

**MINUTES OF A MEETING OF THE
NATIONAL CANCER REGISTRY BOARD (NCRI)**

HELD ON

19 JUNE 2024 AT 1.30 PM

AT

BUILDING 6800, CORK AIRPORT BUSINESS PARK, KINSALE ROAD, CORK / MICROSOFT TEAMS

1. Register of Attendance

Present

Name	Details	Initials
Dr Jerome Coffey	Chairperson	JC
Ms Mary Bourke	Board Member	MB
Mr Niall Murphy	Board Member	NM
Dr Robert O'Connor	Board Member	ROC
Ms Cathy Enright	Board Member	CE
Ms Ellen Farrell	Board Member	EF

In Attendance

Name	Details	Initials
Prof Deirdre Murray	NCRI Director	DM
Ms Rose O'Connor	NCRI Corporate Operations Manager	COM
Ms Catherine McGovern	NCRI Business & Planning Manager	CMCG
Ms Grace Murray	NCRI Governance & Compliance Officer	GM
Mr Alan Kearney	Project Manager	AK (for part thereof)

Apologies

Name	Details	Initials
Prof Mark Lawler	Board Member	ML

2. Quorum

IT WAS NOTED THAT there was a quorum of board members present at the meeting.

3. Declaration of Conflicts of Interest

The board members confirmed that they had no conflict of interest in the matters to be discussed at the meeting.

4. Board Composition

- 4.1. The Chairperson reported to the meeting that he would be stepping down as Chairperson of the board with effect from close of business today and that his replacement had not yet been appointed.
- 4.2. **IT WAS NOTED THAT** pending the appointment of a new chairperson and in accordance with the National Cancer Registry Board (Establishment) Order 1991 (as amended), the members of the board

who are present at a board meeting shall choose one of their number to be chairperson of that board meeting.

5. Director's Report

5.1. DM reported to the board on the NCRI's strategic and operational objectives, during which the following points were noted and discussed:

Visit by Minister Colm Burke

5.1.1. Minister Colm Burke visited the NCRI on 20 May 2024 which gave the NCRI the opportunity to highlight its work and future plans to the Minister and to demonstrate its important role in public health in Ireland;

Strategy

5.1.2. rollout to NCRI of the HSE – wide MedLIS project has been paused. While further progression of the project is beyond the NCRI's control, the successful implementation of the project will significantly enhance the NCRI's electronic data collection capabilities;

KPIs

5.1.3. key metrics as at 31 May 2024 were presented to the meeting and significant inroads into the backlog accrual were noted;

Cybersecurity

5.1.4. the National Cyber Security Centre has confirmed in writing to the NCRI that the NCRI will not fall within the remit of the Network and Information Systems Directive (NIS2). **IT WAS AGREED THAT** the cyber incident response plan would be updated following completion of the tabletop exercise (to be discussed in further detail later in the meeting);

Cancer Intelligence

5.1.5. a report on HPV associated cancers published on 30 April 2024 was well received;

Electronic Data

5.1.6. significant progress in electronic data capture was noted;

Individual Health Identifier (IHI)

5.1.7. the NCRI is integrating the IHI (a number that uniquely identifies a person who has used, is using or may use health services in Ireland) into its registration system. The NCRI provided HSE Health Identifiers (“HIDs”) with all its records which HIDs matched against their database and returned a 74% match, which is a very good result. The NCRI is currently analysing the match rate to determine the optimal pilot for progressing the inclusion of IHI in the NCRI matching processes internally and is in discussion with the National Screening Service as to the mechanism of incorporating the IHI into the record reconciliation processes for the screen detected cancers. There followed a discussion on the impact of immigration on the IHI project.

Future of Registries Taskforce (FoRT)

5.1.8. This working group was established to achieve multi-stakeholder consensus and influence decision-making on a future model for operating patient registries in Ireland. Members of the working group include representatives from current registries, rare disease organisations, patient advocates, clinicians, research organisations, the Health Information & Quality Authority, the Health Service Executive, the National Office of Clinical Audit, data protection representatives, funding bodies, and industry partners including pharma and technology companies. The Department of Health participates in a consultative role. The goal is to develop

a proposal to be submitted to the Department of Health this year. It is recognised that the NCRI's statutory basis positions it differently compared to many other registries; and

HR

5.1.9. recent recruitments include three new eCDRs to backfill vacant posts due to retirements, two roles in Data Integration and a Head of Research and Analysis who will commence the role in September. The board congratulated the NCRI on the successful recruitment of a Head of Research and Analysis and thanked MB for her assistance with various recruitment campaigns.

5.2. There followed a discussion on KPIs and **IT WAS AGREED THAT** the NCRI would review projections for reducing the backlog to take into account: (i) recent hires; and (ii) the strategic objective to expand data collection to capture data on recurrences and metastatic disease, with revised projections to be presented to the board at the next board meeting.

6. Service Plan Dashboard

6.1. CMcG presented the service plan dashboard to the meeting and explained to the meeting how the dashboard measures the NCRI's progress against its strategic objectives each quarter.

6.2. The board reviewed the service plan dashboard and the status of each of the 2024 goals was noted by the board.

7. Update on Website Project

7.1. AK joined the meeting to provide the board with an update on the website upgrade project (the "**Website Project**"). AK explained the rationale for the Website Project noting that the NCRI website is a primary means of communication to NCRI's stakeholders and the general public and as such the Website Project is integral to the NCRI achieving its strategic objectives.

7.2. AK presented the budget approved by the Department of Health in respect of the Website Project to the meeting and reported on accomplishments to date, current activities and next steps for phase I of the project.

7.3. A project activity report, earned value report, and Risks, Actions, Issues and Decisions ("**RAID**") logs were also presented to the meeting and discussed.

7.4. AK reported that the procurement process to identify a vendor for website development and support is currently underway on the eTenders platform and once a vendor has been selected the relevant contract will require execution on behalf of the board (the "**Website Contract**"). **IT WAS AGREED THAT** a summary of the tender request, selection process and screening (the "**Tender Summary**") would be circulated to EF along with a draft of the Website Contract following the selection of a vendor.

7.5. Following careful consideration of the foregoing, **IT WAS RESOLVED THAT**, pending the appointment of a new chairperson of the board and subject to circulation of the Tender Summary and Website Contract to EF:

7.5.1. the Website Contract be approved in principle;

- 7.5.2. EF be empowered, directed, authorised and appointed to execute the Website Contract on behalf of the board once finalised and in consultation with the Project Manager; and
- 7.5.3. EF be empowered, directed, authorised and appointed to execute such other documents and take such other steps on behalf of the board as may be deemed necessary or desirous in connection with or arising out of the Website Contract and the transactions thereby contemplated.
- 7.6. **IT WAS AGREED THAT** a summary of the new ways in which stakeholders will be able to interact with the new website compared to the current website would be presented to the board when the Website Project enters phase II.

8. Stakeholder Engagement Report

- 8.1. The board noted the stakeholder engagement report which detailed all strategic and executive level stakeholder engagements that have taken place since the last board meeting.
- 8.2. ROC noted that the Department of Health had appointed a new Director of Research, Policy & Innovation which may be a useful contact for the NCRI to connect with.

9. ARC Report to the Board

- 9.1. EF provided a report to the board on the Audit & Risk Committee (“**ARC**”) meeting held earlier that morning, during which the following points were highlighted:

Letter of Representation

- 9.1.1. a draft letter of representation to be issued to the C&AG (the “**Letter of Representation**”) in respect of their audit of the financial statements for the year ended 31 December 2023 (the “**2023 Financial Statements**”) was reviewed by the ARC;
- 9.1.2. subject to the minor amendments suggested by the ARC, the ARC formally recommends that the Letter of Representation be approved by the board and signed by the Director and Chairperson;

Annual Report 2023

- 9.1.3. the draft annual report for 2023 which includes the 2023 Financial Statements (the “**Annual Report**”) was reviewed by the ARC and their comments incorporated;
- 9.1.4. following careful consideration, the ARC formally recommends that the 2023 Annual Report be approved by the board;

Financials

- 9.1.5. management accounts as at 31 May 2024 were reviewed by the ARC;

Financial Policies & Procedures Manual

- 9.1.6. the ARC considered proposed changes to the financial policies and procedures manual (the “**Financial Manual**”) to update the procurement thresholds referred to therein in accordance with the Corporate Procurement Plan and consequent update to purchase order and single source supplier form authorisations which is in line with public policy and will enhance day-to-day operations;
- 9.1.7. following careful consideration, the ARC formally recommends that the Financial Manual be approved by the board;

Data Protection

- 9.1.8. the interim DPO, Pembroke Privacy, submitted a report to the ARC on data protection matters;
- 9.1.9. no near-misses or personal data breaches occurred in Q2;
- 9.1.10. the draft data protection policies manual (the “**DP Manual**”) prepared by Pembroke Privacy in consultation with the Senior Management Team was reviewed by the ARC and their comments incorporated;
- 9.1.11. following careful consideration, the ARC formally recommends that the DP Manual be approved by the board;

Risk

- 9.1.12. the ARC reviewed the corporate risk register which now identifies the specific strategic objective to which each risk relates as requested by the ARC;

Annual Report of the ARC to the Board

- 9.1.13. following careful consideration and having regard to best practice in accordance with the Code of Practice for the Governance of State Bodies (the “**Code of Practice**”), commencing in March / June 2025 the quarterly reports of the ARC will be consolidated into an annual written report from the ARC to the board summarising its conclusions from the work it has done during the relevant year (the “**Annual ARC Report**”) with such report to be timed to support finalisation of the Annual Report and financial statements;
- 9.1.14. a template for the format of the Annual ARC Report would be considered by the ARC at the meeting scheduled for 2 December 2024;

Terms of Reference of the ARC

- 9.1.15. having considered the revised terms of reference of the ARC (the “**TOR**”), the ARC formally recommends that the TOR be approved by the board;
- 9.1.16. in accordance with the TOR, a quorum of three Committee Members must be present in order to hold a meeting of the ARC which can prove challenging given that the ARC comprises of four Committee Members in total. Following detailed discussion, the ARC formally recommends to the board that an additional external Committee Member with finance experience in the public sector be appointed to the ARC, thereby increasing the membership of the ARC to five members; and
- 9.1.17. subject to approval by the board, it is proposed that the NCRI would reach out to its stakeholders to try to source an appropriate candidate for appointment to the ARC.

10. Letter of Representation

10.1. **IT WAS NOTED THAT** a copy of the draft Letter of Representation had been circulated to the board for review prior to the meeting.

10.2. Having considered the Letter of Representation and having regard to the ARC’s recommendations in relation thereto, **IT WAS RESOLVED THAT**, subject to the minor amendments requested by the ARC:

- 10.2.1. the Letter of Representation be approved in substantially the form circulated to the board; and
- 10.2.2. once finalised, the Chairperson and Director be empowered, directed, authorised and appointed to execute the Letter of Representation on behalf of the NCRI.

11. Annual Report 2023

11.1. **IT WAS NOTED THAT** a copy of the draft Annual Report including the 2023 Financial Statements had been circulated to the board for review prior to the meeting.

11.2. Following a discussion in relation to the Annual Report and 2023 Financial Statements and having regard to the ARC's recommendations in relation thereto, **IT WAS RESOLVED THAT:**

11.2.1. the Annual Report and the 2023 Financial Statements be approved; and

11.2.2. the Chairperson and chairperson of the ARC be empowered, directed, authorised and appointed to execute the Annual Report and 2023 Financial Statements on behalf of the NCRI and to execute such other documents and take such other steps on behalf of the board as may be deemed necessary or desirable in connection with or arising out of the foregoing resolutions and the transactions thereby contemplated.

12. Financial Policies & Procedures Manual

12.1. **IT WAS NOTED THAT** a copy of the revised Financial Manual had been circulated to the board for review prior to the meeting.

12.2. Having considered the Financial Manual and having regard to the ARC's recommendations in relation thereto, **IT WAS RESOLVED THAT** the Financial Manual be approved.

13. Data Protection Policies Manual

13.1. **IT WAS NOTED THAT** a copy of the draft DP Manual had been circulated to the board for review prior to the meeting.

13.2. Having considered the DP Manual and having regard to the ARC's recommendations in relation thereto, **IT WAS RESOLVED THAT** the DP Manual be approved.

14. Terms of Reference of the ARC

14.1. **IT WAS NOTED THAT** a copy of the revised TOR had been circulated to the board for review prior to the meeting.

14.2. Following a detailed discussion in relation to the TOR and the quorum requirements stipulated therein and having regard to the ARC's recommendations in relation thereto, **IT WAS RESOLVED THAT:**

14.2.1. the TOR be approved; and

14.2.2. the appointment of an additional external Committee Member to the ARC with finance experience in the public sector be approved in principle subject to the identification of an appropriate candidate.

14.3. **IT WAS AGREED THAT** the NCRI would reach out to its stakeholders to try to source an appropriate candidate for appointment to the ARC.

15. Chairperson's Comprehensive Report to the Minister

15.1. The meeting was reminded that the Code of Practice requires the Chairperson to furnish a comprehensive report covering the NCRI to the Minister for Health in conjunction with the Annual Report and 2023 Financial Statements (the "**Chairperson's Report**").

15.2. **IT WAS NOTED THAT** a draft copy of the Chairperson's Report had been circulated to the board for review prior to the meeting.

15.3. Following consideration of the Chairperson's Report, **IT WAS RESOLVED THAT:**

15.3.1. the Chairperson's Report be approved;

15.3.2. the Chairperson be empowered, directed, authorised and appointed to execute the Chairperson's Report; and

15.3.3. arrangements be made for the submission of the Chairperson's Report to the Minister for Health.

16. Form A: Statement of Compliance with the Code of Practice for the Governance of State Bodies

16.1. The meeting was reminded that, in addition to the Chairperson's Report, the Code of Practice requires the Chairperson and Director to complete and sign a Form A: Statement of Compliance with the Code of Practice ("**Form A**").

16.2. Following discussion in relation thereto, **IT WAS RESOLVED THAT** the Chairperson and the Director be authorised to sign a Form A confirming the board's compliance with the Code of Practice for submission to the Department of Health.

17. Board Membership & Succession Planning

17.1. The Chairperson reminded the meeting that a skills matrix had been circulated to board members for completion in order to assess whether the board as a whole has the requisite skills and experience to allow it to perform its functions and to assist the board in succession planning.

17.2. The board reviewed the consolidated results and **IT WAS NOTED THAT** the board may also rely on expertise within the NCRI and obtain external advice in areas such as cybersecurity if and when required.

17.3. There followed a discussion on the tenure of current board members. **IT WAS AGREED THAT** the NCRI would reach out to the Department of Health for details of the required skillsets for recent appointments to the board and a further assessment of required skillsets for the board be undertaken following appointment of a new chairperson of the board.

18. Service Plan with the Department of Health

18.1. **IT WAS NOTED THAT** the 2024 service plan with the Department of Health which provides an overview of the ongoing operational workplan, and special projects and initiatives scheduled within the NCRI during 2024 (the "**DOH Service Plan**") had been circulated to the board for review prior to the meeting.

18.2. Having reviewed the DOH Service Plan, **IT WAS RESOLVED THAT** the DOH Service Plan be approved, ratified and confirmed in all respects.

19. Cybersecurity

19.1. CMcG presented to the meeting on a tabletop exercise carried out by the NCRI Cyber Incident Response Team (“CIRT”) on 6 June 2024 to evaluate the NCRI’s preparedness and response capabilities to cyber incidents.

19.2. CMcG reported on the imagined cyber incident scenario and the observations and recommendations arising from the tabletop exercise were noted and discussed. There followed a discussion on the creation of a “battle box” for use in an emergency situation. **IT WAS AGREED THAT** the battle box be updated on an annual basis and confirmation provided to the board once complete.

19.3. CMcG noted that the CIRT had prepared an action plan based on the recommendations arising from the tabletop exercise (the “CIRT Action Plan”), the details of which were circulated to the board prior to the meeting. **IT WAS AGREED THAT** an update on the CIRT Action Plan would be presented at a future board meeting.

20. Minutes of Previous Meetings

20.1. The draft minutes of previous board meetings held on 20 March and 22 April 2024 (together the “Previous Minutes”) were produced to the meeting and reviewed by the board.

20.2. Following a discussion in relation to the foregoing, **IT WAS RESOLVED THAT:**

20.2.1. the Previous Minutes be approved in the form produced to the meeting; and

20.2.2. the Chairperson be authorised to sign the Previous Minutes in his capacity as Chairperson of the current meeting.

20.3. There followed a discussion on actions arising from previous board meetings and **IT WAS AGREED THAT** an action log would be created and included in the board pack for each meeting.

21. Acknowledgement of Chairperson of the Board

21.1. CMcG acknowledged the NCRI’s achievements since the Chairperson’s appointment in 2017. The board thanked the Chairperson for his invaluable support and dedication to advancing the mission of the NCRI during his tenure before wishing him well with his future endeavours.

21.2. The Chairperson thanked his fellow board members and expressed his confidence that the NCRI will continue to contribute significantly to cancer policy, service development and research.

22. Close

There being no further business, the Chairperson declared the meeting closed.