

# DEPARTMENT OF HEALTH

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# The National Cancer Plan for the Isle of Man 2012-2022







# Foreword

I am delighted to introduce the National Cancer Plan for the Isle of Man. Cancer touches us all, whether we contract cancer ourselves, or have friends and family who have had cancer. In recent years, there has been considerable progress in the understanding of cancer and its treatment, leading to significant advances in the quality of care and the treatment which cancer patients receive.

As our population ages, the number of people who develop cancer will continue to increase. Because of the advances in diagnosis and treatment, more people are living with, and beyond, cancer than ever before.

At a broader level, the Department of Health (DH) has emphasised the need to focus its attention on prevention and early detection, in the Strategy for the Future of Health Services in the Isle of Man. Nowhere is this more applicable than in the field of cancer. The DH, working with other Government Departments and the Third Sector, has already developed several programmes of cancer prevention. Screening offers an opportunity to detect cancer early and eradicate it before it advances. In addition to cervical and breast screening, last year we introduced bowel cancer screening.

The rising cost of healthcare is a challenge that every country in the world faces; in addition, we have to meet this rising cost against a backdrop of financial constraints. Again, cancer is an area where there are rapid advances in diagnosis and treatment - more so than in many other areas. We need to ensure that we provide a Cancer Service which can provide the latest form of treatment, but at the same time make certain that we secure maximum improvement in health for the resources expended. We also need to ensure that we balance the needs of cancer patients with those with other conditions. All these present major challenges which we will need to address.

The National Cancer Plan sets out the direction for the development of cancer services. To address the details and costs, an implementation plan will be developed by DH, working closely with other stakeholders. This implementation plan will focus on the delivery of a high-quality Cancer Service for the Isle of Man.



Hon D M Anderson, MHK Minister for Health





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# 1. Introduction

This Plan seeks to ensure the efficient and effective use of resources to provide a quality-assured Cancer Service for the Isle of Man. The Plan links to the Government Strategic Plan and other strategies that support preventative measures to reduce the incidence of lifestyle-related cancers.

This chapter sets out the context for this Plan - it looks at:

- Issues we are tackling.
- What the public, patients, their carers and clinicians want in relation to cancer services.
- Working with Third Sector organisations.
- Isle of Man issues.
- Vision and Aim for cancer services in the Isle of Man.
- Drivers for change.

### 1.1 Issues we are tackling

Cancer affects us all. Even if we do not develop cancer ourselves, we all have family and friends who have had cancer. Surveys in England show that people fear cancer more than anything else. Therefore, it is paramount that we provide a Cancer Service that meets the needs of the population.

### 1.2 What is the public likely to want with regard to Cancer Services?<sup>1</sup>

1 Department of Health (DH) Improving Outcomes: A Strategy for Cancer (Jan 2011)

- In the Isle of Man the public's wishes are likely to include:
- Reassurance that cancer patients and their carers have rapid access to high-quality diagnostic and treatment services in the Isle of Man and / or in the UK as appropriate.
- Information and advice on how to reduce their risk of cancer.
- Access to services which help them to reduce their risk of cancer for example, the Quit4You service (free, stop-smoking service).
- Information on the signs and symptoms of cancer, so they can seek help early if problems arise and thereby improve their chances of a cure.



- Balanced information on screening programmes so they can make informed choices.
- Access to high-quality screening programmes. These can detect cancer early before it causes signs and symptoms.

### 1.2.1 What are cancer patients and their carers likely to want?

- Good access to assessment and diagnostic services which can either exclude cancer or make a diagnosis without delay.
- Access to reliable and balanced information about their condition, possible treatments and side-effects, so they can make choices appropriate for them.
- Certainty that, if their diagnosis confirms cancer, they will be treated with the minimum of delay.
- To be reassured that everyone involved in their care and treatment will work effectively together, so that their care will feel seamless even when delivered at different locations.
- To know that they will receive the support they require (physical, emotional, social, spiritual and financial) throughout their treatment.
- To know at the end of their treatment they will be supported to regain as normal a life as possible. To be given advice on how to minimise their risk of developing further cancer-related problems, possible signs of recurrence and long-term effects of treatment, and know how to access specialist services without delay should they need to do so.
- To know if they are approaching the end of life, their preferences for care will be discussed with them and every effort will be made to meet their needs and their preferences for care.
- Where possible and appropriate, to regard carers as partners in care provision and ensure they receive the support they need.



# **1.2.2** What are professionals involved in prevention, diagnosis, treatment, and care of cancer patients, likely to want?

- The training, support and information they need to deliver high-quality care.
- To work in a team that has all the necessary expertise to achieve good outcomes.
- To work in a Service that is well-managed / led, so that their time is used effectively to ensure that care is streamlined for patients.
- Appropriate staffing and funding to deliver a high-class Service.

### **1.3** Working with Third Sector organisations

The Department of Health has a significant role to play in leading cancer services for the Isle of Man. However, it is important to recognise that there is a number of Third Sector organisations which provide high-quality innovative support services for cancer patients and their carers, and participate in developing strategies and service delivery planning. Partnership working with, and between, these organisations, cancer charities, individuals and other organisations can make an even bigger difference in the fight against cancer.

For example:

- Cancer charities raise awareness of cancer, raise money to fund research and services, and also deliver some services and programmes.
- Macmillan Cancer Support has assisted in the development of cancer services in the Isle of Man.
- The wider Third Sector of voluntary, charitable and faith organisations funds and provides a wide range of services which complement and supplement statutory provision.
- Hospice Isle of Man provides specialist palliative care for patients and their families facing life-limiting illness.



- The Cancer Services User Forum has been set up to provide a voice for cancer patients and their carers.
- Many people in the Isle of Man affected by cancer support each other, both informally and through support groups.

### 1.4 Isle of Man Issues

### 1.4.1 Financial constraints

The economic recession all over the western world, plus the changes in the VAT sharing agreement locally, have led to financial constraints for the Island as a whole. This calls for a change in culture among professionals, statutory and Third Sector organisations and the public. Interventions need to be prioritised and interventions which do not afford value for money should be considered for decommissioning. For example, the delivery of services that have limited effectiveness or value should be discontinued. This is essential if the Isle of Man is to be able to fund new advances which may offer better health gains.

### 1.4.2 Reconfiguration of Services

The reconfiguration of services is prompted by:

- Financial constraints.
- Scientific evidence of the relationship between volume and outcome.

This means that it is neither affordable nor acceptable for Isle of Man cancer services to be completely separate from those of the UK. The Isle of Man needs to be a part of the Merseyside and Cheshire Cancer Network (MCCN), to establish close links with the network and tertiary services to ensure continuity of care, so as to guarantee the best possible outcomes for Isle of Man patients.



### 1.5 Vision and Aim for Cancer Services in the Isle of Man

### Vision Statement

To provide a comprehensive Service for patients from the Isle of Man, initially on a par with the best region in the UK.

### Aim

Our aim is to reduce cancer incidence, morbidity and mortality for the population of the Isle of Man and to improve the experience and outcomes of cancer patients and their carers.

### 1.6 Drivers for Change

The drivers for change can be grouped as:

- Isle of Man Government key strategies
- Changes in the field of cancer services
- General changes in healthcare organisation and delivery
- Information and choice.

### 1.7 Isle of Man Government Key Strategies

There are several strategies, policies and plans which can influence and help shape the cancer services; these are:

### 1.7.1 Published Strategies

### Isle of Man Strategic Plan 2007 - 2011

This Strategy aims to "develop and target programmes which help to ensure that people have the opportunity to reach their full potential in health terms".

# Department of Health (DH) – A Strategy for the Future of Health Services in the Isle of Man (2011)

This document sets the strategic direction for the health services in the Isle of Man over the period 2010 - 2020.



### **DH Tobacco Strategy**

The Tobacco Strategy has three main objectives:

- To prevent the start of the tobacco habit by nonsmokers, especially young people.
- To reduce the number of users of tobacco products.
- To reduce the exposure of non-smokers (including children) to others' tobacco smoke.

### **DH Physical Activity Strategy**

This Strategy has been developed to encourage the Isle of Man population to become more active with a view to improving their health and well-being.

### Department of Social Care (DSC) Carer's Strategy

The first Carer's Strategy was produced by Government in 2003 and has been continually revised and updated to reflect changing situations. The Department is charged with its implementation.

The Strategy identifies the needs of carers and sets out a programme detailing how Government works with the Third Sector organisations and carers, building upon existing practice to ensure the identified needs are incorporated into all Government Strategies.

### DSC Learning Disability Strategy 2007 - 2012

This Strategy is underpinned by the Island's brand 'Freedom to Flourish', which means that everyone must be valued and have opportunities to live life to the full, making a positive contribution to the Manx economy and society. This can only be achieved by working collaboratively with other Government Departments and the Third Sector organisations.



### DSC 'Living Life to the Full' Strategy

This Strategy focuses on partnership working with other organisations to achieve best-quality outcomes, maintaining independence, and empowering people to be full partners in their care needs.

# Chief Minister's Updated Drug and Alcohol Strategy - 2005 onwards

This Strategy continues to focus on measures to reduce demand and supply of illicit drugs and reduce alcohol-related harm.

### 1.7.2 Strategies being progressed

### **DH Framework for Tackling Childhood Obesity**

This Strategy presents the key issues and actions needed at a local level over the next 10 - 15 years to bring about a comprehensive, well-coordinated and sustained response to the complex problem of childhood obesity among Isle of Man 0- to 18-year-olds.

### **DSC Mental Health Promotion Strategy**

This draft Strategy presents key themes for mental health promotion and well-being. It focuses on mental health improvement across the lifespan. The action plan is organised around the key themes to improve the mental health and wellbeing of the population of the Isle of Man, based on effective partnerships across all sectors.

### **DH End of Life Strategy**

This Strategy, which is currently being developed, looks at the key issues and actions needed for the next 3 years (to 2015) to provide end-of-life care (whatever the disease) to all adults in the Isle of Man.



### 1.8 Changes in the field of Cancer Services

Cancer services have undergone rapid changes within the last 10 - 15 years and this progress is likely to continue. There is a need for a strategic direction to ensure that the developments in the field of cancer are translated into local services so that Isle of Man patients benefit fully from such innovations.

The main changes in the field of cancer services are as follows:

# 1.8.1 Reconfiguration and development of cancer services in the UK <sup>2</sup>

The starting point for reconfiguration of cancer services in the UK was the publication of the Calman-Hine Report. The Calman-Hine review was undertaken because of the observation that cancer survival rates in the UK were poor when compared with those of other Western European countries. The report initiated a series of reforms including the publication of several reports, targeted investment in cancer services, development of targets and the appointment of a National Director for Cancer Services. The impact of these changes has resulted in a rapid development of cancer services in the UK. It is fair to observe that local services in the Isle of Man have lagged behind those in the UK and there is an urgent need to address this inequality.

### 1.8.2 Technical developments in cancer diagnosis and treatment

There has been rapid progress in both the diagnosis and treatment of cancer, new modalities for treatments are being introduced and new drugs are being licensed. It is essential to ensure that Isle of Man patients receive the benefits of such technical developments.

### 1.8.3 Cancer screening

Screening to detect cancers has been well-established in the UK for cervical cancer, breast cancer and bowel cancer. Similarly, in the Isle of Man, screening programmes are established for cervical, breast and bowel cancer. It is likely that over the next decade, screening may be introduced for other cancers such as prostate. Screening for genetic markers of cancer ('genetic screening') - both for the diagnosis and treatment of cancer - is another area in which progress is likely in the next decade. Early

2 The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales: A Policy Framework for Commissioning Cancer Services (Calman Hine Report -April 1995)



detection by screening ensures a better outcome and improved overall survival. It is important for the Isle of Man to ensure that residents receive the benefits of early detection.

### 1.8.4 Advances in prevention of cancer

The role of lifestyle factors in the causation of common cancers is well-established. Advances have been made in identifying effective interventions which will address the lifestyle factors. Further development in this area is the vaccine for the Human Papilloma Virus (HPV). The HPV programme - to prevent cervical (and other) cancers - is well-established. It is likely that other vaccines which prevent cancers will be introduced in the near future - for example, for Hepatitis B.

### 1.8.5 Increased survival of patients with cancer

Due to improvements in diagnosis and treatment, the number of people who recover from cancer is on the rise. Unlike survival following other conditions, survival following cancer treatment creates several unique challenges and it is important to address these.

### 1.8.6 Increase in the number of cases and complexity of cancer

Due to the aging population, the number of cases of cancer diagnosed will increase, cancer being predominantly a disease of over-65s. In addition, elderly people diagnosed with cancer are likely to have other chronic health problems and this renders treatment more difficult.

### 1.9 General changes in Healthcare Organisation and Delivery

These have been detailed in the document 'A Strategy for the Future of Health Services in the Isle of Man'. To summarise the key headings:

- Demographic Changes (with aging population).
- Technological advances (leading to cost inflation, which calls for prioritisation).
- Changes in healthcare workforce.
- Changes in healthcare organisations (with separation of strategic planning and operational management, the two being linked by 'commissioning').



• Increased public expectation and knowledge.

### 1.10 Information and Choice

Information will be central to the drive for better outcomes. Access to good-quality information underpins stronger commissioning and patient choices, helping the public to make the right decisions to reduce their risk of cancer and to support them in accessing screening, diagnosis, treatment and survivorship care. Information also enables commissioners to drive up the quality of services and outcomes and to make efficient use of resources.

### 1.10.1 Information for patients, carers and the public

- Patients and carers must have the information they need, at the time they need it, to make the right choices about help and treatment.
- The public must have the information they need to make the right choices about healthy lifestyles.

### 1.10.2 Statistical information

The Departments of Health and Social Care must have the information they need to enable them to make the right decisions around commissioning and the provision of quality services.

For example:

- Improve the quality of data which underpins expenditure information on cancer services.
- Investigate different aspects of cancer care so that trends, patterns and good practice may be identified.

### 1.10.3 Effective and accessible information

High-quality cancer services for the Isle of Man depend on having accurate, relevant, timely and accessible information available to help patients, commissioners, providers and clinicians.

To be effective, information must be:

• Comprehensive and trustworthy.



- Engaging, so people are willing and able to use it.
- Empowering, so that they know how it can make a difference.

### 1.10.4 Somerset Cancer Register

The Somerset Cancer Register (SCR) is a single database application, designed to be used as a tool to assist in the diagnosis and management of the patient and to reduce duplication of information collected at different points on the patient pathway. It will also provide aggregated input for planning, quality and monitoring. The Department of Health is in the process of implementing the SCR for the Isle of Man to improve cancer services.

### 1.11 Achieving our Vision

To achieve our vision to provide a service for patients from the Isle of Man - initially on a par with the best region in the UK - will be essential to prevent more cancers developing in the first place, and to ensure that those which do, are diagnosed while the cancer is at an early stage. To do this, a range of services relevant to cancer is in place or will be introduced within the timeframe of this Plan.

This includes:

- Public health / cancer intelligence.
- Primary prevention interventions.
- HPV vaccination service.
- Screening programmes, including screening quality assurance (QA).
- Early diagnosis and treatment.
- Targeted campaigns to raise public awareness of symptoms and to encourage early presentation to a health professional.
- Recording and analysis of cancer-relevant data via the North West Cancer Registry (NWCR).



# 2. Cancer Intelligence

Cancer Intelligence refers to analysing and interpreting cancer data. To enable the effective use of data obtained from the health services, the data needs to be analysed and presented in a format which will ensure its appropriate use. It goes without saying that the quality and accuracy of raw data from which the intelligence is gathered is of paramount importance.

### Cancer Intelligence is essential for two broad purposes:

- Epidemiological.
- Service planning and monitoring.

### 2.1 Epidemiological

Data on incidence and prevalence of different cancers is necessary to:

- Identify any unusual patterns of cancer in the Island, so that possible factors contributing to these patterns may be sought and measures put in place to overcome the effects of such factors.
- To monitor trends in incidence of cancers and relate these to interventions such as the introduction of screening programmes.

### 2.2 Service Planning and Monitoring

- To plan the provision of services for Island residents with different forms of cancer.
- To identify gaps in service provision.
- To monitor the quality and effectiveness of services.
- To compare the outcomes for cancer patients and their carers in the Isle of Man with those of other countries so as to redesign local services when appropriate.



### 2.3 Data on Cancer Incidence and Prevalence

At present, the main source of data on cancers across the Island is the North West Cancer Intelligence Service (NWCIS) which produces annual figures on different types of cancers in the Isle of Man as well as North West England.

Coding clerks at Noble's Hospital collect and process the data manually and send it to the NWCR for appropriate analysis.

### 2.4 Data from other Service Providers

Patients with a diagnosis of cancer receive care from a number of other services providers, such as Hospice, Social Services, Social Security and Third Sector organisations. There is no overall data which is made available by these organisations with regard to cancer patients and their carers, since the organisations operate their own systems and there is no linkage between the systems, service data or data collected by other providers.

### 2.5 Data on Risk Factors

Local data on major risk factors for cancer - such as smoking, obesity and diet - was not available until recently. The Public Health Directorate has undertaken an adult health and lifestyle survey and this has filled the gap. It is planned to repeat the survey at least every four years to monitor the trends.

### 2.6 Summary of Data currently available

The following is a summary of the data currently available.

### 2.6.1 Data of risk factors for cancer

Table 1 on the next page summarises the result of the Health and Lifestyle Survey which was published in June 2010.

Many factors appear favourable compared with North West England. However, North West England is not a good comparator since the North West has a poor health status compared with England as a whole, and it includes urban conurbations such as Liverpool, Manchester and Bolton.



# Table 1: Overview of results from the Isle of Man Health and Lifestyle Survey and North West 2007 Survey

		Current C			Smoking		Alcohol		F			al A	Acti		y	-							an		Nutr	itio							Obesity	-					ral	Hea	alth				Domain
	allo and a state of a	nrohlems related to old age	Louis most mine for someone with loss term ill beath or	Carers	Smoking behaviour		Levels of alcohol consumption			Severinely seriesion	Sedentary hehaviour			Level of physical activity			Endt and constable constant	Salt consumption			Type of butter, margarine or spread usually used				Type of oil or fat usually used for cooking or frying food		ope of think for drifting in ope of correct of on certains	lice of milk for drinks in tea or coffee or on cereals			Bread consumption		Obese and overweight					Chronic conditions				Heart attack and stroke		Self-assessed 'not good' health	Group
	Adults who care for someone 50+ hours per week	Adults who care for someone 20-49 hours per week	Adults who care for someone 1-19 hours per week	Adults caring for someone with long-term ill health or problems related to old age	Adults who currently smoke	Adults who binge drink	Adults who consume harmful levels of alcohol	Adults who consume hazardous levels of alcohol	Adults who are sedentary for less than 2 hours a day	Adults who are sedentary for >2 hours $\leq$ 4 hours a day	Adults who are sedentary for >4 hours $\leq 8$ hours a day	Adults who are sedentary for 8 hours or more a day	Adults undertaking low levels of physical activity	Adults undertaking moderate levels of physical activity	Adults undertaking high levels of physical activity	Adults who eat no portions of fruit and vegetables a day	Adults who eat five portions of fruit and vegetables a day	Adults that rarely or never add salt at the table	Adults that generally DO NOT have salt added to food during cooking	Adults who use another spread	Adults who use cholesterol lowering spread	Adults who use low fat spread or half fat ghee	Adults who use butter, full fat ahee or hard margarine	Adults who use vegetable oil	Adults who use bard or soft margarine, half fat butter or ghee	Adults who have no usual type	Adults who use skimmed milk	Adults who use semi-skimmed milk	Adults who use whole milk	Adults who eat wholemeal bread	Adults who eat brown bread	Adults who eat white bread	Adults who are obese or overweight	Adults who are obese	Adults who had suffered from hypertension in the last 12 months	Adults who had suffered from depression in the last 12 months	Adults who had suffered from back problems in the last 12 months	Adults who had suffered from arthritis in the last 12 months	Adults who had suffered from angina in the last 12 months	Adults who had suffered from asthma in the last 12 months	Adults who had suffered from at least one chronic condition in the last 12 months	Adults who had been told by a health professional that they had suffered a stroke	Adults who had been told by a health professional that they had suffered a heart attack	Adults with self-assessed 'not good' health	Measure
	25.5%	18.2%	56.4%	8.0%	19.1%	15.3%	3.4%	10.6%	17.3%	29.8%	35.7%	17.1%	32.4%	28.8%	38.8%	3.9%	48.2%	62.8%	51.8%	4.0%	7.8%	22.4%	65.9%	97.0%	0.5%	2.4%	19.8%	61.7%	16.1%	32.9%	20.7%	35.3%	50.4%	15.9%	15.6%	5.4%	15.3%	12.5%	2.5%	8.5%	43.9%	2.5%	3.8%	5.1%	value
Contraction of the second s	32.2%	15.1%	52.7%	9.6%	22.5%	18.3%	3.4%	13.0%	22.0%	34.7%	31.6%	11.7%	34.8%	26.3%	39.0%	4.8%	41.9%	59.8%	51.5%	3.7%	7.7%	31.0%	57.6%	95.2%	0.8%	2.2%	17.3%	65.7%	14.9%	28.0%	21.1%	35.7%	49.1%	15.0%	17.6%	9.8%	16.7%	17.8%	3.5%	9.1%	48.7%	2.7%	3.7%	8.2%	value

Source: Isle of Man Health and Lifestyle Survey and North West 2007 Survey

No significant difference

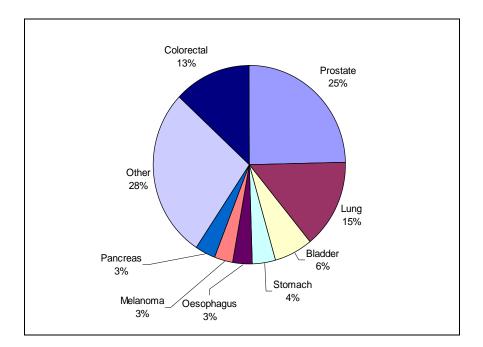


• It is not possible to compare accurately the Isle of Man figures with those obtained from other regions in England, because different regions have used different questionnaires and survey methodology.

### 2.6.2 Data from North West Cancer Intelligence Service (NWCIS) - Isle of Man Cancer Registrations

Complete analysis has been undertaken by NWCIS for the cancer registrations for the 5-year period from 2001 to 2005.

The following pie charts show the distribution of cancers by organ in the Isle of Man. During the 5-year period there were 901 cancer registrations for males and 922 for females. For men, the most common site was prostate (25%), lung (15%) and bowel (13%). For women, the most common sites were breast (35%), bowel (12%) and lung (11%).

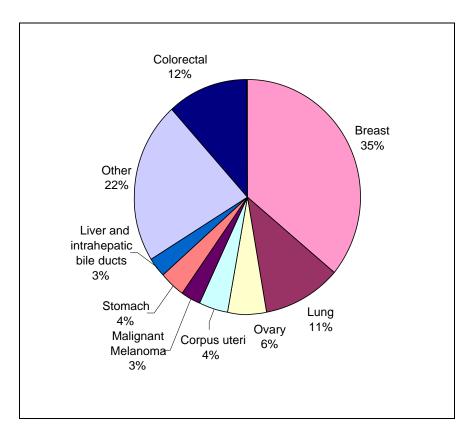


### Cancer Incidence 2001 - 2005Males, N = 901

Source: Review of Isle of Man Cancer NWCIS - November 2008



### Cancer Incidence 2001 – 2005 Females, N = 922



Source: Review of Isle of Man Cancer NWCIS - November 2008

### 2.6.3 Where do we want to be in the future?

The ideal data system for cancer should satisfy the following criteria:

- Data collected only once and transferred to all systems electronically.
- All data is electronic.
- Patients are identified using NHS numbers.
- Data from all service providers feeds into one patient record with level access restricted on a need-to-know basis.
- There should be a linkage between the screening systems and the hospital-based diagnostic system.



• The system could be used for operational purposes (patient consultations, Multi-disciplinary Teams (MDTs)) as well as being capable of providing aggregated data for service planning and epidemiological purposes.

### Strategic Objective

To implement the Somerset Cancer Register in the Isle of Man.

### Priority Targets

- To ensure accurate and complete data collections, including staging data, on all Isle of Man cancer patients.
- To ensure linkage between screening systems and hospital systems to permit longitudinal follow-up.
- To link finance data with activity data to enable appraisal of cost-effectiveness and value for money.

### Key Implementation Tasks

- Implementation of the SCR and ensuring that it links with other optimal systems.
- Adequate training and back-up for all users to enable the efficient use of the SCR.
- Linkage of screening systems with the SCR or Medway.
- Auditing the outcome for Isle of Man cancer patients in comparison with those of the UK and Europe, standardised for each stage.



# 3. Prevention and Early Diagnosis

### 3.1 Cancer Screening Programmes

Screening for some types of cancer is well-established and remains the most effective way of early detection. The aim of screening is to detect disease at the earliest possible time. When used as a public health measure, screening implies the widespread use of a simple test in the apparently healthy (asymptomatic) population. Screening will not diagnose the disease but it will separate the population by separating them into two groups – those who require further investigation to confirm or refute the diagnosis, and those who are unlikely to have the disease and require no further testing.

The natural history of any disease and the ideal time for screening can be illustrated schematically as follows:



Therefore, screening is possible only for those diseases for which there is a relatively long pre-clinical phase during which it is possible to detect the disease.

### 3.2 Screening Programmes available in the Isle of Man

The Isle of Man at present has three screening programmes which fulfil the criteria as proposed by the World Health Organisation (WHO), and are as follows:

- Cervical
- Breast
- Bowel



### 3.3 Cervical Screening

Data on cervical screening is produced every quarter. Data on uptake rate and on inadequate smears by Practice is then circulated to all Practices. There is no data for detection rates or stage of cancer detected.

### 3.4 Breast Screening

Since the Isle of Man breast screening is co-ordinated from Coventry, the UK standards apply. The data is produced using the National Breast Screening System (NBSS).

### 3.5 Bowel Screening

The full roll-out of the Isle of Man Bowel Screening Programme for 60- to 69-year-olds (using the Faecal Occult Blood test – FOBt) took place in July 2011.

### 3.6 Problems with the Data

The data for cervical screening is produced primarily for finance purposes and is not linked to Secondary Care data or outcomes.

### 3.7 Where we are now

- The Isle of Man has introduced Cervical, Breast and Bowel Screening Programmes.
- The Quality Assurance (QA) process for breast screening follows that of the UK.
- The Cervical Screening Programme needs to have a co-ordinated quality assurance programme.

# 3.8 Maximising the benefits of Screening Programmes in the Isle of Man

In order to maximise the benefits from the screening programmes, we need to empower the greatest number possible from all groups in the population to make an informed choice to participate in cancer screening. The Department of Health will work with partners to consider options for informed choice and devise and deliver campaigns to raise awareness of cancer signs and symptoms as a lever to raise awareness of screening programmes in the Isle of Man.



### Strategic Objectives

- To introduce screening programmes in line with recommendations of the UK National Screening Committee.
- To monitor the developments in genetic screening, preventive medicine and vaccines for cancer and introduce these interventions provided that they meet the appropriate criteria.
- To provide community education and information in a variety of formats that are easily accessible to the public.
- To undertake periodic audits of the information provided to ensure that the information is accessed, is adequate, is easily understood and is helpful to the public, and to modify the information in the light of audit results.
- To raise awareness of the conditions for which screening is offered and the details of how to access the screening programme among professionals and the public, to ensure a high uptake.

### **Priority Targets**

- Establishment of a co-ordinated QA programme to cover all screening programmes.
- Horizon scanning to identify new scanning programmes / techniques which are being considered by the UK National Screening Committee with a view to introduction locally.

### Key Implementation Tasks

- Ensure adequate QA mechanisms for all screening programmes.
- Educate the population to ensure a high uptake of screening programmes and to reduce socio-economic disparities.
- Link the screening data with hospital data to assess the effectiveness of the screening programmes.
- Educate the public to prevent the introduction of untested and ineffective screening projects.



### 3.9 Risk Reduction <sup>3</sup>

 World Health Organisation (WHO) Cancer Fact sheet No. 297 (October 2011) Improving health outcomes and quality of life are key priorities and major focus points of the Strategy for the Future of Health Services in the Isle of Man.

According to the World Health Organisation (WHO), more than 30% of cancers could be prevented by modifying or avoiding key risk factors. Modifying key lifestyle factors can also have important health benefits across a range of life-limiting diseases such as heart disease, stroke and respiratory disease.

If we are to tackle the health problems caused by smoking, poor diet, obesity, alcohol misuse and lack of physical activity, we need to work in partnership across Government, private and Third Sectors to create an environment that encourages the population to make healthy choices by making the healthier choice the easier option.

### 3.10 How are we tackling the Risk Factors?

Much is already being done in the Isle of Man with regard to health improvement and health protection programmes to increase the awareness of preventable risk factors for cancer. Examples of such programmes are:

- Tobacco Control
- Weight Management
- Sun Safety
- Physical Activity programmes
- HPV vaccination programme
- Alcohol awareness interventions, help and advice.

Health improvement interventions and healthy lifestyle factors are supported by various existing and emerging strategies and programmes.

These strategies and initiatives have objectives related to cancer risk reduction and early detection. For example, the Government, with key partners, is committed to reducing the prevalence of smoking, tackling obesity, supporting skin cancer prevention campaigns and promoting good health and well-being for all.



### Strategic Objectives

- To ensure that the Isle of Man is in the lowest quartile for negative lifestyle indicators (for example smoking, alcohol consumption, obesity) and the highest quartile for positive lifestyle indicators (for example five portions of fruit and vegetables per day, physical activity) in comparison with the distribution of these indicators in England.
- To raise awareness of the signs and symptoms of cancer within the population to enable them to seek medical advice as early as possible.
- To provide community education and information in a variety of formats that are easily accessible to the public.
- To undertake periodic audits of the information provided to ensure that the information is accessed, is adequate, is easily understood and is helpful to the public, and to modify the information in the light of audit results.

### Priority Targets

- Increase and sustain positive multi-agency working with public, private and the 'Third' sectors to raise awareness of prevention, and to enable earlier recognition and presentations of cancer symptoms.
- Ensure the accessibility of services for prevention of cancer, in the areas of smoking cessation, physical activity and screening.
- Support the delivery of the Framework for Tackling Childhood Obesity, and the Tobacco, Drug and Alcohol, and Physical Activity Strategies.
- Regulate the use of sun beds.
- Improve public awareness of the main preventable factors for cancer.
- Maintain the HPV vaccination programme and expand it, if appropriate.



### Key Implementation Tasks

- Continue to implement wide-ranging programmes to reduce smoking levels and exposure to second-hand smoke in the Isle of Man.
- Work with other Government Departments to implement the Framework for Tackling Childhood Obesity, and the Tobacco, Drug and Alcohol, and Physical Activity Strategies.
- Increase the rates of those who breastfeed for 3 months or longer.
- Continue to deliver multi-agency weight management programmes for children and adults to reduce obesity levels in the Isle of Man.
- Contribute to a reduction in hazardous and harmful drink consumption through education, training and publicity.
- Work with primary and secondary schools and with the community to promote the limitation of excessive artificial and natural ultraviolet (UV) exposure.
- Enable the public to access information from a variety of media appropriate to their needs, should they choose to do so.
- Implement health-related social marketing concepts and techniques to achieve specific behavioural goals relevant to risk reduction and early detection of cancers in the Isle of Man population.
- Deliver the HPV programme.
- Devise programmes to specifically address the needs of at-risk groups for example, those with learning, mental or physical disability.



# 4. Improving Clinical Outcomes for Cancer Patients

### 4.1 Introduction <sup>4</sup>

4 Royal College of Physicians Working Party Report: The cancer patient's physician (November 2000) The current Isle of Man Cancer Service approaches that of a Type II Cancer Unit as defined by the Royal College of Physicians (RCP) and has a link with the Merseyside and Cheshire Cancer Network (MCCN).

Ensuring that all cancer patients receive the appropriate treatment, delivered to a high standard, is critical to improving cancer outcomes. The right treatment can also be the most cost-effective treatment. The quality of cancer treatment has improved significantly with access to the latest forms of surgery, radiotherapy, drugs and the establishment of MDTs.

This section of the Plan considers how the Isle of Man Cancer Service can achieve the best outcome for patients.

### 4.2 Referral Process <sup>5 & 6</sup>

- National Institute for Clinical Excellence (NICE): Referral for suspected cancer (CG27 - June 2005)
- 6 Department of Health: Cancer Reform Strategy and Implementation (November 2007 & 2011)

It is crucial that the referral process is simple and streamlined to ensure that patients are on the correct path to diagnosis as quickly as possible, because early diagnosis is likely to lead to a better outcome. This will require a co-ordinated approach across Primary and Secondary Care for developing referral criteria and referral routes.

At present, patients with suspected cancer are referred by a variety of different routes into the system such as:

- General Practitioners (GP)
- Accident and Emergency (A&E)
- Outpatient clinics
- Radiology
- Clinical laboratory
- Allied Health Professionals.

All cancer referrals are to be made to Consultants at Noble's Hospital, following the National Institute of Health and Clinical Excellence (NICE) approved guidelines and referral pro forma.



All GPs and relevant healthcare professionals will be trained to use the pro forma in order to identify patients who require to be fast-tracked to the clinicians for urgent clinic appointments.

### 4.3 Cancer Care Pathways

Waiting for cancer diagnosis and treatment of any kind is worrying, often painful and sometimes can be life-threatening.

The steps for the diagnosis and treatment of different cancers are largely predictable. Therefore, clinical care pathways should be developed for all cancers so that patients will know that they are moving swiftly through the right steps to ensure an accurate diagnosis and that the most appropriate treatment is provided on time.

### 4.4 Multi-disciplinary Team (MDT) Working

MDT working has led to improved decision-making, more co-ordinated patient care, and improvement in the overall quality of care. MDTs bring together staff from all sectors and disciplines, with the necessary knowledge, skills and experience to ensure high-quality diagnosis, treatment and care for patients with cancer, and support for their carers.

Due to the size of the population, and patient numbers in the Isle of Man, it is neither feasible nor cost-effective to establish a separate Multidisciplinary Team process for each tumour site. Therefore, a general Cancer Multi-disciplinary Team (CMDT) will consider the management of patients with cancers from any tumour site; this would be a pragmatic way to establish Multi-disciplinary Team working in the Isle of Man.

### 4.5 Relationship with UK-based Site-specific CMDT meetings (SCMDT)

Some patients will be deemed by the consultant in charge of the case to require consideration by a Site-specific Cancer Multi-disciplinary Team (SCMDT) based in the UK. Videoconferencing can facilitate this process. Management of the individual patient would then proceed based on the conclusions of this SCMDT.



### 4.6 Review of Cancer Performance <sup>7</sup>

7 NHS Improvement – Cancer <u>www.improvement.nhs.</u> <u>uk/cancer/</u> This will take place at regular intervals to identify any bottlenecks in delivering service so that remedial measures can be put in place to improve the Service. This can be achieved by individual clinicians participating in Regional and National Audits, setting up a Cancer Service Review Group (CSRG) locally and by external peer review process.

Participating in regional, Royal Colleges' and national audits will help to understand better the incidence of different cancers within the Isle of Man and the UK, to describe the range of treatments utilised and to explore the variations in treatment and outcomes.

CSRG will review the functioning of the various clinical pathways that make up the Cancer Service. They will ensure that appropriate clinical pathways exist for each tumour site, allowing cancer patients to flow through these pathways as smoothly as possible. Factors causing delays in a patient's progress through clinical pathways will be identified through audit / analysis utilising SCR as a tool and an action plan for addressing these delays will be developed and implemented.

External peer review process has been shown to improve service for cancer patients. This will be considered for the most common tumours.

### 4.7 Inter-hospital Transfers

These transfers relate to patients for whom on-going management requires the input of non-Isle of Man-based services. Approximately 30 -40% of cancer patients are referred to UK hospitals for further assessment and / or treatment. These referrals are done by clinician to clinician. However, not all clinicians receive feedback from UK hospitals, due to the information being sent directly to the GP, and then missed for the follow-up appointment at Noble's Hospital. In order to improve efficiency, an effective hand-over and take-over of these patients should take place between Noble's and UK hospitals, monitored by staff at Noble's Hospital.



### 4.8 Communication Skills <sup>1</sup>

1 Department of Health (DH) Improving Outcomes: A Strategy for Cancer (Jan 2011) Written information is an addition, not a substitute, for high-quality verbal communication. The way healthcare professionals communicate with those using the Health Service profoundly affects the experience of care for patients. For example, good communication can:

- Facilitate early diagnosis.
- Improve self-management.
- Reduce numbers of emergency admissions.
- Reduce inequalities in access to, and provision of, care.
- Support people to return to as normal a life as possible following cancer treatment.

All healthcare professionals dealing with cancer patients have an important role to play in guiding and supporting cancer patients and their carers through all stages of care and treatment. From the very beginning, it is essential to communicate adequately about diagnostic information, prognosis, mental distress and treatment options. Good communication skills of health professionals have been found to increase treatment adherence, as well as improved psychological functioning of cancer patients and their carers.

There is some evidence to suggest that advanced communication skills training can have a beneficial effect on behavioural change in professionals working with cancer patients and their carers<sup>5</sup>. Therefore, it is essential that all healthcare professionals involved in the care of cancer patients and their carers are trained in advanced communication skills.

### 4.9 Delivering high-quality Cancer Treatment <sup>8</sup>

### 4.9.1 Chemotherapy

Chemotherapy is now an integral part of the cancer experience for many patients. Changes in practice, new treatments, and the increasing number and complexity of treatments offered to patients, present staff with many challenges. These also affect how services are planned, delivered and managed.

8 National Chemotherapy Advisory Group Chemotherapy Services in England: Ensuring quality and safety (August 2009)



In the Island there is a dedicated Chemotherapy Day-case Unit. It is managed by an Oncology Clinical Nurse Specialist (CNS) and staffed by three part-time chemotherapy nurses. Given the rapid growth in chemotherapy provision, it is important to ensure that services are planned, and that there is an adequate workforce - both in terms of size and expertise - to cope with this demand in the Island.

The increased workload of the chemotherapy service is a national phenomenon, not just a local one, as seen below:

The observed increase in chemotherapy utilisation can be attributed to several factors:

- The availability of new drugs which are given in addition to existing treatments, rather than as a substitution, and are often given for longer durations than conventional chemotherapy.
- The complexity of chemotherapy regimes.
- Patients receive more lines of chemotherapy than before.
- Chemotherapy is now being used in a wider range of solid cancers than previously.
- Increasing adjuvant (after) and neoadjuvant (before) surgery indications for treatment, especially in the more common malignancies.
- The pattern of chemotherapy utilisation is also changing. Oral drugs are in some cases replacing intravenous drugs, bringing greater convenience to patients<sup>6</sup>.
- The use of monoclonal antibodies has increased.

Access to cancer drugs in the Isle of Man follows the Merseyside and Cheshire Cancer Network (MCCN), NHS-approved, cancer drug protocols.



## 4.9.2 Surgery

Capacity and demand for cancer surgery must be assessed for operating theatres, in-patient beds, day-case facilities and intensive / high-dependency beds, to improve clinical outcomes for cancer patients undergoing surgical procedures.

## 4.9.3 Radiotherapy

It is not possible to establish this service in the Isle of Man for the following reasons:

- a) The National Radiotherapy Advisory Group (NRAG), UK, recommends one linear accelerator for a minimum population of 250,000. The population of the Isle of Man is not large enough to meet this criterion.
- b) At least 8,000 fractions of radiotherapy would need to be delivered per linear accelerator per annum. The Isle of Man will not be able to meet this due to the low volume of cancer patients needing radiotherapy.
- c) High set-up and maintenance costs, adequate staffing level (linear accelerator, simulator, 3 4 radiographers per unit, physicist, clinical oncologist, administration staff) and a contingency plan for continuing treatment in the event of breakdown of the linear accelerator (spare machine) would not justify commissioning this service locally<sup>4</sup>.

### 4.10 Research

Research into all aspects of cancer is essential if the burden of the disease is to be reduced, and for the benefit of future generations. At present, Isle of Man patients are not entered into research studies and clinical trials locally. It is not possible to conduct research locally due to the low volume of cases.

However, it is possible for Isle of Man patients at Noble's Hospital to be given an opportunity to take part in research studies and clinical trials as part of the Merseyside and Cheshire Cancer Network. Appropriate resources need to be put in place to facilitate this process.



## 4.11 Island-specific Issues

There are some features specific to the Island. Any service model from the UK would need to be adapted to ensure that the service meets the needs of the local population. The main factors which need to be taken into consideration when adapting any UK model are:

### 4.11.1 Small size of population

Most UK service models are based on much larger population sizes than that of the Isle of Man. Due to the relatively small size of our population, the number of cases of different types of cancer occurring in the Island will be much smaller compared with the UK. These numbers may not be sufficient to achieve the critical mass figure for some cancers. We need to consider innovative ways of dealing with such issues; for example, reexamining the evidence-base for critical mass numbers and offer sessions at UK hospitals for local consultants.

- The Royal College of Physicians (RCP) recommends 1 whole time equivalent (WTE) Clinical Oncologist and 1 WTE Medical Oncologist for a population of 200,000 – 250,000. This would translate to the Isle of Man requiring 0.4 WTE of each. While the posts can be covered by visiting medical consultants, there is a need to ensure that resident expertise is available in the Island.
- Because of the small number of cases of cancer and the limited number of professionals, who have to cover a wide variety of conditions, it would not be feasible to set up separate MDTs for each cancer site.
- For similar reasons a CNS for each site would not be either appropriate or feasible.
- Patients requiring treatment for rare tumours will need to travel off-Island to ensure that the care they receive is of the highest quality. Similarly, patients who need specialised treatment which requires major capital equipment for example, radiotherapy will continue to travel off-Island.



## 4.11.2 Geographical separation

The stretch of water between the Isle of Man and the UK poses a geographical barrier, making access more difficult.

#### Strategic Objectives

- To equip GPs and other healthcare professionals, through educational programmes, with the skills to recognise the early signs and symptoms of cancer.
- To develop protocols to ensure early referral of suspected cancer cases.
- To ensure that all cancer referrals are 'streamlined through' to minimise the delay in diagnosis and staging.
- To minimise the delay in initiating treatment.
- To ensure that all patients have a comprehensive treatment plan designed by the relevant MDT.
- To provide as much treatment as possible in the Isle of Man, subject to cost and quality considerations.
- To ensure that all Isle of Man cancer patients are provided with the opportunity to participate in cancer research studies and clinical trials at Noble's Hospital.
- To ensure that the Isle of Man Cancer Services are a part of the Merseyside and Cheshire Cancer Network and implement similar care plans and protocols of treatment; also, proactively influencing the network to ensure they take into account Isle of Man patients in their planning process.
- To undertake periodic patient feedback using a variety of methods, and implement changes in services and information provided based on the results of such feedback.
- To provide the most recent information in a variety of formats that is easily understood by both patients and carers at every stage of the cancer journey.



## Priority Targets

- Develop a referral process for all cancer patients to enter hospital by a number of routes.
- Monitor waiting times for diagnosis and treatment.
- Develop patient care pathways and map the progress of the patient's journey through the pathway.
- Develop the skills and abilities of professionals working with cancer patients and their carers:
  - Maintain and update skills through continuing professional development (CPD).
  - Train health professionals to take on the changes in cancer services.
  - Keep roles (functions) under constant review.
  - Ensure all professionals working with cancer patients and their carers attend advanced communication skills training courses in order to improve communication between health professionals and patient.
  - Monitor and analyse cancer survival and experience of Isle of Man patients at regular intervals and compare with UK and European figures.

### Key Implementation Tasks

- Develop referral criteria between Primary and Secondary Care taking into account NICE Guidelines on who should be referred urgently and how referrals should be made.
- In clinical areas where cancer diagnoses are made, to develop and establish a system ensuring the patient is referred into the Cancer Care Service at the appropriate place.



- Develop tumour site-specific cancer pathways for all cancers and set up a Cancer MDT.
- Monitor the waiting times for pathology and radiology results.
- Set up an efficient hand-over and take-over (in both directions) of Isle of Man patients referred to UK Hospitals.
- Set up external peer review visits for common tumours.
- Investigate the opportunity for Isle of Man patients to participate in MCCN research studies and clinical trials at Noble's Hospital.

#### 4.12 Current Pressures and Risks

- a) Fulfilling the need within the cancer workforce to meet the growing demand for cancer services and the requirements of new treatments.
- b) Rising costs of new anti-cancer drugs.

#### 4.13 Workforce Developments

- a) To better enable the most effective use of skills, work with managers to reduce demarcations between groups of staff to maximise the potential of this valuable resource.
- b) Workforce needs to be reviewed in relation to the improvements of the cancer services as set out in the Plan.



## 5. Children and Young People with Cancer

## 5.1 Introduction

Cancers in children are rare; the incidence is about 14 per 100,000 children. This will mean 10 - 12 cases per year in the Isle of Man. The most common childhood cancers are lymphomas, leukaemias and brain cancers; in teen years there is an increase in the incidence of Osteogenic sarcoma (bone cancer).

Special features of cancers in childhood and adolescence are as follows:

- Across the western world there has been an increase in the number of childhood cancers. The reasons for this are not clear but it results partly from better diagnosis.
- Approximately 70% of children with cancer are cured; this means that there is an ever-increasing number of children and adults who have survived childhood cancer.
- Cancer at any age creates psychological problems; these are often more severe in the case of childhood cancers as the parents and siblings are affected by a child in the family being diagnosed with cancer.
- Like adult cancer, cancers in children are treated by drugs, radiotherapy and surgery; however, the treatment often creates long-term problems in children and special efforts to address this have to be considered.

### 5.2 Improving outcomes for Children and Young People with Cancer

Improving outcomes for children and young people with cancer is uniquely different because it does not deal with tumour type, but rather with a group of cancer patients defined by age and with a wide variety of tumour diagnoses.

The principle that underpins the guidance and key recommendations is that of 'age-appropriate, safe and effective services as locally as possible, not local services as safely as possible'. This underpinning principle presents particular and unique challenges to the rural location and demographics of the Isle of Man.



## 5.3 Children and Young People's Cancer Clinical Network Group <sup>9</sup>

It is the role of the Children and Young People's Cancer Clinical Network Group (CNG) to implement the improving outcomes guidance. This is done through the application of the 'National Cancer Peer Review Programme: 'Children's Cancer Measures'. It will involve a 'shared care' agreement between Noble's Hospital and Alder Hey Children's NHS Foundation Trust.

### 5.4 Island-specific Issues

There is a number of challenges for Cancer Services for Children and Young People in the Isle of Man - these are as follows:

- a) Within the existing services, the specific needs of patients aged 16 to 24 years should be met through the development of age-appropriate care pathways.
- b) The growing numbers of survivors of childhood cancer who become adults and who require long-term follow-up. Currently, these patients are followed up by the Paediatric Service locally, some now in their third or fourth decade of life. A pathway is required for the long-term management of their care.
- c) Cancer in children is relatively rare in the Isle of Man. The need for palliative care is infrequent, which creates a particular and unique challenge that requires multi-disciplinary co-operative work between Primary Care, Secondary Care and the Third Sector.

#### Strategic Objectives

- To ensure that cancer services for children and young people, including funding and resources at all levels, are equitable with those available to adult cancer patients.
- To ensure that cancer services for children and young people are implemented according to the Children's Cancer Measures (see above), subject to peer review and underpinned by a 'shared care agreement'.

9 Peer Review Team -National Cancer Action Team: Children's Cancer Measures - Manual for Cancer Services (Nov 2008)



- To ensure age-appropriate diagnostic and treatment pathways are in place for children and young people aged 16 to 24-years of age.
- To ensure that all patients and their carers receive appropriate psychological support.
- To ensure that a plan and care pathway is developed in collaboration with Children and Adult Services, Primary Care and Secondary Care for adults who are childhood cancer survivors.

## Priority Targets

- Develop a care pathway for the 16 to 24-year-old age group.
- Develop a pathway to manage the care of survivors of childhood cancer who require long-term follow-up.
- Develop the skills and abilities of professionals working with children and young people in order to meet the peer review measures:
  - Maintain and update skills through continuous professional development.
  - Train health professionals working with children and young people to take on the changes in cancer services.
- To invest in adequate pharmacy support for children's cancer as recommended through liaison with the Principal Treatment Centre (PTC), and peer review.

### Key Implementation Tasks

- Initially, to undertake an internal peer review with the PTC in 2012, with formal peer reviews in subsequent years.
- To develop and implement a plan in collaboration with partner agencies for adults who are childhood cancer survivors.
- To sign a shared care agreement with the PTC and the CNG.



## 6. Living with, and beyond, Cancer

## 6.1 Introduction

The focus of this section is on the experiences of cancer patients and their carers when living with, and beyond, cancer. The number of people living with cancer is increasing. This is mainly due to our aging population, treatments being more sophisticated, and improved screening programmes. As a result, cancer is increasingly being seen as a long-term condition.

The diagnosis and treatment of cancer has a significant impact on the quality of patients' lives, and those of their families and carers. Cancer patients face uncertainty and may have to undergo unpleasant and sometimes debilitating treatments which can have both physical and psychological consequences for a long time after the treatment has finished. These consequences include those that are health-related, psychosocial, or related to work and finances. Patients, their families and carers - both formal and informal - need access to current information and support throughout their cancer experience.

Many patients, their families and carers find the following particularly challenging:

- Diagnosis.
- Treatment.
- The period immediately following completion of treatment.
- The time of any relapse.
- When treatment is unlikely to change the natural history of the condition.
- Dealing with the many concerns about the effects on their daily living, coping with everyday situations and the financial impact the disease may have.

People living with, and beyond, cancer, and their carers, often have specific support and social care needs which, if left unmet, can damage long-term prognosis and ability to lead an active and healthy lifestyle.



These needs can include:

- Information about treatment and care options.
- Psychological support.
- Access to advice on financial assistance.
- Support in self-managing the condition.
- Clear pathways for return to the system if needed.

Carers play a vital role in supporting people with cancer and it is important that their needs are addressed.

## 6.2 National Cancer Survivorship Initiative <sup>10, 11 & 12</sup>

10 MacMillan www.macmillan.org.uk

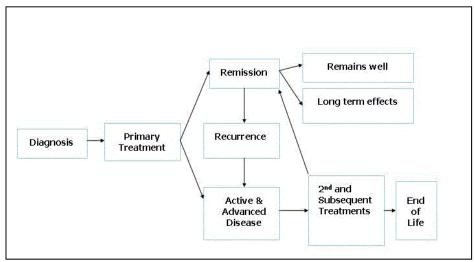
11 Cancer Research UK www.cancerresearchuk.org

12 NHS Improvement: Adult Cancer Survivorship Initiative Living with and beyond cancer: The improvement story so far (July 2010) There are currently 2 million cancer survivors in the UK and this figure is increasing at a rate of 3% per year. At the end of 2006 there were 1.1 million people in the UK who had been diagnosed with cancer up to 10 years previously. Information available suggests that there are more than 2,500 cancer survivors in the Isle of Man.

The National Cancer Survivorship Initiative (NCSI) is co-ordinating efforts to improve the quality of services available to people affected by cancer. They have developed a cancer survivorship pathway to describe different phases of health or illness that a person with cancer may experience from diagnosis onwards. This pathway will help identify the services and support that individuals in the Isle of Man may need at different times after a cancer diagnosis.



### Stages of a cancer survivor's journey



Source: Michael Feuerstein Cancer Survivor's Journey, DH, NHS Improvement 2010.

## 6.3 Support for people living with, and beyond, Cancer

Although there have been significant improvements in support for people in the Isle of Man living with and beyond cancer, more needs to be done in order that cancer survivors have the care and support they need to live as healthy a life as possible.

Therefore, this Plan will continue to work towards improving the outcomes which are relevant for people living with and beyond cancer.

For example:

- Reducing ill-health associated with cancer treatment.
- Reducing the risks of recurrence.
- Reducing the number of people who report unmet physical, psychological or social welfare support needs following cancer treatment.
- Increase the proportion of cancer survivors who are able to live independently.
- Working with statutory and Third Sector organisations to ensure social care programmes are implemented alongside healthcare.
- Ensuring access to advice on benefits, assistance with financial planning, employment and support for the family.



### 6.4 Where we are now

Work has taken place in the following areas to assist patients through their Cancer Care Pathway, and is as follows:

- The effects of cancer are addressed by hospital clinicians, GPs, specialist nurses, District Nurses, Practice Nurses and Palliative Care Clinical Nurse Specialists.
- Providing support for patients from the point of diagnosis and as they move along the patient pathway is a key component of the role of the CNS.
- The Psycho-Oncology Service assists in addressing the psychological and emotional needs of patients, their families and carers both formal and informal. There are four levels of psychological support offered in the Island:
  - Level 1: Effective information-giving, compassionate communication, general psychological support.
  - Level 2: Psychological interventions.
  - Level 3: Counselling.
  - Level 4: Specialist psychologist.
- Non-medical effects of cancer are addressed by social care workers, including inputs from Social Services and Social Security.
- The entitlement to benefits, assistance with financial planning, employment, and support for the family are addressed at present. Their availability must be communicated clearly and they must be made readily accessible.
- The Third Sector in the Island is engaged in delivering quality medical and social care which supplements and complements statutory services, but links need to be strengthened and further developed.
- More needs to be done to provide information locally about the requirements of those who have survived cancer there is a strong case for addressing this.



#### Strategic Objectives

- To ensure that the needs of cancer survivors are identified and met as far as possible.
- To ensure that there is a seamless transfer of care from Tertiary and Secondary Care to Primary Care.
- To provide adequate help and advice for patients with long-term complications following cancer treatment, including specialist advice for specific complications if required.
- To ensure that social care involvement starts at an early stage.
- To ensure all patients receive an individualised assessment and care plan focussed on their needs after treatment.
- To ensure that psychological support continues even after the patient has been formally discharged from the hospital.
- To provide the most recent information in a variety of formats that is easily understood by both patients and carers at every stage of the cancer journey.
- To ensure that the most recent information covers all aspects of the cancer experience, including availability of practical help and benefits.

## Priority Targets

- To continue to improve the experience of people living with and beyond cancer by:
  - Supporting and informing patients to enable them to understand their cancer and its management.
  - Involving them in decision-making, as they wish.
  - Giving them information and advice to make informed choices about their care



- To ensure all patients receive an individualised assessment and care plan focussed on their needs after treatment.
- To ensure that there is a seamless transfer of care from Tertiary and Secondary Care to Primary Care.
- To provide adequate help and advice for patients with long-term complications following cancer treatment, including specialist advice for specific complications if required.

### Key Implementation Tasks

- Address the specific needs of increasing numbers of cancer survivors by:
  - Identifying the experiences and needs of local survivors.
  - Improving the care and support for cancer survivors with a focus on recovery, health and well-being.
- Improve the way healthcare and social care professionals view and communicate with patients and carers, post-treatment:
  - Build on the existing partnerships between the Department of Health, the Department of Social Care and the Third Sector to meet the growing demands of healthcare and social care in the Isle of Man.
- Improve information for patients, their families and carers, as appropriate, through a range of initiatives.
- Ensure all patients receive an individualised assessment and care plan focussed on their needs after treatment.
- Develop and implement a plan to strengthen communication between Primary and Secondary Care, Community Teams, Social Care, Third Sector providers, the patient, their families and carers - both formal and informal.
- Ensure the delivery of high-quality training to equip professionals in all sectors, and informal carers, with the skills necessary to support cancer patients living with and beyond cancer.



## 7. Palliative Care Services

## 7.1 Introduction

Palliative care is an integral part of the care delivered by any healthcare or social care professional to those living with, and dying from, any progressive and incurable disease.

## 7.2 Definition of Palliative Care

The World Health Organisation (WHO) defines palliative care as:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

## 7.3 Palliative Care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

In the Isle of Man there are provisions for general and specialist palliative care services.



## 7.4 General Palliative Care

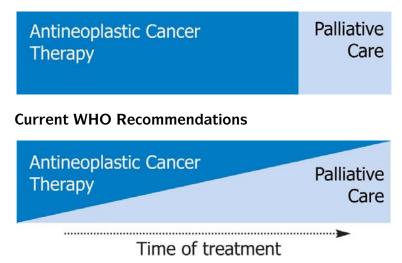
General palliative care is provided by the professional carers of the patient who has a low to moderate complexity of palliative care need. A general palliative care service comprises a health and social workforce in which all the patient's and family's usual professional carers provide palliative care as a vital and integral part of their routine clinical practice.

## 7.5 Specialist Palliative Care <sup>13</sup>

**13** World Health Organisation (WHO) Expert Committee: Cancer pain relief and palliative care (Technical Report 804, Geneva 1990) Services are provided for patients and their families with moderate to high complexity of palliative care need. They are defined in terms of their core service components, their functions and the composition of the multiprofessional teams that are required to deliver them. They are underpinned by the same set of principles as for general palliative care service.

The diagram below shows the traditional medical treatment focus and the current WHO recommendations which indicate the need for palliative care to support the patient from the early stages of treatment.

## **Traditional Medical Treatment Focus**



Source: WHO Cancer Pain Relief and Palliative Care, Geneva, WHO, 1990



## 7.6 Where we are now <sup>14</sup>

14 National Institute for Clinical Excellence (NICE): Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer (March 2004) Palliative care services were reviewed by NICE in 2004, resulting in the document 'Guidelines on Improving Supportive and Palliative Care for Adults with Cancer'. This document provides a suitable blueprint for palliative care services in the Isle of Man.

Palliative care services are well-established in the Island and exist across the whole range of clinical settings.

#### 7.7 Hospice Isle of Man

Hospice Isle of Man is the major palliative care provider in the Island for patients with cancer.

#### 7.8 Community Care Support Systems

An integrated information technology system would support cancer and palliative care. The full introduction of Community Care Support Systems (CCSS) across healthcare and social care would lead to continuous electronic records in the Hospital, Hospice and community. Furthermore, the introduction of the Somerset Cancer Register will enable cancer patients' treatments to be tracked and monitored.

#### 7.9 Psychological Support for Cancer Patients and their Carers <sup>15</sup>

15 Professor Robin Davidson Consultant Clinical Psychologist, Hon Lecturer Faculty of Medicine (QUB): Isle of Man Psycho-Oncology Service, (Three Year Audit and Review - May 2011) The need for better psychological support for cancer patients and their carers at levels 3 and 4 of the 4-stage cancer progression model was identified and, as a result, the appointment of a cancer-dedicated clinical psychologist (working 2 days per month) was achieved in April 2008. Following on in January 2009, a part-time counsellor was appointed. These positions have been funded by Manx Cancer Help and the Isle of Man Anti-Cancer Association.

#### 7.10 Liverpool Care Pathway

The introduction of the 'Liverpool Care Pathway for the Dying Patient' (LCP) in the Isle of Man is acknowledged to be an important step in providing high-quality end-of-life care.



## 7.11 The Gold Standards Framework <sup>16</sup>

16 Gold Standards Framework www.goldstandardsfram ework.org.uk/

The Gold Standards Framework (GSF) facilitates front-line staff to provide quality care for people nearing the end of life. GSF improves the quality, co-ordination and organisation of care leading to better patient outcomes in line with their needs, preferences and greater cost efficiency through reducing hospitalisation. This Framework has been implemented in all GP Practices in the Island. GP Practices keep palliative care registers and hold multi-professional meetings when patients on these registers are discussed.

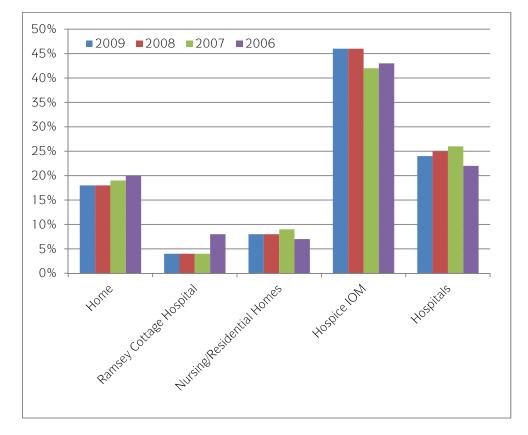
A GP Practice 'Locally Enhanced Service' scheme for Palliative Care / Gold Standards Framework commenced in April 2009 and has facilitated the implementation of this initiative.

## 7.12 Choice – End-of-Life Care

Patients want to choose where they are cared for in the last phase of their lives. This can only occur when sufficient and flexible care provision is available in all health settings to supplement that provided by family and friends. The lack of community nursing out-of-hours services to complement Third Sector services hinders the provision of choice in the Isle of Man at present.

The chart overleaf shows the current situation regarding final place of care for cancer patients in the Isle of Man. Only 18% - 20% of cancer patients die at home, which is low compared with other parts of the United Kingdom, where levels closer to 30% are achieved.





#### Place of Death for Cancer Patients in the Isle of Man

Source: B Harris, 2006-2009 Hospice, Isle of Man

### Strategic Objectives

- To ensure that all patients with cancer and their carers receive psychological support at the appropriate level for their need (levels 1 – 4, as defined in NICE guidelines).
- To ensure that all healthcare workers likely to be dealing with cancer patients and their carers are trained to provide psychological support at levels 1 and 2.
- To ensure that there is adequate input at level 4 for patients and carers requiring support at this level.
- To provide adequate facilities in the community so that patients have complete choice of their place of death.



- To provide the most recent information in a variety of formats that is easily understood by both patients and carers at every stage of the cancer journey, including practical help and benefits.
- To undertake periodic audits of the information provided to ensure that the information is accessed, is adequate, is easily understood, is helpful to both patients and their carers, and to modify the information in the light of audit results.

### Priority Targets

- Actively track patients through their cancer pathways and collect, collate and provide cancer statistics.
- Achieve 'single patient, single record' system in the Hospital, Hospice and the community.
- Provide high-quality care in the last few days of life by using the 'Liverpool Care Pathway for the Dying Patient' (LCP) in all clinical settings.
- Provide high-quality palliative care in Primary Care by embracing the principles set out in the Gold Standards Framework project.
- Invest in staff and services to continue to improve cancer services.
- Establish sufficient and flexible care provision in all health settings so that patients truly have a choice as to their preferred place of care and death.

### Key Implementation Tasks

- Implement the Somerset Cancer Register to allow tracking of cancer patients and provide statistical information to improve cancer services.
- Fully implement CCSS in the Hospital and Hospice, with the RiO system in the community.
- Encourage health professionals to utilise the 'Liverpool Care Pathway for the Dying Patient'.



- General Practices in the Isle of Man to move towards compliance with the measures set out in the Gold Standards Framework documents.
- Develop community nursing out-of-hours services to complement Third Sector services in the community, based on patient and carer needs.
- Incorporate the findings and recommendations of the on-going development of the End of Life Strategy as appropriate.



## 8. Commissioning

Commissioning in the Health Services context involves separation of strategic planning from operational delivery and linking them by explicit agreements. To enable strategic planning of any service, the starting point is the assessment of the health needs of the population, both at present and in the future. For further details of commissioning, please refer to the Isle of Man DH document: Strategy for the Future of Health Services.

Commissioning cancer services is complex as cancer treatment spans different specialities and care sectors. Such complexity only adds to the need for explicit commissioning standards as cancer patients, irrespective of the site of their cancer or the place where they are treated, all need to receive equally high standards of care.

Commissioning services for cancer patients will be undertaken by the Department of Health and services commissioned via:

- Noble's Hospital for Secondary Care.
- Tertiary hospitals not only Clatterbridge Centre for Oncology (CCO), but many other hospitals where cancer patients receive tertiary care; for example, Alder Hey and the Royal Liverpool University Hospital.

The Department of Health (DH) will set explicit standards when commissioning 'care for cancer' from various specialities and hospitals. These standards will include:

- Waiting times to include referral-to-diagnosis and to initiation of treatment.
- Qualitative aspects of care for example, communication and counselling.
- Staffing.
- Outcomes.
- Patient experience.

The overall purpose of the commissioning process is to improve the quality of care and patient outcomes by identifying explicit standards and monitoring these.



The DH will monitor the overall quality of cancer care using a combination of hard data (comparative 5-year survival rate adjusted for stage of the cancer) and soft data (patient / cancer surveys) and ensure that appropriate modifications are made in the service specification for commissioning, so that continuous improvements in the standards of care can be achieved.

Commissioning also offers an opportunity to link finance data with service data so that decisions regarding prioritisation can be taken more rationally.

#### Strategic Objectives

- To ensure that the information systems are robust enough to provide data for the introduction of commissioning.
- To introduce commissioning for Secondary Care services, incorporating cancer issues within the agreements for different specialities.
- To monitor and evaluate the provision of cancer services provided to patients in the Isle of Man.

#### **Priority Targets**

- To link finance and activity data to enable meaningful commissioning.
- To enhance health needs analysis so that services are re-designed to meet the needs of the local population.
- To develop provision for specific actions for cancer services.

#### Key Implementation Tasks

- To review the commissioning arrangements for tertiary care with CCO and other providers.
- To ensure the availability of accurate data on health needs, Health Service activity, and finance.
- Monitor the quality of cancer services by working with professionals, patients and carers, ensuring that the responses are incorporated into the planning process to develop and improve services.



## 9. Conclusion

Ensuring that all cancer patients receive the appropriate treatment and care delivered to a high standard is critical for improving cancer outcomes in the Isle of Man. In recent years the quality of treatment has improved significantly, with more widespread access to the latest forms of surgery, radiotherapy and drugs.

However, there is always more to do to improve the quality of cancer services in the Island - this requires action from providers of services, and commissioners, to ensure that the necessary action is taken to provide a high quality of service and care to cancer patients in the Isle of Man.



## Acronyms/Abbreviations

CCSS CMDT CNG CNS CPD CSRG DH DSC FOBt GP GSF HPV LCP MCCN MDT NBSS NCSI NCSI NICE NRAG NWCIS NWCR NWCIS NWCR NWCIS NWCR NWCIS NWCR NWPHO POSCU PTC QA RCP RIO SCMDT SCR UV WHO	Cancer Multi-disciplinary Team Clinical Network Group Clinical Nurse Specialist Continuing Professional Development Cancer Service Review Group Department of Health Department of Social Care Faecal Occult Blood test General Practitioner Gold Standards Framework Human Papilloma Virus Liverpool Care Pathway for the Dying Patient Merseyside and Cheshire Cancer Network Multi-disciplinary Team National Breast Screening System National Breast Screening System National Institute for Health and Clinical Excellence National Radiotherapy Advisory Group North West Cancer Intelligence Service North West Cancer Registry North West Cancer Registry North West Public Health Observatory Paediatric Oncology Shared Care Unit Principal Treatment Centre Quality Assurance Royal College of Physicians Patient Administration and Clinical System, within CCSS Site-specific Cancer Multi-disciplinary Team Somerset Cancer Register Ultra-violet (radiation) World Health Organisation



# Glossary

Adjuvant Therapy	Treatment given after the primary treatment to increase the chances of a cure. Adjuvant therapy may include:
	• Chemotherapy
	Radiation therapy
	Hormone therapy
Children's Cancer Measures	See NHS National Cancer Action Team document: National Cancer Peer Review Programme, Manual for Cancer Services 2008 - Children's Cancer Measures (Gateway reference 12770).
Fraction	One day's radiotherapy treatment, being a 'fraction' of the total treatment.
Linear Accelerator	The device most commonly used for external beam radiation treatments for patients with cancer.
Monoclonal antibody	An antibody, produced by a single clone of cells grown in a culture, that is both pure and specific and is capable of proliferating indefinitely to produce unlimited quantities of identical antibodies. Used in diagnosis, therapy and biotechnology.
Neoadjuvant Therapy	When treatment is given before the primary treatment. Examples of neoadjuvant therapy may include:
	• Chemotherapy
	Radiation therapy
	Hormone therapy
Third Sector	Voluntary, charitable and faith organisations.



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15.	Professor Robin Davidson Consultant Clinical Psychologist, Hon Lecturer Faculty of Medicine (QUB): Isle of Man Psycho-Oncology Service Three Year Audit and Review (May 2011).	p.51
16.	Gold Standards Framework: <u>www.goldstandardsframework.org.uk</u>	p.52



## DEPARTMENT OF HEALTH

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