

Oireachtas Committee on Health – National Cancer Strategy

Opening Statement from Health Research Board

Health research saves lives. But turning research discoveries into real benefits for people's health and patient care doesn't happen by itself. The Health Research Board (HRB) supports the people, the infrastructure and the great ideas that help make it happen.

We are the lead Irish agency funding health research. Our annual budget is €45 million, and we manage an investment portfolio of €170 million.

We fund research across a broad range of health areas to prevent illness, improve health, enhance health care and inform policy. These include

- **applied biomedical research**, for example, a study reducing resistance to antibiotics, as a new treatment strategy for MRSA infections
- **clinical trials**, for example, testing effective therapies for preventing recurrence of a stroke
- **population health**, for example, monitoring the impact of HPV vaccination in Ireland
- **health services research**, for example, developing a standard assessment tool to reduce the number of adverse events happening in Irish hospitals

Our €45 million budget also covers the HRB's role in -

- Providing evidence to government to inform health & social care decision-making. Some recent examples include:
 - Public Health Alcohol Bill
 - Regulation and financing Home Care costs
 - The health effects of water fluoridation
- Managing four key health information systems that assist service planning in relation to drug and alcohol use, drug deaths, disability and mental health.

International evidence tells us that **research-active healthcare systems have better outcomes for patients.** The HRB has been at the forefront of some key research developments to enable research for health and better health care: -

- The HRB has invested in an extensive **network of three clinical research facilities, five clinical trial networks, a HRB Clinical Research Coordination Ireland 'hub'** that will coordinate Ireland's involvement in clinical trials, and a **HRB Trial Methodology Research Network** to strengthen the approach taken to trials and the way they are reported.
 - These developments were achieved in collaboration with the Health Service Executive, health professionals and the research community. This enables the best researchers and health professionals to carry out clinical research that will change people's lives for the better.
- Whether improving lives, prolonging lives or saving lives, health research must be patient-focused. The HRB has been taking a lead on **putting the patient first** by driving Public and

Patient Involvement in research that enable researchers to involve the public in their research from the start and supporting the public to participate in reviews of research proposals.

- The HRB is delivering **evidence for policy and practice**. All decision-making in relation to health must be founded on strong evidence. The HRB Evidence Centre is at the forefront of generating evidence reviews that inform health policy and practice. We also fund Evidence Synthesis Ireland, a university-based all-Ireland consortium, which aims to build evidence synthesis awareness and capacity among the public, health care institutions, policymakers, clinicians and researchers on the Island of Ireland.

Cancer research

The HRB recently analysed the spend on health research across all public funding agencies in Ireland. In the five years between 2011 and 2015, the main agencies and government departments funding health research reported commitments of over €750 million. When we looked at the spend on different disease areas, we found that cancer accounted for about 20% of national funding.

This level of investment is reflected in the HRB's portfolio. Although we fund in all disease areas and in cross cutting areas such as public health, approx. 20% of our funding is allocated to cancer research. The HRB allocated €50 million to cancer research in the five years from 2011 to 2015 making it the largest funder of cancer research in Ireland. However, it is not the only funder. For example, the next largest funder is Science Foundation Ireland with a spend on cancer research between 2011 and 2015 of over €30 million.

This pattern of expenditure on cancer is also found in other countries. For example, in the UK, about 20% of national funding for disease specific health research is allocated to cancer; in Norway it is about 25%.

Compared to the burden of disease, spend on cancer research in Ireland is reasonably well aligned, in other words the level of expenditure reflects the burden of the disease. By the same comparison, research in cardiovascular disease, stroke and mental health is relatively underfunded.

The National Cancer Strategy

We at the HRB welcome this review of the National Cancer Strategy, and the fact that attention is being given to research as part of that review. We have three recommendations that we believe will drive the research agenda for cancer into the future.

- 1. Establish the National Cancer Research Group to improve coordination of national cancer research** (Ref NCS Recommendation # 46)

As noted in the National Cancer Strategy, in the absence of a national framework for cancer research, there is a need for better coordination between different initiatives, research entities and governmental agencies through the establishment of a National Cancer Research Group to ensure cancer research is relevant, focused and cohesive.

We view the establishment of this group as an important action for 2019. The initiative would require the involvement of a range of stakeholders including the Department of Health (DoH), the National Cancer Control Programme (NCCP), Health Service Executive (HSE), research funders, including, but not limited to, HRB and SFI and the charities that fund cancer research, most notably the Irish Cancer Society.

There are several ways in which the group might set priorities for cancer research. One approach would be the James Lind Alliance facilitated Priority Setting Partnerships. However, such an approach would need to be resourced appropriately and involve public and patients.

2. Develop a culture in the cancer care system that values research for the benefit of patients, by supporting the people and leadership within an integrated healthcare system (Ref NSC Recommendation # 47 and 48)

As noted in the National Cancer Strategy, there is a lack of recognition within the healthcare system that research is a relevant, vital and critical activity. Cancer research, as with all health research, should be a core activity within the healthcare system and healthcare professionals should have the protected time to pursue research.

We strongly support the recommendation within the strategy to ensure that newly appointed cancer consultants and Advanced Nurse Practitioners have protected time to pursue research. The appropriate mechanisms must be put in place to make this a reality, not just in employment contracts, but also on the ground since in reality they are so consumed by service provision that they don't get the time to do research. So it's one thing having it written in a contract but actually delivering on it is what is needed.

We recommend that the NCCP/HSE, fund, or at a minimum co-fund, more of the core positions in the research infrastructures such as clinical research nursing and data management. This would free the HRB to invest in more trial activity. This approach would help to provide more patients with access to clinical trials and other benefits of research as the norm rather than the exception, and would create a sustainable environment for cancer research.

3. Build patient and public trust by improving the use of cancer data in an open and transparent manner (Ref NCS Recommendation #52)

The National Cancer Registry Ireland (NCR) is a world-class data infrastructure that, at a high-level, informs us about the incidence and mortality of all cancers in Ireland. However, many other data sources also exist, for example disease-specific registries, population cohort data, such as TILDA and HIPE. If these datasets were linked in a safe, controlled and trustworthy manner to the NCR data, this could provide valuable insights into cancer in the Irish population. For example, linking information on cancer incidence and mortality, to information on demographics, socioeconomic indicators and lifestyle, would help us to target cancer treatment and develop prevention strategies much more effectively.

We recommend that, under the current National Cancer Strategy recommendation 52, a 'National Health Data' project should be initiated, using the principles established in the Health Research Board's proposal for an Enabling Data Environment for Health and Related Research in Ireland (the DASSL model, [published in 2016](#)), with an initial focus on cancer.

The HRB believes that with a focused and concerted effort, Ireland - given its size, relatively centralised health system, well-connected ecosystem and growing sense of citizen engagement – could become a leader in health data management and use. This would also lay the foundations for people in Ireland to benefit fully from the advances in genomics and precision medicine that are increasingly important in cancer treatment.

A critical first step in the project would be to develop public trust. This could be achieved through citizens assembly-style meetings to build understanding of the concept, gain buy-in and establish safe data sharing and linkage principles.

Thank you for the opportunity to present at this important committee meeting. We are happy to take questions.