



Strategic Plan 2020-22

September 2020

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1 Foreword from the Chair of the Board



This Strategic Plan has been developed during a time of significant change for Ireland's public health policy, and the size and age profile of our population. Research, organisation and investment have resulted in better patient care and outcomes.

The National Cancer Registry plays a key role in the national response to this changing landscape through its core functions and activities of recording data and providing insights to inform the planning of healthcare services to deliver cancer prevention,

diagnosis, treatment and follow-up.

The people of Ireland expect world-class public health and cancer services. This document has been developed to contribute at both a system and organisational level to the development of these services, within a policy and economic environment greatly influenced by the current pandemic.

It is substantially driven by the goals and objectives of the National Cancer Strategy 2017 – 2026, as well as the obligation to implement the recommendations of the Report of the Scoping Inquiry into the CervicalCheck Programme and international best practice in cancer registration.

This is also a time of change and evolution within the Registry itself. Having achieved a great deal in recent years, this plan outlines what the National Cancer Registry intends to deliver within the next three years as a world-class public health agency and cancer registry.

A handwritten signature in black ink, appearing to read 'J. Coffey'.

Dr Jerome Coffey

Chair of the National Cancer Registry Ireland Board

2 Introduction from the Director



In 2018 the National Cancer Registry Ireland celebrated its 25th year collecting data on cancer patients in Ireland. This Strategic Plan 2020 – 2022 builds on the solid foundations of the Registry since its establishment and sets out our ambition for the Registry to evolve and grow for the future.

The period encompassed by this critical planning document will be a challenging one for the organisation in terms of our internal organisational growth and the external environment we operate within. Our plan and ambition during this time is to ensure that our own systems and capacity grow at a rate and scale that supports our technical and scientific objectives to improve the collection, aggregation, abstraction and interpretation of cancer data and the dissemination of meaningful and useful information about cancer in Ireland to support the delivery of cancer services for patients in Ireland.

There will be structural and operational changes within the Registry to support this plan. We will be asserting the statutory basis for Registry activities while working distinctly between supporting research and providing insights for service planning. We will be keenly focused on capturing cancer patient data beyond diagnosis into survivorship within a changing population.

These are welcome challenges which we are confident of addressing within the scope of this plan. This plan has been prepared following collaboration and consultation with our stakeholders, information recipients and our own staff. The priorities and goals herein reflect growing expectations from the health service and wider public and also honest questions about the nature and role of a modern cancer registry.

It will be an exciting period for the National Cancer Registry Ireland and we look forward to achieving success within this strategic planning cycle.

A handwritten signature in blue ink that reads "Kerri M. Clough". The signature is fluid and cursive, written over a light blue horizontal line.

Professor Kerri Clough
Director, National Cancer Registry Ireland

3 Who We Are and What We Do

3.1 Background

Since our establishment in 1991, as a body under the aegis of the Department of Health (DoH), we have worked to support cancer prevention, detection, treatment and support in Ireland by recording cancer incidence and providing insight to help inform the planning and implementation of cancer services. The NCRI has been collecting data and publishing information since 1994.

Our functions (as set out in legislation¹) are summarised graphically in Figure 3.1.

These functions have a commensurate obligation on other bodies within the health services (public and private) to *provide* the Registry with data and to support us in our functions.

The past 28 years have seen significant changes in the demographic composition and health profile of the population of Ireland; advances in and greater understanding of cancer, and; the field of data sciences and the technology supporting the collection and analysis of health and population data.

National policy for public health and cancer services have also changed dramatically during these years. This strategic plan charts a course for the Registry to manage with the challenges of fulfilling its role and driving improvements in the Irish public health sector.

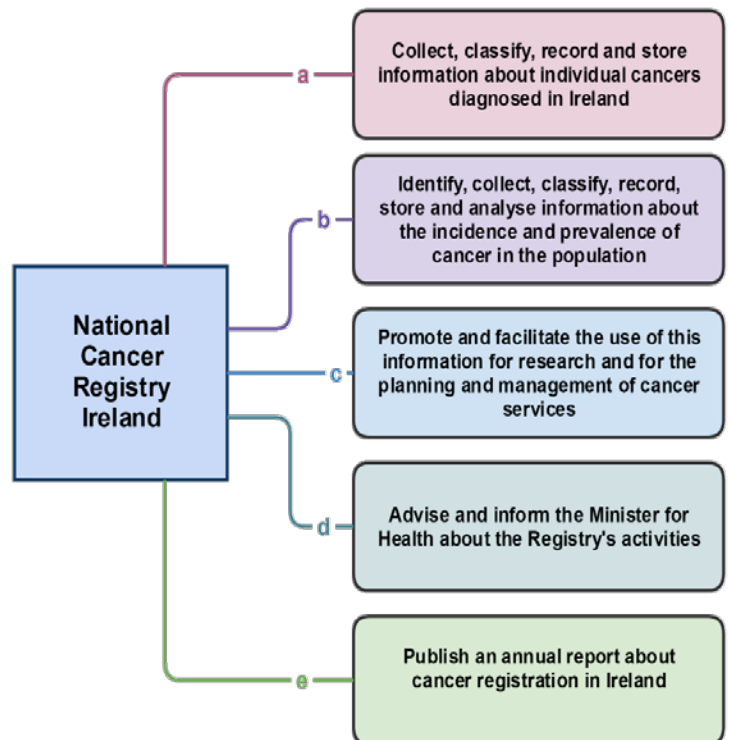


Figure 3.1 Functions of the NCRI

¹ The National Cancer Registry Board (Establishment) Order, 1991; National Cancer Registry Board (Establishment) Order, 1991 (Amendment) Order, 1996; Health (Miscellaneous Provisions) Act, 2009, sec. 65; Data Protection Act, 2018, sec. 184.

3.2 Some Vital Statistics



19 Cancer Data Registrars working in the Irish Health Service

23,886

Invasive cancers diagnosed and registered annually (2017 – 2019)

85% increase from 1994 - 2016



180,550 People living with or beyond cancer in 2016

3.8% of the Irish Population

63%



Was 41%

61%



Was 48%

5-year survival 2010 - 2014

In 1994 - 99



19 Reports Published from 2016 to 2019 inclusive

94 peer-reviewed papers from 2016 to 2018

More than 144,000 unique web page visits and more than 200 unique visitors per month

If current cancer rates persist, NCRI estimates that further population growth and ageing could result in a doubling of numbers of annual cancer cases between 2015 and 2045, even if we account for recent trends in decreasing cancer risk, the increase could still exceed 50% over this period. This represents an increasing burden of disease on patients and their families. To accurately collect information on this increasing volume of cancers, more efficient data capture methods will be required.

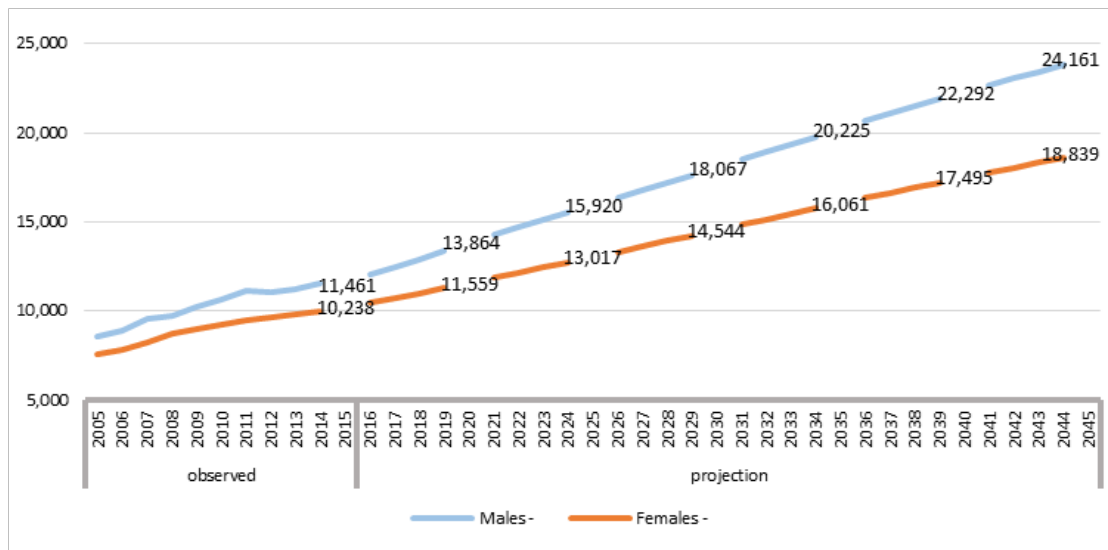


Figure 3.2: Invasive cancer incidence trends (male / female, excluding non-melanoma skin cancer) 2005 – 2015 and cancer projections 2015 – 2045 based on population growth and ageing.

3.3 What We Do

The Registry plays an important supporting role for cancer services in Ireland. While we don't interact with patients directly, all of our work is ultimately intended to improve outcomes for those affected by cancer, and to reduce the cancer burden in the country.

Our role is illustrated graphically below in Figure 3.3:

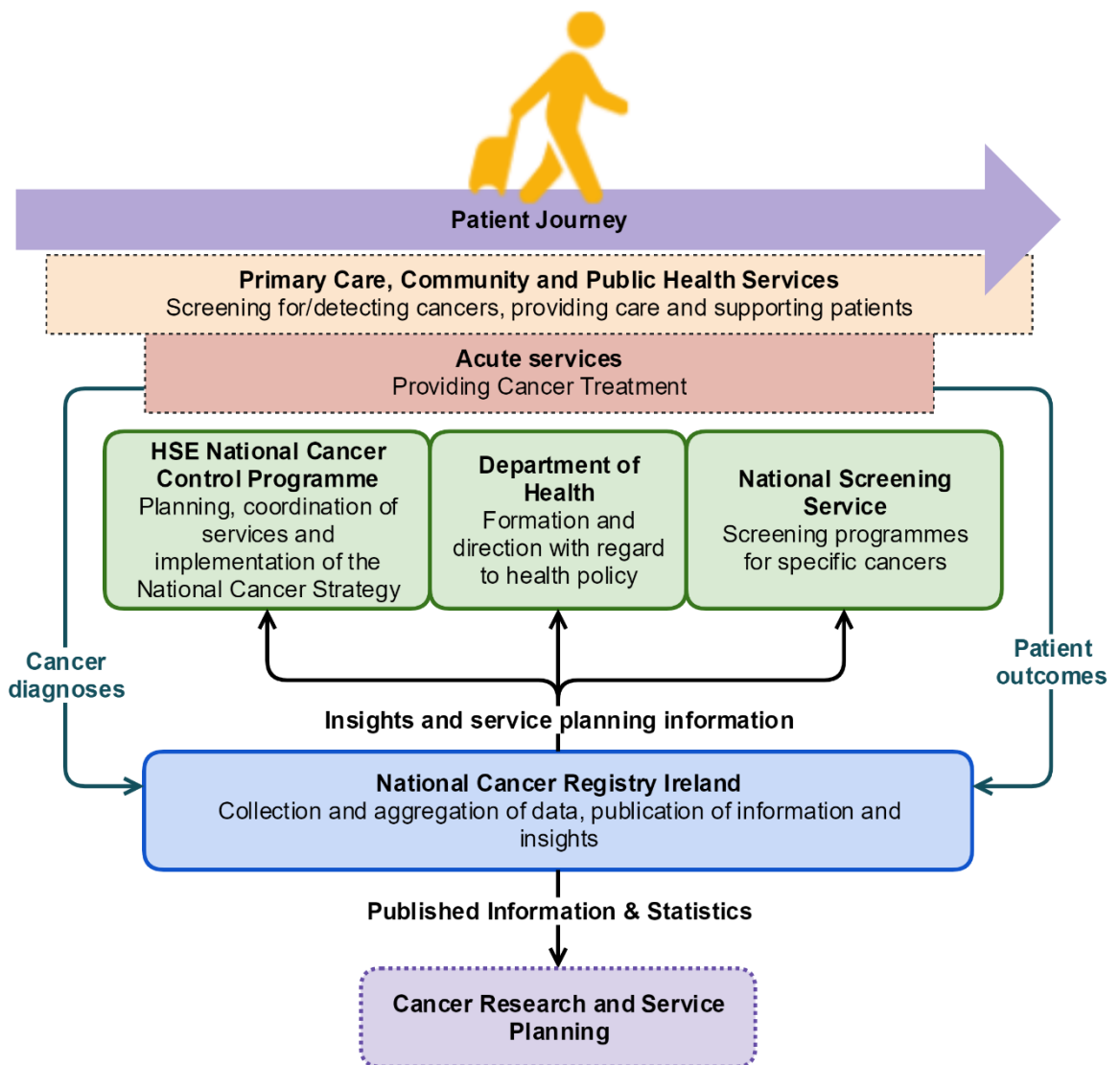


Figure 3.3 The NCRI's role in the Cancer Treatment and Prevention System

Carrying out our functions (as summarised in Section 3.1) and fulfilling our role depends entirely on the provision of data in relation to identified instances of cancer by other health sector bodies (hospitals, screening services, etc.) in line with their legal obligations.

Implementing our functions involves two principal types of activity:

1 - Data Collection and Integration	2- Information, Intelligence, Research
Cancer data registrars working in hospitals, or remotely connected to hospital systems, across the country to record cancer diagnoses, demographic and outcome data.	Using data collected to provide useful information and information about cancer in the population in Ireland.
Collection of both physical and electronic records and aggregating these into a coherent register of cancer incidence.	Providing key information to support the planning of cancer treatment services and the understanding of cancer in the population of Ireland.
Integrating and matching data to maintain a record of cancer in Ireland.	Publishing information and cancer intelligence outputs, and promoting their use in academia, cancer research, service planning and other areas of interest.

3.4 Our Structures

The Registry is a body under the aegis of the Department of Health. Our work is led by the Director and overseen by the NCRI Board, who report directly to the Minister and work with the Department in respect of the achievement of our strategic priorities, budgetary and resource management and policy direction.

Our work is enabled by IT and Corporate Services teams who provide the necessary infrastructure for our core functional activities of collection and analysis of data and the publication of information.

Our corporate structure is evolving to meet the needs of the organisation and will continue to do so throughout the lifetime of this strategy.

4 Context and Strategic Drivers

The mission, vision, and values set out in Section 5, as well the three strategic priorities and objectives within these described in Section 6, are informed by the present environment in which the Registry operates and a number of key strategic drivers, summarised below:

	Strategic driver	Our commitment
A	National Cancer Strategy 2017-2026	The Registry's work over the course of this strategic plan will support and align with the goals and sub-objectives of the <i>National Cancer Strategy 2017-2026</i> . The Registry has a direct role in the achievement of recommendations 36, 45, 51 and 52 ² and will work and consult appropriately to assist with the delivery of these objectives. These are summarised in Appendix I.
B	Recommendations of the Report of the Scoping Inquiry into the CervicalCheck Programme	Nine of the recommendations of Dr Gabriel Scally's report of the <i>Scoping Inquiry into the CervicalCheck Screening Programme</i> ³ relate to cancer registration. As part of this strategic planning process and as part of the State's response to the report, the Registry has adopted these recommendations as a strategic driver and will work to implement them. These recommendations and their context are set out in in Appendix II.
C	Timeliness of capture and analysis of routine NCRI data	Routine NCRI data are currently first published approximately 23 months after the most recent diagnosis. This contrasts dramatically with the UK-wide average of 14.5 months. Poor timeliness restricts applicability of data for service planning and limits research usability. This strategy is in part intended to improve timeliness of capture and analysis of routine NCRI data.
D	Quality and audit of data capture and analysis	Consultation and the operational consideration of the National Cancer Strategy and Scally Report Recommendations suggests that the Registry ought to give enhanced consideration to quality management and audit of data (both data stored within the Registry, and external data sought by

² Department of Health, 'National-Cancer-Strategy-2017-2026', 2017 <<https://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf>>.

³ Dr Gabriel Scally, *Scoping Inquiry into the CervicalCheck Screening Programme*, 2018, p. 181.

	Strategic driver	Our commitment
		the Registry) This strategy is in part intended to improve the quality of capture and analysis of routine NCRI data.
E	Evaluation of data captured	The Registry is in a position to evaluate and develop a plan to meet the needs of cancer services in respect of cancer prevention, treatment and follow-up. The need to evaluate the suite of clinical characteristics, outcomes and treatment data collected has been identified internally and through stakeholder consultation. This strategy specifically addresses this strategic driver.
F	Comprehensive cancer intelligence and reporting	The Registry facilitates and promotes research based on data capture and analysis. There is an opportunity to consider the strategic approach to promoting and enabling research based and the national priorities for cancer intelligence in the medium to long term.
G	Restructuring	As the Registry's ambition and technical capability grows, its resourcing and structural needs will continue to adapt and change. This document addresses the organisational structural requirements to implement the priorities and goals of the entire Strategic Plan 2020 – 2022.
H	Planning and Insight	The Registry has identified the need to increase the emphasis placed on the third of its functions – to assist in the planning and building of cancer service capacity within the health system.

5 Our Mission, Vision and Values

5.1 Mission

Our mission is to capture data and communicate information on cancer patients nationally to support the improvement of cancer outcomes in Ireland

5.2 Vision

NCRI will be a modern, dynamic and high-performing state resource, working collaboratively within the health system, and across the population, for the prevention, detection, treatment, management and support services for cancer in Ireland

5.3 Values

Our values are the core principles shaping the way we operate and engage with our stakeholders and our staff.

Enthusiasm
Quality
Collaboration
Transparency
Accountability
Integrity
Independence

6 Our Strategic Priorities for 2020-2022

Our Strategic Priorities for the coming three years are grouped into three principal areas of focus: capturing data, communicating information, and developing the organisation. Within these areas, we have identified a number of strategic objectives for the Registry.

In the following pages, we set out our strategic objectives in more detail, with the associated key actions and success measures, showing how we will address our strategic priorities.

Capture Data



- *Plan and evaluate the scope of data captured by the Registry*
- *Enhance data quality, security, timeliness, and access*
- *Increased use of technology and electronic data capture*

Communicate Information



- *Improve routine reporting*
- *Comprehensive statistical and analytical reporting/publication*
- *Improve our linkages with other bodies*

Develop Organisation



- *Develop our organisational structures to maximise our contributions to national cancer services*
- *Develop our personnel, resources and skills*
- *Improve our operational planning capability*

Capture Data

A core function of the Registry's is to capture, integrate, and analyse data in respect of the prevention, detection, treatment and support of cancer patients in Ireland. It is also mandatory for healthcare organisations to supply the required data to the Registry. Along with continuing to collect and process cancer data as we currently do, we have the following strategic objectives in relation to data capture:

- 1) In line with our legal basis and core functions, we will evaluate, plan and appropriately update the scope of the NCRI core dataset, to contribute to the improvement of cancer patient outcomes by ensuring that additional useful data may be collected and shared in respect of the detection, treatment, management and prevention of cancer in Ireland.

Key Actions:

- Examine the potential for sources of additional electronic and other data in relation to the cancer patient experience in Ireland
- Consult with health system stakeholders to identify the key needs in respect of cancer data, and to improve the capture of this data
- Continually review the NCRI core dataset (and corresponding change control process) and disseminate the core dataset as the central organising feature of the Registry's data collection work
- Identify the most useful and feasible data to collect and analyse.
- Implement appropriate staff and IT resource changes where relevant to support the capture of additional data

- 2) We will improve data quality, security, timeliness, and access. We will institute improved quality management processes to ensure the highest quality data. Data audit and a system of continuous data quality improvement will be implemented within the Registry.

Key Actions:

- Develop and refine the Registry's data quality assurance processes to ensure they are in line with best practice
- Identify key quality responsibilities and accountability within the Registry
- Implement a quality audit process
- Ensure data security and storage are in line with regulatory requirements and best practice
- Identify the factors affecting timeliness of cancer data and develop a plan to improve this

- 3) We will increase our use of technology to support the work of the Registry, in particular in respect of the capture and analysis of electronic data in respect of the cancer patient experience.

Key Actions:

- Work with the HSE, acute hospitals, and others as relevant to increase the capacity of the Registry to capture electronic patient data in relation to cancer
- Implement necessary changes to the Registry’s IT systems to facilitate and support electronic data capture and integration
- Review the database and information architecture within the Registry

How will we know we have been successful?

Ways to measure our progress and outcomes		
Objective	By end 2020	By end 2022
1	Plan will be presented to NCRI Board outlining the embedding of the core NCRI dataset and associated change control process.	Actively capturing an updated NCRI core dataset, having implemented the necessary resource and process changes (with regard to data architecture) required to achieve this.
2	Clear, best-practice data quality processes and audit plan will be in place. A plan to improve timeliness will be presented for approval to the Board.	Regular data quality audits will indicate a high standard of quality within Registry data. Timeliness of cancer data will have improved.
3	Areas where increased capture of electronic data may be feasible will have been identified	Significant increase in electronic data capture

Communicate Information/Data Use

The data captured by the Registry are only useful once it can be transformed into information and communicated to the health system, the research community, and the public to facilitate awareness, advances in cancer research, and improvements in the prevention, detection, treatment and support services for cancer in Ireland. Our strategic objectives in respect of communicating information are as follows:

- 1) We will improve and increase the level of reporting in respect of cancer data and information. We will develop a rolling three-year publication plan and will liaise with our key stakeholders in a collaborative way to ensure our outputs are as useful and informative as needed to enable others in the health system and beyond to use our data to improve outcomes for cancer patients.

Key Actions:

- Consult with health system and other relevant stakeholders (such as academic research institutions) to identify the most useful information in the appropriate formats to ultimately support better outcomes for cancer patients
- Draw up a three-year communication plan, revised annually, to address the needs of the stakeholders in respect of cancer reporting
- Produce high-quality, robust reports, based on reliable and timely data, to a regular schedule
- Review our website from the perspective of developing a public communication platform.

- 2) We will facilitate and promote research based on the NCRI core dataset. We will develop a three-year research strategy and implement this to ensure that our research-related work is targeted, appropriately funded, and sustainable.

Key Actions:

- Develop a three-year translational research strategy setting out the core areas of focus for research activity and identify criteria for measurable impact
- Align the research work within the Registry with our strategic priorities and focus
- Support research undertaken and led by other institutions and organisations

- 3) We will improve our approach to collaboration with other organisations in respect of cancer services, the wider health system, and academia, to mutually support the achievement of better outcomes for cancer patients in Ireland.

Key Actions:

- Develop closer links with the National Cancer Control Programme and consider centralisation of registration staff. This could be accomplished, for instance, through having NCRI office space in Dublin.
- Further develop collaborative links with academic institutions and research partners.
- Participate in multi-stakeholder initiatives relevant to the work of the Registry and cancer control in Ireland
- Consult and collaborate, as outlined in other objectives, with health system and other stakeholders to identify how the Registry can support their work and improve outcomes for cancer patients

- 4) We will provide support for the planning and improvement of cancer services to improve outcomes in relation to cancer.

Key Actions:

- Participate in established working groups (the Irish Cancer Prevention Network, and the Irish Cancer Epidemiology Network for instance) with the Department of Health, NCCP, HSE, acute hospitals, and others involved in cancer prevention, care, and research to identify ways in which the Registry's capture, processing, and reporting of cancer data could be used to develop policy for cancer services
- Design appropriate reporting outputs to address the needs of stakeholders in improving services
- Provide useful, relevant information in a timely fashion to enable cancer services to be evaluated, compared, and improved

How will we know we have been successful?

Ways to measure our progress and outcomes		
Objective	By end 2020	By end 2022
1	Consultation completed and findings will be presented to Board Three-year publication plan will be presented to Board for approval	Regular publication of timely, robust reports in respect of cancer data in Ireland
2	Three-year research strategy will be developed and presented to Board for approval	Research activity in the Registry will be clearly aligned with the research strategy and is supporting future development of the organisation
3	Dedicated Registry space in Dublin will be in place A plan will be presented to Board for approval in respect of linkages and collaboration	NCRI will be an active partner in policy and implementation initiatives in respect of cancer prevention, detection, treatment, and outcomes
4	Working groups with key stakeholders will be identified	Registry will provide reports and information as relevant to the appropriate stakeholders to support service improvement for cancer patients

Develop Organisation

The Board notes the Department of Health review of the composition of the NCRI Board to ensure more robust governance, in line with the Scally Report. We are committed to building a governance structure and culture that is optimum to support and to safeguard the work of the organisation and we will be available to assist the Department in this regard.

- 1) We will work to incorporate the perspective and voice of those affected by cancer as well as those involved in the provision of cancer services into our work providing information and insight to the health service

Key Actions:

- Establish an advisory group (patient and clinical)
 - Identify and implement mechanisms to ensure that the voice of those affected by cancer and public health expertise can be effectively incorporated into the strategic and operational activities of the Registry
- 2) We will develop and implement a new organisational and management structure to ensure that the work of the Registry is organised and overseen in the most effective and efficient way, providing key leadership and management responsibilities to support the operational activities.

Key Actions:

- Continue to develop and optimise our organisational and management structures. We must base this on effective practice, the operational needs of the Registry, and maximising our contributions to the prevention, treatment and follow-up services for cancer patients and their families within the Irish health services
 - Recruit, with Department of Health sanction, appropriately skilled and qualified staff to the vacant positions within the reformed organisation
- 3) We will continue to develop our personnel resources and skills within a culture of continuous improvement. We will build capacity both by recruiting key skills and expertise as needed and by developing and maintaining the skillsets of existing staff, in order to ensure a dynamic, collaborative, and high-performing organisation.

Key Actions:

- Identify the key skills and expertise required across the Registry
- Draw up a training and development plan for staff to maintain, improve, and further develop the skills and competences needed to deliver the Registry's functions

- Proactively recruit appropriately skilled and qualified staff as and when required, considering future skills as well as skills replacement needs when roles become vacant or additional resources are required
- 4) We will continue to be transparent and accountable in respect of our activities, finances, and governance. We recognise our responsibility to be fully accountable and open in relation to our remit and the funding provided to us to carry this out. We will develop and implement an accountability framework and provide clear and comprehensive reporting in respect of our financial and governance affairs along with an account of how the funding has been spent, the activities this has supported, and the outcomes in relation to cancer data capture and communication.

Key Actions:

- Publish clear, timely reports in respect of the governance, finances, and activities of the Registry, regularly and in accessible formats
 - Communicate more frequently and clearly with our stakeholders and with the public, in the form of reports, updates, briefings, and similar activities
 - Develop an outcomes-based approach to reporting on the Registry's work
- 5) We will complete this strategic planning cycle by evaluating the successes and lessons learned from the 2020-2022 period and preparing a successor strategy document.

Key Actions:

- Review the implementation of the Strategic Plan 2020 – 2022
- Develop a successor strategic planning document

How will we know we have been successful?

Ways to measure our progress and outcomes		
Objective	By end 2020	By end 2022
1	Board effectiveness review will be completed	NCRI will have a Board that is appropriate in size and function to govern and support the work of the Registry
2	Plan will have been presented to Board for approval regarding advisory groups and a mechanism for including the voice of those affected by cancer	Clinical and patient advisory groups will be in place and providing inputs to Registry planning and operations Effective clinical oversight, including public health input, is in place
3	Evaluation of opportunities for optimisation and further development of management and organisational processes to optimise the Registry's role in the Irish health service. Reported presented to Board on the suitability of organisation and management systems for our functions.	NCRI will operate within an effective management and organisation structure, with all key roles filled with appropriately qualified and skilled post-holders
4	Skills needs update will have been presented to Board Training and development plan will be in place	Training and recruitment will be aligned with the skills needs of the organisation
5	Plan for improved communications with stakeholders and public will have been presented to the Board	Regular reporting on financial and governance of NCRI. Regular communications in relation to Registry activities and outputs to stakeholders and to public
6		This strategy document will have been reviewed at the end of 2021 with regard to the success of implementation and achievement of objectives.

A successor strategy document will have been prepared and presented to the Board for approval.

7 Implementing the Strategic Plan

7.1 Responsibility and Accountability for Implementation

This strategy charts an ambitious course for the Registry for the coming years, setting goals and objectives which are both challenging and exciting. Implementation of this strategy is a shared responsibility between the Board and all of the staff of the organisation.

The Registry reports to the Minister of Health and works with the Department in respect of implementation of:

- Execution of our statutory functions, our budget and performance delivery framework;
- The recommendations and objectives of the National Cancer Strategy, and our role within that;
- The recommendations of the report of the *Scoping Inquiry into the CervicalCheck Programme*;
- **Our own strategic plan**, and;
- Emerging policy and day-to-day operational service planning as it relates to cancer.

The Board's role is to adopt the strategy, and to monitor its implementation through reports from the Director and staff. The Director is accountable to the Board for the delivery of the goals and objectives set out in this strategy by the entire organisation.

7.2 Reporting

We are cognisant of our responsibility for robust and proactive reporting to the Department of Health. Throughout the implementation of this strategy we will work within our established governance framework, which includes quarterly meetings between the Department and the Registry, at which we will report on our high-level strategic progress.

We will report on progress against each action in the strategic plan within our annual report, with a formal mid-term review of our strategic plan taking place at the end of 2021

The Director will present routine detailed quarterly reports on the progress towards the goals and objectives at each Board meeting, providing granular detail on the project, initiatives and outputs of each key action within the strategy. Reporting templates and tools for use in reporting on and tracking the strategy will be used to ensure that the Board is kept informed and up-to-date on progress.

7.3 Operational Planning, Mid-point Review and Successor Strategy

Based on the strategy, the Director and staff of the organisation will establish detailed annual work and operational plans setting out the approach to implementing the strategy and bringing the vision set out herein to life.

All staff will be responsible for contributing to and working toward those operational plans, as part of ongoing operational work. This strategy, combined with our operation plans will form the roadmap for the organisation for the coming years, documenting the detail of how the Registry will work towards its goals and objectives.

Following year 2, the Registry will conduct a mid-point review of the strategy to evaluate the fitness for purpose of the goals and to reassess our strategic drivers. The final objective within this strategy is the initiation of a new strategic planning cycle to create a new plan to succeed this document as the guiding document for the Registry.

This strategic planning cycle dynamic is illustrated in Figure 7.3 below:

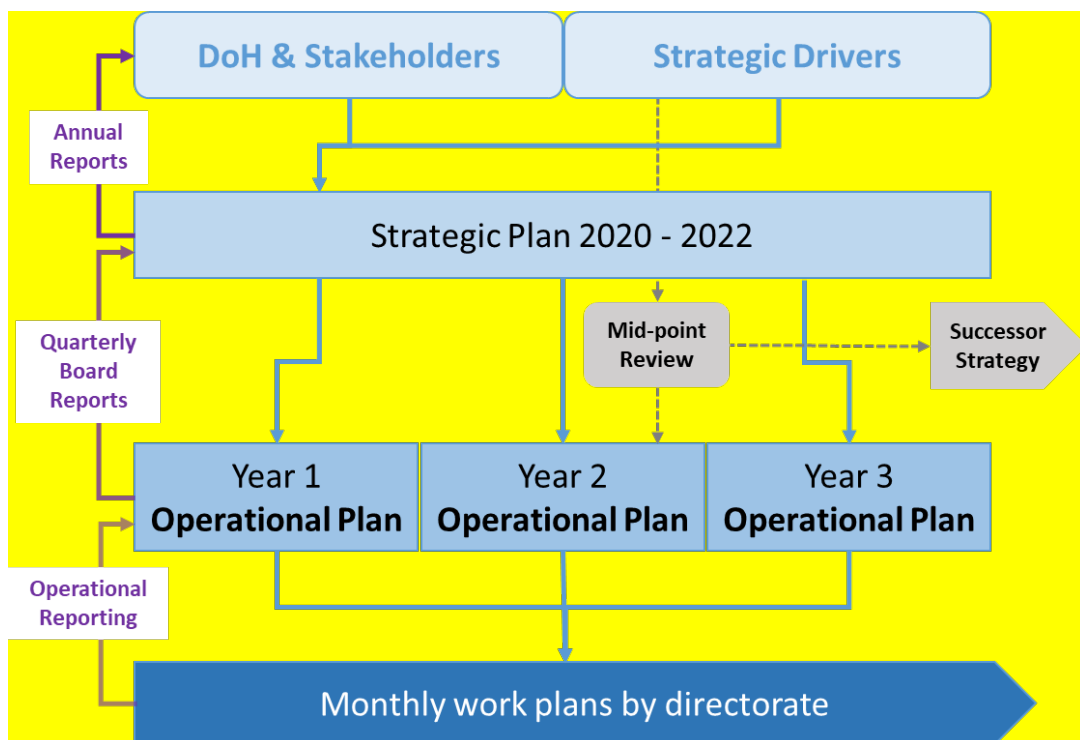


Figure 7.3: Strategic Planning Lifecycle

Appendix I – Goals and Objectives of the National Cancer Strategy 2017 - 2026

The National Cancer Strategy 2017 - 2026⁴ comprehensively sets out the context, goals and key objectives for Ireland's proposed approach to the prevention, treatment and follow up services for those affected by cancer. The Registry plays an important role in the implementation of these goals, which are summarised below.

Goal 1 :Reduce Cancer Burden	Goal 2: Provide Optimal Care
Ensure prevention programmes are prioritised to reduce cancer incidence	Ensure effective and equitable treatment throughout the care pathway to improve outcomes for all patients
Improve symptom awareness in the population	Further develop treatment facilities and infrastructure
Increase early diagnosis	Maintain a strong focus on patient safety and quality assurance
Focus on social inequalities	Ensure that appropriate palliative care supports are in place
Goal 3: Maximise Patient Involvement and Quality of Life	Goal 4: Enable and Assure Change
Strengthen the role of patients in the planning and delivery of cancer care including through the establishment of structures for patient involvement	Strengthen the role of the NCCP in the oversight of cancer control and in implementing the recommendations of the Strategy
Develop and implement survivorship care programmes	Ensure ongoing workforce planning to fulfil changing needs
	Utilise technology, research and data to create a sustainable, high quality and accountable cancer service
	Build better systems and processes to ensure evidence-based prioritisation and service delivery

⁴ Department of Health, 'National-Cancer-Strategy-2017-2026', 2017 <<https://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf>>.

The Registry sees the goals and objectives of the National Cancer Strategy 2017 – 2026 as a central strategic driver for the Strategic Plan 2020 – 2022 and has some part to play in the achievement of each objective. There are some key objectives where the Registry’s role is more obvious and important, which we have highlighted in the table above.

More specifically, the NCRI has a direct role in the achievement of three recommendations of the strategy:

...

36	The NCCP will develop, publish and monitor a programme of national quality healthcare indicators for cancer care, involving both process and outcome measures, in line with international standards.
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...

45.	The NCCP will work with the private sector providers to achieve voluntary participation in cancer data collection, audit, compliance with guidelines and reporting of outcomes..
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...

51	The HSE will ensure that all hospitals provide the National Cancer Registry with data related to cancer in an appropriate timeframe to allow for sufficient surveillance of cancer rates and outcomes in Ireland
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52	The Department of Health will review the scope of the National Cancer Registry with a view to increasing and optimising the use of available data to drive improvements in cancer care for patients.
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...

The NCRI Strategic Plan 2020 – 2022 sets out priorities and objectives which are aligned with the achievement of this vital national policy initiative and strategic plan.

Appendix II – Implementation of the recommendations of the Report of the Scoping Inquiry into the CervicalCheck Programme

Arising from the 2018 public controversy concerning the CervicalCheck Screening Programme, Dr Gabriel Scally conducted a scoping inquiry into the programme and its management and interactions with other elements of the Irish healthcare system.

The recommendations in the Scoping Inquiry report were wide-ranging and are not wholly owned by the Registry. **Nine** of the **fifty** recommendations listed in the report concern cancer registration and the national approach to this.

The report, including its recommendations have been endorsed by all of Government and the entire health service, including the National Cancer Registry. These recommendations have been adopted as a key strategic driver for the NCRI Strategy 2020 – 22, and the implementation of these recommendations is considered a critical success factor for the Registry's execution of this strategic plan.

For this reason, it is worth listing the nine recommendations and to unequivocally state that **we adopt these and will work to implement them through** this strategy:

36) NCRI should urgently negotiate and implement data sharing agreements with all major providers and users of registration data. This is necessary in order to meet the requirements of the new EU General Data Protection Regulation but also, and more importantly, represents good governance. Where such an agreement is with an overarching statutory body, such as the HSE, there should also be individual MoUs in place with distinct organisational users of data, such as the cancer screening programmes.

37) Timely data is important to assure the effectiveness of both cancer screening and treatment services. This is a patient safety issue. To fulfil its role properly as a cancer registry:

- a. NCRI must be given additional support to recruit cancer registration officers and strengthen its public health medicine capacity.
- b. The Department of Health and the HSE should commit to make progress on electronic data capture by NCRI from hospitals, and set clear targets for its achievement.

38) NCRI should review data definitions related to cervical cancer and CIN (cervical intra-epithelial neoplasia) cases to ensure that the screening flags are meaningful for analysis of the effectiveness of the CervicalCheck programme

-
- 39) The need to duplicate the collection of patient level details of cervical cancers by both NCRI and CervicalCheck should be reviewed. It is notable that both CervicalCheck and NCRI have identified patients that the other has not. If it is determined that both systems should continue then properly functioning data sharing agreements must be put in place.
-
- 40) The Department of Health must review the composition of the Board of NCRI in order to ensure more robust governance, in particular in QA, data sharing and patient safety.
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- 41) Any future consideration of the governance of the NSS needs to acknowledge, and contribute to the effective oversight of, the specific role played by NCRI in working in conjunction with the cancer screening programmes.
-
- 42) The Department of Health should work with the Board of NCRI to commission an annual peer review, for at least the next three years, by external cancer registration and cancer control experts. The report of each review and the response to it by NCRI should be forwarded to the Minister for Health.
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- 43) NCRI should establish stronger and more regular contacts with external clinical and public health experts to ensure scrutiny of, and advice on, outputs from NCRI so as to enhance the level of its clinical and public health interpretation, importance and impact.
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- 44) One of the requirements for the establishment and good management of a screening programme is that health services should be of a good standard to manage those people detected with disease by the screening programme. NCRI, through links with the clinical community, should seek to engage actively in the assessment of the quality of cancer services, comparing these for screen and non-screen detected cases
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Appendix III – Extracts from Relevant Legislation

S.I. No. 19 of 1991.

THE NATIONAL CANCER REGISTRY BOARD (ESTABLISHMENT) ORDER, 1991.

[...]

2. A body to be known as the National Cancer Registry Board is hereby established.

3. In this Order:

"the Board" means the National Cancer Registry Board established by this Order;

"the Chairman" means the Chairman for the time being of the Board;

"the Minister" means the Minister for Health.

4. The functions of the Board are as follows:

(a) to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland;

(b) to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs;

(c) to promote and facilitate the use of the data thus collected in approved research projects and in the planning and management of services;

(d) to publish an annual report based on the activities of the Registry;

(e) to furnish advice, information and assistance in relation to any aspect of such service to the Minister.

[...]

18. (1) In order to facilitate the discharge of the functions of the Board, the Board may establish committees whose function shall be to assist and advise the Board in relation to the performance of its functions.

(2) The membership of such committees may consist of members of the Board and persons who are not members of the Board.

(3) Any committee so appointed shall act subject to such directives as may be given by the Board, and any expenditure of monies by such committee shall be subject to the approval of the Board.

[...]

22. (1) The Board shall in each year, not later than such day as the Minister shall direct, make a report to the Minister of its activities during the proceeding year.

(2) The Board shall submit to the Minister such information regarding the performance of its functions as the Minister may from time to time request.

S.I. No. 293 of 1996.

**NATIONAL CANCER REGISTRY BOARD (ESTABLISHMENT) ORDER, 1991 (AMENDMENT)
ORDER, 1996.**

[...]

(2) The National Cancer Registry Board (Establishment) Order, 1991 (S.I. No. 19 of 1991) is hereby amended:

a. by the substitution of the words "not more than ten members" for the words "not more than nine members" where the latter occur in article 5. (1).

b. by the insertion after article 5. (1) (vi) of the following:

(vii) One member shall be appointed on the nomination of the Faculty of Public Health Medicine of the Royal College of Physicians of Ireland.

c. by the substitution of the following article for the existing article 23:

23. (1) The Board may, with the consent of the Minister and the Minister for Finance, appoint such and so many officers and employ such and so many servants as the Board may, from time to time, think proper and in appointing any officer or employing any servant the Board shall comply with any directions given by the Minister relating to the procedure to be followed.

(2) The Board shall, with the consent of the Minister, determine the remuneration and conditions of service of each officer and each servant.

(3) Any officer of the Board holding office in a permanent capacity shall cease to hold his or her office on attaining the age of sixty-five years.

(4) The Board shall, from time to time, assign such duties as it considers appropriate to each officer and servant of the Board and each such officer and servant shall perform the duties so assigned to him or her.

(5) The Minister may, whenever and so often as he or she thinks fit, declare that any of the powers conferred on the Board by this article shall be exercisable only with the consent of the Minister, and whenever any such declaration is in force, the said powers may, in relation to any office or employment to which the declaration applies, be exercised only with such consent.

Health (Miscellaneous Provisions) Act, 2009 (section 65)

65.—Article 5 (as amended by Article 2 of the National Cancer Registry Board (Establishment) Order 1991 (Amendment) Order 1996 (S.I. No. 293 of 1996)) of the National Cancer Registry Board (Establishment) Order 1991 (S.I. No. 19 of 1991) is amended by the substitution of the following for paragraph (1):

“(1) The Board shall consist of 7 members.

(1A) In appointing members of the Board the Minister shall appoint persons who—

(a) have knowledge or experience of—

- (i) the collection, recording and analysis of information, or
- (ii) the use of such information in research projects and the management and planning of services,

or

(b) have any other relevant competency which would assist the Board in the performance of its functions.”.

Data Protection Act 2018 (Section 184|1)

1. (1) The National Cancer Registry Board (established under the Health (Corporate Bodies) Act 1961) may request from any person personal data (including data concerning health and genetic data within the meaning of the Data Protection Regulation) held by, or in the possession of, that person for the purposes of the performance of that Board of its functions.

(2) Without prejudice to his or her obligations under the Data Protection Regulation and the Act of 2018, the person to whom a request is made under subsection (1) shall provide the personal data requested to the extent it is held by, or in the possession of, that person.