

10:00am, 14th June 2018

NCCP offices, King's Inn House, 200 Parnell St, Dublin 1.

Minutes

1. Register of attendance/apologies

Present:	Dr Jerome Coffey Dr Cathy Kelly Mr John McCormack
By teleconference:	Ms Orla Dolan Dr Anna Gavin
Apologies:	Dr Fenton Howell
In attendance:	Prof Kerri Clough-Gorr Mr Shane McQuillan Ms Vanya Sargent
By teleconference:	Ms Rose O'Mahony

2. Minutes of the previous meeting

The minutes of the February 2018 meeting were approved by the Board for publication on the Registry website.

3. Matters arising from the minutes not otherwise on the agenda

Recruitment of Board Members

The Chair reported that the Dept. of Health had commenced the recruitment process for replacement Board members.

Lease Break Clause

It was noted that the lease can be broken after five years with a notice period of one year. It is important that this is brought to the attention of the Board prior to the one year notice period.

4. External Organisational Review

Crowe Horwath walked the Board through the final draft of the report on the Organisational Review.

The Board are supportive of the report and approved the report as presented to them. They also support the recommendation to move beyond the traditional role of the Registry and into the collection of more comprehensive cancer patient experience data. Based on that recommendation the new strategy for the Registry will be developed during the next year in line with the National Cancer Strategy. The Board agreed management changes would be a priority and full implementation of the review will be delayed by development of strategy and dependant on Department of Health funding. Further funding will be sought for external HR, implementation and strategy support costs during this period. The Board approved the commencement of a tender process for external support for strategy development.

The Board expressed their gratitude to Mr McQuillan and Ms Sargent of Crowe Horwath for their work on the review.

5. Finance, Tender and Contract matters

Management Accounts to 30/04/2018

The Board reviewed the management accounts to 30th April 2018. It was reported that the Registry received the full allocation it requested for the year. Management expressed their gratitude to the Department of Health for the allocation. The Registry is in line to draw down the full allocation for the year. The extra spending on external support for the implementation of the CRS system was noted. The system is central to the Registry's business and these funds are vital to ensure adequate support is in place for the system. Continued expenditure on external support for the CSR was approved by the Board.

6. Director's Report

Two-way data transfer agreements

Prof. Clough-Gorr updated the Board on the Registry's efforts in putting data sharing agreements in place with all healthcare organisations involved in cancer-related care. She has requested that the Minister require the HSE to have a two-way data transfer agreement in place with the Registry. Such an agreement with the HSE would cover all public hospitals and organisations within the remit of the HSE. This issue will be discussed at the next governance meeting with the Department of Health (Correspondence Item 5). Once the agreement is in place with the HSE, the same will be sought with all private organisations.

In preparation for this, the staff have been requested to compile a complete list of the data received by the Registry and a list of any data fed back to the hospitals. A similar list will be compiled for each private institution.

Cervical Check

The Director reported on the role played by the Registry in the Cervical Check inquiry. Prof. Clough-Gorr has had one meeting to date with Dr Gabriel Scally who is heading up the inquiry and she expects to meet with him or one of his representatives again shortly. All of the documentation requested by Dr Scally (Correspondence Item 2) was sent to the inquiry team on Friday 8th June. The Board thanked Prof Clough Gorr and the Registry staff for their efforts.

The request for data on all women screened by CervicalCheck was queried. It was clarified that this is for the purpose of crosschecking and proper identification of patients by the Registry.

Staffing

The recruitment campaign to fill the post of Data Protection Officer/Records Manager failed to fill the post. The post will need to be redesigned and re-advertised.

Aberrance Policy

The policy (Appendix 4) was discussed by the Board. The Cancer Data Registrars are evaluating clinical data and on occasion they query whether something is clinically correct or not. The policy makes it

clear that this is not within the remit of the Registry and it is not a precedent that should be set. The policy was approved by the Board.

Data Request Approval Policy

The policy (Appendix 5) aims to maximize the accessibility and availability of the Registry's data to external researchers while maintaining patient confidentiality and compliance with the Registry's data security policies. It sets out the roles, responsibilities and approval levels for different categories of data. The policy was approved by the Board.

Publication Schedule for 2018

The Board discussed the publication schedule for the remainder of the year. They emphasised again that all draft reports, publications, factsheets etc. should be reviewed by the Board and the Department of Health at least a week or two prior to publication. The Director will update the Board on any upcoming publications.

7. Data Protection

The external DPO is currently working more than 2 days a month due to the number of subject access requests being received. His contract was initially up to 31st May. He can continue to provide Data Protection services to the Registry on a monthly basis with a months notice required for termination of contract.

The DPO is to be invited to attend the next Board meeting in September.

There are currently a large number of requests being submitted for access to personal data. These are coming from individuals and from solicitors acting on behalf of individuals. Each request is time consuming and adding to workloads. A temporary process has been implemented to deal with these requests. The process will be reviewed regularly in order to streamline the procedure. A report is to be provided to the Board at the next meeting on the volume of requests received with an approximate cost in terms of hours and resource time involved.

8. Report of the Audit and Risk Committee

The minutes of the Audit and Risk Committee meeting held in February had been included in the agenda and any items raised were discussed at the Board meeting on that date. Ms Dolan reported that the Committee had a meeting on 5th June.

The Audit and Risk Committee reviewed the management accounts to 30/04/18. They were informed that the Registry received the full allocation it requested for the year and that the Registry expects to draw down the full allocation for the year. The extra spending on external support for the implementation of the CRS system was also noted at this meeting.

The Committee was informed that auditors from the office of the Comptroller and Auditor General (C&AG) were onsite for three weeks commencing on 27th February. The final accounts have been released for Board approval but will not be ready for signing for another week as minor changes are required to the presentation and formatting. To date, the management letter has not been issued by the C&AG.

The Risk Register was reviewed by the Committee. It was agreed that the Register requires a comprehensive review prior to the next meeting.

9. Service Plan and 2018 Allocation

The Board reviewed the Service Plan which was submitted to the Department of Health. The budgeted allocation for 2018, which was included in the Service Plan was also discussed. It was noted that there is a change in the balance carried forward from 2017 relating to a pension accrual. The budget will be re forecast as the year progresses.

The Service Plan and the Budget were approved by the Board.

10. Final Accounts 31/12/2017

The final accounts 2017 were reviewed by the Board. They noted that a qualifying note (Correspondence Item 1) will be inserted by the C&AG relating to the treatment of pensions. In many public sector organisations such as the Registry, pensions are not accrued for as required under FRS102. This is under the direction of the Minister.

They were informed that the accounts had been amended since approved at the February meeting. An adjustment had been included to reflect a matured pension liability relating to a former employee who had reached the age of 60 and thus was entitled to a pension and lump sum from the Registry. Steps have been taken to ensure that such former employees are identified as soon as they reach pension qualification age.

The Board approved the signing of the accounts by Dr Coffey and Ms Dolan subject to their being no material changes.

11. Correspondence

There was no other correspondence not already discussed by the Board.

12. Other business

Dr Coffey will prepare his foreword for the Annual Report.

The submission of the Registry's performance indicators for UKIARC was queried. Prof. Clough-Gorr stated that the Registry will be included in the performance indicators next year as long as the timing of indicators does not require the Registry to submit based on incomplete data.

The next Board meeting coincides with the ENCR meeting in September. Prof Clough-Gorr assured the Board that this will not prevent Registry staff from attending.

13. Date of next meeting

The next Board meeting will be on September 25th in Cork.