

# Section D

## Managed Cancer Control Networks

### Key messages

- All cancer care should be provided through a national system of four Managed Cancer Control Networks, each serving a population of approximately one million people
- Managed Cancer Control Networks will provide integrated primary, hospital, palliative, psycho-oncology and supportive care underpinned by a formal structure of clinical leadership
- A Network Director should be appointed by the HSE as soon as possible to each Managed Cancer Control Network to support and direct implementation of cancer policy. The Network Director will lead a team consisting of a lead clinician for each major site specific cancer and a lead clinician for each Cancer Centre within the network
- The HSE should develop care pathways for cancer care to link primary care, hospital care and other relevant services. They will be specific to major cancer types and will reflect guidelines and standards set down by HIQA
- A 'designated health professional' should be identified to provide patients, their families and carers with education, support and coordination in cancer care
- Cancer Centres that each serve a minimum population of 500,000 should be designated by the HSE as soon as possible. Ireland will require about eight such centres
- The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government
- Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams
- There is a need for continued expansion in capacity which should be addressed by a needs assessment for cancer services with a particular emphasis on hospital-based cancer treatment that maximises the use of ambulatory care
- Service level agreements between the HSE and the private sector for specific cancer services – with centres licensed and accredited for such services – will enable a cooperative relationship between the public and private sector
- A National Cancer Genetics Policy should be developed by the National Cancer Forum
- Each Managed Cancer Control Network should have comprehensive specialist palliative care, psycho-oncology and psychosocial support services
- A partnership framework should be developed between the HSE and the voluntary sector.

## D.1 Introduction

Cancer care is a dynamic process involving the interaction of many different elements of the health system. Although they are often considered separately (e.g. primary care versus hospital care, or palliative care versus cancer treatment), the overall quality and performance of services as delivered to patients is dependent in a very significant way on how well these elements integrate and coordinate with each other. Services must be planned and organised in a manner that facilitates integration so that, from the perspective of the user, the whole system operates in a complementary and efficient manner.

This section sets out a series of recommendations based on the findings set out in the Analysis section (Section B). They are aimed at creating a system – based on Managed Cancer Control Networks – that is fully integrated in addressing the needs of populations and patients with cancer. It identifies requirements for clinical leadership and quality systems that will enable the successful operation of these networks. The agenda for change extends to patients and the general public, and requires a growing awareness and acceptance of the requirement for services to be organised around specialist care as well as around appropriate technologies.

## D.2 Managed Cancer Control Networks

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**All cancer care should be delivered through a national system of four Managed Cancer Control Networks, each serving a population of approximately one million people.**

Cancer care has traditionally formed a hierarchy connected by clinical referral (i.e. local to regional to national). Patients are often transferred within and between services with varying levels of coordination and integration of care. This has not made best use of the knowledge, expertise, experience and technology that our system has to offer. The organisation of cancer services should ensure that patients receive the highest standards of care possible and that their care will not depend on where they live, where or to whom they initially present, or their knowledge of the services.

To achieve this, a national framework is required consisting of Managed Cancer Control Networks in which care is fully integrated between primary care, hospitals, palliative care, psycho-oncology and supportive care. This should take full advantage of the resources available to ensure the delivery of services that are of the highest quality and are equitable and accessible.

A Managed Cancer Control Network will feature the sharing of patients, expertise and resources. It will allow, for example, hospitals to cooperate to provide services when the population base of each is too small for them to do this in isolation. The emphasis in such a network will be on connection and partnership rather than isolation and self-sufficiency, on distribution of resources rather than centralisation, and on maximising the benefits for all patients.

The Health Service Executive should organise all the services it provides (primary, community and continuing care, as well as the National Hospitals Office) in four networks on a national basis, each serving a catchment population of approximately one million people. This is a tried model for cancer care in that cancer control networks in other countries are organised around similar population sizes. At this level each Managed Cancer Control Network should be self-sufficient in all but a small number of comparatively uncommon or complex cancers.

Establishing Managed Cancer Control Networks and operating them effectively will present new challenges to culture and attitudes across primary care, hospital care, palliative care, psycho-oncology and supportive care. Relationships between health professionals will have to be carefully and clearly defined if staff are to function effectively and realise their potential. Mobility of staff should be facilitated. As the key 'collegiate' resource within each network, consultants should have sessional commitments to the network as well as to specific institutions.

### D.2.1 Managed Cancer Control Network Director

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**A Network Director should be appointed by the HSE as soon as possible to each Managed Cancer Control Network to support and direct implementation of cancer policy.**

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**A lead clinician for each Cancer Centre should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site-specific cancer in partnership with all stakeholders within the network. The Cancer Control Network Director should head this team of lead clinicians.**

The National Cancer Forum, based on experience to date, on consultation with the current Regional Directors, and on evaluation of the 1996 National Cancer Strategy, is strongly of the view that the regional clinical leadership role needs to be strengthened. In particular, this should ensure that the Network Director has a meaningful role in cancer services in the network including resource allocation, priority setting, service planning and evaluation. The post should involve at least a half-time commitment.

The role of the Network Director should be to provide strong and effective clinical leadership in the implementation of cancer policy within a given network. The director will oversee the development and implementation of cancer care pathways for major site-specific cancers that reflect national policy and priorities and are based on guidelines and standards set down by HIQA.

There should be one director for each Managed Cancer Control Network. In order to ensure equity and balance between Cancer Centres (as defined in Section D.3), the postholder position should be rotated within a given network area every two to three years. The four Network Directors should be a significant resource within the national cancer programme of the HSE.

A lead clinician for each Cancer Centre should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site-specific cancer in partnership with all stakeholders within the network. The Network Director should lead this team of senior clinicians.

These positions should be seen as key leadership positions in bringing cancer care in each network to the highest possible standard and as such should lead to identified individuals having a 2–3 session per week protected time commitment. As with the director position, these positions should be appointed as quickly as possible and rotated every two to three years.

It would be especially important in the early years that the persons appointed to these roles are senior clinicians from the Cancer Centres in the network. This will be essential to create the necessary buy-in during the process of developing and implementing the critical functions ascribed to the networks. It would be equally important that after the initial development phase these positions would involve clinicians drawn from other elements of the Managed Cancer Control Network.

## D.3 Elements of the Managed Cancer Control Network

The following sections describe each of the elements that will comprise a Managed Cancer Control Network:

- primary care
- hospital care
- palliative care
- psycho-oncology
- supportive care.

### D.3.1 Primary care

Primary care is usually the first point of contact with the health system. It acts as a gatekeeper for secondary care services. Patients usually begin the cancer care process in primary care with symptoms or signs being initially presented to general practitioners (GPs). The process usually involves referral into the acute hospital system and, if required, on to palliative care services or one of a number of community based services as they live with their cancer.

There is a wide variety of cancer care roles carried out in primary care at present (Box D.1) and its importance in relation to cancer services was recognised clearly in the first National Cancer Strategy. However, there is considerable scope to develop a much greater role for primary care in cancer control. The Primary Care Strategy, *Primary Care: A New Direction* provides a clear strategic focus for the development of primary care. The expansion and development of this model will ensure that primary care can have a greater impact on the burden of cancer.

This aim could be facilitated by ensuring that the contractual relationship with GPs reflects the requirement for a greater emphasis in primary care on health promotion and disease prevention activities (including national population screening programmes). It would be further facilitated by improved direct access to hospital-based diagnostic facilities from primary care.

### Box D.1: Primary care cancer services

<b>Health promotion</b>
<ul style="list-style-type: none"> <li>• raising awareness of lifestyle-related risks for cancer</li> <li>• smoking cessation initiatives</li> <li>• alcohol advice and management services</li> <li>• diet and exercise advice</li> <li>• risk factor modification</li> </ul>
<b>Early detection and screening</b>
<ul style="list-style-type: none"> <li>• recognition of early signs and symptoms of cancer</li> <li>• raising awareness of early signs and symptoms of cancer</li> <li>• delivery of population-based screening programmes e.g. smear taking</li> <li>• raising awareness and uptake of screening</li> <li>• advice regarding nature of and indications for screening</li> </ul>
<b>Direct service provision</b>
<ul style="list-style-type: none"> <li>• palliative care</li> <li>• managing social, nursing and other aspects of cancer care in the community</li> </ul>
<b>Communication</b>
<ul style="list-style-type: none"> <li>• explaining cancer to patients and families</li> <li>• explaining cancer services to patients and families</li> <li>• providing ongoing reassurance to patients and families</li> <li>• explaining/interpreting hospital care services for families of cancer patients</li> <li>• liaising with hospital care services</li> </ul>

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**The HSE should develop care pathways for cancer care to link primary care services, hospital services and other relevant services.**

Cancer care pathways can be described as a map that is followed by patients with the same or similar conditions between various services, centres and settings involved in the management of cancer. Care pathways should be at the heart of Managed Cancer Control Networks. The development of care pathways should guide the process of cancer care delivery within a particular network. Once drawn up, they will provide a source of information for primary care professionals on cancer care services within a given Managed Cancer Control Network in an integrated and organised manner centred around the needs of individual patients.

Primary care is pivotal in the coordination of the wide variety of services that patients may use. It therefore needs to see itself and be seen as a key partner in the delivery of effective secondary care services. This coordinating role should be reflected in care pathways that integrate all services.

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**Improved cancer information services should be available to primary care.**

A significant challenge for primary care is the fact that GPs may see on average only one or two new diagnoses of cancer among their patients each year. However, they may see many patients who have cancer and others who have survived cancer. They must be able to differentiate between those patients whose symptoms may be due to cancer and the much larger number with similar symptoms due to other causes.

GPs and other primary care professionals need information about cancer and its symptoms. They need to know when, how and where to refer patients. They also need to understand the process of cancer care as delivered in hospitals and other settings. They need this information because they are often required to explain cancer to patients, to describe the process of care to patients and families, and to provide reassurance.

Information for primary care professionals concerning all aspects of cancer and its treatment should be available, using all media, to ensure that professionals have timely and trusted information on which to base decisions. HIQA will have a central role in the development of such services. This is dealt with in more detail in Section E.

## **26 The HSE should develop programmes that support primary care professionals in the provision of cancer services.**

Continuing medical education and professional development programmes should be developed that ensure primary care professionals are fully aware, *inter alia*, of signs and symptoms of cancer, the role and use of screening and diagnostic technologies, indications for referral, and processes of specialist care.

## **27 The HSE should ensure that systems are in place to identify and support a 'designated health professional' as a contact person for each individual cancer patient who may require it.**

Patients with cancer often have complex care processes to follow. Even in the event of well laid out care pathways, the course that an individual patient may follow can vary. Many patients may not be able to manage the coordination of their own care as well as managing their illness and may come to rely on others who can help them navigate through the system. The 'designated health professional' would fulfil this role. Designated health professionals provide patients, their families and carers with education and support and coordinate care through the continuum of care.

### **D.3.2 Hospital care**

Cancer care in hospitals faces significant challenges to enable it to meet the aim of providing appropriate and timely access to services that are of the highest standards of quality by international standards. Hospital services need to expand to ensure that they meet the needs of an ageing and changing population. Paradoxically, the analysis set out in Section B shows that there are too many hospitals and too many consultants providing surgical care for many types of cancers.

In addition to this fragmentation of cancer care, the analysis also raises considerable uncertainty about the ability of smaller hospitals to adapt and implement future changes in the delivery of cancer care, especially for complex cancers. Several factors contribute to this uncertainty, including having too low a caseload to maintain clinical expertise in the use of complex diagnostic and treatment techniques, staff training, quality assurance and risk management strategies.

## **28 Cancer Centres that each serve a minimum population of 500,000 should be designated by the HSE as soon as possible. Ireland will require about eight such centres.**

It is clear that the hospital sector must address the need for continued expansion of capacity while limiting cancer care to a smaller number of Cancer Centres which then come together in Managed Cancer Control Networks to pool knowledge, expertise, experience, skills and technology. There is clear evidence that people who have surgical treatment for many common cancers in centres with higher throughput, experience better quality of care and better survival rates. Services that take place in such centres are generally characterised by the following features:

- care is more specialised, thus increasing the likelihood of better survival
- there are higher caseloads of patients, increasing the experience and ability to sub-specialise of individual clinicians and clinical teams
- diagnosis and treatment planning is conducted by multidisciplinary teams
- care delivery is informed by evidence-based guidelines
- audit and other quality assurance programmes are in place
- there is participation in clinical trials and other forms of cancer research
- undergraduate and postgraduate teaching takes place.

Cancer Centres should serve a minimum population of 500,000 and must be networked to all other elements of the health system. This catchment size will ensure that there is a balance between geographical access and the need to ensure that caseload and other economies are maximised. A smaller size will prevent minimum evidence-based thresholds for breast cancer surgical care being achieved. Breast cancer is chosen as a benchmark because it is one of the commonest forms of cancer and because the evidence relating the organisation of services to the outcome of care is stronger for breast cancer than for any other cancer type.

While a population of 500,000 would provide sufficient workload for the management of breast, prostate or colon cancer, it could not support the management of more complex but less common cancers, such as cancer of the pancreas or the oesophagus. Some Cancer Centres should therefore provide a higher level of care for certain types of cancer, based on their existing subspecialty expertise and on the need for larger volumes than would present in a single Cancer Centre. Examples of such expertise would include BreastCheck, oesophageal surgery, pancreatic surgery, haematological malignancy and radical prostatectomy.

No single centre should lead on all such services within the network. Rather, the Cancer Centres within a Managed Cancer Control Network should work together to provide services it would not be appropriate to replicate in all Cancer Centres. Cancer Centres should be seen as equal partners within each network, rather than being related in a hierarchical fashion. A network consisting of two or three Cancer Centres would provide a level of comprehensiveness unattainable by a single centre.

Individual centres may also function as national centres; all services of a particular nature for the country may either be delivered or directly led by them. Existing examples in this regard include paediatric oncology, surgery for transplantable hepatobiliary malignancy, stem cell transplantation, neurological tumours and bone cancer.

It is important that the HSE designates Cancer Centres as soon as possible so they can begin to plan their development, to ensure that they can best fulfil their role in terms of appropriate staffing and infrastructure.

The development of Cancer Centres should allow for certain circumstances in which care may need to be delivered in other centres (non-cancer centres) for pragmatic reasons such as patient convenience. It is essential that this should happen only under the direct supervision of a Cancer Centre. The Cancer Centre should retain responsibility for the diagnosis and all aspects of treatment planning. This is the model that is successfully operating in the field of paediatric oncology.

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**The HSE should conduct a needs assessment for cancer services with a particular emphasis on hospital-based cancer treatment that addresses the need for continued expansion in capacity and maximises the use of ambulatory care.**

There has been substantial expansion in cancer services in recent years. However, the analysis conducted in the preparation of this Strategy shows that there will be a continued need for services to expand to meet the rising needs in the coming years. The need for additional capacity throughout the Managed Cancer

Control Network and in particular in the hospital system, will have to be carefully planned to take account of the need to reorganise and reform care within the existing hospital system and to maximise the efficient utilisation of infrastructure and services.

Length of hospital stay for cancer in Ireland compares unfavourably with many other EU15 countries. While the reasons for this are likely to be multifactorial, it may represent inefficiency in the process of care in hospitals. It is in the interest of patients and the service as a whole that best possible use is made of hospital-based services.

Hospital care can be provided on an ambulatory basis, as in day case or outpatient services, or it can be delivered on an in-patient basis. Patients would prefer not to spend unnecessary time in hospital and one of the aims of cancer treatment provision should be to maximise the potential role of ambulatory care to ensure that people are managed as in-patients only where ambulatory care is not possible or appropriate. Sufficient dedicated cancer bed capacity should be available to provide necessary in-patient services.

There is a need for the HSE to plan the development of cancer service capacity at both national and network levels in a way that maximises the use of ambulatory care. These developments should be based on detailed needs assessments for hospital care that take account of:

- changing demography and epidemiology
- existing levels of service provision
- current developments such as radiation oncology, BreastCheck etc.
- the provision of cancer care as an integrated programme delivered by specialised teams
- the need to align developments within the HSE with Managed Cancer Control Networks and a limited number of Cancer Centres
- the need to ensure equity in the provision of hospital care between networks
- trends in medical technology.

In order for additional capacity to be developed in the interim, the HSE may choose to enter into service level agreements with the private sector. Such interactions may improve cooperation between the public and private sectors. However, in order to ensure that minimum safety and quality standards are equivalent in both the public and private sectors, service level agreements between the HSE and the private hospital sector should only be developed with private hospitals that have been licensed for the provision of those services and participate in ongoing national accreditation processes as described in Section E.

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**The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government.**

In July 2005, the Tánaiste and Minister for Health and Children announced a National Network for Radiation Oncology Services. This plan represents a major expansion in radiation oncology services that will bring Ireland into line with its future capacity requirements and with international best practice.

It will ensure that cancer services are fully integrated by arranging for services to be provided by multidisciplinary teams covering the modalities of surgical oncology, medical oncology and radiation oncology. The National Radiation Oncology Network is based on the major recommendations of the Expert Group Report *The Development of Radiation Oncology Services in Ireland* approved by the Government in September 2003.

Given the major shortfall in existing radiation oncology services documented in this Report, it is imperative that the National Network for Radiation Oncology Services should be established as quickly and efficiently as possible and in accordance with the timelines set by Government.



### **31 Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams.**

Cancer services are best provided by teams of clinicians (doctors, nurses, allied health professionals and other specialists) who work together effectively. Team working brings together staff with the necessary knowledge, skills and experience to ensure high-quality diagnosis, treatment and care. Together with Recommendation 27, this will also improve the coordination and continuity of care for patients. Irrespective of the type of cancer, or the point in the system where a patient initially presents, care planning and delivery by an appropriate specialist team is essential.

There is good evidence that patients with many common cancers are more likely to survive and to experience better outcomes if they are treated by specialist teams. Patients need to be assured therefore that their care is being provided by specialist teams. Progress has been made in establishing multidisciplinary teams for some cancers and in some institutions. However, the provision of cancer care by specialist teams needs to be developed as a consistent feature of care across the various types of cancer within each Managed Cancer Control Network.

The Network Director of each Managed Cancer Control Network should seek to ensure the establishment of inter-Cancer Centre or inter-network case conferences where appropriate to major site-specific cancers, so as to ensure that the best available expertise and skills are brought to bear on patient care.

### **32 The HSE should conduct a review of the number of centres required for the management of symptomatic breast disease to bring them into line with designated Cancer Centres.**

The Report of the Sub-Group of the National Cancer Forum on the Development of Services for Symptomatic Breast Disease (2000) recommended the development of fourteen centres, on the basis of a minimum annual caseload of 100 new cases of breast cancer. This volume of activity is necessary to guarantee quality care for women with breast cancer.

BreastCheck is being rolled out nationally. Taken together with the recommended extension in the upper age limit for screening to 69, screening can be expected to reduce the number of women who present with symptomatic breast cancer by one third to one half. It will, therefore, bring a number of previously identified centres below the minimum recommended caseload. Consequently, the number of centres required for the management of symptomatic breast disease must be reviewed to ensure that they align with the Cancer Centres to be designated by the HSE.

### **33 The HSE should conduct a national needs assessment for rare cancers.**

A number of highly specialised areas of oncology have not been addressed to the extent that they should. Examples include neuro-oncology and ocular oncology. There is a requirement to ensure that the needs of patients requiring highly specialised national services can be met. This will require the HSE to plan developments in these areas on the basis of a national needs assessment for rare cancers. There will continue to be a need for recourse to international services in exceptional circumstances.

### **34 A National Cancer Genetics Policy should be developed by the National Cancer Forum.**

Major advances have been made in recent years in cancer genetics. Because of easy access to cancer cells (from blood or bone marrow), genetic abnormalities in haematological malignancies (leukaemias and related disorders) are now well documented. These abnormalities not only serve as a very useful diagnostic tool but

have also allowed stratification of patients into different risk groups in terms of prognosis and treatment. An understanding of the molecular basis of the genetic abnormalities has facilitated the development of a new generation of effective anti-cancer drugs.

The increasing worldwide understanding of the role of genetics in the provision of cancer care is leading to an increased demand for the development of services in the area and presents major medical, organisational and financial challenges that need to be addressed to ensure patients get the highest quality care. The opportunity now exists to bring policy into line with medical advances in the area.

The National Centre for Medical Genetics at Our Lady's Hospital for Sick Children, which has received significant recent funding for staff and equipment, provides a national diagnostic service for patients with acute and chronic leukaemia and related malignancies. It is imperative that this national service is maintained at its current level of activity and expertise and avails of future developments in technology in this important area of cancer care.

A National Cancer Genetics Policy should be developed by the National Cancer Forum. The plan should address the organisation, development and priorities in the following key areas: (i) inherited familial predisposition to cancer; (ii) cancer risk profiling of persons without inherited mutations; and (iii) molecular diagnostics and molecular therapeutics.

### D.3.3 Palliative care

#### ***What is palliative care?***

Palliative care is the continuing active total care of patients and their families, at a time when the expected medical outcome is no longer cure. It responds to physical, psychological, social and spiritual needs, and extends to support in bereavement. The goal of palliative care is to ensure the highest possible quality of life for both the patient and their family. Specialist palliative care services are those services with palliative care as their core specialty and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

#### ***The Report of the National Advisory Committee on Palliative Care, 2001***

**35** The HSE should ensure that each Managed Cancer Control Network has a comprehensive specialist palliative care service.

*The Report of the National Advisory Committee on Palliative Care* (2001) describes a comprehensive palliative care service and acts as a blueprint for its development. The service should support the patient wherever the patient may be – at home, in hospital, in residential care, or in a specialist palliative care unit.

The HSE should ensure that each Managed Cancer Control Network has a comprehensive specialist palliative care service to meet the needs of patients and families. This will enable a range of benefits including the incorporation of palliative care into patient care plans at an appropriate stage in the management of their disease; an enhancement of the palliative care capacity of primary care; integrated care pathways and multidisciplinary teams that incorporate palliative care services.

**36** A formal linkage should be established between the National Cancer Forum and the National Council for Specialist Palliative Care.

The Tánaiste and Minister for Health and Children has established a National Council for Specialist Palliative Care in line with the recommendations of *The Report of the National Advisory Committee on Palliative Care*. Its role is to advise on the development and implementation of national policy on palliative care services in

Ireland. In order to ensure effective integration of policy, there should be formal links between the National Council for Specialist Palliative Care and the National Cancer Forum.

### D.3.4 Psycho-oncology

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**The HSE should ensure that access to comprehensive psycho-oncology and psychosocial support is provided for cancer patients and their families in each Managed Cancer Control Network.**

Multidisciplinary psycho-oncology services need to be provided to identify and manage distress in cancer patients. Structures should be developed in each Managed Cancer Control Network to ensure that each Cancer Centre has a dedicated psycho-oncology service and is capable of meeting the psychosocial needs of patients and their families. An important part of meeting this obligation will be the provision of ongoing training for cancer team members to ensure effectiveness in the management of psychosocial distress in cancer patients. Training should include communication, the detection of psychosocial problems, provision of support to patients and families, and identification of the need for onward referral as necessary.

### D.3.5 Supportive care

All patients with cancer deal with issues that cause some level of distress at some stage. Regardless of prognosis, the initial diagnosis of cancer is still perceived as a life-threatening event. While many patients cope well, a high proportion develops significant psychosocial distress. More than a third of patients experience anxiety and/or depression. However, most busy oncology services are not currently set up to reliably detect distressed patients. Evidence shows that when people experiencing cancer receive good social and psychological support, their quality of life improves.

#### **Cancer support services**

The main policy developments in cancer support services in Ireland have been informed by *Cancer Support Services in Ireland: Priorities for Recommendation* (1999) and *The Report of the National Advisory Committee on Palliative Care* (2001). The latter is dealt with in Section D.3.3. *Cancer Support Services in Ireland: Priorities for Recommendation* found that there was an absence of adequate formal psychosocial support services. It made a series of recommendations for the development of supportive care services.

The voluntary sector in Ireland has, to date, been the mainstay in the provision of supportive care for cancer patients in the community. The Irish Cancer Society has been a major provider of nursing services to patients with cancer and has also made other major advances in support services such as help-lines, help promotion campaigns, printed literature and public information days. The Society also aids the development of support groups by offering professional advice and assistance to those affiliated to the Society.

A range of voluntary cancer support groups, centres and advocacy groups exists throughout the country providing invaluable assistance and support to patients. Examples include ARC Cancer Support Centres, Reach to Recovery, EuropaDonna and Canteen. In addition, about 400 self-help groups exist throughout Ireland. They provide support for cancer patients and their families, especially in dealing with emotional and practical challenges of the disease.

#### **Future direction of supportive care services**

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**A partnership framework should be developed between the HSE and the voluntary sector.**

Significant work is done by the voluntary sector and merits continued support, particularly in the development of supportive care. Practical help, for example dealing with everyday concerns of patients and their families in relation to financial strains, hidden costs and transport issues, is of particular value.

The necessary expansion of these roles is best carried out by the voluntary sector. There would, however, be a benefit in seeking to develop a more structured partnership with the voluntary sector to ensure the provision of services on a consistent national basis in a manner that best complements services provided by other sectors and organisations.

**39**

**A code of practice should be developed for self-help groups, support groups and support centres.**

Support groups and self-help groups exist nationwide. Cancer support centres, set up near Cancer Centres but independent of them, are recent and successful developments. Their further development, with integral outreach services to ensure widespread patient access would be beneficial to patients and to the system as a whole.

The development of a code of practice for the spectrum of support groups and self-help groups would be beneficial. This would greatly strengthen supportive care. There is no umbrella body at present to which all self-help and support groups are affiliated. Affiliation to the Irish Cancer Society of these voluntary groups would constitute a progressive step forward.