Section E
National Framework for Quality in Cancer Control

Key messages

- The health system must deliver quality assured cancer control services based on best practice internationally. A National Framework for Quality in Cancer Control is required to achieve this objective
- HIQA should establish national site-specific multidisciplinary groups to develop guidelines for quality in major site-specific cancers
- All patients should receive care in designated Cancer Centres and services that are licensed and participate in continuous accreditation mechanisms devised by HIQA for the management of cancer
- The establishment of HIQA, which will subsume the National Cancer Registry, provides a significant opportunity to develop a cancer surveillance system that will build on the existing system of cancer registration
- Mandatory notification of cancer should be put in place through appropriate legislation
- HIQA should ensure that the public has access to high-quality up-to-date information about all aspects of cancer
- GPs should have comprehensive information that enables informed referral and other management decisions
- Health technology assessment is a key component of evidence-based practice. HIQA should convene a national group representative of the stakeholders in cancer care to determine priorities for health technology assessment.

E.1 A National Framework for Quality in Cancer Control

40 **HIQA should establish a National Framework for Quality in Cancer Control.**

It is essential that the health system is capable of delivering and quality-assuring cancer control services that are based on best practice internationally and deliver the best possible health return for a given level of investment.

The analysis set out in Section B shows significant gaps in the performance of cancer services and clearly demonstrates the need for specific measures to enhance and measure the quality of services. In addition, it identifies a need to strengthen the information base of all aspects of cancer care and to provide assessment mechanisms for the rapidly advancing technological environment.

One of the reasons why care has not always reflected the highest possible standards is that a national mechanism to develop, implement, monitor and update cancer control plans and guidelines has not existed. In order to ensure that all elements of cancer control conform to best practice and that this can be demonstrated, HIQA should establish a National Framework for Quality in Cancer Control consisting of:

- National Quality in Cancer Control Groups for major site-specific cancers
- A statutory system of licensing and accreditation that should apply to both public and private sector services
- An information model and infrastructure to meet the information needs of patients, professionals, managers and policy-makers
- A model of health technology assessment.

Each of these elements of the National Framework for Quality in Cancer Control is outlined in the following sections.

E.2 National Quality in Cancer Control Groups

41 **HIQA should establish site-specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers.**

HIQA should convene groups at a national level (National Quality in Cancer Control Groups) to address quality in respect of major site-specific cancers. These groups will produce guidance for all common cancers. The precise cancers to be addressed at any given time should reflect national cancer priorities and should be agreed between HIQA and the Department of Health and Children.

National Quality in Cancer Control Groups should broadly address each of the following areas:

- evidence-based guidance and standards
- performance indicators which relate to the guidance and standards
- information and data requirements
- arrangements for the monitoring and updating of the guidance.

National Quality in Cancer Control Groups will therefore require substantial involvement of clinicians and other staff involved in the direct delivery of cancer care. This will ensure that, to the greatest degree possible, the standards and guidelines are 'owned' by cancer care professionals and other stakeholders.

The National Cancer Forum views the recent initiative of the Tánaiste and Minister for Health and Children in setting up the National Quality in Cancer Control Group for Symptomatic Breast Disease Services under the auspices of the Irish Health Service Accreditation Board as an excellent model for the development of similar National Quality in Cancer Control Groups for other site-specific cancers. Its terms of reference are shown in Box E.1.

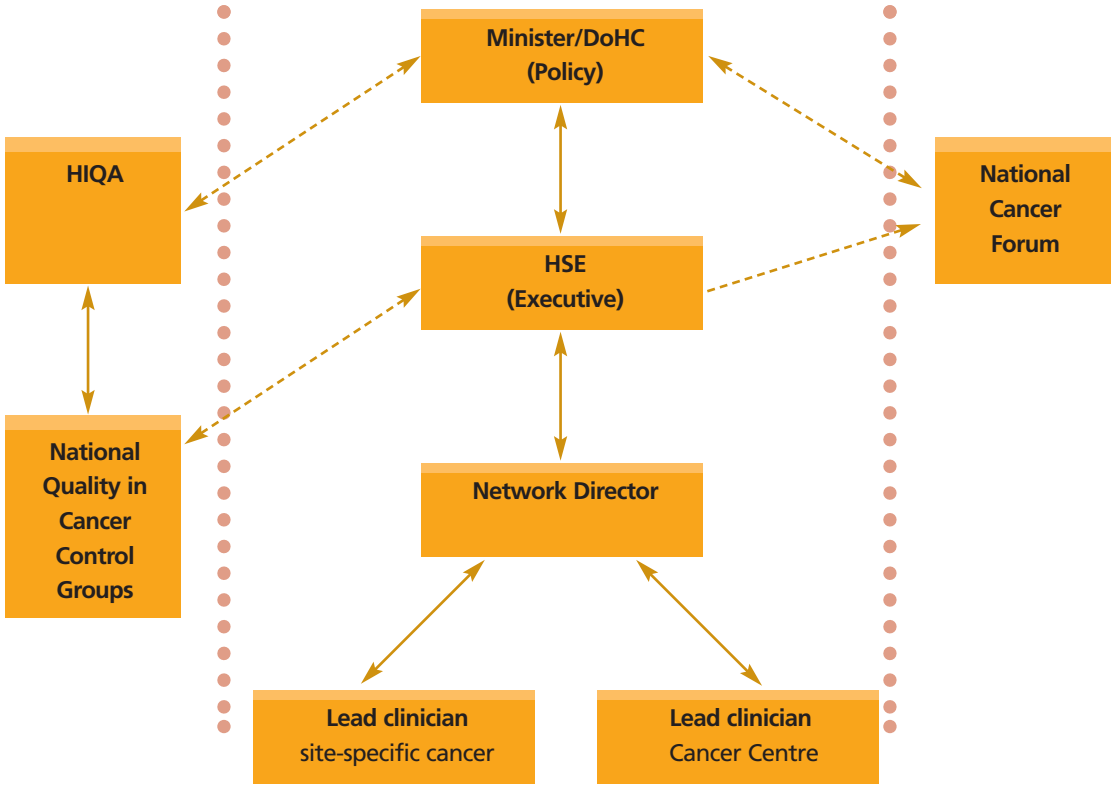
Box E.1
Terms of reference of the National Quality in Cancer Control Group for Symptomatic Breast Disease Services

Having regard to international best practice and best available evidence and the requirements regarding quality assurance as set out in the Report to the National Cancer Forum on the Development of Services for Symptomatic Breast Disease, to:

1. develop an agreed set of guidelines for the interdisciplinary management of breast cancer
2. convene relevant subspecialty groups to develop subspecialty specific guidance for surgery, pathology, radiology, medical oncology and radiation oncology
3. develop an agreed set of interdisciplinary performance indicators for the management of symptomatic breast cancer
4. convene relevant subspecialty groups to agree on subspecialty specific performance indicators for surgery, pathology, radiology, medical oncology and radiation oncology
5. agree a minimum dataset of information to be collected in each unit which would enable the performance indicators set out to be generated
6. establish information technology requirements to gather the agreed minimum dataset
7. set out a plan to enable the implementation of these guidelines and performance indicators, having regard to the existing service planning process
8. continually update guidance and performance indicators for the management of symptomatic breast cancer
9. produce an annual report based on the agreed performance indicators.

Figure E.1 shows key national relationships for quality in cancer control. The Minister has overall responsibility for cancer policy and is supported in that role by the National Cancer Forum. The HSE is responsible for implementation of policy and should do so by developing the Network Director and clinical lead roles on a geographic and cancer site-specific basis as described in the section on Managed Cancer Control Networks. HIQA will convene the individual National Quality in Cancer Control Groups in order to develop guidance and standards.

Figure E.1 Key national relationships for quality in cancer control



E.3 Licensing and accreditation

42 **HIQA should develop a system of licensing and accreditation of Cancer Centres and services that should apply to both the public and private sectors. The system of licensing and accreditation should be given statutory effect.**

Given the evidence of variation in the performance of cancer services in Ireland set out in Section B, there is a requirement to license and accredit Cancer Centres and services* through the development of national licensing and accreditation systems. While these will reflect international experience, a system that is Irish-designed and reflects the requirements of this country is necessary. This will drive improvement in quality and safety of cancer services by providing a mechanism to apply evidence-based standards.

** In this context, services applies to other cancer services that take place in the network but outside the designated Cancer Centres and includes diagnostic and other services in private hospitals, palliative care etc.*

It should be necessary for each Cancer Centre and service that participates in the provision of cancer services to be licensed for the provision of those services. Centres and services that are licensed should – as a condition of licensing – participate in ongoing accreditation processes aimed at continually raising standards. This will require the development of a statutorily based licensing and accreditation scheme that should apply to all services, both public and private.

Criteria for licensing and accrediting Cancer Centres and services should be based on international best practice models and should conform to standards and guidelines developed by the National Quality in Cancer Control Groups. These should include case volume, multidisciplinary care, clinical structure, process and outcome of care, user satisfaction etc. Only centres that meet licensing standards should be designated as Cancer Centres. Once licensing and accreditation mechanisms have been devised and implemented, no patient should receive care outside of Cancer Centres and services that are licensed for the management of cancer.

E.4 Information and cancer control

Accurate, timely and relevant information is a central requirement of a strategy for cancer control. Good information underpins appropriate decisions, whether by patients, health professionals, researchers, managers or policy-makers. Consistent availability and use of health information leads to better-informed patients and a better-informed public, improved service delivery, enhanced quality and efficiency and effective planning. This is necessary for the development of a high-quality cancer control system in Ireland.

E.4.1 Cancer surveillance

43 **HIQA should develop a cancer surveillance system that will build on the existing system of cancer registration.**

In the health arena, surveillance consists of the ongoing collection, analysis and dissemination of data of public health importance to allow for the planning and implementation of health policy. Cancer surveillance provides a quantitative portrait of cancer and its determinants in a defined population and allows the effectiveness of cancer policy to be evaluated. It also raises questions that form the basis for cancer research and interventions for cancer prevention and control. Cancer surveillance functions include:

- monitoring trends in cancer incidence, prevalence and survival over time and between different geographic areas, social groups, and other defined populations
- evaluating the effectiveness of cancer prevention and screening
- evaluating the quality and outcomes of cancer care
- evaluating the impact of environmental and social factors on cancer risk
- supporting investigations into the causes of cancer
- providing information in support of cancer genetic counselling services for individuals and families at higher risk of developing cancer.

The development of cancer surveillance will allow services to be planned and evaluated in keeping with evolving needs for services. The establishment of HIQA, subsuming the National Cancer Registry, provides a significant opportunity to make early progress on the development of cancer surveillance.

44 **Mandatory notification of cancer should be put in place through appropriate legislation.**

Cancer reporting needs to be as complete and as accurate as possible. Many countries, and some individual states in the US, have put in place legal requirements for notification of cancer in order to protect the integrity of cancer registration. The National Cancer Registry has been a very successful element of the cancer services here. A legal requirement to notify cancer cases to HIQA would preserve this function, which is vital to planning, evaluation and research in cancer. The Department of Health and Children should pursue this as matter of urgency.

45 **HIQA should ensure that a minimum national dataset should be collected for all cases of cancer.**

Cancer surveillance will require unified national approaches to information standards, information collection and the technology required to underpin these activities. This will require that data from hospitals and other notification sources be released more frequently, ideally each month. A minimum national dataset should be collected for all cases of cancer. This will ensure that standard, comprehensive and appropriate information is collected on all cancers. It should reflect similar developments in related areas, such as the minimum dataset for palliative care. It will require information collected by HIQA to be extended to include risk factor surveillance (including lifestyle-related risk factors), as well as process and outcome of care indicators relating to all aspects of care from prevention to palliation.

E.4.2 Information for patients, families and carers

46 **HIQA should ensure that the public has access to high-quality up-to-date information about all aspects of cancer.**

Access by patients to the right information at the right time is a vital component of cancer care. Empowered and informed members of the public can make better decisions that can, for example, help to prevent cancer. This empowerment can also enable earlier detection of cancer, and when a diagnosis of cancer is made, enable patients to participate more fully in decisions about their care.

The principal strategic benefit to the system of empowering and informing patients in this way is improvement in the health of the population. It will also improve public accountability in that people will be more empowered to have a say in matters that directly bear upon their health and their lives.

HIQA, in partnership with the voluntary sector, should produce cancer-related information for the public, consumers, patients, relatives and carers. This should be easily accessible and understood by those of different educational standards and cultures and should be trusted by users. It should cover causation, prevention, early detection and screening, diagnosis and treatment, pathways of care and 'What to do' guides.

E.4.3 Information for health professionals

47 **General practitioners should have comprehensive information that enables informed referral and other management decisions.**

GPs have a particularly important role in the control of cancer as reflected in Section D. Many patients will consult a GP to explore symptoms and it is at this level that the diagnosis of cancer will often be initially suspected. The decision the GP makes in terms of referral direction and timing can have an important bearing on the process and outcome of care that a patient may experience.

It is therefore necessary for the GP to be as informed as possible about services available. This will require that Managed Cancer Control Networks and Cancer Centres supply all GPs with a range of information designed to ensure informed and appropriate decisions. This should include information relating to care pathways, waiting times, caseload for site-specific cancers and implementation of quality standards according to external quality assurance processes.

48 **Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.**

Information systems and information technology should support the management and delivery of patient care services as well as their quality assurance through audit, accreditation and other processes. The development of electronic care records would facilitate a number of developments to support cancer care such as:

- integrated care pathways
- integration of hospital care with primary care and other services
- access to evidence and knowledge resources
- decision support systems
- costing of interventions and processes of care
- audit
- accreditation.

E.5 Health technology assessment

49 **HIQA should establish a Cancer Health Technology Assessment Panel.**

Health technology assessment (HTA) is a key component of evidence-based practice. It involves the application of the best available evidence about the medical, organisational, social, ethical and economic implications of the development, diffusion and use of health technologies. These aspects are usually specific to the technology being examined. HTA has a vital role in ensuring that care technologies, including drugs, are used in a manner appropriate to their ability to maximise health gain and achieve value for money.

The knowledge base of technology assessment is multidisciplinary, spanning clinical science, epidemiology, sociology, anthropology, bio-statistics, law, business management and economics. Experts who assess drugs, devices, tests, procedures and other types of health care technologies and interventions seek to derive credible findings from numerous and sometimes contradictory studies of widely varying quality.

Research findings are published in detailed reports that serve a principal objective of disseminating results in a form useful to decision-makers who are in a position to use them. By identifying and communicating how limited health care resources can be most effectively applied, technology assessment can assist in policy development and planning efforts. The analytic frame applied in assessment activity may take into consideration any or all of the following concerns:

- the benefit of using a technology or procedure for a particular clinical problem
- the safety of the technology
- the implications of using the technology
- considerations of costs, cost benefits and volume of services.

HIQA will oversee the development of HTA and promote its use to inform vital policy decisions, from initial evaluation to implementation, monitoring and review of outcomes. It will draw upon HTA work carried out in other countries. HTA structured on this basis will enable the system to:

- speedily introduce technologies with proven, significant health benefits
- ensure that technologies which are introduced meet appropriate evidence-based standards
- continuously monitor the effectiveness of technologies after introduction.

HIQA should convene a national group representative of the stakeholders to determine priorities for health technology assessment in cancer care. The initial emphasis should be on diagnostic and therapeutic technologies, including drugs that are new to the system. These health technology assessments should identify the levels in the system at which a given technology should be provided. It should also – where appropriate – identify the relevant disciplines to provide a given technology.

Resource allocation processes within the HSE should ensure that technologies of proven benefit are rapidly disseminated through appropriate services. These processes must have substantial involvement from relevant clinical disciplines and this will require appropriate information to be available to ensure that technologies are applied in this way. The Cancer Health Technology Assessment Panel should monitor and report annually on the distribution and utilisation of new technologies throughout the cancer care system to ensure effectiveness, fairness and equity.