National
Cancer
Registry
Ireland

National Cancer Registry Ireland

Strategic Plan 2024 -2026

Contents

Foreword from the Chair of the Board

The National Cancer Registry is the key organisation in understanding cancer incidence, prevalence and survival rates in Ireland, reflecting demographic changes and new diagnostic and treatment options. Over three decades the Registry has grown and evolved, working with hospitals, academia, the voluntary sector and other organisations involved in the care of people with cancer. It's reports and research output are recognised as world class by international peer organisations.

The development of this Strategic Plan was an important project for the organisation and I am sincerely grateful to each of the many stakeholders who contributed to the process. The positive response is hugely encouraging for the future and the values and strategic objectives clearly reflect the needs and priorities of the stakeholder groups.

A renewed focus on collaborative research is already evident, with recruitment to the Research Lead role underway and a new research strategy and multiyear publication plan due in the coming months. The other area of accelerated change, prompted by the recent pandemic, is in digital health, with remote access to a large proportion of hospital information systems now in place. This will increase in the near and medium term, with the goal of automated, real time data feeds to the Registry and faster reporting by the Registry.

On behalf of the Board I wish to thank the Registry management and staff for their work on the Strategic Plan and to reiterate the support of the Board in implementing its objectives over the next three years.

J. Coffey

Dr Jerome Coffey, Chairperson

1. Introduction by Director

Welcome to our Strategic Plan as we continue to advance cancer control through comprehensive data collection, analysis and collaboration. Our ambition is to build on the foundation of remarkable progress made in cancer detection, prevention, and treatment over the past decades, to help make an even greater impact. Our knowledge-based workforce will leverage advancements in digital technologies and foster collaboration among policymakers, healthcare providers, researchers, and stakeholders to drive positive change in cancer control.

Recognising and acknowledging the evolving landscape of technology and research, the National Cancer Registry Ireland's (NCRI's) strategy is designed to be agile and anticipatory. There have been many advances in medical research and technology in recent years, along with an increased focus on public health. As survival improves, an increasing number of people are living in Ireland with or beyond cancer.

NCRI plays a crucial role in monitoring and understanding the patterns of cancer incidence, prevalence, and outcomes. We also facilitate monitoring and evaluation of the impact of cancer control measures such as screening programmes. Additionally, we support research, resource allocation, and policymaking in the field of cancer control, contributing to improved patient outcomes and reduced cancer burden. Data are collected from multiple sources with NCRI processes ensuring these diverse data sources are merged and aggregated to ensure all cancer cases are fully and accurately captured.

The NCRI provides policymakers with vital information to develop evidence-based policies, target interventions, evaluate their impact, and allocate resources efficiently. To achieve this, data completeness, accuracy and timeliness are critical aspects. We continue to embrace technological advancements to improve the cancer registration processes. Over the last two decades, there have been significant advances in technology, with the pace of change in this sector transformative. Personal computers (PCs), laptops, and smartphones have become part of the fabric of daily life, with internet transforming communication and business operations. For the NCRI, this has changed how data are collected and processed. With ever increasing levels of connectivity, data collection has transited from predominately physical charts to predominantly digital systems, often accessed remotely. Digital transformation continues, with the introduction of electronic health records (EHRs), which will further improve the interoperability of data and sharing of information from and among healthcare providers.

This Strategy aims to position the NCRI so that we continue to be the trusted source of cancer data, cancer research and analysis in Ireland. We will continue to provide important insights on the current health status of the Irish population and will keep abreast of the many changes in cancer care and delivery, ultimately contributing to improved patient outcomes and enhancing cancer control.

Deirdre Murray

Deirdre Murray, Director, National Cancer Registry Ireland

2. Our Vision, Mission & Values

OUR VISION

Excellent data insights for better cancer outcomes

OUR MISSION

To collect, analyse and disseminate comprehensive information to improve cancer outcomes

Our Values

RESPECT

We treat everyone with dignity of respect

TRUST

We honour our commitments

COLLABORATION

We work collabotatively with all our stakeholders

ENTHUSIASM

We are passionate about and take great pride in our work

QUALITY

We are committed to continuous quality improvement

CONFIDENTIALITY

We treat all our patient information with the highest level of data security

3. Context

What we do

National
Cancer
Registry
Ireland

- Collect, classify, record and store information about individual cancers diagnosed in Ireland
- Identify, collect, classify, record, store and analyse information about the incidence and prevalence of cancer in the population
- Promote and facilitate the use of this information for research and for the planning and management of cancer services
- Advise and inform the Minister for Health about the Registry's activities
- Publish an annual report about cancer registration in Ireland

Registered tumours per year

41,767
in 2020

20,500
in 1994

9,621
Deaths per year

Invasive cancers per year
*excl NMSC

24,424
in 2020

11,900
in 1994

Population growth

1994
3.6M

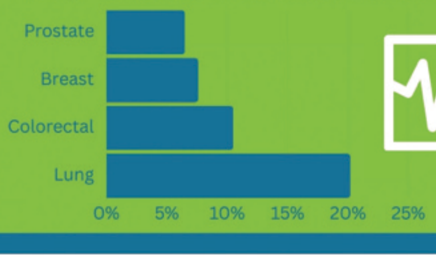
5M
2023

Life expectancy at birth

73.0 in 1996
80.8 in 2020

78.5 in 1996
84.4 in 2020

Top causes of cancer death



65%
5-year net survival (2014-2018)

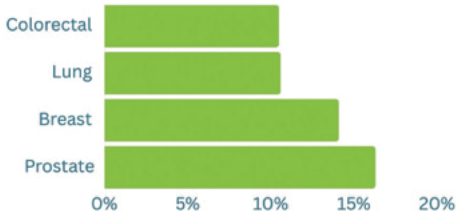
>50%
increase in cancer survivors vs a decade ago

Most common invasive cancers
*excl NMSC

Prostate
Breast
Lung
Colorectal

1 in 2
Lifetime risk of developing cancer
*excl NMSC

Ranking & Percentages



91%
% of tumours created electronically

Our operating environment

Cancer is a major public health issue in Ireland and the incidence is predicted to increase nationally and globally. As the Irish population grows and ages, the number of people diagnosed with invasive cancer every year is expected to increase by at least 50% from 21,700 in 2015 to over 32,000 by 2045[1]. Improvements in the management of cardiovascular disease have resulted in cancer now becoming the leading cause of death in adults in Ireland, though Irish death rates in cancer have declined over the last decade.[2]

As we embark on implementation of our cancer registry's strategy, we recognise the ever-evolving ecosystem that is the Irish health system. The anticipated advances in digital health systems are pivotal to this strategy. The implementation and integration of these digital systems are essential, with many of our objectives contingent on this. We are also cognisant of the changing landscape of cancer control, with increasing numbers of diagnosis and survivorship. NCRI has been instrumental in collecting and analysing valuable data, providing insights that have guided interventions and improved patient outcomes. Building upon this foundation and anticipating digital health advancements, our strategy aims to further enhance our data collection methods, strengthen collaborations, and leverage advanced analytics to drive evidence-based decision-making. By doing so, we will continue to play a vital role in shaping the future of cancer control, ultimately making a positive impact on the lives of those affected by cancer.

Aligned with digital advancement, the success of this strategy depends on securing adequate funding and resources to deliver on the ambitious programme set out for NCRI to develop and enhance strong partnerships and collaborations with healthcare providers and institutions. It will be underpinned by continuing to ensure data privacy and security compliance, by the implementation of robust data collection and management systems, by training and retaining skilled staff, promoting data sharing and data linkages across different healthcare systems and providers, and having supportive policies and regulations in place. Additionally, stakeholder engagement, public awareness, and ongoing evaluation and quality assurance are important factors for the successful implementation of this strategy.

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[1] National Cancer Registry (2019) Cancer incidence projections for Ireland 2020-2045

[2] Health in Ireland Key Trends 2022 - https://www.gov.ie/en/publication/fdc2a-health-in-ireland-key-trends-2022/

4

Strategic Objectives

4. Strategic Objectives

The strategy has five key objectives, and each objective sets out key actions through which the strategic objective will be delivered. Stakeholders referenced throughout include patients, people affected by cancer, policymakers, health service providers and researchers.

01 Capture a comprehensive picture of the patient cancer journey.

02 Be the independent, expert and trusted source of cancer data and trends.

03 Enhance research capabilities and develop vibrant and collaborative research networks in Ireland and internationally.

04 Be at the forefront of informing health information regulation and in the deployment of Digital Health Initiatives.

05 Enhance organisational capabilities through investment and strengthened governance.

01 Capture a comprehensive picture of the patient cancer journey.

Actions

1.1 Pro-actively identify current data needs and future data priorities to meet mandatory requirements and stakeholder needs in line with international cancer registry standards and emerging cancer diagnosis and care.

1.2 Build on current rapid datasets and enhance the speed, accessibility and functioning for data health service providers, policy makers, researchers, and people affected by cancer.

1.3 Conduct a gap analysis to identify the dataset needed to capture the full patient journey from initial diagnosis and treatment through to living with and beyond cancer.

1.4 Take a dynamic and adaptive data collection approach to enhance data capture of the patient journey, cancer surveillance and be responsive to evolving trends, cancer diagnosis and care.

1.5 Utilise forthcoming advances in hospital information systems to expand NCRI electronic capture and enhance automated collection from information sources with linkage, staging and quality assurance completed by the NCRI.

What this objective is about:

This objective seeks to collect data about the full patient journey, capturing data relating to diagnosis, staging and treatments. Since the establishment of the NCRI in 1991, the diagnosis and treatment of cancer has changed significantly, leading to larger volumes of more complex data. In addition, there has been a significant increase in the population and a change in its age profile. These trends are expected to continue, resulting in changing needs and expectations of key stakeholders, including those affected by cancer.

As Irish health information systems evolve and hospitals adopt electronic health records, we aim to enhance our electronic capture and move to a more streamlined, less manpower intensive data collection approach, where diagnosis and treatment information is sent to the Registry by hospitals, allowing us to focus our expertise on processing, quality assurance and analysis. This will ensure that current datasets will continue to be collected for long term trends and new datasets associated with the full patient journey from initial diagnosis and treatment through to living with cancer can be collected. Moving to a more automated collection process will allow the NCRI resources to focus more on data quality, analysis, surveillance and cancer trends and less on the administrative burden of collecting data.

What success looks like:

01 Capture a comprehensive picture of the patient cancer journey.	2024	2025	2026
Gap analysis identifying additional fields to be collected	■	□	□
Incorporate additional fields	□■	■	■
A full review of current data collection processes	■	□	□
Incorporate additional streamlining of data collection	□■	■	■
Process to deliver additional rapid datasets	■	□	□
Additional rapid datasets	□■	■	■

02 Be the independent, expert and trusted source of cancer data and trends.

Actions

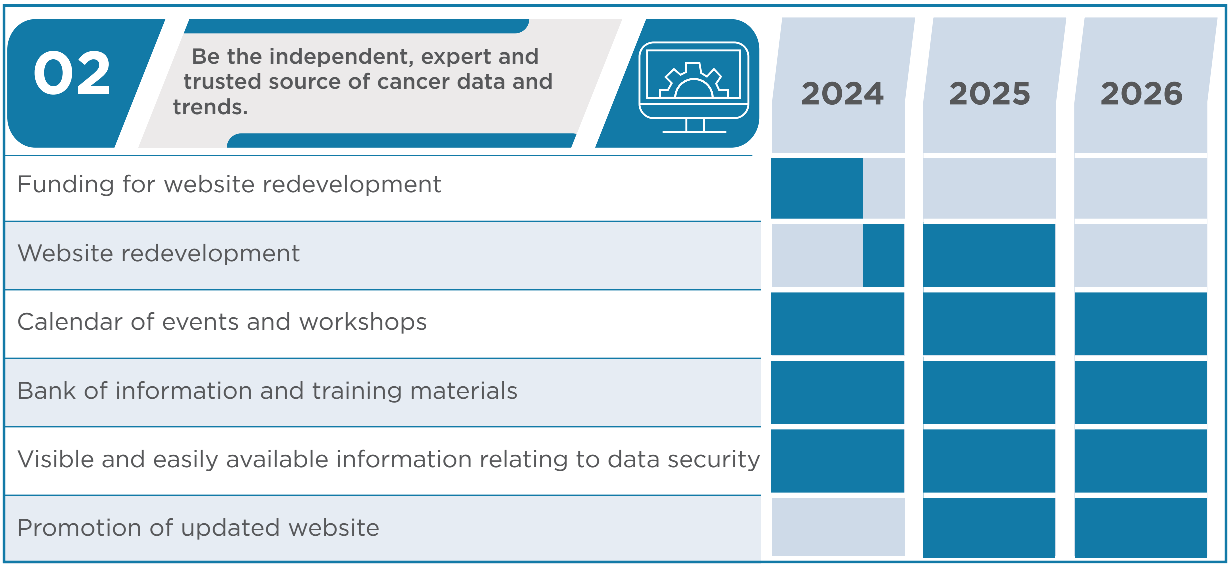
2.1	Build on and enhance NCRI's reputation as the independent trusted repository of cancer data and information, trends and projections in Ireland.
2.2	Develop and maintain a calendar of events and workshops showcasing the activities, data and research of NCRI to specific stakeholders to strengthen the reputation of NCRI and build strong relationships and collaborations through better engagement and understanding.
2.3	Continue to implement and improve the strategy for communicating with people affected by cancer, stakeholders and collaborators, on cancer trends and data.
2.4	Outline and communicate the data protection and security protocols NCRI has in place to protect and maintain the security and safety of sensitive data.
2.5	Update NCRI's website to make information easily available, communicate trusted cancer data to the public in plain English, promote Patient & Public Involvement (PPI), to increase engagement and increase accessibility for target groups, i.e. clinicians, researchers, media & public.
2.6	Develop a bank of information and training materials for use in educational programmes focused on data types, usage and awareness which can be used to communicate and inform different stakeholders including healthcare professionals, people affected by cancer and their families and policy makers.

What this objective is about:

With this objective, we seek to enhance our role as the independent, expert and trusted resource on cancer data and trends in Ireland, for the public, those affected by cancer, clinicians, researchers, policy makers and other key stakeholders.

In the lifetime of this strategy, we aim to increase communication with our stakeholders, showcasing our work and providing information and materials for use by academics, clinicians, researchers, media, and the public. The data processed and stored by the NCRI are of a highly sensitive nature and a key part of this objective is to communicate and assure that we safeguard and secure these data with the highest of standards in data protection and security protocols.

What success looks like:



02 Be the independent, expert and trusted source of cancer data and trends.	2024	2025	2026
Funding for website redevelopment	■□	□	□
Website redevelopment	□■	■	□
Calendar of events and workshops	■	■	■
Bank of information and training materials	■	■	■
Visible and easily available information relating to data security	■	■	■
Promotion of updated website	□	■	■

03

Enhance research capabilities and develop vibrant and collaborative research networks in Ireland and internationally.

Actions

3.1 Set out NCRI's research strategy, including engagement with key researchers, working on collaborative projects, and supporting data and information sharing to enhance cancer research in Ireland and internationally.

3.2 Engage with users and stakeholders to identify areas for improvement, and then develop and implement a stream-lined and user-friendly online platform for requesting and accessing datasets.

3.3 Engage with Researchers, Oncology professionals, Health Service Executive (HSE), Department of Health and other relevant organisations on future projections of cancer numbers, treatments, advances and economics.

3.4 Engage and collaborate with key agencies involved in cancer research, drug/treatment development, and clinical trials, to link and integrate data from genetics, genomics, proteomics and other emerging treatment developments.

3.5 Conduct refreshed research providing an evaluation of data quality, including comparability, completeness, validity and timeliness, to inform discussions on operations and future dataset capture.

3.6 Investigate the feasibility of capturing quality of life data, such as incorporating patient-reported outcome measures (PROMs) into data collection processes.

What this objective is about:

This objective aims to optimise our research function, increasing collaboration at a national and an international level, and increasing our number of research projects carried out annually. As part of our stakeholder engagement approach, we will enhance engagement with those requesting data not readily available from the website. This dialogue will ensure that the optimal dataset is made available to the researcher / requester.

What success looks like:

03 **Enhance research capabilities and develop vibrant and collaborative research networks in Ireland and internationally.**	**2024**	**2025**	**2026**
NCRI research strategy	■	■	■
Expand stakeholder engagement strategy to include research and academic stakeholder engagement	■	□	□
Engagement and collaboration	■	■	■
Data quality framework	□	■	□
Feasibility review of capture of quality of life indicators	□	□	■

04

Be at the forefront of informing health information regulation and in the deployment of Digital Health Initiatives.

Actions

4.1 Proactively engage with and input into the Health Information Bill to inform current and future data gathering, processing and sharing requirements.

4.2 Review and align the Registry's future business requirements with the emerging Digital Health & Social Care Strategic Framework and establish how technology and digital health can best support NCRI into the future.

4.3 Identify pathways to utilise digital health to help automate the Registry's data collection, processing and validation into the future, ensuring it can handle larger and more complex volumes of data.

4.4 Engage with the major hospitals to agree on a standardised template and approach for data summaries to be delivered back to the institutions to support benchmarking and collaboration and to inform the future provision and automation of data from the hospitals.

4.5 Continually assess and update, as appropriate, measures to ensure the highest level of NCRI's data protection and security.

4.6 Working with the Department of Health and the HSE, progress advances in electronic and automated data capture and intelligent data processing. Support the rapid adoption of the Individual Health Identifier at the NCRI and by those providing data to the NCRI.

What this objective is about:

Over the coming years the Irish Health System will undergo a profound change in the way that health information is shared, managed and used, with the advancement of the Health Information Bill 2023, and the Digital Health and Social Care Strategic Framework. The Health Information Bill provides the legislative framework for a modern national health information system and the collection, use and sharing of health information both for care and treatment and wider health service goals.

NCRI has expertise in these areas, gleaned from many years of collecting, processing, storing, securing, analysing, and sharing sensitive data. This expertise places the NCRI as a thought leader, shaping legislation and steering the successful implementation of these legislative changes.

We will work with the Department of Health, HSE, National Cancer Control Programme (NCCP) and major hospitals to put in place standardised templates for data sharing, data collection, automated data capture and intelligent data processing to ensure the management of larger and more complex forms of data.

What success looks like:

04 Be at the forefront of informing health information regulation and in the deployment of Digital Health Initiatives.	2024	2025	2026
Validation of NCRI's data protection and security measures	🟩	🟩	🟩
NCRI taking a leading role in shaping systems and processes	🟩	🟩	🟩
NCRI's plans and actions aligned with new initiatives in Digital Health	🟩	🟩	🟩
Standard templates for data transfer agreed with stakeholders	🟩		
NCRI's expertise utilised in the utilisation of the Health Information Bill processes		🟩	🟩
Blueprint for NCRI's future technical landscape			🟩

05

Enhance organisational capabilities through investment and strengthened governance.

Actions

5.1 Continue developing organisational structures to ensure strong leadership, accountability and transparency, in managing all aspects of operations.

5.2 Promote gender balance, diversity and inclusion throughout the organisation.

5.3 Continue to develop staff skills and competencies.

5.4 Implement environmentally friendly practices aiming to reduce carbon footprint while maintaining data integrity and accessibility.

5.5 Focus on the strategic development of the HR function in support of the delivery of current and future plans.

5.6 Enhance the internal communication programme to support staff in understanding the work and functions of departments and keep up to date on changes and workflows in each area.

5.7 Investment in systems, technologies, and the necessary infrastructure to support operations and strategic goals.

What this objective is about:

This objective ensures we maintain a focus on continuously improving the capability, skillsets and effectiveness of the organisation by investing in resources, such as technology and training, and implementing stronger governance practices to ensure efficient decision-making and accountability.

In addition, maintaining the positive collaborative culture is essential, requiring a focus on positive work practices, communication, and staff development, thereby ensuring that the skillsets are available to meet the future needs of NCRI and our stakeholders.

What success looks like:

05 Enhance organisational capabilities through investment and strengthened governance.	2024	2025	2026
NCRI as an employer of choice	■	■	■
Monitoring delivery of and communicating NCRI strategy	■	■	■
Refreshed Governance Framework and Customer Charter	■		
People and Performance Strategy	■		
Learning and Development Organisation		■	■
Open and collaborative culture			■

5. Key Enablers

This strategic plan builds on the solid foundations of the past three decades. The key enablers to deliver on our vision are the people, resources, structures, systems, and culture. These areas require ongoing attention and investment to deliver to our vision, mission, and strategic goals in an effective and efficient manner.

01 People:

We are committed to continuing to cultivate a supportive and encouraging work environment where our people can thrive. The successful implementation of the strategic plan will involve the Board and staff working collaboratively, both internally and externally. It will also include involving all staff in target delivery, expanding employee skills through training and recruitment, further developing departments such as Research & Analysis and HR, bringing in additional expertise, and continuing to receive support from the Department of Health. This will be underpinned by adopting new technologies and change practices.

02 Resources:

We rely on ongoing support from the Department of Health to fulfil our mandate and deliver our strategy. In addition to people development, we will invest in the continuous improvement of data systems, technology, and IT infrastructure. An upgraded website will play a pivotal role as a communication and collaboration tool. We will also focus on the development of education programs, communications, digital assets, collaborations and research partnerships. In addition, a strategic allocation of staff and Board time is planned to ensure the delivery of our strategic goals.

03 Structures:

The NCRI's structure ensures effective authority and oversight of the strategic plan, fostering open communication with staff. The structures will continue to adapt within a Governance Framework encompassing data protection, quality assurance, risk management, and accountability.

The NCRI Board oversees the Strategic Plan and receives updates regularly. Management reviews progress monthly and at annual planning and evaluation days. We are dedicated to improving structures such as data requests, project task groups, cross-departmental working groups, data quality forums, and research partnerships.

04 Systems:

NCRI maintains robust and secure centralised systems for data storage, supported by our IT infrastructure and other organisational systems. In a fast changing and increasingly complex environment, we prioritise continuous improvement through digital advancements, automation, and streamlining. This strategic plan requires continued investment in various areas, including analysis and reporting tools, data standardisation and dataset generation, communications and content creation, HR integration systems, website and other collaboration platforms, stakeholder engagement, feedback, and evaluation systems, QA systems, research funding and grant management, and tracking resource utilisation and "green" procurement systems.

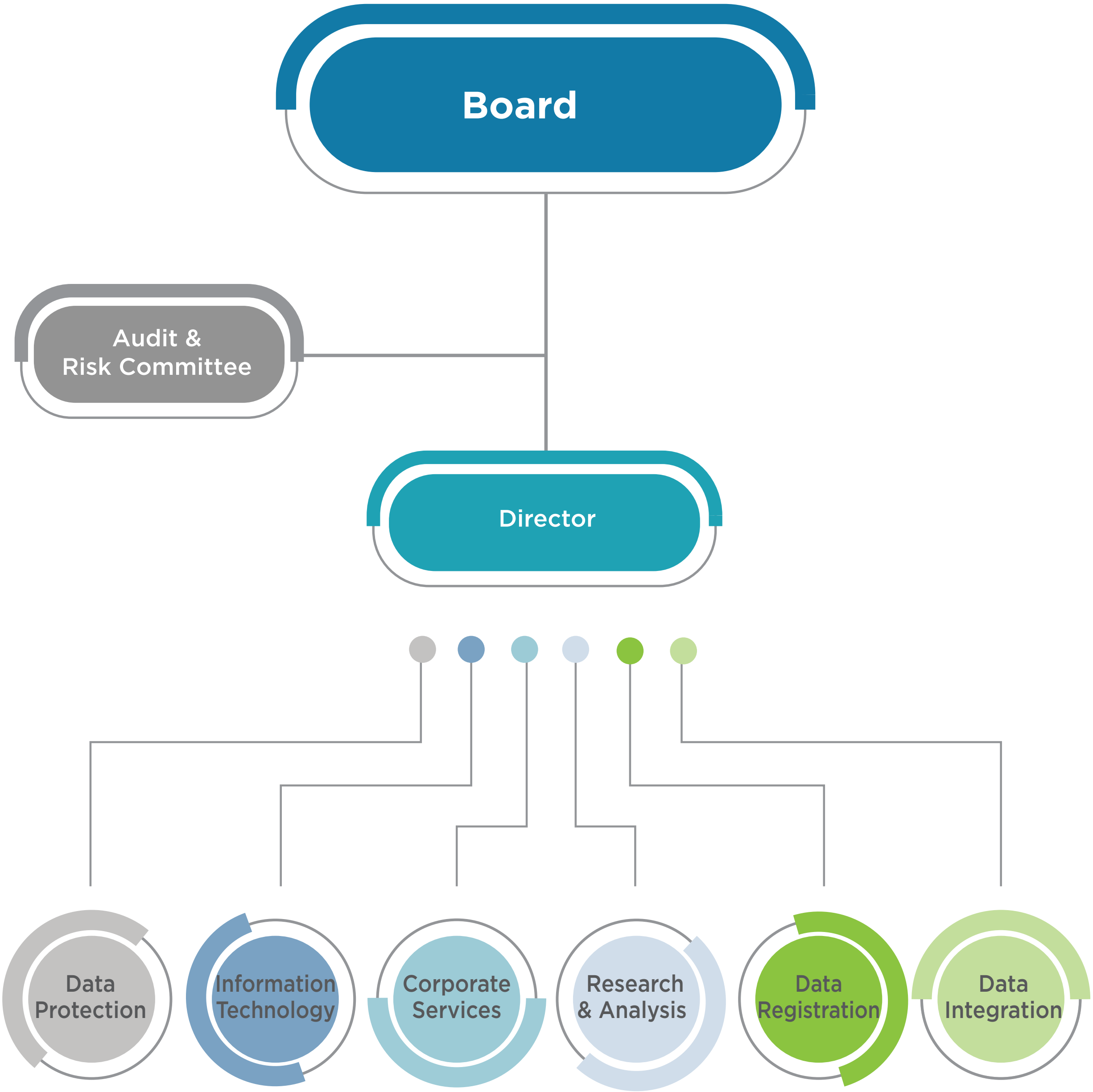
05 Culture:

Our culture at NCRI is guided by our values and aims to deliver on our organisation's vision of *"Excellent data insights for better cancer outcomes"*. We foster a collaborative and inclusive environment that promotes openness, transparency, innovation, continuous improvement, and continuous learning. We are committed to supporting cancer services, research, data privacy awareness, scientific and data-driven decision making, compliance, and accountability.

6. Overview of the NCRI

Establishment

The National Cancer Registry Board was established by Statutory Order 19 of 1991, "The National Cancer Registry Board (Establishment) Order" under the Health (Corporate Bodies) Act, 1961. The Board discharges all its statutory responsibilities through the National Cancer Registry. The Order was amended twice; in 1996 by S.I. No. 293/1996 (The National Cancer Registry Board (Establishment) Order, 1991 (Amendment) Order) and in 2009 by the Health (Miscellaneous Provisions) Act 2009.



Governance

As a State Body, our governance arrangements are set out in the Code of Practice for the Governance of State Bodies (2016). The responsibility for governance is with the Board of the NCRI, which is appointed by the Minister for Health and comprises a chairperson and six ordinary members. There is one sub-committee of the Board: - the Audit and Risk Committee. The regular day-to-day management, control and direction of the NCRI are the responsibility of the Director and the senior management team, with clear delineation of roles and responsibilities between each.

The National Cancer Registry (NCRI) is a population-based register and operates under a statutory order to collate cancer data from all Irish hospitals since 1994. Health policy makers in Ireland have developed a number of cancer strategies (1996, 2006, 2017) over the decades, the current being the National Cancer Strategy 2017 – 2026[3] to address this public health challenge. In 2007, the National Cancer Control Programme (NCCP) was established to implement the National Cancer Strategy, reduce the incidence of cancer, reduce cancer morbidity and mortality and improve the quality of life for people living with cancer.

The NCRI has supported the development of these strategies by setting the scene, describing the trends in cancer incidence, mortality and survival in Ireland. Its rich database has assisted researchers to devise new ways to improve patient outcomes, enhancing cancer prevention, early diagnosis and treatment. Reducing cancer incidence and deaths and improving patient survival are also core indicators of cancer control and the NCRI supports the NCCP, National Screening Service and other health service providers to monitor their progress against these cancer control objectives.

Annual Business Plans

We prepare our Annual Business / Service Plan following a process of engagement with the Senior Managers to set “SMART” targets (Specific, Measurable, Achievable, Relevant, Time-bound) and establish agreed-upon milestones to track progress, aligned to our strategic goals. The plan includes key initiatives, resource allocation, and timelines to ensure the NCRI’s objectives are met effectively and efficiently. It is then approved by the NCRI Board and presented to the Department of Health for their consideration and approval.

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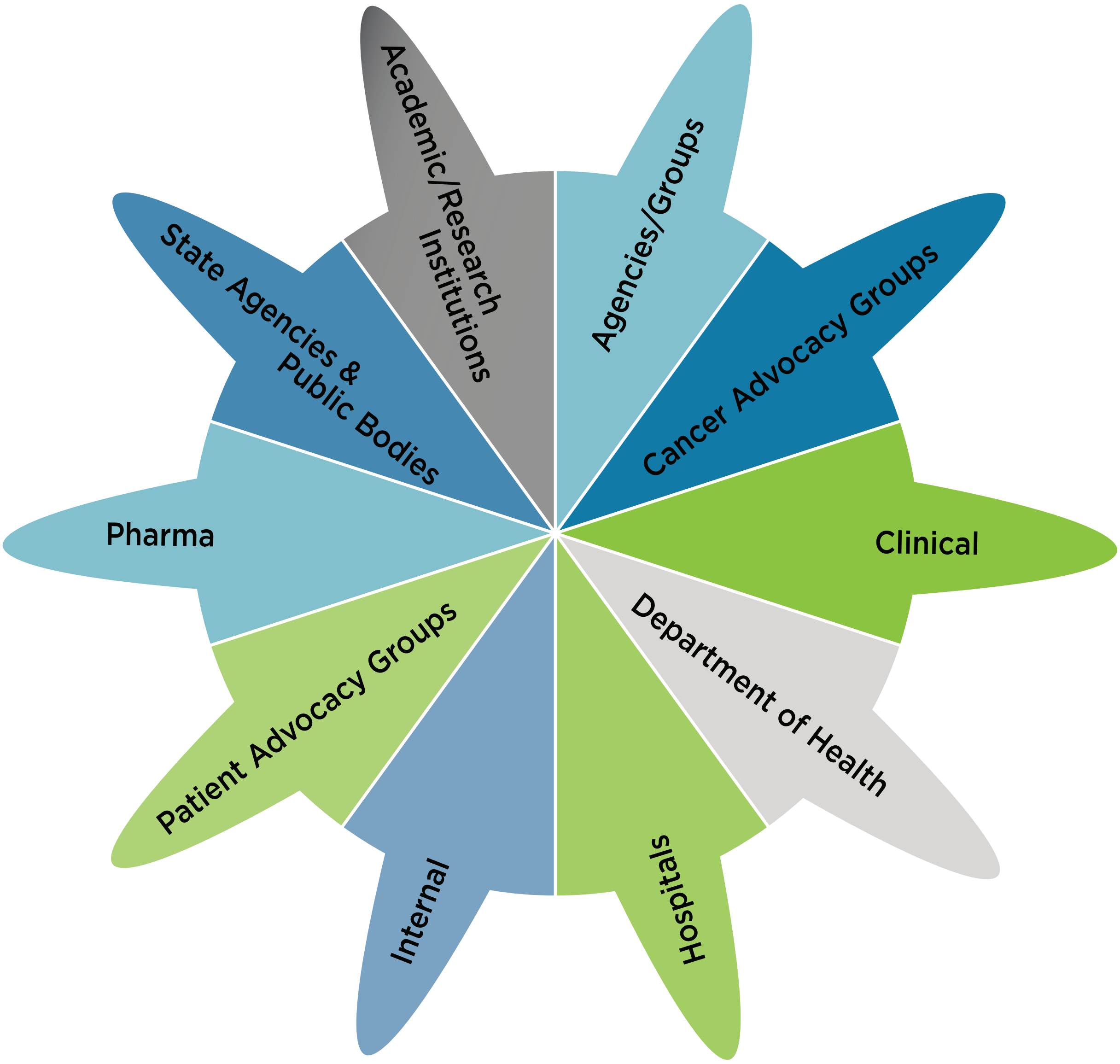
[3] National Cancer strategy 2017 -2026
https://www.gov.ie/en/publication/a89819-national-cancer-strategy-2017-2026

7. NCRI Strategic Plan Development

To provide the best service, we engaged extensively with stakeholders through interviews, workshops, and surveys. We also assessed the external environment using a PESTLE methodology to understand factors influencing the organization. The feedback from stakeholders and the review of past successes informed the development of our strategic plan.

Stakeholder Engagement



Stakeholder Group	Stakeholder
Academic/Research Institutions	All-Island Cancer Research Institute (AICRI)
	Health Research Board (HRB)
	Royal College of Surgeons in Ireland (RCSI)
	Science Foundation Ireland (SFI)
	University College Cork (UCC)
Agencies/Groups	Belgian Cancer Registry
	International Cancer Benchmarking Partnership (ICBP)
	Irish Society of Medical Oncology (ISMO)
	National Centre for Pharmacoeconomics (NCPE)
	Netherlands Cancer Registry
	Northern Ireland Cancer Registry (NICR)
	Royal College of Physicians in Ireland (RCPI)
Cancer Advocacy Groups	Breakthrough Cancer
	Childhood Cancer Charities
	Irish Cancer Society (ICS)
	Marie Keating Foundation
Clinical	Association of Oncology Nursing
	Cancer Trials Ireland
	Oncologists Group
Department of Health	Cancer Policy Unit
	Health Analytics
	Healthy Ireland
	Population Health
	Primary Care
	Research Services & Policy
	Sláintecare
Hospitals	Beaumont Hospital
	Cork University Hospital
	Children’s Health Ireland (CHI), Crumlin
	St James’s Hospital
	St. Vincent’s University Hospital
	The Mater Hospital
	University Hospital Galway
	University Hospital Limerick
	University Hospital Waterford

Stakeholder Group	Stakeholder
Internal	Advisory Council
	Auditors
	Board
	Staff
Patient Advocacy Groups	Cancer Trials Ireland
	Irish Health Research Forum
	Irish Hospice Foundation
	Patient Voice in Cancer
	PPI Ignite
Pharma	Irish Pharmaceutical Health Care Association
State Agencies & Public Bodies	Central Statistics Office (CSO)
	Chief Information Officer, HSE
	Chief Clinical Information Officer, HSE
	Chief Clinical Officer, HSE
	Digital Project Teams, HSE
	Genetics and Genomics Office, HSE
	Health Information and Quality Authority (HIQA)
	National Office of Clinical Audit (NOCA)
	National Health Information Unit (NHIU)
	Private Hospitals Association

Table 1 Stakeholder Engagement

Notes

Notes

Building 6800
Cork Airport Business Park
Kinsale Road Cork
Ireland
+353 21 4318014

www.ncri.ie
info@ncri.ie