

appropriate services. A Paediatric Psycho-Oncology Model of Care is under development and will require proper resourcing to meet the needs of CA, survivors, their families. In the second section of this document, to better support children and adolescents living with cancer, their families, and survivors, in Budget 2022 we are asking Government to take action to fund a CAYA specific public psycho-oncology support hub-and-spoke service (covering the cancer care pathway).

2.8 Fund fertility treatment for cancer patients and survivors

Fertility preservation is an important consideration for adult, childhood and adolescent cancer patients. In Ireland, survivorship rates of people diagnosed with cancer aged 15-44 are generally high. The UK’s National Institute for Health and Care Excellence (NICE) suggests that approximately 15% of people undergoing cancer treatment will have fertility problems.^{xliii} Fertility preservation can provide cancer patients at risk of infertility due to treatment with an opportunity to start a family.

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.

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Children and pre-pubescent adolescents are not covered through this system. Currently, the Irish Cancer Society funds the Merrion Fertility Clinic at the National Maternity Hospital to provide fertility preservation services to children and adolescents.

While fertility preservation is an important service, it is one part of the journey.

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.

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.

A cycle of IVF usually costs €4,500 per round, depending on which treatment is required and which clinic you are using.

There is also the additional cost of transferring eggs, sperm or embryos that have been taken as part of fertility preservation and 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.

The Programme for Government commits to implementing publicly funded fertility treatment and a new model of care for infertility. The Department of Health is in the process of developing regional hubs as phase one of the model of care, which may help mitigate this particular challenge.

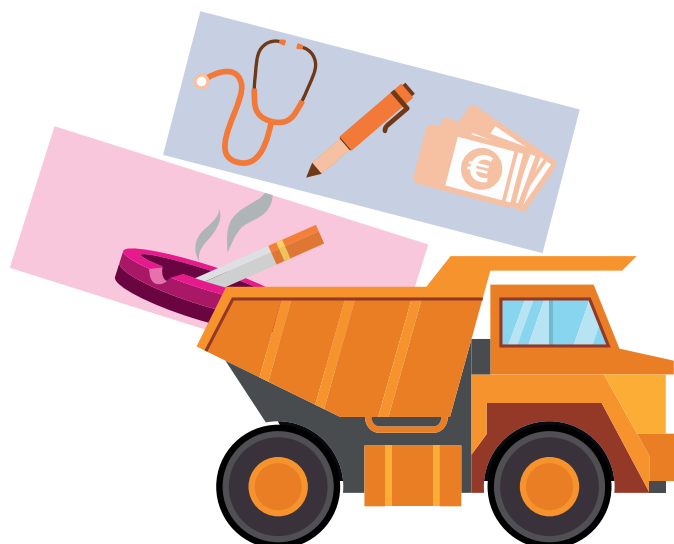


“Funding of €2m was provided to the HSE to commence Phase One of the roll-out of the model of care in 2020. This was utilised specifically in respect of the development of the first four Regional Fertility Hubs – Cork Maternity University Hospital, the Rotunda Hospital, the National Maternity Hospital and the Coombe Women and Infants University Hospital.

Additional funding of just over €1m has been made available to enable the continuation of Phase One of the roll-out in 2021, including through the setting-up of the final two Regional Fertility Hubs, one to be located within the Saolta Hospital Group and one within the University of Limerick Hospital Group.”

- Minister for Health, Stephen Donnelly TD, 21 April 2021^{xiv}

This effectively acts as a step towards trying to have a more organised system which would then act as a referral system. However, there is still no public funding for IVF once referred.



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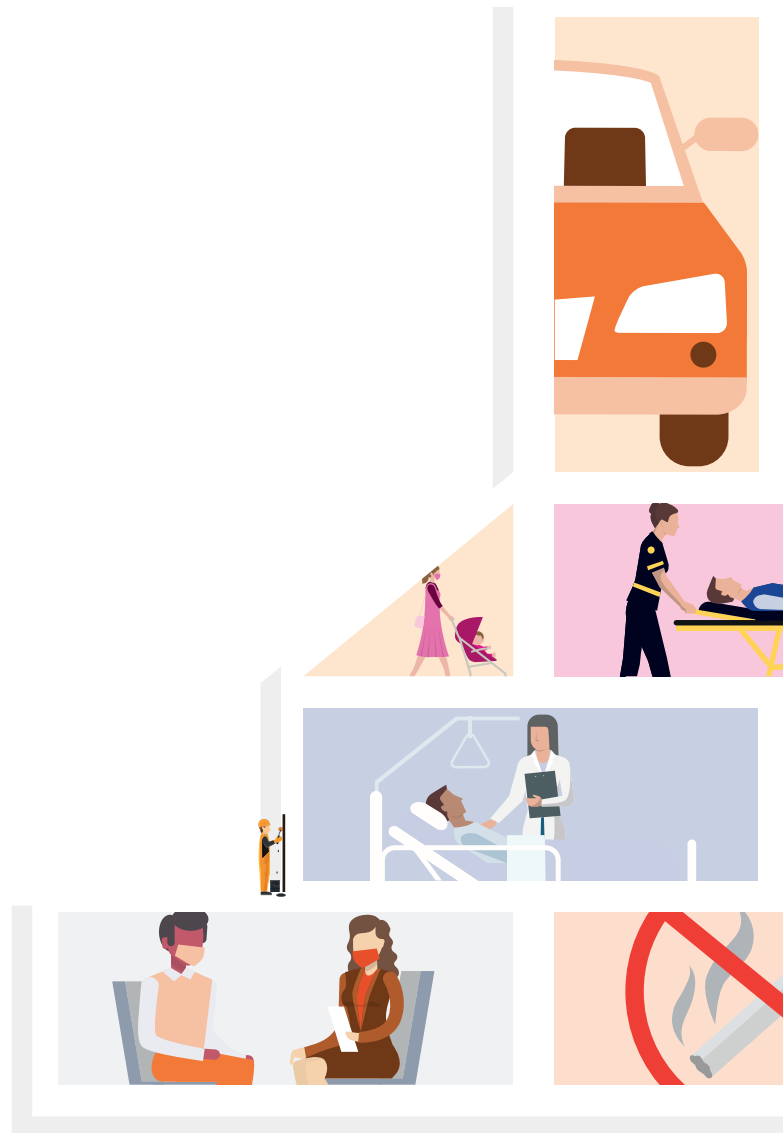


Phase Two of the roll-out will be set to facilitate the introduction of advanced infertility interventions including IVF, in the public health system, but the timelines as to its introduction are unclear and have been closely tied to progress on the Assisted Human Reproduction Bill, which has not progressed beyond pre-legislative scrutiny completed in July 2019.

Phase Two will not commence until such time as infertility services at secondary level have been developed across the country, required resources have been allocated, and the assisted human reproduction (AHR) legislation is commenced. This is despite the fact that those who can afford to have fertility treatment in the private system may continue to do so.

Currently, Ireland is the only EU member state which does not provide publicly-funded fertility treatment, despite an announcement in 2017 that a €1 million euro fund would be rolled out in 2019^{xlvi}, and a further announcement of a €2million euro fund that would be implemented in 2021^{xlvii}.

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 to deliver publicly funded fertility treatment in Budget 2022.



Prioritise Cancer Prevention



4 in 10 cancers are due to preventable causes.^{xlviii} As many as 19,000 avoidable cancers are found each year, and that number is growing.^{xlix} This means that we have the tools at our disposal to stop tens of thousands of cancers ever occurring in the first place.

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

Most concerningly, there is a clear relationship between preventable cancers and social and economic disadvantage.^l We must recognise this relationship and take targeted action to offer everyone in society the best chance of living a life free from cancer.

There are low-cost, simple interventions we can make as part of Budget 2022 which will reduce the behaviours which lead to cancer. We can increase excise duty on cigarettes, and subsidise programmes that support smokers who want to quit. We can properly fund the National Skin Cancer Prevention Plan. We can increase public funding for active transport infrastructure that encourages walking and cycling.

Tackling the root causes of cancer not only saves lives, but is also incredibly cost-effective. The more that is spent on effective prevention programmes in Budget 2022, the more resources the State will have at its disposal in future budgets thanks to reduced pressure on healthcare systems.

We have a huge opportunity to save thousands of lives each year by preventing cancer before it ever occurs. We must be ambitious and seize this opportunity.



“Prevention is more effective than any cure... Prevention is also the most cost-efficient long-term cancer control strategy.”

- EU Beating Cancer planⁱⁱ

3.1 Fund the elimination of HPV-caused cancers and HPV catch-up plans

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 and most do not cause any problems. Certain types are considered high risk. Most cervical and anal cancers are caused by HPV; the virus also causes most cancers of the vagina, vulva, penis, and throat.^{lii}

In total, every year around 420 men and women in Ireland are diagnosed with a cancer caused by HPV infection.^{liii} These HPV-caused cancers claim up to 130 lives annually.^{liv}

The fact that we now have a vaccine that can significantly reduce these cancer incidences and save lives should mean that these numbers will fall substantially in the coming years. In Ireland, the HPV vaccine is offered free of charge to all students in their 1st year of secondary school. This is because the vaccine works best for girls and boys who have not been exposed to the virus through sexual activity.

400 – Number of cancers caused by HPV each year

130 – Deaths due to a HPV-caused cancer each year

The Irish Cancer Society believes that the elimination of HPV-caused cancers is within our grasp. There is clear guidance setting out how this can be achieved in the European Cancer Organisation's 'Viral



Protection: Achieving the Possible. A Four Step Plan for Eliminating HPV Cancers in Europe’ and the World Health Organisation’s ‘Global strategy to accelerate the elimination of cervical cancer as a public health problem’.^{lv} These recommend steps which Ireland is already making significant progress on, including—

- Preventing HPV through gender neutral vaccination programmes;
- Using HPV testing to detect cervical cancer early;
- Raising awareness and education to combat vaccine hesitancy.

Additionally, HPV vaccination has been impacted at separate points throughout the pandemic by the closure of schools and the redeployment of public health nurses administering vaccines.

Thankfully in the 2021/22 school year the vaccine will be administered in schools to first year students. The Irish Cancer Society believes that, as part of the 2021/22 roll out, those who did not or could not take up the offer of the HPV vaccine in the 2019/20 and 2020/21 should be offered it again.

While uptake rates of the vaccine were relatively stable during the pandemic, with temporary measures for vaccination in the community introduced, we believe there is a window of opportunity to increase these further and reduce more people’s risk of cancer in the future. As such, we have asked the Department of Health to examine a catch-up programme for these years to protect young people from the risk of HPV-related cancers in future, save lives, and save many invasive and expensive treatment.

We believe this should be accompanied by a distinct catch-up programme for all second- level students, who have not yet availed of HPV vaccination.^{lvi} This would mirror the approach taken in the UK. If you’re eligible and miss the HPV vaccine offered in Year 8 (aged 12 – 13) at school, you can avail of it for free on the NHS until your 25th birthday.

Currently, anyone not in first year of secondary school or age equivalent in special schools or home schooled during the 2020/2021 school year who wishes to get the HPV vaccine, must go to their GP or sexual health clinic and pay privately for the vaccine and its administration . The Irish Cancer Society believes that no child should miss out on a potentially life-saving vaccine and every attempt should be made to encourage later take-up of the vaccine where it wasn’t in the first year of secondary school.

In Budget 2022, we are asking the Government to prioritise the publication of, and funding for, a country specific elimination plan based on international best practice, along with providing necessary funding to support catch-up programmes for those who did not avail of the HPV vaccine in previous school years.

3.2 Increase excise duty on cigarettes by €1 a pack, and invest in helping smokers to quit

In Ireland, more people die from lung cancer than any other cancer.^{lvii} It is the second most common cancer among women and the third most common among men.^{lviii} It is among the most deadly of cancers: just 1 in 5 lung cancer patients survive 5 years after their diagnosis.^{lix}

Tobacco use causes 9 in every 10 lung cancers.^{lx} It also causes a range of other cancers and other diseases, killing almost 6,000 people prematurely in Ireland every single year.^{lxi}



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

Ireland has seen some remarkable successes in reducing smoking rates. Successive governments have faced down the lobbying of the tobacco industry and introduced measures such as the workplace smoking ban, plain packaging, and advertising restrictions. As a result, smoking prevalence has declined from 28% in 2003 to 15.4% in 2020.^{lxii}

But there is more work to do. Tobacco Free Ireland, Ireland's strategy to reduce smoking rates, commits to reducing smoking prevalence to less than 5% of the population by 2025. We have made great strides towards this ambitious goal, but this will require hundreds of thousands more people to quit. For Budget 2022, the Irish Cancer Society is urging the Government to adopt the well-evidenced, cost-effective policies that will support people to quit smoking.

Firstly, we are asking the Government to commit to a €1 increase in the excise duty charged on a packet of 20 cigarettes. This increase is based on a tobacco tax escalator, which, if implemented would see continuous increases in excise of 5% plus inflation. Its implementation would act as a sure sign from Government that it is serious about its Programme for Government commitment to "increase the excise duty on tobacco in the years ahead to further discourage smoking".^{lxiii}

This would see an increase of €1.01 in the price of a packet of cigarettes from €14.09 to €15.10 in 2022*.

There is clear international evidence demonstrating that increases in the price of cigarettes lead to drops in smoking prevalence. International agencies, including the World Health Organisation^{lxiv}, the World Bank^{lxv}, and the International Agency for Research on Cancer^{lxvi} endorse the use of tobacco taxation to reduce tobacco use. We know from their work that demand for tobacco drops by 4% for every 10% increase in price.^{lxvii}

Secondly, we are calling for excise duty increase on roll-your-own tobacco to ensure their tax is equivalent to that on cigarettes, ensuring that roll-your-own tobacco cigarettes' price does not make them a more attractive alternative to cigarettes. A report by the HSE found that the proportion of smokers using roll-your-own tobacco has increased dramatically, from 3.5% in 2003 to 24.6% in 2014.^{lxviii} By 2020, the proportion was even higher, at 29.6%.^{lxix} This is largely driven by the fact that roll-your-own cigarettes are cheaper to access, making them especially attractive to children and teenagers taking up smoking.

Thirdly, and most importantly, we believe the State must provide greater supports to smokers to help them quit. Excise receipts from tobacco in 2020 amounted to over €1.2 billion, and figures from previous years are similar.^{lxx} Yet in 2017, the HSE's spending on measures to tackle tobacco use amounted to a little over €14 million.^{lxxi} That is less than 1.2% of the revenue collected. We think it should be more.

Given the social and economic impacts of smoking detailed above, there is a strong budgetary case for providing these supports. The Tobacco Free Ireland strategy notes that "an economic appraisal of the introduction of a comprehensive system for treating tobacco dependence in the UK found that the cost per life year gained ranged from £210 to £870, which was considerably cheaper than a range of over 300 other medical treatments."^{lxxii} There is a considerable body of research setting out the benefits of reimbursing Nicotine Replacement Therapy and other smoking cessation supports.^{lxxiii}

For Budget 2022, we urge the Government to be more ambitious, and to look at ways the significant revenue raised from excise duty on tobacco can be used to help smokers to quit.

This figure is based on a 2.2% annual rise in inflation as measured by the Consumer Price Index for July 2021, and a survey of 20 packets of 20 cigarettes at a major retailer in August 2021, which showed an average price of €14.09.



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

The Programme for Government and Budget 2021, demonstrated significant ambition providing the infrastructure that will enable everyone in society who can to walk and cycle. The Programme for Government commits to allocating of 10% of the total transport capital budget for cycling projects and 10% to pedestrian infrastructure.^{lxxiv} The Irish Cancer Society was delighted to see this commitment delivered upon in Budget 2021.

In addition to the environmental benefits of reducing Ireland's reliance on fossil fuel, a systemic shift to low-carbon modes of transport will have a hugely positive effect on public health.

Excess fat in our bodies produces hormones such as oestrogen and insulin, which increase the risk of breast, bowel, pancreatic and other cancers developing.^{lxxv} The National Cancer Registry Ireland estimates that 5% of all cancers in Ireland are attributable to being overweight or obese, making it the second most important preventable cause after smoking.^{lxxvi}

1,061 – The number of cancers attributable to being overweight or obese in 2016 in Ireland^{lxxvii}

1,790 – the annual number of cancers projected to be attributable to being overweight or obese by 2035 in Ireland^{lxxviii}

By integrating exercise into our everyday lives, we can see it as a normal part of our day-to-day routine. This makes it much easier to sustain healthy habits and reduce our risk of cancer. Indeed, recent research has demonstrated that commuting undertaken totally or partially by bike is associated with a lower risk of developing cancer, cardio-vascular disease, and other adverse health outcomes.^{lxxix}

Publicly-funded infrastructure needs to be in place to allow this to happen for everyone: it is not just a matter of individual decision-making. We need safe, segregated cycle lanes. We need junctions that prioritise pedestrians over cars. We need our children to again be safe to play with their friends outside.

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

3.4 Fund the National Skin Cancer Prevention Plan

Skin cancer is the most common form of cancer in Ireland, with over 13,000 skin cancers diagnosed each year.^{lxxx} It is projected that this number will more than double by 2045.^{lxxxi}

Nine out of every ten skin cancer cases are caused by UV rays from the sun or sunbeds.^{lxxxii} Getting sunburned five or more times doubles a person's risk for melanoma, the most serious form of skin cancer.^{lxxxiii}

The close relationship of skin cancer to people's behaviour in the sun means it is an eminently preventable disease. Behavioural changes such as covering exposed

skin when in the sun, applying suncream, wearing a hat, seeking shade and wearing sunglasses can reduce your personal risk of skin cancer significantly. But at a population level, we need to make sure everybody knows this.

Thankfully, following continued calls from the Irish Cancer Society and engagement with the Society and other stakeholders, the Department of Health published a Skin Cancer Prevention Plan in 2019 which aims to increase awareness and adoption of skin cancer preventative behaviours and reverse the rising incidence of skin cancer in Ireland.^{lxxxiv}

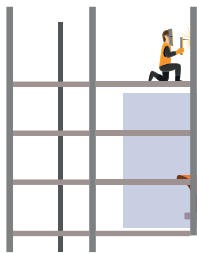
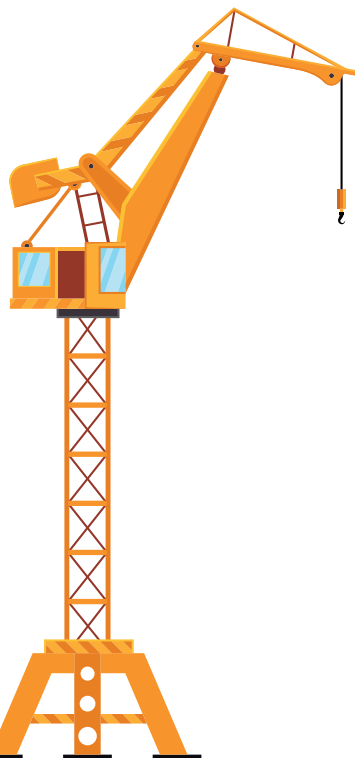
We need to ensure that the Department of Health, the HSE and their partners have the funds they need to implement the plan. Funding evidence-based skin cancer prevention programmes makes good economic sense: the Government of the Australian state of Victoria have calculated that their SunSmart programme, which has been running since 1988, has not only prevented more than 43,000 skin cancers and 1,400 deaths, but has also saved the state \$2.20 for every dollar spent.^{lxxxv}

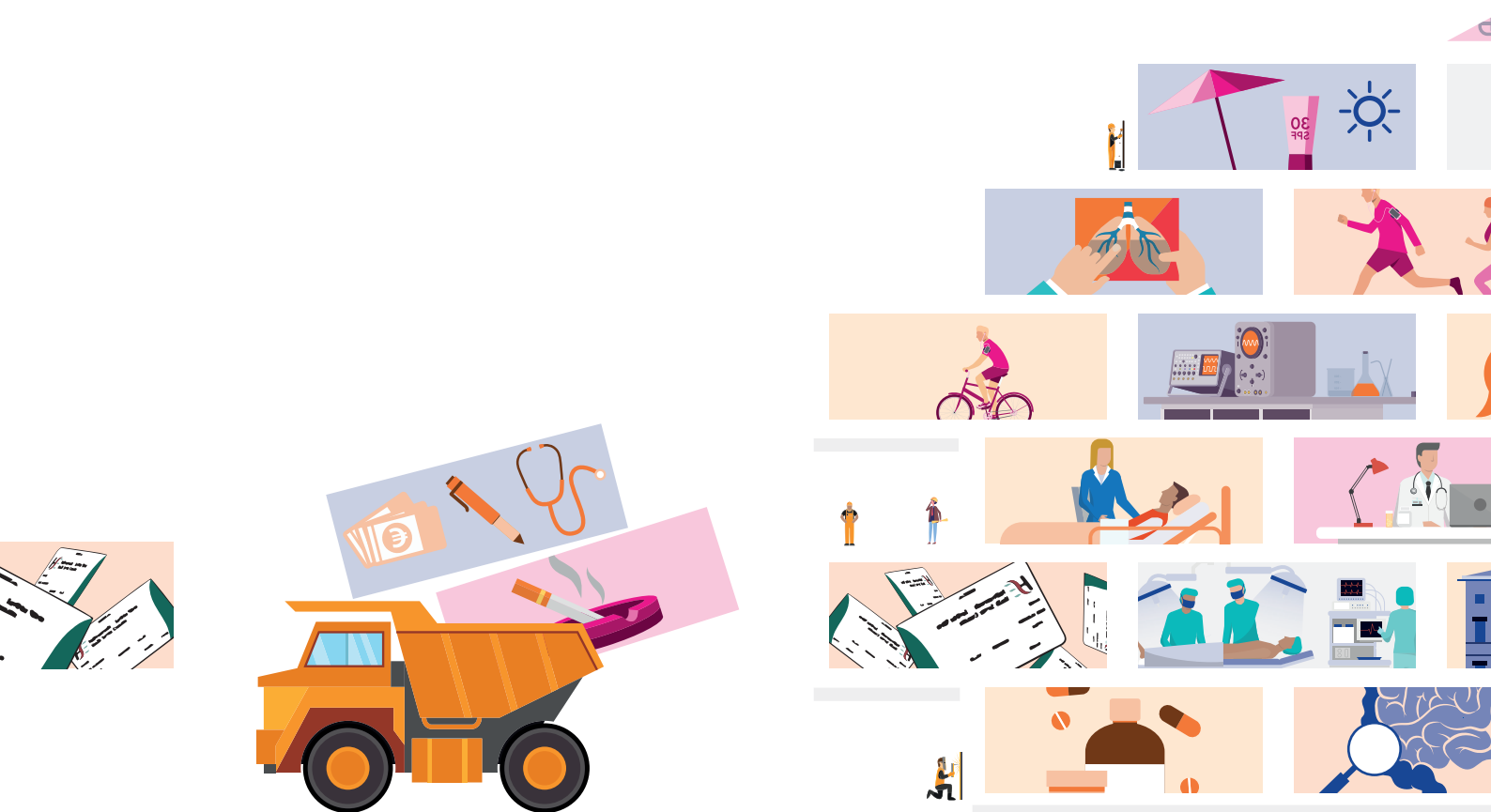


“Over time, skin cancer prevention offers the important potential to redirect some of the \$56 million impact on Victorian public hospitals each year to other non-preventable diseases. Based on the present study, the cost per head incurred by skin cancer treatment in Victoria was in the range of \$9.20... to \$10.39... Compared with the cost in Victoria of skin cancer prevention of \$0.37 per head, this adds weight to arguments to increase resources going into prevention.”

– Shih et al, 2017^{lxxxvi}

On this basis, the Irish Cancer Society is calling for full funding to be provided to the National Skin Cancer Prevention Plan.





Supporting Children,
Adolescents and Young
Adults (CAYA) through
the cancer pathway
and beyond



Irish Cancer Society

Pre-Budget Submission 2022

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The recommendations in the Irish Cancer Society pre budget submission which relate to CAYA are supported by the following organisations:



Introduction

A childhood, adolescent or young adult (CAYA) cancer diagnosis is devastating. In Ireland, in 2017 alone 231 children and adolescents (CA) between the ages of 0-19 were diagnosed with cancer, excluding non-melanoma skin cancer (NMSC)ⁱ. 84 young adults aged 20-24 received a cancer diagnosis in the same year. Table 1 below provides an overview of cancer incidence in people aged 0-24.

Table 1: Incidence amongst CAYA since 1994	1994 – 2017	1994	2017
0-9 years ⁱⁱ	2205	72	108
10-14 ⁱⁱⁱ	842	42	48
15-19 ^{iv}	1579	61	75
20-24 ^v	2259	82	84

Four in five children under the age of 15 will live at least five years after their diagnosis.^{vi} Despite huge improvements in survival rates in recent decades, CA cancer survivors can experience a range of health and socio-economic impacts into adulthood. While survival is the main goal of treatment, quality of life beyond cancer must be brought to the forefront of practical and policy considerations.

The cancer care pathway stretches from diagnosis to survivorship, and, in some circumstances, end of life. As such, the impact of cancer on an individual does not stop with treatment. Cancer treatment can bring lifelong health and psychological effects as well as impact on a person's education and finances, amongst other challenges.

Families, too, feel the impact of a child's cancer diagnosis, during and after treatment. Families manage family stress, alter working patterns and working hours, and live on reduced incomes all while prioritising the care of their child.



Our main priorities

While there are many aspects of treatment and care for CAYA with cancer which work well, there is much that we can do to support and improve the quality of life for this community. The Irish Cancer Society would like to assert the need for quality support structures built around CAYA and their families across the cancer care pathway so that CAYA and their family can thrive in life beyond cancer. **Budget 2022 should deliver on quality of life priorities for children, adolescents and young adults with cancer, survivors and their families, through the following actions:**

1. Recognise the Costs of Cancer to Patients and their Families

- Provide funding for grants to parents/guardians, or up to the age of 18 for adolescents who are responsible for their own care, to cover non-medical expenses as a result of their treatment needs.
- Extend Carers' Allowance and Domiciliary Care Allowance to parents/guardians whose child is treated in hospital for longer than 13 weeks, in recognition of the fact that children must be accompanied. Similarly, entitlements for Domiciliary Care Allowance must be extended to parents/guardians of 16 and 17 year olds.
- Establish and fund a CAYA specific public psycho-oncology support hub-and-spoke service (covering the entire cancer care pathway).
- Provide funding to public hospitals to waive car parking charges for parents of children/adolescents.

2. Supporting better outcomes from care

- Invest funding in age-appropriate, multi-disciplinary care for adolescents and young adults.
- Foster mechanisms to enable more health and social care professionals at all career stages, across different disciplines, to participate in

research activities to improve outcomes for CAYA living with and beyond cancer.

- Dedicate resources for the continuous monitoring of the workforce capacity to ensure sufficient staffing for adolescent and young adult oncology services.
- Ringfence and provide a predictable funding stream for clinical trials to ensure that children and AYA can access clinical trials to support an improvement in outcomes.
- Provide new funding to develop a world-class cancer genetics service.

3. Supporting quality of life beyond cancer

- Extend publicly funded fertility preservation services to children and adolescent cancer patients as well as access to fertility preservation post-treatment for those who require it.^{vii}
- Fund the Model of Care for Infertility, with dedicated funding available to adult survivors of CA cancer to access fertility treatments such as in-vitro fertilisation (IVF) and intrauterine insemination (IUI).
- Enhance funding to extend access to a special needs assistant for survivors of childhood and adolescent cancer who need it. Provide a lifelong medical card to survivors of childhood and adolescent cancer.
- Ringfence funding for survivors of childhood and adolescent cancer through the full implementation of the Priority Actions outlined in the NCCP's health needs assessment in survivorship after childhood cancer (Barrett et al. 2018)

4. Building Palliative Care Capacity

- Provide funding for delivery of age-appropriate palliative services for children and young adults with untreatable cancers in their local community.

Supporting families financially through treatment

Childhood cancer services are based on a Hub and Spoke model. Services are largely centralised at Children's Hospital Ireland at Crumlin, while other shared care centres support with a patient's care. As such, families can face additional expenses in travel, parking, and accommodation.

For families with a child in hospital, travel is one of the most significant costs.^{viii} The Irish Cancer Society's Real Cost of Cancer 2019 report^{ix} outlined some of the non-medical costs facing people living with cancer. The report did not focus specifically on the CA population but serves to illustrate some of the travel expenses associated with accessing care. For instance, average monthly travel costs tend to be high, particularly for those who live outside of Dublin – ranging from €150 to €192, while people in Dublin paid €130.^x Overall, given the need to travel for care, people faced long journeys (e.g. an average of 143 kilometres from Connaught/Ulster, and 81km from Munster).^{xi}

Car parking, too, is a significant cost. Parents/guardians with a child in hospital report that they rely on a family car, based on a 2020 Children in Hospital Ireland report.^{xii} Many are subject to car parking charges, which they believe are unjustified, and often different rates apply across different hospitals.^{xiii} At Children's Health Ireland at Crumlin, parents/guardians of inpatient children who stay for more than 10 days for each stay can apply for concession rates at €36 for week one, and €10 for each subsequent week.^{xiv}

Accommodation costs can also have an additional impact on a family's finances. Parents of sick children must stay close to their child while they remain in hospital. Many may sleep in their child's room or ward; others may have to pay between €10 and €30 per night for accommodation provided in hospitals or by voluntary organisations, even if costs are partly covered.^{xv} In examining the Real Cost of Cancer, 1 in 5 people reported that they had to pay for accommodation linked with attending appointments, with an average cost of €210 per month.^{xvi}

At a time non-medical costs increase, the responsibility to care for a child with cancer usually means that families face a decline in income.^{xvii} Mothers, in particular, are impacted.^{xviii} Some parents report the need to give up work, reduce their working hours, take a temporary leave of absence, and/or take a job with a lower income to care for their child (while they were in hospital).^{xix} Furthermore, few non-medical financial supports were available to parents/guardians.^{xx} For some, financial supports for parents/guardians taking care of children with long-term needs can be suspended if a child spends 13 weeks or more in a hospital.^{xxi}

Already, some supports exist for families of CA with cancer. The Irish Cancer Society administers the National Cancer Control Programme's Travel2Care scheme, which is available to children visiting approved children's hospitals, whose family has a financial need and who do not qualify for other schemes.

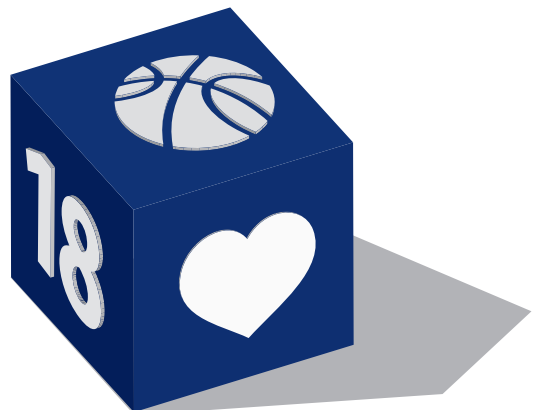
All children under the age of 18 who have been diagnosed with cancer in the last 5 years are eligible for a medical card.^{xxii} At the State level, parents can claim some tax relief on the costs of bringing a child to and from hospital and in travelling to visit a child in hospital (provided the visit is necessary). Nonetheless, based on the 2019 rate of 18c per kilometre,^{xxiii} assuming the maximum average of 143 kilometres (based on the Real Cost of Cancer study) a person can expect approximately €25.74 in tax relief to travel to a hospital. In addition, this option requires an upfront expense. There is no such relief for car parking.

People can apply for tax relief on accommodation costs deemed necessary to be close to a child; however, it is not immediately clear if the full cost can be reimbursed.^{xxiv} While some supports are available, the Irish Cancer Society calls for greater recognition and subsequent alleviation of the upfront burden on families of CA with cancer. For instance, retrospective declaration of expenses to claim tax relief or reimbursement can add a great burden to families.

Families and survivors face many challenges as a result of a cancer diagnosis and may rely on charitable organisations for a range of supports and services. COVID-19 has had wide ranging impacts on families, and on charitable and civil society organisations, their resources and their ability to support.

Understanding the financial burdens placed on the shoulders of parents/guardians, in addition to the emotional toll of caring for a child/adolescent with cancer, we recommend the following actions for Budget 2022:

- Provide funding for grants to parents/guardians, or up to the age of 18 for adolescents who are responsible for their own care, to cover non-medical expenses as a result of their treatment needs.
- Extend Carers' Allowance and Domiciliary Care Allowance to parents/guardians whose child is treated in hospital for longer than 13 weeks, in recognition of the fact that children must be accompanied. Similarly, entitlements for Domiciliary Care Allowance must be extended to parents/guardians of 16 and 17 year olds.
- Establish and fund a CAYA specific public psycho-oncology support hub-and-spoke service (covering the entire cancer care pathway).
- Provide funding to public hospitals to waive car parking charges for parents of children/adolescents.



Enabling access to psycho-oncology services

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.^{xxxv}

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

The effects of a childhood cancer diagnosis and treatment often follow a person and their family into adulthood.^{xxxix} Parents can continue to carry their stress and anxiety including fear over their child's health throughout their lifetime.^{xxx} The psychological effects of a childhood cancer diagnosis can be delayed for a number of years.^{xxxi} Survivors can endure anxiety linked to their health and experience higher rates of psychological challenges,^{xxxii} prescriptions for anti-depressants, and hospitalisation for mental disorder, compared to the general population.^{xxxiii} The delayed effects of a cancer diagnosis amongst survivors can be stratified by age, life decisions (e.g. starting a family if facing infertility), chronic health conditions, educational attainment, employment, etc.^{xxxiv}

In addition, where a child, adolescent or young adult reaches the end-of-life phase due to their diagnosis, targeted support should be made available to them at this time. Their family, too, should have access to essential psychology services following their bereavement.

People who live with cancer and who have their psychological needs met have better health outcomes.^{xxxv} However, current provision of mental health services in Ireland is insufficient.^{xxxvi} According to a recent audit, the psychology care service in the National Children's Cancer Service (NCCS) is currently unable to meet international standards of psychosocial care.^{xxxvii} 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.^{xxxviii}

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).^{xxxix}

To better support children and adolescents living with cancer, their families, and survivors, in Budget 2022 we are asking Government to take action to fund a CAYA specific public psycho-oncology support hub-and-spoke service (covering the cancer care pathway).

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.^{xl} This funding should be used to adequately staff the service, for outreach, and to embed services within hospitals and the community.^{xli} These services should also include bereavement support for parents/guardians and siblings of children and adolescents who die of cancer. In addition, this funding should also cover peer support infrastructure for parents.

Supporting better outcomes from care



Adolescents and young adults tend to have lower survival improvements and lower numbers enrolled in clinical trials compared with children and older adults.^{xliii} Clinical trials are beneficial to outcomes amongst cancer patients; however, enrolment amongst AYA in clinical trials is not as high as for other groups. Adolescents and young adults who can access clinical trials may benefit from better outcomes. Children, too, also require continued access to clinical trials. Given small population sizes for CA, many trials are pan-national and carry burdensome costs for institutions overseeing them.^{xliii}

Across a number of cancer types, AYA tend to have poorer outcomes when compared to children.^{xliv} However, survival improvements have been noted for leukaemia and CNS tumours, subtypes for which there is centralisation of services.^{xlv} Age-appropriate and multi-disciplinary care is also a priority to enhance outcomes for AYA.^{xlvi} The New Children's Hospital will not be completed for another few years. Adolescents and young adults living with cancer today need access to age appropriate care, with relevant multi-disciplinary healthcare and support professionals available to meet their needs.

The National Cancer Strategy calls for the integration of and protected time for clinical cancer research as well as an increase in participation in clinical trials. Protecting the time of healthcare professionals is essential towards enabling cancer patients in Ireland to benefit from world-class expertise, much like the Irish Cancer Society's Clinician Research Leadership Award.^{xlvii} Furthermore, sustainable investment in research across different disciplines is required to support the holistic care of CA living with cancer, e.g. medicine, psychology, survivorship.

Most children's cancers originate from a mutation and hence genetic issues and heritability are much more common in this context than adult cancers. Therefore, specific investment in cancer genomics and genetic support services is crucial for the CA population as well as for their families.

In its fifth year of implementation, progression of the National Cancer Strategy cannot continue to be hampered by the challenges of COVID-19 and the cyber-attack. Rather, additional efforts and resources must be dedicated to ensuring that vulnerable groups are protected during such crises.

To provide world-class care and ensure better outcomes for adolescents and young adults, we call for the following priorities to be reflected in Budget 2022:

- Invest funding in age-appropriate, multi-disciplinary care for adolescents and young adults.
- Foster mechanisms to enable more health and social care professionals at all career stages, across different disciplines, to participate in research activities to improve outcomes for CAYA living with and beyond cancer.
- Dedicate resources for the continuous monitoring of the workforce capacity to ensure sufficient staffing for adolescent and young adult oncology services.
- Ringfence and provide a predictable funding stream for clinical trials to ensure that children and AYA can access clinical trials to support an improvement in outcomes.
- Provide new funding to develop a world-class cancer genetics service.

Support quality of life beyond cancer

Planning for lifelong survivorship must be at the forefront of every child, adolescent and young person's care and treatment plan from the day on which they received their first diagnosis.

Fund fertility preservation for children and adolescents

Children and adolescents undergoing cancer treatment can risk loss of fertility. Fertility preservation is recognised as a key component of quality of life in survivorship following cancer.^{xlviii} Fertility problems following cancer treatment are recognised as having a negative impact on quality of life beyond cancer.^{xlix} For some, this can link to psychological distress.

Currently, the Irish Cancer Society funds the Merrion Fertility Clinic at the National Maternity Hospital to provide fertility preservation services to children and adolescents. However, there is no national public fertility preservation service which caters specifically to this group free of charge.

In addition, some pre-pubescent fertility preservation services are not available in Ireland due to some infrastructural considerations, leading some children and their parents/guardians to travel abroad with their child, at their own expense, to avail of such a service. As such, families have to contend with the cost of treatment and storage, travel and accommodation, and general living expenses while away.

Beyond fertility preservation, fertility treatment is not available in the public healthcare system to cancer survivors or the general population. Rather it is an out-of-pocket expense, which may mean that some people simply cannot afford it.

We ask Government in Budget 2022 to extend publicly-funded fertility preservation services to children and adolescents with cancer. We also ask that the government progress and adequately fund the Model of Care for Infertility, with funding made available to adult survivors of CA cancer to access fertility treatments such as in-vitro fertilisation (IVF) and intrauterine insemination (IUI).

Extend special needs support to children and adolescents following a cancer diagnosis

Generally, survivors of childhood cancer have lower levels of educational attainment due to a number of factors compared with their peers, and are less likely to attend higher education.ⁱ There is currently no centralised or uniform guidance on how to support children and adolescents as they continue their education throughout and beyond cancer treatment. Support across different schools can vary, particularly as they do not have guidance on how to support this vulnerable group.ⁱⁱ As such, some children can avail of appropriate practical supports, while others do not given that it is not streamlined.ⁱⁱⁱ Access routes to higher education, too, should be made easier for survivors of CA cancer. For instance, some barriers for application for dedicated access routes e.g. Disability Access Route to Education (DARE) could be removed, e.g. costs of funding psychological assessment report, expansion of eligibility criteria, etc.

Some access routes to higher education for which survivors of CA cancer might apply require a number of criteria.

In Budget 2022, we believe funding should be made available to extend access to a special needs assistant for survivors of childhood and adolescent cancer who need it.

This will help alleviate some of the challenges children and adolescents face in returning to education.

Provide medical cards for all survivors of CA cancer

Children and adolescents under the age of 18 qualify for a medical card for 5 years following their diagnosis.

^{liii} This is a useful resource for many; however, the medical card expires within 5 years of a diagnosis.

Survivors can experience adverse financial and socio-economic impacts as a result of their cancer diagnosis. For instance, survivors of CA cancer can have lower educational attainment compared to people who did not have a CA cancer diagnosis, which in some circumstances has an impact on income.^{liv} In Ireland, some survivors reported that the expiry of medical card and 'employment barriers' also contributed to the residual financial burden of a CA cancer diagnosis.^{lv} Survivors of childhood cancer have expressed that the financial burden they experience could be somewhat addressed through practical supports, such as access to a medical card beyond the 5 year cut off since diagnosis.^{lvi}

To support the health and financial wellbeing of survivors of childhood cancer, in Budget 2022, we are calling on Government to provide a lifelong medical card to survivors of childhood and adolescent cancer.

It is important that children and adolescents with cancer, survivors and their families are supported to live well. This includes psycho-social wellbeing as well as physical health.

In Budget 2022, we call on the government to ringfence funding for survivors of childhood and adolescent cancer through the full implementation of the Priority Actions outlined in the NCCP's health needs assessment in survivorship after childhood cancer (Barrett et al. 2018).

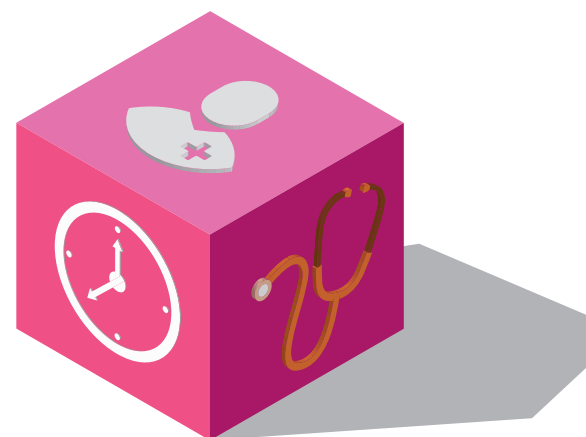
4 Build palliative care capacity

In Dublin, there is one children's hospice. Some adult palliative care services cater to children, but many children have no direct access to paediatric palliative care services.^{lvii} The service is not specific to children with cancer; rather, it is open to children with life-limiting conditions.^{lviii} There is one specialist Paediatric Palliative Care service, and 2.2 whole time equivalent (WTE) consultants in paediatric palliative medicine.^{lix} The service provides consultative support to services in Ireland.^{lx} A December 2020 HSE report outlined the need for protected time for the support of paediatric palliative care services amongst consultant paediatricians (0.4 WTE), in addition to filling more Clinical Nurse Coordinator WTE roles (increase to 22 funded roles from the current 16).^{lxi} Amongst paediatricians, access to education and training in paediatric palliative care is limited^{lxii} and a comprehensive training plan and core competences for healthcare professionals should be developed.^{lxiii}

In addition, the Irish Cancer Society Night Nursing service is available to support children at end-of-life in their homes.

To support children and adolescents who require palliative care, we are asking that in Budget 2022 funding is provided for the delivery of age-appropriate palliative care services for children and young adults with untreatable cancers in their local community.

This funding should cover staff training, staffing salaries and appropriate infrastructure to deliver paediatric palliative care.



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