Section F
Thinking ahead

Key messages

- Shortages of personnel in the cancer workforce are limiting current capacity and impairing service quality, education and research
- The HSE should develop a National Cancer Workforce Plan to ensure that there are adequate highly skilled cancer care staff across all cancer-related disciplines
- Cancer education and research are essential components in the development, implementation and evaluation of a national cancer control programme
- Ireland needs to address cancer control at all levels with the assistance of a comprehensive research portfolio, encompassing all fields of cancer research
- The National Cancer Forum, in partnership with the Health Research Board, should advise on the development of a specific plan for cancer research
- The percentage of cancer patients enrolled in clinical trials is a marker of quality of care. There should be improved cancer clinical trial access for patients.

F.1 Cancer human resources

50 **The HSE should develop a National Cancer Workforce Plan designed to fully implement national cancer policy.**

Shortages of personnel in the cancer workforce are limiting current capacity and impairing service quality, education and research. Shortages can result in delayed treatment, disruption of referral patterns and interference with multidisciplinary programmes of clinical care, education and research. Many elements of the cancer control system are operating at present with reduced staffing while facing increasing caseloads. Cancer caseload is rising inexorably due to increasing incidence, expanded indications for treatment and growing prevalence of cancer survivors, all of which place additional demands on the cancer workforce.

Although cancer system requirements can be predicted using population-based models, the difficulties in obtaining accurate up-to-date information and data impede planning and policy development. Currently, it is difficult – or impossible – to obtain data on workforce numbers, vacancies, work life issues and supply factors such as training programme intakes and migration. Human resources planning must address technology change, evolution of workplace roles and changes in service delivery.

There is a clear need for a National Cancer Workforce Plan to be developed by the HSE to support the operational planning needs of the cancer system. This should further inform the development and expansion of both undergraduate and postgraduate education programmes to ensure that existing and projected workforce needs can be met. The absence of such a plan in the past has led to supply shortages in critical components of services. The rapid pace of change in demography and in technology makes this need all the more pressing.

The essential requirement of human resource planning for the cancer workforce should be the capability to collect, analyse and disseminate reliable information and data to inform all elements of the system where policies, plans and decisions regarding human resource aspects of cancer are made. This should consist of the following components and activities:

- an accurate and comprehensive registry of cancer control personnel, developed and maintained by the HSE. Individuals should be registered by discipline with data compiled and maintained from multiple sources including professional associations, the HSE and training programmes
- adequate stakeholder participation and communication in the development and maintenance of the National Cancer Workforce Plan
- an annual report describing the cancer workforce inventory and a database reporting on staffing needs and vacancies by discipline, geographic area, cancer programme or centre or other parameters as required
- a focus on the development of cancer nursing roles that reflects recent successful developments in oncology nursing and maximises the potential role that nurses can play in all aspects of cancer care
- appropriate linkages to processes to determine and implement workload-planning standards by professional disciplines, taking into account care delivery systems, role and practice models, and technical change and workforce evolution
- coordination between organisations and authorities responsible for training members of the cancer workforce
- research on issues of compensation, benefits, work life satisfaction and career development for cancer professionals to improve the attractiveness of career opportunities and enhance recruitment and retention of staff
- research and ongoing assessment of service delivery models, technical change in the workforce, including role development and evolution of different types of staff in an ever-changing health care environment, focusing on comprehensive, patient centred and community-based care of cancer patients.

F.2 Research

Research is a key factor in promoting health, combating disease, reducing disability and improving quality of care. Cancer research* is an essential component in the development, implementation and evaluation of a national cancer control programme. A scientific basis needs to be established for identifying the causes of cancer and for specifying effective strategies for the prevention, treatment and control of cancer, as well as for evaluating overall programme performance. Ireland needs to address cancer control at all levels with the assistance of a comprehensive research portfolio, encompassing all fields of cancer research.

F.2.1 Scope of cancer research

Cancer research is wide-ranging, extending over a number of key areas including:

- **epidemiological research**, which relates to the study of the distribution and determinants of disease in populations
- **prevention research**, which encompasses research into health promotion and education, screening and other early detection initiatives
- **laboratory research**, which has been a major activity in Ireland, particularly in cell and molecular biology. Extensive laboratory-based research programmes exist at various major hospitals
- **clinical research**, which is concerned with the study of the natural history of the cancer process in humans and the assessment of efficacy and toxicity of treatment
- **translational research**, which is concerned with the integration of bench and clinical research for the benefit of cancer patients and those at risk of developing cancer
- **health services research**, which is a wide-ranging, multidisciplinary field that investigates the structure, processes and effects of health care services.

In reviewing the challenges posed by cancer and the scope for improving cancer services, the 1996 National Cancer Strategy emphasised the clear case for establishing a more formal and coordinated approach to cancer research, with particular reference to clinical research. The evaluation of the 1996 National Cancer Strategy pointed to the significant increase in capacity that has taken place in cancer research since 1997, but found that there was considerable scope to further increase capacity for research, to achieve a better balance between clinical and non-clinical research, and to develop the research infrastructure needed to coordinate and govern cancer research.

The Health Strategy acknowledged the ongoing need for research with the aim of improving survival and quality of life for patients. The National Health Research Strategy *Making Knowledge Work for Health* (2001) provided a framework for the development of health research to enhance health and quality of life and to ensure that Irish research compares favourably with research elsewhere. It proposed the establishment of research and development functions within health agencies.

F.2.2 Cancer research capacity

The Health Research Board (HRB) is a statutory body that promotes, funds, commissions and conducts medical, epidemiological and health services research in Ireland. It works closely with partners in Northern Ireland, the United States and Europe to promote health research on the island of Ireland. The HRB is the main channel of public funding for research at national level. Other sources of health research funding are varied and include voluntary bodies (e.g. Irish Cancer Society), Science Foundation Ireland, pharmaceutical companies, multinational organisations and charities.

This funding has helped to significantly improve the capacity for cancer research here in recent years. In addition, specific initiatives have led to the establishment of world-class basic research facilities in a number

* *For the purposes of this strategy, cancer research includes all research relevant to cancer control, e.g. research on smoking cessation.*

of third-level institutions. In spite of this, the capacity for health services research and – to a lesser extent – epidemiological research is less well developed.

F.2.3 All-Ireland NCI Cancer Consortium

The National Cancer Institute (NCI) is the world leader in developing, conducting and supporting research in cancer control. The All-Ireland NCI Cancer Consortium was launched in 1999 as a trilateral partnership between the governments of Ireland, Northern Ireland and the United States, represented by the NCI. The major research goals of the Consortium are to enhance clinical research, conduct joint clinical research studies and sponsor formal scholar exchanges.

The Consortium has been instrumental in the development of a clinical trials infrastructure in Ireland. This model has led to the funding, by the governments on both parts of the island, of a number of hospitals or groups of hospitals to support them in carrying out high-quality research clinical trials. An all-island clinical trials group coordinates the trial activity of funded hospitals. The Consortium supports joint research fellowships, research collaborations and prevention fellowships. There is a significant potential to further develop research in cancer control on the island under the Consortium.

F.2.4 The way forward

51 **The third National Cancer Forum, in partnership with the HRB, should advise on the development of a specific plan for cancer research.**

The need for high-quality research on all aspects of cancer is critical. While excellent research is currently being conducted in Ireland in most fields of cancer control, it is far better developed in some fields than others. There is a need to establish a strategic and continuing process for identifying, overseeing and facilitating cancer research.

Funding is a recognised research development issue; the effort required to attain funding is time-consuming and resource intensive, demanding skill and experience in application. Most funding for research goes to topics chosen by investigators and has typically supported the high-profile areas of laboratory-based biomedical research and clinical research, both producing work of the highest international calibre. However, this now needs to be balanced with specific earmarking of funding for other areas such as epidemiological and health services research in order to fully inform planning related to cancer control. A recurring impediment to proactive research is the absence of dedicated research time, for health professionals. There is a need, therefore, to provide for dedicated research sessions in the contracts of appropriate health professionals.

There is a need for a specific plan for all cancer research, to ensure a strategic approach, to reach consensus on cancer research themes, to identify gaps in current research and opportunities, and to foster an effective, inclusive research function. This will help to coordinate funding initiatives, reduce duplication and guide the development of a critical mass of research activity across Ireland to meet priorities in cancer research. A specific function should be to improve the quality and use of information that would support the evaluation of programmes, treatments and outcomes.

A key element of such a plan will be the development of a formal partnership of cancer research funders. The Department of Health and Children, the Health Service Executive, the Health Research Board, the Irish Cancer Society, Science Foundation Ireland and other funders should agree a policy of national funding for cancer research that would be at the heart of a national cancer research plan. This will help ensure the identification of dedicated funding for less-developed areas of cancer research, particularly epidemiology and health services research.

The All-Ireland NCI Cancer Consortium, and other cooperative initiatives involving Northern Ireland and the European Union, should enable international collaboration in the area of cancer research to be considerably strengthened. Our small size means that we will always benefit more from international partnerships in research than from working alone.

52 There should be improved clinical trial entry for patients, both in terms of the number of trials conducted and the enrolment to them.

While entry of cancer patients into clinical trials has improved, it should be further developed. This will be achieved by raising both the number of trials that take place and the number of patients who are enrolled in them. In many other systems, the percentage of cancer patients recruited into clinical trials is a marker of quality of care. It is not just that trial patients do better – the culture change that occurs in an institution undertaking clinical research is also very important. Clinicians in these circumstances are reported to become more open to scientific approaches, more likely to comply with guidelines, and generally to improve their evidence-based care. In order to ensure that this is addressed as a key element of cancer service provision, a specific target should be set for recruitment of patients into clinical trials in each network and each Cancer Centre.

53 Ireland should establish a national tissue bio bank to support research and service delivery.

Ireland should establish a national tissue bio bank that is based on international standards and collects appropriate data on stored samples. The initial aim of such a development will be to support research, but as technology develops it may have a more direct service delivery benefit.

54 The HRB should establish a national cancer research database.

A national database containing information on all cancer research would prove an invaluable asset to cancer researchers nationally and internationally. All cancer research undertaken in Ireland should therefore be captured and classified using a standardised system. This will greatly facilitate the coordination of cancer research as well as facilitating insight into the overall national balance and direction of cancer research.