



THE IRISH CANCER SOCIETY'S
Strategy Statement 2013 - 2017

Towards a future
without cancer



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Foreword

Our vision and our ambition is nothing less than a future without cancer. Our mission is to eliminate cancer.

To some this will sound like a completely unrealistic goal. How can we aim for a future without cancer if we already know from expert predictions that more and more people are going to get cancer because they are living longer, and cancer is statistically a disease of older people?

Some people might urge us to set our sights on a more realistic and realisable set of ambitions, such as working to prevent, or reduce the death rate from cancer, investing more in research, and ensuring that the Government is acting to fight cancer. It could be said that we should educate people in how to cut their risk of getting cancer, while also encouraging them to quit smoking, mind the sun, watch their weight and the alcohol they consume, and to exercise every day. We are sure they would also want us to take care of people who have cancer.

We are doing all of this already.

In the 50 years of the Irish Cancer Society's existence, we have grown our work and our leadership. During this time, Ireland has seen huge strides and made significant breakthroughs in the battle against cancer.



Through our work to empower people to reduce their risk, to support those living with the disease, to advance research and to inform and influence public policy, many more people will have a future without cancer.

In this, our Strategy Statement for 2013 – 2017, we have set our sights on four big goals which, we hope, if realised, will make a significant difference to cancer in Ireland, to patients and to their families.

Those goals alone, while very important, are not enough, and are not the full picture. For us, they cannot be enough. And we know, because they tell us, that for patients and their families, these goals alone are not sufficient.

Our joint mission, our ambition, is to eliminate cancer, and so we are working towards a future without cancer.

Nothing less is good enough for us, or the people we work for: you.

Prof. John Kennedy,
Chairman Irish Cancer Society

Mr. John McCormack,
CEO Irish Cancer Society



Our Vision

A future
without cancer

Our Mission

To eliminate
cancer

Our Values

Being compassionate and caring

We are deeply concerned about people in Ireland who are affected by cancer and those who may be at risk of getting cancer. That's why we are here. The Irish Cancer Society could do nothing without our committed volunteers, funders, supporters and staff. We honour, value and respect them.

Being available and accessible

We make ourselves available to everyone equally. We are concerned that people living in disadvantaged communities have a greater risk of getting cancer and of dying young from cancer than other people. We are determined to work collaboratively with these communities to change this.

Being committed to excellence

We are in constant contact with people affected by cancer, the medical community and the public in order to find out what people need and what works best. We make sure that our services and decisions are informed by best quality knowledge, data and expertise. We strive for excellence in all that we do.

Working in collaboration and partnership

Wherever and whenever we can, we collaborate with others, from the local community to the global community, and build alliances to get results – when we lobby, when we conduct research, when we work with others. We believe that collaboration and partnership are the best ways to advance our vision.

Being transparent and operating with integrity

Accountability, transparency and cost-effectiveness are vital to the Irish Cancer Society. We are honest and ethical in all that we do and work hard to be worthy of the ongoing trust and support of our volunteers and donors. We act responsibly and work to high standards of governance.

Introduction

For its first years the Irish Cancer Society has worked for and on behalf of everyone in Ireland who is affected by cancer. Since we began our work in 1963, we have grown into the national cancer charity with a set of goals which have shaped our mission to prevent cancer, detect it early and fight it at every level.

We strive to ensure that fewer people in Ireland get cancer and that those that do so receive the best care, treatment, information and support. We listen, we support, we provide care and financial assistance, we create awareness, we provide information, we fund research and we influence decisions about cancer. We are an independent voice for cancer patients and their families. Our work is only made possible by the commitment, generosity and tireless efforts of our donors, supporters, volunteers, researchers and staff.

Our long-term vision is a future without cancer. This will not be achieved in the lifetime of this Strategy Statement, but we are ambitious to succeed, and each year brings new developments, new services and renewed hope. Each year we learn more about what causes cancer and how to prevent it. Each year there are new advances in treatment, and we learn more about how to improve the quality of life of people who have cancer, their families and friends.

To match our ambition, we have agreed a set of priorities and plans for the next five years 2013 - 2017 which are comprehensive and far-reaching. We are determined to deliver.

We are an independent voice for cancer patients and their families

It is this culture of leadership, innovation and determination that has underpinned many of the achievements of the Society in the past. Some of these include:

- ▶ **Research:** Since 1963, the Irish Cancer Society has invested more than €30 million in cancer research. We have funded over 200 research projects throughout Ireland, leading to significant improvements in our understanding of how the disease develops and to better treatments and outcomes. Our research funding helped to nourish the All-Ireland Co-operative Oncology Research Group (ICORG), the national cancer clinical trials organisation, which has allowed thousands of people in Ireland to avail of new treatments.
 - ▶ **Influencing policy:** We played a significant role in the preparation and implementation of both National Cancer Strategies. We led the coalition which successfully advocated for the first ever workplace smoking ban, and which has influenced similar initiatives throughout the world.
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- ▶ **Screening programmes:** We demanded top-quality screening programmes, and Ireland now boasts two world-class programmes: BreastCheck and Cervical Check. We lobbied tirelessly for the introduction of a bowel cancer screening programme and pledged €1 million towards the set up costs. It has now commenced.
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- ▶ **Daffodil-funded Home Care Teams and night nursing:** In 1985 we introduced Ireland's first Home Care Service. Through Daffodil Day funding we led the development of nationwide day and night nursing care for people with terminal cancer in their own homes, making a fundamental difference to the choices people can exercise at this stage of their lives.
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We look forward, with your support, to our future achievements and realising our vision.

See page 23 for more about what we do.

The Challenge Ahead

Each year during the lifetime of this Strategy, approximately 30,000 people in Ireland will be told they have cancer. Cancer is a disease that knows no boundaries, does not distinguish between sex, race or class, and has or will affect us all either directly or indirectly during our lifetime.

The good news is that more people are surviving cancer and this is thanks to increased awareness of signs and symptoms, early detection of the disease and greatly improved treatments.

However, there are still many challenges and obstacles that face us.

More people will get cancer

Despite all we know about what causes cancer and how to prevent it, cancer cases in Ireland are expected to rise to 42,000 annually by 2020. The number of people aged over 65 in Ireland will double over the next 30 years. While many people will enjoy good health, the number of new cancer cases will rise steadily, to reflect the ageing population.

Health Inequalities and Cancer

Cancer affects all parts of Irish society, but some people are more at risk than others. The Irish Cancer Society is aware that people in marginalised communities have a far greater risk of getting cancer and of dying young.

Data from both Northern Ireland and the Republic of Ireland show that people in disadvantaged communities have higher cancer incidence rates and poorer chances of survival. Cancer related deaths in the lowest occupational classes are **double** those in the highest occupational class.¹ Lung, stomach, mouth, head and neck and

Smoking accounts for up to half of the difference in life expectancy between the richest and poorest groups in Ireland

cervical cancers are all more common in areas of higher unemployment and deprivation.² Smoking accounts for up to half of the difference in life expectancy between the richest and poorest groups in Ireland. It is the single biggest cause of preventable death in this country. Almost one million adults (26%) continue to use tobacco, and at least 5,200 people die prematurely each year as a result of smoking. It is the principal cause of lung cancer, and in populations with prolonged cigarette use, nine out of ten lung cancer cases are due to cigarette smoking³.

The Irish Cancer Society is determined to work closely with these communities to turn this situation around. This will mean developing different and more focussed ways of working with and communicating new messages and innovative services. It will also mean ensuring that the issue of health inequalities and cancer is addressed by Government and state agencies, as the urgent public health issue which it is.

Support for Cancer Survivors

The rising incidence of cancer is coupled with significant improvements in diagnosis and treatment. More people are living longer and the number of cancer survivors continues to grow. Nearly 100,000 people are now living with and beyond cancer in Ireland. Many, however, do not receive the longer term support they require.

International research and policy statements have clearly identified what constitutes effective post-treatment care and support. In Ireland there are still significant gaps. One third of people with cancer are known to experience significant distress and anxiety, yet few hospitals providing cancer treatment offer adequate psycho-oncology services⁴. The challenge is to consult survivors, design sustainable services to meet their needs and to advocate for their rights.

The mobilisation of survivors as advocates, supporting others and raising awareness, is a growing aspect of our work.



The economic crisis and its impact on our health services

The resilience of our health system is being tested by the current economic downturn and the need to make wide ranging, significant and on-going cuts in health spending. In addition, the structure of the health service is in a process of significant reform and changes are proposed which may affect how cancer care is delivered. During the lifetime of this Strategy, major reforms, including the introduction of universal health insurance and free GP care are proposed. We will closely monitor how the pressures resulting from less funding, as well as changes to key services, impact on cancer patients and the care they receive.

In addition, access to the full range of cancer drugs, including new drugs and treatments, has also emerged as a significant issue, particularly in the context of the debate about how best to manage resources.

In light of these changes and developments, maintaining good relationships with Government and relevant state agencies will be essential in order to make best use of reduced resources. Strong lines of communication, cooperation and collaboration will be necessary to deliver the best outcomes for people with cancer and their families.

We are also aware that in this climate of scarcer resources, it is incumbent upon us to ensure cost-effectiveness while continuing to meet our challenging goals.

The Society will continue to inform statutory policies in relation to cancer prevention, treatment and care, and to ensure that these policies are continually influenced by the voice and experience of people in Ireland affected by cancer.

Our Opportunity

Community Mobilisation

It is now recognised that health promotion is most productive through concrete and effective community action⁵. At the heart of successful health promotion is the empowerment of communities to own and control their own actions and results.

This approach will inform our mission to reduce the risk of preventable cancers. The Irish Cancer Society is determined to work closely with communities in order to empower them to adopt practices and take action aimed at reducing their risk of cancer.

Excellence in Cancer Research

Excellent cancer care results from high-quality cancer research. Since its foundation the Irish Cancer Society has promoted and extensively funded such research. In the current economic climate, strategic engagement in collaborative and innovative research both on a national and international level is essential.



Information and the Internet Revolution

The internet has revolutionised how people access information. The availability of reliable and accessible information on cancer is a key function of the Society. The delivery of our information mission, and our communication with people who have cancer and the general public, must continue to evolve to ensure that our messages are accessible through more online and web-based information sources, including social media.

Global connections

The Irish Cancer Society is part of a group of global alliances working towards a future without cancer and in the process, minimising its impact on people's lives. We share information and insights, provide leadership and support, and work in partnership and collaboration with other organisations throughout the world in a wide range of areas, including advocacy and communications, research and the development of support services.



Our Goals

The Irish Cancer Society will concentrate on four strategic goals over the lifetime of this strategy 2013 - 2017:

- 1 Goal One: **Reduce the risk of cancer**
- 2 Goal Two: **Improve lives**
- 3 Goal Three: **Lead excellent collaborative research**
- 4 Goal Four: **Inform and influence public policy**

Several strategic objectives are contained in each goal. We have also outlined how we intend to achieve our objectives. Each goal and its objectives are strongly interlinked with the others, and are not listed in any order of importance.



Goal One: Reduce the Risk of Cancer

Why this goal is important

Each year we know more and more about the causes of cancer. Some risk factors, such as a person's age and genetic make-up, cannot be changed. Others, such as tobacco use, an unhealthy diet, excess weight, physical inactivity, alcohol consumption and overexposure to the sun, can be avoided. A person's risk of developing some forms of cancer can be reduced by up to 50% through healthy lifestyle choices⁶.

We know that smoking is the single biggest cause of preventable death in Ireland, and that increased levels of physical inactivity, alcohol consumption and obesity add to the challenge of cancer prevention. The Irish Cancer Society intends to play its part in reversing these trends. In the next five years we are going to develop new programmes so that more people become aware of how they can reduce their risk of cancer.

To do this well, we want to help communities and individuals make positive changes. This is especially important for people from marginalised groups. Throughout Ireland people who live in these

communities have a higher incidence of cancer and poorer survival rates than those in higher socio-economic groups⁷.

The Society wants to close this gap. To do this, we are going to extend our reach into under-served and marginalised communities. We are going to work with other organisations and individuals to find effective ways of helping people to reduce their risk of cancer by adopting a healthier lifestyle.

To make this work the Society will need to find new ways of providing information and building relationships at local level. We plan to work with communities so that they can take ownership and control of their own health futures.

This new direction is going to be a significant challenge for the Society. It will take a lot of time, effort and investment. We are determined that it will result in more people having more chance to enjoy the healthy future that they deserve.

Our Strategy

- a. The Irish Cancer Society will develop and deliver evidence-based, high-impact cancer risk reduction programmes targeted at individuals, specific communities and the population as a whole. These will be informed by an assessment of our existing cancer prevention and health promotion activities.
- b. We will develop “Cancer Action Communities” as ground-up, collaborative, community-level projects designed for specific communities identified as being at high risk.
- c. We will grow partnerships and collaborations with other groups and organisations in order to ensure that our message about cancer risk reduction reaches as many people as possible.
- d. We will work to have fewer people start smoking and those who do smoke are enabled to quit.

Our Targets

- ▶ The establishment of “Cancer Action Communities” in two communities by 2014, to be rolled out following evaluation to two further communities in 2015 and two in 2016.
- ▶ The introduction of innovative, evidence-based cancer prevention programmes for targeted population groups in the area of smoking and lifestyle, including diet and physical activity, UV protection and alcohol, informed by independent qualitative and quantitative evaluation.
- ▶ The resourcing and support of communities to become smoke-free environments.
- ▶ A reduction in smoking prevalence nationally to 15% in adults and 7% in young people by 2017.

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Goal Two: Improve Lives



Why this goal is important

Cancer treatments continue to improve and change. Many people now receive treatment as outpatients. The outlook for people diagnosed with cancer is better than ever. The cancer experience can still be very difficult and confusing, however, both for people who have cancer, and for those who care for them. The Irish Cancer Society is determined to help to take the fear out of cancer by offering, high-quality, timely information that is easy to understand.

As well as information, people deserve to receive practical and emotional support. People who have cancer have different needs at different times. Long periods of treatment challenge the physical, financial and psychological resources of people who have cancer, their family and friends. People who become seriously ill at home need additional care and support⁸.

The longer-term needs of the increasing number of cancer survivors will challenge the health services over the coming years. Many survivors will still require regular medical care, and some will have continuing financial or rehabilitation needs, or mental health challenges. For some, a cancer diagnosis creates a fundamental shift in the way in which they live their lives. Research shows that one in four people diagnosed with cancer experiences significant distress, and needs more support than just information alone in this context. Psycho-oncology services in Ireland are very underdeveloped at present.

Over the next five years the Society will work to identify the gaps in post-treatment care and support, and will advocate for them to be filled. We will make sure that our services are relevant, meaningful and accessible to everyone.

Our Strategy

- a. The Irish Cancer Society will assess the impact and effectiveness of our own existing information, support and community services. This will allow us to develop and deliver targeted, evidence-based, high-impact and relevant services that meet identified needs in the most effective way.
- b. We will ensure that everyone gets appropriate and relevant information on cancer treatment and care to help them to make informed decisions.
- c. We will assess and draw attention to gaps in post-treatment care and support, and will identify the most effective ways of filling them. Where these relate to our own services, we will change them to meet the needs identified.
- d. We will promote the need for, and value of, easy and equitable access to psycho-oncology services.

Our Targets

- ▶ By the end of 2013 we will have identified the gaps in statutory services and follow-up care.
- ▶ We will advocate for supports and services to be provided by the Government and HSE which address the identified gaps in statutory services and follow-up care.
- ▶ By 2017 80% of people with a cancer diagnosis will be accessing the Irish Cancer Society's Cancer Information Service as a valued source of support.
- ▶ Informed by our assessment process, by 2017 we will have overhauled our information, support and community services, as required, to ensure their increased relevance and impact in meeting the identified needs of target populations.
- ▶ Where appropriate, the Society will pilot new services to provide evidence based programmes that will be evaluated and their outcomes published.

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Goal Three: Lead Excellent Collaborative Research



Why this goal is important

The Irish Cancer Society is the leading voluntary funder of cancer research in Ireland. Our credibility in this role is key to the development of innovative, high-impact research in this country.

In recent years research has improved knowledge about cancer biology, early detection, diagnosis and treatment, and has deepened understanding of the kinds of supportive care which enhance quality of life and advance survivorship.

The Irish Cancer Society believes that the quality of cancer care available in Ireland depends on the quality of cancer research taking place here. We support and fund leaders in cancer research so that people who get cancer in Ireland will have better access to new approaches to the diagnosis and management of their condition. We believe that this will lead to improved medical care and better outcomes.

A close relationship between research and clinical work is an important way of raising the standard of both. We support the concept of “clinician scientist” as a way of strengthening this relationship.

To get the best results, we intend to develop the most extensive possible collaboration among those involved in cancer research in Ireland. We believe that collaboration between institutions and across research disciplines can help to stimulate the kinds of excellent research which will improve the prevention and treatment of cancer in Ireland.

Research is also important in informing the work of the Society. We want to find out more about the quality of life and lived experience of cancer survivors in Ireland, so that their lives can be made easier, healthier and more secure.

Our Strategy

- a. The Irish Cancer Society will instigate and fund up to five Collaborative Cancer Research Centres by 2017.
- b. We will develop strong collaborative relationships with other organisations including the Health Research Board (HRB), Science Foundation Ireland (SFI) and ICORG.
- c. We will encourage and fund capacity building in research into survivorship and into health inequalities in cancer in Ireland.
- d. We will initiate research to inform the Society's programmes and direction.
- e. We will support clinician scientists and the career development of junior cancer researchers.

Our Targets

- ▶ The establishment of up to five Collaborative Cancer Research Centres by 2017, leading to a greater understanding of cancer patterns in Ireland and the development of strategies which can be tested clinically.
- ▶ The development of a Cancer Research Strategy for Ireland in consultation with other organisations, including the HRB, SFI and ICORG.
- ▶ The instigation of research to define and evaluate the factors that affect survivorship in cancer.
- ▶ The identification of clear guidance on how inequalities of access to prevention, screening and treatment in cancer can be resolved.

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Goal Four: Inform and Influence Public Policy



Why this goal is important

Public policy is as important as scientific discovery in determining outcomes for people affected by cancer. Every day, Government Departments and state agencies make important decisions about policies and resources that affect the lives and wellbeing of people who have cancer, survivors, families and caregivers, and everyone at risk of developing cancer. Advocacy is one of the Irish Cancer Society's most essential and powerful roles.

Being the informed voice of those affected by cancer is fundamental to who we are. The Irish Cancer Society is a not-for-profit organisation which receives less than 5% of its total income from state funds. Our independence, coupled with our ongoing contact with people affected by cancer, and with the nursing, research and medical professions, means that we can speak out in a credible and informed way. We seek to represent people affected by cancer, and to make sure that the people who shape cancer policy and provide statutory cancer services in Ireland hear their voice. We also lobby Government to introduce policy changes that can reduce cancer risk.

The Irish Cancer Society is determined to lessen the risk of getting cancer, and to improve the health, wellbeing and quality of life of those who have it. As advocates for people affected by cancer, we create a demand for these outcomes by offering leadership, shaping public opinion and influencing decision-makers. We hold Government and state agencies to account and work to maintain cancer as a public policy priority. We both challenge and work with policy-makers and legislators to influence decisions on patients' rights and healthy public policy, such as tobacco control and sunbed legislation.

We know that partnership can bring about better outcomes. Wherever relevant, we work in collaboration with other organisations and groups on health promotion initiatives aimed at reducing chronic diseases and cancer risk.

Our Strategy

- a. The Irish Cancer Society will hold the State to account in relation to its commitments under the current National Cancer Strategy and annual National Cancer Control Programme plans.
- b. We will inform and influence the development of a new National Cancer Strategy, paying increased attention to health inequalities, risk reduction and support for survivors.
- c. We will foster understanding at national policy level, and in Irish society in general, of the link between health inequalities and cancer risk.
- d. We will advocate for urgent and coordinated action to reduce smoking prevalence in Ireland.
- e. We will use relevant and influential communications channels and messages to harness maximum support at public policy level for the goals and objectives of the Society.

Our Targets

- ▶ The Irish Cancer Society's emphasis on cancer risk reduction, support for survivors and our recognition of the link between health inequalities and cancer risk, will be clearly visible in a new National Cancer Strategy.
- ▶ Our emphasis on the importance of setting specific measurable targets to reduce smoking prevalence, and of targeting smoking in disadvantaged communities, will be clearly visible in a new Tobacco Control Strategy.
- ▶ There will be widespread public recognition of the link between health inequalities and cancer, and the need to take action at a personal, community and societal level to reduce the risk and prevalence of cancer in Ireland. This will result from the work of a coalition of interest led by the Irish Cancer Society and informed by research into the link between disease and health inequalities in Ireland.

How We Will Achieve These Goals

The four goals outlined in this strategy statement comprise the Society's far-reaching ambition for 2013-2017. To support the achievement of these goals, we have identified four enabling objectives. By working on these we can maximise the organisation's capacity to deliver the outcomes that people affected by cancer deserve:

- ▶ We will ensure that the Irish Cancer Society is an adaptable, flexible and innovative organisation, equipped with robust corporate governance, management controls and financial controls that will help us to achieve the highest standards of transparency and accountability with maximum cost-effectiveness.
- ▶ This strategy statement will be a living document that guides all our activities until 2017. We will revisit it regularly to ensure that it remains relevant and effective in the context of the economic crisis and changes in the environment for cancer care and control. The strategy may change according to circumstances.
- ▶ We will strengthen our organisational structures and practices, encouraging the continued training and development of staff and optimising the deployment of our resources.
- ▶ We will develop and implement an annual fundraising programme to generate sufficient income to support the Irish Cancer Society's strategic goals. All fundraising activities will be informed by the Statement of Guiding Principles for Fundraising and will be compliant with the Charities Act, 2009. We will investigate new funding sources both within and outside Ireland, with an emphasis on sustainable funding.

What We Do

This strategy statement outlines a set of ambitious initiatives to be implemented in the next few years. At the same time however, we will continue to provide our established and highly valued programmes and services. These are set out below.

Prevention and early detection

- ▶ Awareness-raising initiatives aimed at behavioural change, for example Xhale, which engages young people in projects about the dangers of smoking.
- ▶ National Smokers' Quitline. Callsave 1850 201 203.
- ▶ Public awareness campaigns, up-to-date information leaflets and booklets for hospitals, GPs and communities throughout the country.
- ▶ Physical activity programmes aimed at reducing the risk of getting cancer, and the risk of recurrence for cancer survivors.
- ▶ Community Health Education Programme (CHEP), training community volunteers to make presentations on cancer prevention.

Support services

- ▶ Cancer information services, comprising the National Cancer Helpline Freefone 1800 200 700, online and walk-in support.
- ▶ Hospital-based information and support services, specifically Daffodil Centres.
- ▶ Night nursing care for people with terminal cancer in their homes.
- ▶ Survivors Supporting Survivors, through which volunteers with first-hand experience of cancer meet or talk on the phone with people affected by cancer.
- ▶ Patient support groups at local level.
- ▶ Professional counselling.
- ▶ Care to Drive, assisting people who have cancer to attend their hospital appointments.
- ▶ Financial assistance.

Research

- ▶ Research into the causes of cancer and clinical trial support.
- ▶ Provision of fellowships and scholarships.
- ▶ Development of cancer research strategies.

Advocacy

- ▶ Lobbying and influencing Government and other decision-makers on cancer-related issues.
- ▶ Maintaining communication with and, as appropriate, working in partnership with key agencies, including the Health Services Executive, the National Cancer Control Programme and the National Cancer Screening Service.
- ▶ Development of policy responses to cancer-related issues.
- ▶ National and international collaboration in the area of cancer and tobacco.
- ▶ Development of an advocacy network.

Fundraising

- ▶ Providing thousands of volunteers, supporters and companies' with different ways for them to donate their time, money and energy, which each year delivers over 95% of our income.
- ▶ Daffodil Day, the country's biggest fun fundraising event where communities, companies and individuals throughout Ireland mobilise to raise funds to fund our services and our cancer research projects.
- ▶ Innovative campaigns where people committed to our work can get involved, raise funds and make a difference – Shave or Dye, Movember, Gethegirls.ie, Relay For Life, Run4Life, Run Walk & Roll.
- ▶ Fundraising with thousands of individuals and local groups to deliver local fundraising events from cake sales to nationwide events, all raising funds to support our work.
- ▶ Partnering with companies to deliver innovative Corporate Social Responsibility programmes that make a real difference to communities and people affected by cancer and help realise cancer research breakthroughs.

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