**EXTRAORDINARY MEETING OF THE BOARD**

**18th OctoBER 2018 12 noon.**

National Cancer Control Programme Office, Kings Inn House, 200 Parnell Street, Dublin 1.

1. ***Register of Attendance/ Apologies***

Present: Dr. Jerome Coffey

Ms. Orla Dolan

Dr. Anna Gavin

Dr. Fenton Howell

Mr. John Mc Cormack

Apologies: Dr. Cathy Kelly

Present: Prof. Kerri Clough-Gorr

Ms. Rose O’Mahony

Mr. Hugh Sullivan (Crowe)

1. ***Dr. Gabriel Scally’s Report on the Scoping Inquiry into the Cervical Check Screening Programme - Recommendations for NCRI***

The Board reviewed Dr. Scally’s report, in particular Chapter 12, the chapter relating to the Registry. The consent signed by CervicalCheck patients was perceived to be different to that of the Breast Screening Programme in which patients signed a consent form for the exchange of data. The Board agreed that in future there should be one single consistent approach to all screening programmes.

Dr. Comber’s letter to the Board Chair, following publication of the report, will be discussed at the next Board meeting on 22nd November. The Registry’s legal firm Ronan Daly Jermyn and the outsourced Data Protection Officer have reviewed the recommendations made in the report prior to implementation of the recommendations by the Registry.

The Board agreed that the responsibility for the screening programme and any audit thereof remains with CervicalCheck but this should be supported by the Registry.

The report highlights that in some instances it was easier for CervicalCheck to obtain information from hospitals than for the Registry to do so. The Registry has had issues with office space in some hospitals but these are being addressed. Remote access to hospital systems and increased electronic data transfer will solve many of these issues. With a data sharing agreement in place with the HSE and to be negotiated with all other organisations, the Registry is hoping to develop a suite of reports which can be given back to each hospital so that a mutually beneficial two way sharing process can commence.

Initiatives which have already had initial discussion in the Registry, such as Clinical Advisory and Patient Advisory Groups, are welcome. The Board discussed the possibility of forming a sub-committees with Registry staff and external expertise to look at clinical issues. In addition to the valuable involvement with the UKIACR, the Registry needs clear internal data quality assurance and audit mechanisms. This is to be discussed in detail at the next Board meeting.

The Board agreed that the Director and Chair will respond to Dr. Scally on the report’s recommendations, acknowledging the good work and effectiveness of the Registry and the opportunities for developing and strengthening the organisation.

The first draft of the action plan for implementation of Dr. Scally’s recommendations was presented to the Board. Some actions are predicated on the proposal for formation of a National Screening Registry within the Registry. This would be a joint initiative with the National Screening Service and would require Department of Health approval.

**Report Recommendation No 36**

The HSE has signed a two way data sharing agreement with the Registry. Similar documents will have to be signed with all other organisations such as private and voluntary hospitals etc. In addition to good data governance these will facilitate remote access to data and access to electronic data. A copy of a standard MOU will be circulated to the Board. These documents will require regular review and updating.

**Report Recommendation No 37**

The Registry acknowledges the importance of timely data to cancer screening and treatment services. In 2017-8, an external organisation review was completed which highlighted the need for additional Cancer Data Registrars (CDRs) as well as CDR supervisors and increased capacity for data management intelligence. The Registry intends to develop a data architecture system which will be phased in over the next two years. Over the course of the next year, it is hoped to employ three CDR supervisors and two additional Electronic CDRs. An Electronic Data Use Register will be utilized to improve access and track progress of the Registry’s electronic data.

Dr. Gavin extended an invitation to Registry staff to visit the Northern Ireland Cancer Registry to view how electronic data is processed there. Dr. Coffey was delighted to accept this invitation on behalf of the Registry.

**Report Recommendation No 38**

The review of data definitions is an important recommendation that could and should be fully implemented within a National Screening Registry. This would apply for all current and future screening programmes not just CervicalCheck. Minimum datasets, which will include clear documented definitions, are currently being finalized. The current cancer registration system will be expanded to include fields for the screening history of all registered patients with cancer screening history. The Registry will work with the HSE and the National Screening Service (NSS) to ensure that all organisations use agreed screening-related variable definitions.

**Report Recommendation No 39**

The duplication of information by the Registry and CervicalCheck should be eliminated with the two way data sharing agreements and MOUs which will ensure proper data sharing between both organisations in the near term. The Registry proposes the establishment of a National Screening Registry as a longer term solution. The Board recommended the establishment of a working group with senior Registry and NSS staff to progress the issue of duplication in the short term.

**Report Recommendation No 40**

The composition of the Board was discussed as there are currently two vacancies to be filled. These can be used to ensure more robust governance in the areas of QA, data sharing and patient representation. The Board may request that two more non-executive directors be added to the current total of 7. The possibility of inviting experts from Europe to join the Board was discussed as an option.

**Report Recommendation No 41**

An oversight agreement is currently being drafted between the Department of Health and the Board. This agreement will incorporate the role of the Registry within the cancer screening process.

**Report Recommendation No 42**

The Registry will work with the Department of Health to develop a formal framework and funding for an annual peer review process.

**Report Recommendation No 43**

The Registry is planning to undertake a stakeholder survey before the end of the year, in addition to forming patient and clinical advisory groups as soon as possible thereafter. This will incorporate patient, external clinical and public health expertise.

**Report Recommendation No 44**

The Registry is actively working towards the assessment of the quality of cancer services via closer ties with the HSE (including the National Cancer Control Program and the National Screening Service) and the Department of Health, regular hospital reporting, a stakeholder survey, implementation of patient/clinical advisory committees and increased access to Registry data. A National Screening Registry would facilitate involvement of the NCRI in the assessment and quality of cancer services. This is firmly within the remit of the Registry’s establishment order 1991 whereby one of its functions is “To promote and facilitate the use of the data thus collected in approved research and in the planning and management of services”.

1. ***Strategy and Organisation Review***

Mr. Hugh Sullivan of Crowe joined the meeting to report on Strategy development and the implementation of the Organisation Review.

1. ***Date and time of next meeting***

The next meeting is scheduled for 1:30pm on 22nd November. If Dr Scally has not revisited the Registry by then, the meeting will be postponed until after his visit.