

The Joint Committee on Health

May 31st, 2017. Committee Room 3, Session A: 1.30 p.m.

Engagement with the Chair Designate of the National Cancer Registry Board:

Dr Jerome Coffey, Director, National Cancer Control Programme

Chairman, Committee members,

Thank you for the invitation to appear before you today. I am honoured to have been nominated to chair the Board of the National Cancer Registry. In this brief opening statement I would like to focus on the development of cancer services in Ireland over the last decade, the central role of the National Cancer Registry in this and the likely direction of short and medium term developments.

By way of introduction I am a Radiation Oncologist, appointed to the St. Luke's Radiation Oncology Network in 2006. I succeeded my colleague and mentor, the late Professor Donal Hollywood, as radiation oncology advisor to the National Cancer Control Programme in March of 2010 and, at the end of 2014, I took on the role of Director of the National Cancer Control Programme within the HSE.

In May of 2015 the steering group and patient forum charged with developing the third National Cancer Strategy were established, concluding their work two months ago. Working on this it became clear how much has changed in cancer services since publication of the last strategy in 2006. The programmatic approach and the national scale of organisation and investment have been commended by an international external evaluation panel and are in perfect alignment with EU cancer control principles. The concentration of specialist staff in the designated cancer centres has enabled multidisciplinary decision-making and the co-ordination of patient-centred care. At the same time there has been integration between primary care and hospital care with collaboration between the NCCP and the Irish College of General Practitioners on referral guidelines and electronic referral systems for common cancer types.

In preparation for today's meeting I have reviewed the National Cancer Registry Board (Establishment) Order of 1991, under the 1961 Health Act, and the 1996 and 2009 amendments to the Order. I have read the Annual Reports and Accounts from 2007 onwards and I have made contact with the outgoing Board Chair and all current Board members.

The statutory functions of the National Cancer Registry Board are to collect and analyse information relating to the incidence (all new cases) and prevalence (all existing cases) of cancer and to promote and facilitate the use of the data thus collected in approved research projects and in the planning and management of services. By international standards the Registry has been hugely successful in

fulfilling these functions. For example completeness of population coverage is 100%. Registry data are used as the starting point for all local and national cancer service design projects.

Based on the modelling work of the Registry we know that the incidence of cancer will go up by 50% between 2015 and 2025 and by approximately 100% by 2040. These figures underline the importance of the third National Cancer Strategy, to be published by the Minister shortly. Several things have to happen as a matter of urgency. About 40% of cancers can be attributed to lifestyle factors so we have to focus heavily on cancer prevention, good examples being the Healthy Ireland initiative and HPV vaccination. Secondly we have to stress the importance of early diagnosis, screening, direct access to diagnostics for GPs and a nett increase in the capacity of the healthcare system to absorb the very significant projected increase in patient numbers.

The increase in the number of both patients and long term survivors will generate a very large volume of additional data for the Registry to collect and analyse. To meet this challenge there is a clear opportunity to automate and facilitate data collection from hospitals by linkage to the national Medical Laboratory Information System (MedLIS), the national Medical Oncology Clinical Information (MOCIS) and other clinical datasets. The Registry makes it's anonymised data freely available to inform clinicians, healthcare providers and external researchers. It has it's own highly productive research output and this is going to expand significantly since the appointment of the current director last year. This is an innovative joint appointment creating a new Professor of Cancer Epidemiology in University College Cork.

In closing I would like to reiterate the importance of the National Cancer Registry as a critical element of cancer services in this country. It will become an increasingly important agency as we anticipate a return on exchequer investment in prevention, diagnostics and treatment reflected by way of improved cancer survival rates and other outcomes.

I would be honoured to contribute to it's future.

Thank you.