

The National Cancer Plan

2011-2015



Ministry for Health, the Elderly
and Community Care

The National Cancer Plan

2011-2015



Strategy and Sustainability Division
Ministry for Health, the Elderly and Community Care

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Ministry for Health, the Elderly and Community Care
Palazzo Castellania, 15 Merchants' Street, Valletta VLT 2000, Malta
Tel: (356) 2122 4071
Email: dgss.mhec@gov.mt

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Foreword

Ensuring the best quality of life for cancer patients

It is with great pleasure and satisfaction that I present Malta's first ever National Cancer Plan. This plan will seek to tackle the cancer problem at the national level and will span a time frame of five years from 2011 to 2015. It is setting out the objectives and measures that need to be addressed in order to bring about the desired improvements in an all-inclusive manner and is testimony to the Government's determination to prioritise the challenges of cancer. The overarching approach of this Plan is to put cancer patients and their families at the centre of our health system.

The purpose of the National Cancer Plan is to reduce incidence, prolong survival and ensure the best quality of life possible for cancer patients by ensuring the prevention of preventable cancers and the provision of high-quality and equitable cancer services to all cancer patients in Malta. This Plan is the result of feedback and contributions obtained from various stakeholders over the past three years. The implementation of this Plan will likewise require collaboration and joint working with all those whose efforts can directly or indirectly contribute towards the achievement of the plan's overarching aims.

The Plan cannot be developed, implemented and monitored in isolation. It will be taken forward in tandem with other strategies and developments in the health sector and indeed with sectors outside health such as finance, transport, agriculture and education.

Malta has already made big strides forward in combating the challenges that we are facing in the field of cancer. A new Cancer Hospital is being built, new specialists in oncology have joined the service and new cancer drugs have been included in the Government formulary during 2010. The measures in this Plan are aimed at complimenting all these ongoing improvements and plan for other initiatives that will be implemented over the next five years. These will include the installation of Positron Emission Tomography (PET) scanner in the public healthcare service, the strengthening of the breast cancer screening programmes and the introduction of colorectal and cervical cancer screening programmes.

I augur that this Plan will continue to consolidate Malta's indefatigable efforts to ensure that we continue to witness reductions in cancer incidence and mortality, and improvements in cancer outcomes, and to promote the attainment of excellence in this field of medicine which is expected to increase in prominence in tandem with the increasing longevity of our population.



Dr Joseph Cassar
Minister for Health, the Elderly
and Community Care



Executive summary

Around one in three people in the Maltese islands will develop cancer at some stage in their lives and one in four will die of the disease. The overarching purpose of the National Cancer Plan 2011-2015 is to reduce incidence, prolong survival and ensure the best quality of life possible for cancer patients. This Plan aims at ensuring the prevention of preventable cancers and the provision of high-quality and equitable cancer services to all cancer patients in Malta. This comprehensive plan explicitly sets out the objectives and measures that need to be put in place in order to bring about the desired developments and improvements. The primary approach of this plan is to put cancer patients and their families at the centre of the health system.

The National Cancer Plan has identified five priority areas for intervention. These include prevention, screening and early diagnosis, quality of care, personal and social support, and research and evaluation

Cancer prevention requires intervention on identified determinants that can be modified through public health actions related to the environment and lifestyle habits. A significant number of cancers can be prevented if people adopted healthier lifestyles. Preventive measures included aim to continue the fight to i) reduce tobacco consumption and passive exposure to tobacco smoke, ii) control alcohol consumption, iii) further promote the adoption of healthy eating and body weights, and iv) prevent exposures to carcinogens in the environment and at work.

Screening involves testing for disease in people without symptoms, with the primary purpose of reducing mortality from the target disease. The national programme for breast cancer screening was the first national cancer screening programme to be implemented in Malta. This programme will be followed by the introduction of other national organised cancer screening programmes namely for cancers of the cervix and of the large bowel.

The organisation and delivery of clinical services for patients diagnosed with cancer is complex. It involves a wide range of professional expertise, and contributions from organisations at all levels of the health systems. Essential features for the delivery of quality care to cancer patients include prompt access to the appropriate specialists, a multi-disciplinary service, the coherent development of well aligned cancer services given at all levels of healthcare and effective coordination and communication. This plan will be promoting the role of primary health care and family doctors in cancer prevention, diagnosis and management of cancer cases. This plan is mandating and promoting i) the setting up and updating of clinical guidelines in the major fields of cancer care; ii) the fast-tracking of cancer referrals; iii) improvements in access to electronic clinical records; and iv) an expansion of the oncological and palliative care services.

Diagnostic and therapeutic services shall be improved through the setting up of inter alia a human resource plan which shall increase the capacity of the generic and specialised cancer workforce, together with the evaluation and addition of new drugs to the government formulary, purchasing and modernizing of equipment, evaluation of new and emerging technologies and collaboration with reference centres.

The goal of palliative care is to improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, and spiritual and psychosocial support from diagnosis to the end of life and bereavement. Palliative and supportive care provision will be strengthened by setting up a dedicated unit at the new Cancer Hospital, increasing planned respite facilities, improving the provision of community palliative care and enhancing patient psychological and spiritual support, as well as psychological support for the service-providers. The process of providing cancer care should not be aimed solely at treating the cancer patient's disease, but should equally be geared towards making the patients' and their carers' experience as positive and empowering as possible. This is believed to have a beneficial effect on the outcome of the care process. The central role of the patient shall be ensured through patient empowerment, information, advocacy of patient rights, facilitation of self-care and a return to an active life, and training staff in communication skills.

A national infrastructure for the coordination of cancer research will be established. The aim is to increase opportunities and boost the infrastructure for research in all aspects of the cancer pathway, to strengthen surveillance and monitoring of disease prevalence and survival and to evaluate the quality of cancer services and their outcomes. Cancer surveillance will be strengthened, whilst cancer research will focus on molecular science and genetics, cancer services and epidemiology.

Tackling cancer aggressively and holistically over a five-year span (2011-2015) as is being proposed in this strategy is a formidable challenge that entails a hefty financial investment in the required physical and human resources. Nevertheless, in view of the serious social and economic impact of cancer on Maltese society, Government is determined to deploy all the necessary financial instruments and resources at its disposal towards implementing this strategy. The implementation of this strategy shall be overseen by a specially appointed steering committee, whilst financial control and monitoring mechanisms shall track expenditure.

The National Cancer Plan is the result of feedback and contributions obtained from various stakeholders over the past three years. The implementation of this Plan will likewise require collaboration and joint working with all those whose efforts can directly or indirectly contribute towards the achievement of the Plan's overarching aims. The National Cancer Plan cannot be developed, implemented and monitored in isolation. It will be taken forward in tandem with other strategies and developments in the health sector.



Chapter 1

Introduction to the national cancer plan 2011-2015

The global cancer burden has doubled in the last thirty years of the twentieth century. It is estimated that this will double again between 2000 and 2020 and nearly triple by 2030. Cancer is set to overtake cardiovascular disease to become the leading cause of death worldwide by 2010.¹ Around one in three people in the Maltese islands will develop cancer at some stage in their lives. One in four will die of cancer. We have all had some close experiences with cancer in our families or places of work. Therefore we understand what cancer means to individuals, families and society at large. Better prevention of cancer, better detection of cancer and better treatment and care, make a difference in our lives. It is for this reason that Government is proposing a national plan to address cancer. Over half of all cancers can be prevented by changes in lifestyle. Action on cancer must focus more than ever on prevention and reducing the risk of people developing this disease. This requires individual responsibility to adopt healthy lifestyles, such as not smoking, to reduce one's personal risk.

Our cancer services have registered remarkable progress over the years. Today survival rates for certain cancers have greatly improved. This continues to encourage us to step up the fight against cancer. The commitment of those working to fight cancer in the Maltese health

care sector, the voluntary sector, the community and families across the country is enormous. However, there remain significant challenges that need to be overcome in order to ensure that our cancer services continue to improve and attain the standards that everyone desires. Attaining excellence in the health sector is one of this Government's key pillars to promote economic development and social well-being in the coming years as part of Government's vision up to 2015. Tackling cancer in a concerted manner at national level is one of the priorities that will enable Government to work towards attaining its vision for the health sector. Investing in cancer services to support a healthy and productive workforce is also a key priority in Government's National Reform Programme 2008-2011.

For this purpose, the Ministry responsible for health is explicitly setting out the objectives and measures that need to be addressed in order to bring about the desired improvements in a comprehensive plan.

This first National Cancer Plan intended to span the next five years (2011-2015) is testimony to our determination to make cancer a priority. It is our health system's collective effort to address the key challenges we are facing. It demonstrates that our approach is to put cancer patients and their families at the centre of our health system.

The plan's approach to tackling cancer encompasses two broad perspectives. The micro perspective deals with the experience of patients and families at all stages in the care pathway and is therefore concerned with cancer's impact on the quality of life of patients and their families through the whole course of the disease and care process. The macro perspective, or the public health aspects of cancer, deals with the impact of cancer on the Maltese society in terms of the incidence,

mortality and survival rates associated with cancer in Malta. Both perspectives are important and are complementary in achieving the plan's objectives.

This plan has to be supported by an ambitious programme of investment. It sets out the actions that are required to bring about a marked improvement in all phases of the cancer care pathway: from prevention and early diagnosis, to living with cancer, terminal care and bereavement support.

The overarching aims of the National Cancer Plan 2011-2015 are:

- To prevent those cancers which are inherently preventable
- To provide accessible and high quality cancer services geared towards improving survival and quality of life

These aims are consistent with our overall vision of "a society that fosters an environment that is conducive to persons attaining their maximum potential for health and well-being"

These aims are reflected within the five selected priority areas for intervention:

- Prevention
- Screening and early diagnosis
- Quality of care
- Personal and social support
- Research and evaluation

Cancer outcomes can be influenced by various interventions – from primary prevention to end-of-life care.² Inevitably, the organisation and

delivery of public health programmes designed to improve cancer outcomes is complex. It is therefore necessary to involve a wide range of professional expertise and contributions from organisations both within and outside the health system and from society in general.

This plan is the result of feedback and contributions obtained from various stakeholders over the past three years. The Ministry is grateful to all those who have in some way contributed towards the development of this plan.

The implementation of this plan will likewise require collaboration and joint working with all those whose efforts can directly or indirectly contribute towards the achievement of our overarching aims. The cancer plan cannot be developed, implemented and monitored in isolation. It will be taken forward in tandem with other strategies and developments in the health sector.

The plan starts out by setting forth the challenges that we are facing with regards to cancer and provides information on the current situation in Malta in comparison with other European countries. It draws upon international and European guidelines as well as local realities to propose a series of specific measures to be undertaken in the coming years. These measures are built on core guiding principles and are accompanied by specific targets and indicators where appropriate. Our actions will be guided by continually emerging evidence and best practice guidelines and our actions will be synchronous with those being taken in other European countries also within the framework on the European Partnership for “Action against Cancer”.³

Current and future challenges posed by cancer

1.1 The patients’ perspective

Cancer can bring psychological and physical suffering.

A diagnosis of cancer often severely disrupts the psychological equilibrium of patients. The psychological ordeal associated with cancer starts with the anxiety of suspicion and the shock of diagnosis and pervades the whole course of the disease. Relatives and close friends of cancer patients also experience considerable psychological suffering throughout the whole process and most notably at the final bereavement stage of the course of the disease. Cancer patients can also experience difficulties in carrying out activities of daily living and become dependent on others.

1.2 Patients may experience loss of control over their care

The feeling of being in control of their care and care plans can help cancer patients to alleviate feelings of helplessness. Patients need to have better access to high quality information and support tailored to their needs about all aspects of their illness and care in a manner which is thorough, truthful, timely, comprehensible to the patient and his carers and humane. Informed patients will benefit from an active participation in their care if their feedback is constantly heeded in the planning of the care process.

1.3 Cancer survivors may struggle to return to normal living

Surviving cancer means a lot more than simply not dying from it. Survival is the opportunity to start living one’s life afresh for those who overcome the acute phase of cancer but continue living with it and for those who are fortunate enough to be cured of the disease. Patients and their families also need assistance and support during the “after cancer” period.

1.4 The population perspective

1.4.1 The number of new cancer cases will continue to rise

Every year, almost 1400 people in Malta are diagnosed with cancer.⁴ In other words, every day an average of four people are diagnosed with some form of cancer.

Between 1997 and 2006, Malta experienced a significant and steady increase in the incidence of all cancers (Figure 1). A strong contributory factor towards this increased incidence is the growing proportion of elderly cancer patients as a result of the ageing of the Maltese population. In fact, two-thirds of patients (66.4%) diagnosed with cancer between 2001 and 2005 were 60 years and older at the time of diagnosis. Incidence and mortality from cancer in Malta is projected to continue to be on the increase.



“every day an average of four people in Malta are diagnosed with some form of cancer”

These projections are in line with expected changes in most European countries (Table 1). The trend in cancer incidence is expected to continue increasing as the proportion of elderly people in the population continues to increase. Irrespective of future changes in risk, foreseeable demographic changes will substantially increase the magnitude of cancer incidence and consequently of the cancer burden in most countries over the next few decades. The largest increase will be in the number of cancers diagnosed in older persons and the rise in the total cancer burden will occur among women and men aged 65 or over. It is therefore vital to make adequate provision for greater numbers of cancers among the elderly. Besides the aging phenomenon, socio-economic inequalities in cancer incidence, in the access

to services and in outcomes experienced by different sectors of the population have been shown in several countries and present an added challenge in the fight against cancer from an equity point of view. Further research on possible socio- economic and regional inequalities in cancer incidence and survival is needed so as to inform appropriate policies that will serve to specifically address inequalities in cancer epidemiology.

1.4.2 The financial and economic impact of the burden of cancer

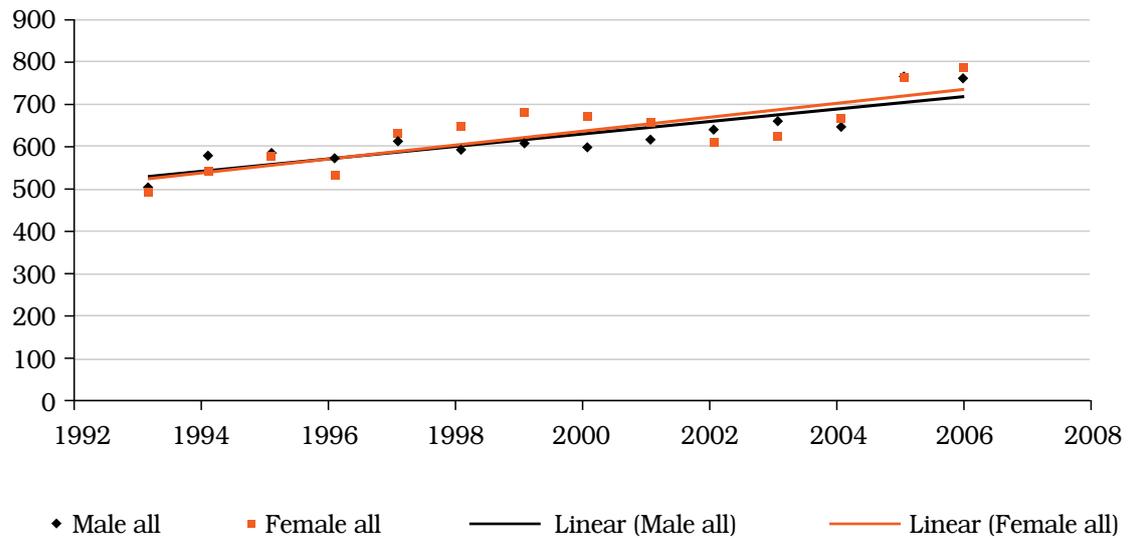
The costs of the rising incidence of cancer in Malta are both human and economic in nature. Cancer patients and their families tend to suffer from a reduced quality of life as a result of the disease. The disease is also responsible for significant losses of productivity and contributions to society by the affected persons and is a leading cause of premature mortality. The health services in Malta offer free and universal access to cancer treatment. The costs of these services are set to rise not only as a result of the increased incidence of the disease but also in view of the escalating costs of the new and emerging treatments and technologies for cancer management.

1.4.3 Cancer is set to become the commonest cause of death

Cancer already contributes in a major way to the number of deaths in Malta and mortality from cancer as a proportion of all mortality is increasing. In fact, whereas in 1997 there were 696 cancer deaths (24% of all deaths), in 2007 there were 826 deaths (26.6% of all deaths) attributed to cancer in Malta. More importantly, cancer is the leading cause of death in persons under the age of 75 years (Table 2).

Just like the rest of the world, mortality from cancer in Malta is expected to continue to increase significantly. The costs of the high and rising mortality from cancer are human, social and economic. Cancer often brings about a person's demise several years before the age of average

Figure 1: Time trend analysis for all cancers 1993-2006



Source: Malta National Cancer Registry, Department of Health Information and Research

Table 1: Predicted numbers (thousands) of new cancer cases in 2020 in Europe, based on crude scenarios for annual change in the overall cancer incidence rates

	Males		Females	
	Cases in 2020 (thousands)	Change since 2002 (%)	Cases in 2020 (thousands)	Change since 2002 (%)
3% decline in rates	1077	-28	877	-34
2% decline in rates	1296	-14	1054	-20
1% decline in rates	1555	4	1266	-4
No change in rates	1864	24	1517	15
1% increase in rates	2230	49	1814	37
2% increase in rates	2662	77	2166	64
3% increase in rates	3173	112	2582	95

Source: Ferlay et al., 2004⁵

Table 2: Causes of premature deaths for people aged under-75 in Malta in 1997 and 2007

Major disease groupings	Percentage of all deaths in people aged under 75 years	
	1997	2007
Cancer	33.6	39.5
Circulatory	38.2	30.4
Respiratory	6.1	5.7
External (Accidents, Suicides, Homicides)	5.7	7.4
Digestive	3.2	3.5

Source: National Mortality Registry, Directorate Health Information and Research, Ministry for Health the Elderly and Community Care

Table 3: Age-adjusted 5-year relative survival for breast, lung, colorectum, skin melanoma and all malignancies for period analysis 2000-2002

	Breast		Lung		Colorectum	
	RS	95%CI	RS	95%CI	RS	95%CI
Malta	76.0	70.7-81.8	4.6	2.7-7.8	51.5	45.8-57.9
EUROCARE-4 mean	79.0	78.1-80.0	10.9	10.5-11.4	56.2	55.3-57.2

	Skin melanoma		All malignancies (women)		All malignancies (men)	
	RS	95%CI	RS	95%CI	RS	95%CI
Malta	94.8	84.5-106.4	54.6	51.7-57.5	42.3	39.5-45.3
EUROCARE-4 mean	86.1	84.3-88.0	55.8	55.3 -56.2	47.3	46.8-47.8

life-expectancy is reached, thus effectively cutting the person's life short. More so, cancer deprives families and society of a valuable human, social and economic resource.

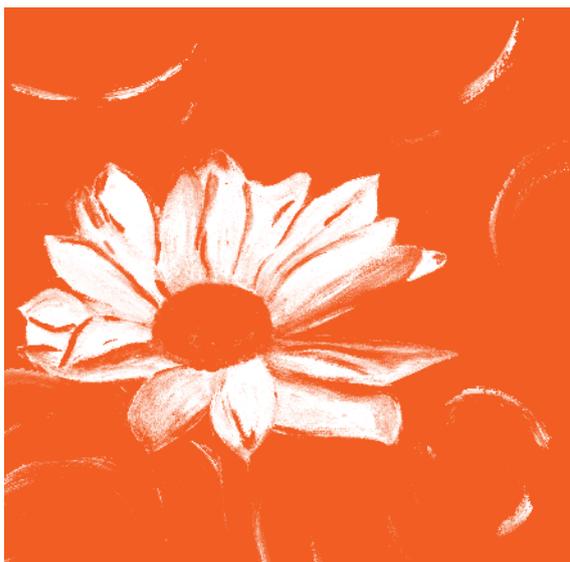
1.4.4 The need to continue to improve cancer survival

The EUROCARE-4 project analysed data on the incidence of cancer and follow-up information on patients with cancer who were diagnosed between 1996 and 2002 and followed until December 31, 2003.⁶ Table 2 shows age-adjusted 5-year relative survival for selected major cancer sites for Maltese patients and EUROCARE-4 mean as derived from this study.

Survival rates for the most common and lethal cancers in Malta have improved. When adjusting for age factors, it is shown that over 40% of male cancer patients and over 50% of female cancer patients survive at least five years from the date of diagnosis. However, this is still lower than the European mean. Focusing on initiatives to improve the survival from the most common cancers will be the most effective way to ensure a sustained improvement in the cancer survival rates for current and future cancer patients in Malta.

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- 3 Communication from the Commission to the European Parliament, the Council, the European Economics and Social Committee and the Committee of the Regions on Action Against Cancer: European Partnership COM(2009)291 final.
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Chapter 2

Policies for prevention

Our overall goal is to avoid having people coming down with preventable cancers.

Cancer prevention requires intervention on identified determinants that can be modified through public health actions related to the environment and lifestyle habits. Cancer prevention policies must therefore be located in the broad context of social and economic environments, far beyond the health sector.

2.1 Promoting and adopting healthy lifestyles

Lifestyle factors play an important role in the causation of cancer. There is a strong justification for cancer prevention activities focused on reversing behavioural patterns linked to tobacco smoking, alcohol drinking, unhealthy diet and physical inactivity.

The good news is that tackling these risk factors has the potential to address the underlying causes of many other major diseases. Therefore, there are great opportunities to prevent not only cancer but also cardiovascular disease, diabetes and respiratory illness.

Over half of all cancers could be prevented if people adopted healthy lifestyles such as:

- Not smoking
- Maintaining the appropriate body weight
- Eating a healthy diet
- Undertaking a moderate level of physical activity
- Avoiding excessive alcohol intake
- Avoiding excessive exposure to sunlight⁷

Between 25 and 30% of all cancers diagnosed in developed countries are directly linked to tobacco smoking. Cigarette smoking harms both smokers and those exposed, i.e. passive smokers. As an acquired voluntary habit, tobacco smoking is the largest single avoidable cause of premature death.⁹

Over 80% of all lung cancers are attributable to cigarette smoking. Up to 60% of cancers arising in the oesophagus, larynx and oral cavity are attributable to the effect of tobacco either alone or in combination with alcohol consumption. It is never too late to stop smoking. The benefit of smoking cessation is clear within 5 years and is progressively more noticeable with the passage of time.¹⁰

The three main strands that need to be pursued to prevent cancer are:

- Education and awareness activities
- Legislation that restricts access and exposure to harmful products and environments
- Supporting individuals to sustain lifestyle changes

2.1.1 Intensifying our efforts against tobacco smoking

i. Smoking as a risk factor for cancer

Tobacco smoking is the most significant preventable cause of cancer. From the 4000 substances isolated from tobacco products, around 40 are known to be carcinogenic.⁸

ii. Current overall situation regarding tobacco smoking in Malta

Malta was the second EU Member State after Ireland to prohibit smoking in public places. Much has been done to raise awareness regarding the negative consequences of tobacco smoking. Despite the efforts to increase awareness about the negative consequences of tobacco smoking, the overall prevalence of smoking among the Maltese adult population over the past years remains largely unchanged with one in four adults smoking regularly or occasionally. During the last decade, death occurred as a direct consequence of smoking

Table 4: Percentage of regular and occasional smokers (aged 16 and over) in Maltese residents

Regular and occasional smokers aged 16+ (%)		
	2002	2008
Men	32.5	31.0
Women	20.7	21.4
Total	26.2	25.8

Source: Department of Health Information and Research, Health Interview Survey: 2002 and 2008

Table 5: Number of smoking related deaths registered in Malta

Number of smoking related deaths 1996 - 2007 ¹¹		
Years	Males	Females
1996 - 1998	733	319
1999 - 2001	720	351
2002 - 2004	753	307
2005 - 2007	784	319

in approximately 360 individuals each year. A considerable proportion of children under 16 years are also still experimenting with tobacco smoking. This habit is also leaving a negative impact on non-smokers with around a quarter of the adult population reporting exposure to passive smoking at home. Despite the enactment of legislation, 27% report being exposed to smoking in public places and 14% in the workplace. As a consequence, smoking remains an important public health problem and more remains to be done.

2.1.1.1 Reducing tobacco smoking in Malta – the way forward

Tobacco smoking is still posing a major burden on the Maltese society. Changing the risk profile for cancer in the Maltese population requires strong action to combat tobacco smoking. To achieve this goal, Government is setting itself the following objectives:

- To reduce the overall rate of tobacco smoking by 20%
- To reduce the rate of smoking in pregnancy by 25%
- To halt the increase in tobacco smoking in teenage girls
- To adopt a zero tolerance policy towards exposure to tobacco smoking in public places

Table 6: Number of children reporting that they have already smoked tobacco

		Children who have smoked tobacco (%)^{12,13}	
		2002	2006
11 years	Boys	8.7	10.0
	Girls	5.1	4.0
13 years	Boys	25.9	24.0
	Girls	32.9	23.0
15 years	Boys	37.6	42.0
	Girls	40.1	49.0

To achieve the above objectives Government is proposing to undertake the following measures:

- Introducing smoking bans in children's playgrounds, sports facilities and mass leisure events
- Prohibiting the consumption of food or drinks in designated smoking rooms
- Restricting the availability of cigarette vending machines
- Restricting the availability of tobacco products to young people by increasing and enforcing distance zones round educational facilities where tobacco cannot be retailed
- Strengthening compliance with the ban on sale of tobacco products to under-18 years old
- Introducing pictorial warnings on cigarette boxes and other tobacco products
- Undertaking smoking cessation initiatives specifically targeting health professionals and education professionals so that health care settings and schools may function as role model environments
- Introducing a specific programme for pregnant women to stop smoking in conjunction with maternity staff
- Working with family doctors to develop a specific 'quit smoking' advisory service
- Considering the feasibility of partial subsidy on proven nicotine replacement therapies within the framework of an approved smoking cessation programme for specific target groups.

Table 7: Percentage of Maltese residents by frequency of alcohol consumption

Frequency of alcohol consumption (any volume) age 16+ (%)		
	2002	2008
Once a week or more	39.7	20.7
Less than once a week to once a month	14.5	20.7
Less than once a month	17.6	22.2
Never	28.0	36.4

Source: Department of Health Information and Research, Health Interview Survey: 2002 and 2008

2.1.2 Acting upon harmful alcohol consumption

i. Alcohol as a risk factor for cancer

Alcohol consumption plays an important role in the causation of cancer. The more a person drinks, the higher the risk of developing certain cancers. Higher risks for breast, colorectal and liver cancer have been associated with alcoholic beverages.^{14,15} Alcohol drinking increases the risk of cancers of the upper digestive and respiratory tracts, even in the absence of tobacco smoking, and the risk for cancer increases exponentially when these two factors are combined.

ii. Current overall situation regarding alcohol consumption in Malta

A downward trend for self-reported alcohol consumption in adults has been noted with an increase in the number of alcohol abstainers.

Table 8: Number of children reporting that they consume alcohol on a weekly basis by ages 11-15

		Children who consume alcohol weekly (%) ^{12,13}	
		2002	2006
11 years	Boys	9.1	17.0
	Girls	3.2	7.0
13 years	Boys	21.0	28.0
	Girls	18.1	21.0
15 years	Boys	55.8	51.0
	Girls	39.8	39.0

Table 9: Percentage of adults who consume fruit and vegetables daily

		Adults who consume fruit & vegetables daily (%)	
		Fruit	Vegetables
2002	total	63	29
2008	total	74	51

Source: Department of Health Information and Research, Health Interview Survey: 2002 and 2008

On the other hand, while a small decrease in reported alcohol consumption was recorded among 15-year-olds, alcohol use appears to be increasing in the younger age groups. The 2007 European School Survey Project on Alcohol and other Drugs (ESPAD) shows the prevalence of consumption of alcohol (over the one-year period prior to the study) among school children in Malta (87%) to be higher than the average in Europe (82%).

To stem this worrying trend, the minimum age for sale of alcohol was raised to 17 years in 2009.

2.1.2.1 Reducing alcohol consumption in Malta – the way forward

Prevention and control policies for alcohol consumption are best directed by the axiom: 'Less is better'. It is intended to particularly target young persons to prevent adoption of unhealthy drinking patterns.

To achieve the above goal, Government is setting itself the following objectives:

- To increase awareness on harmful effects of alcohol consumption
- To reduce alcohol consumption in under 16-year olds by 25%
- To quantify alcohol consumption in pregnancy with a view to promoting abstinence from alcohol in pregnancy

To achieve the above objectives Government is proposing to undertake the following measures:

- Increasing the minimum age for sale of alcohol to 18 years
- Reviewing regulation on advertising and labelling of alcoholic products
- Creating alcohol-free settings in environments frequented by young people, including sports facilities
- Setting up an awareness programme on the dangers of alcohol consumption during pregnancy

2.1.3 Encouraging healthy dietary lifestyles

i. Healthy eating as a protective factor against cancer

About one third (30-40%) of all cancer mortality may be related to diet. However, this is not firmly established and research in this area is very dynamic with frequent new reports being published about diet, nutrition and the risk of cancer.¹⁶ A diet rich in fruit and vegetables seems to reduce the risk for a wide variety of cancers, particularly those of the digestive tract, since fruit and vegetables contain a particularly large number of potentially anti-carcinogenic agents.

The WHO and American FDA recommendations advocate the five-a-day regime of fruit and vegetables. Following these dietary recommendations may have the potential to reduce cancer incidence by as much as 30-40%. Benefits may also accrue from a reduction in intake of saturated fats, added sugar and salt and the removal of trans-fatty acids from the diet.

ii. Current overall situation regarding healthy dietary lifestyles in Malta

Self-reported daily consumption of fruit and vegetables in adults indicates that uptake is increasing. Although a marked increase in vegetable consumption was reported, only half the adult population consumes vegetables daily and there remains room for improvement.

Unfortunately, the positive trend in adults is reversed in children. A drop in fruit and vegetable consumption has taken place and the tendency is for both boys and girls to consume less fruit and vegetables as they grow older.

2.1.3.1 Promoting the adoption of healthy dietary lifestyles in Malta – the way forward

To achieve this goal, Government is setting itself the following objectives:

- To achieve a rate of 75% self reported daily vegetable intake in the adult population
- To double the daily rate of reported fruit and vegetable consumption in children aged 11-15 years
- To reduce use of trans-fatty acids in cooking
- To combat obesity.

To achieve the above objectives, Government is proposing to undertake the following measures:

- Strengthening compliance with the ban of sale of junk food from school canteens
- Designing innovative children-oriented campaigns to increase daily consumption of fruit and vegetables
- Adoption of a National Obesity Action Plan and of a Food and Nutrition Action Plan
- Promoting increased availability of fruit and vegetables in canteens and restaurants
- Conducting a feasibility assessment of a ban on the use of trans-fatty acids in cooking oils

Table 10: Percentage of children who consume fruit and vegetables daily^{12,13}

		Fruit		Vegetables	
		2001	2006	2001	2006
11 years	Boys	48	42	19	12
	Girls	59	46	25	19
13 years	Boys	44	33	10	7
	Girls	50	47	15	14
15 years	Boys	38	35	12	8
	Girls	44	34	15	14

2.2 Exposure to cancer-causing substances

2.2.1 Addressing occupational exposures

i. Occupational risk-factors for cancer

Approximately 5% of cancers worldwide have been attributed to occupational environments. However, like most work-related ill-health, it is probable that the importance of exposure to carcinogenic risk factors in work settings is underestimated.¹⁷ Studies have shown that occupational exposures are linked with the following cancers: lung, bladder, upper airways, liver, leukemia and certain types of skin cancer.

ii. Current overall situation regarding occupational exposures in Malta

In Malta, occupational exposures to some of the common occupational carcinogens is prevalent in specific occupational settings such as solar radiation in those who work outdoors (agricultural and construction workers, deliverymen, post-persons), passive smoking in the hospitality sector and diesel exhausts and hardwood dust in the car repair and furniture manufacturing industries respectively. With respect to ionising radiation, employers are obliged to ensure that all radioactive doses received by employees are as low as reasonable. The recorded doses received by workers in Malta are well below the limits set down in the EU Directive laying down basic safety standards for the protection of the health of workers and the general public against the dangers arising from ionizing radiation.

2.2.2 Reducing occupational exposures in Malta – the way forward

To achieve this goal, Government is setting itself the following objective:

- To assess carcinogenic exposure and take measures to reduce exposure where necessary

To achieve the above objective Government is proposing to undertake the following measures:

- Setting up systems to gather more information about occupational exposures and diseases
- Strengthening the capacity of the Occupational Health and Safety Authority for inspection and enforcement of a non-carcinogenic working environment.

2.3 Reducing environmental exposure

i. Environmental risk factors for cancer

Cancer-causing agents most commonly present in the environment worldwide include air pollutants (including combustion products, particulate matter, radionuclides, organic fibres such as asbestos and radon), water contaminants, ionizing and solar radiation, food contaminants such as pesticide residues, dioxins or environmental estrogens, and chemicals from industrial emissions. Long-term exposure to these agents is believed to be an important contributing factor to the global cancer burden in the EU as it potentially affects entire communities for long periods of time.

The possible carcinogenic effects of non-ionizing radiation and electromagnetic fields from sources such as power lines, electrical equipment and mobile phones are a matter of public concern but there is little evidence of an associated risk of cancer. Studies that enrolled large sample sizes of cancer cases found no excess risk of cancer among adults living in the vicinity of power lines and studies on childhood cancer and power line exposures were inconclusive.¹⁸

ii. Current overall situation regarding environmental exposures in Malta

a) Air Pollutants

In recent years, air pollution in Malta has significantly decreased as a result of the abolition of leaded petrol in 2003. The phasing out of coal as a source of electricity generation has also improved air quality in densely populated urban areas situated close to a power station. Nevertheless, the number of vehicles per capita

has risen well above the EU average in recent years. Furthermore, current levels of particulate matter are in excess of the limit values¹⁹ established by the EU, largely as a result of the recent boom in Malta's construction industry, while the average benzene concentrations increased by 8% between 2005 and 2006.²⁰ Steps have been taken to provide incentives for cars that pollute less through taxation initiatives.

b) Ionising Radiation

In Malta, persons can be exposed to ionising radiation by three different methods: as part of their occupation, from the natural background or from a medical diagnostic examination or therapy. Occupational exposure is under stringent control and local evidence indicates that natural background radiation, particularly from radon is minimal.^{21,22} A variety of medical diagnostic procedures use ionising radiation (chest x-rays, mammograms, CT scans, nuclear medicine procedures, cardiac catheterization procedures, radiotherapy). While there are no dose limits for medical exposures, judicious use of these diagnostic procedures ensures that the benefit obtained by using them outweigh potential harm that they may cause.

c) Solar Radiation

Sunlight exposure is the main environmental cause of skin cancer and UV light is the solar radiation spectrum component involved. Squamous cell carcinoma is attributed mostly to cumulative sun exposure and is the most common form of skin cancer among people who work outdoors. On the other hand, cutaneous melanoma (and basal cell carcinoma) is more related to intermittent sun exposure, as with sunbathing and outdoor sports. All types of skin cancers have been increasing in incidence over the last few decades and their treatment poses a considerable financial burden on individuals and health-care systems.

In a survey carried out among Maltese adults in 2004,²³ 19.2% of those interviewed admitted to spending at least some of their leisure activities during peak sunshine hours (spring or summer) more than three times a week. Half of all those interviewed (50.2%) reported using sunscreen regularly during leisure activities carried out during peak sunshine hours. Females reported a higher use of sunscreen products than males. In this survey, 28.7% of those interviewed admitted to working in the sun for one hour or more on a typical working day. Only 9.3% of these reported regularly using sunscreen, or wearing a hat, during outdoor work activities.

d) Non-ionising Radiation and Electromagnetic Fields

In 2001, the Malta Communications Authority (MCA) initiated a comprehensive audit programme of mobile phone base stations. This programme has been expanded and is ongoing. Emission levels in the vicinity of base stations and neighbouring areas are measured to confirm their compliance to the applicable guidelines and the results are regularly published on the MCA website. On-demand audits are also carried out. To date, all sites audited by the MCA were found to be well compliant with the International Committee on Non-Ionising Radiation Protection (ICNIRP) guidelines.

2.3.1 Reducing environmental exposures in Malta – the way forward

To achieve this goal, Government is setting itself the following objectives:

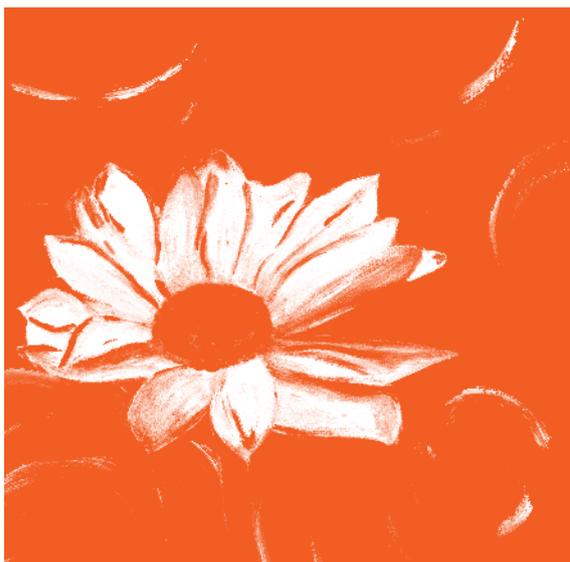
- To promote a cleaner and healthier environment
- To continue to raise awareness on environmental exposures and cancer risk
- To protect against solar radiation
- To reduce unnecessary exposure to medical radiation.

To achieve the above objectives Government is proposing to undertake the following measures:

- Adopting the Second National Environment and Health Action Plan
- Taking steps to reduce National Emission Ceilings
- Educating health care professionals and the public on the harmful effects of exposure to unnecessary medical radiation
- Continuing with awareness campaigns on avoidance of solar radiation
- Providing sun protection gear to outdoor workers
- Regulating local solaria/salons offering sunbed facilities.

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Chapter 3

Policies for early diagnosis

Our overall goal is to diagnose cancers as early as possible.

Survival rates for a number of common cancers can be greatly improved through early diagnosis and treatment. Cancer is a potentially lethal disease; therefore the primary goal of screening and treating patients is to save lives. Mortality is the most important outcome indicator for effectiveness of screening programmes. Studies that are from time to time performed on cases registered by the Malta National Cancer Registry (MNCR) tend to show that cancer patients present for diagnosis and consequently for treatment at relatively advanced stages of disease when it is no longer localized to the organ of origin. This is particularly true of some of the commonest cancers, such as female breast cancer²⁴ and colorectal cancer,²⁵ and partly explains the relatively high mortality and variable survival rates associated with these cancers.

3.1 Cancer screening

Screening involves testing for disease in people without symptoms, with the primary purpose of reducing mortality from the target disease, in this case cancer. In addition to its effect on enhanced survival, screening also has other important consequences and implications for quality of life.²⁶

Table 11: Components of an organised cancer screening programme

1. Definition of target population	Population Component
2. Identification of individuals	
3. Measures to achieve sufficient coverage and attendance, e.g. personal invitation	
4. Test Facilities for collection and analysis of screen materials	Test execution
5. Organized quality-control programme for obtaining screen material and its analysis	
6. Adequate facilities for diagnosis, treatment and follow-up of patients with screen-detected disease	Clinical Component
7. Referral system linking the persons screened with laboratories (providing information about normal screening tests) and clinical facilities (responsible for diagnostic examinations following abnormal screening tests and management of screen-detected abnormalities)	Coordination
8. Monitoring, quality control and evaluation of the programme: availability of incidence and mortality rates for the entire target population, and for attenders and non-attenders respectively.	

Source: Responding to the challenge of cancer in Europe, Institute of Public Health of the Republic of Slovenia, 2008 (Chapter 4, Cancer Screening; page 73)

Screening for cancer is best achieved by means of organized screening programmes whereby whole cohorts of the population are periodically screened for cancer at particular body sites where the disease could develop. A screening programme incorporates a range of activities that starts with the definition of the target population and extends to the treatment and follow-up of screen-detected patients.

There are three cancer screening methods that are presently sufficiently well documented in the international literature and for which the establishment of screening programmes has been recommended.

These programmes have also been recommended by virtue of the EU Council recommendation on Cancer Screening²⁷ and include:

1. Breast cancer screening (mammography) in women;

2. Cervical cancer screening (cytological tests for cell changes in the cervix);
3. Colorectal cancer screening (examination for faecal occult blood; FOB) in women and men.

3.1.1 Breast cancer screening

Breast cancer is the most common cancer among women and its incidence is increasing in most populations. Currently, more than 200 new cases of breast cancer in women are being registered each year in Malta, with around 70 women dying from breast cancer annually. The primary target lesion for screening of the female breast is early invasive cancer. Mammography involves radiological imaging of each breast (usually using 2 views especially in the first screen) and read by one or preferably two radiologists. A screen-positive finding is a lesion that is suspicious for breast cancer and will need to be assessed further by a needle biopsy or excision (open surgical) biopsy.

Table 12: Cancer screening recommendations by various organisations

Organisation	Cervical cancer	Breast cancer	Colorectal cancer
WHO	Recommended without details	Every 2-3 years at ages 50-69	Mortality can be reduced; no clear recommendation
International Union against cancer (UICC)	Pap smear every 3-5 years from age 20-30 until 60 years or over	Mammography every 2 years at ages 50-69	FOB test every 2 years at ages over 50
EU	Start at ages 20-30, screening interval 3-5 years, discontinue at age 60 or over	Mammography every 2-3 years at ages 50-69	FOB test every 1-2 years at ages over 50-74
US Preventive Services Task Force	Pap smear at least every 3 years among sexually active women until age 65	Mammography every 1-2 years at ages 50-69	FOB test every year after age 50; sigmoidoscopy as alternative

Source: Responding to the challenge of cancer in Europe, Institute of Public Health of the Republic of Slovenia, 2008 (Chapter 4, Cancer Screening; page 89)

3.1.2 Cervical cancer screening

Cervical cancer is the second most common cancer among women worldwide and especially in developing countries. To date, Malta has a low rate of cervical cancer. On average, only 8 new cases of cancer of the cervix are diagnosed annually.

Virtually all cases of cervical cancer are a consequence of infection with human papilloma virus (HPV), but most infections clear spontaneously within 12 months or less. The detectable pre-clinical phase has been estimated to be as long as 12-16 years. The objective of cervical cancer screening is to reduce both incidence and mortality. A successful screening programme detects early, pre-invasive lesions during the pre-clinical detectable phase and is able to reduce deaths by preventing the occurrence of invasive cancer. Diagnostic assessment requires colposcopic as well as histological examinations.

Most screening programmes start with women in their third decade of life and are discontinued after age 60-70. The frequency of screening may vary according to the individual's initial result and the intervals between screens may be increased after repeated negative results.

3.1.3 Colorectal cancer screening

Colorectal (large bowel) cancer ranks as the second most common cause of cancer death in Europe. The annual average number of new cases of colorectal cancer diagnosed in Malta is around 180 (98 for men and 81 for women). On the other hand, the average number of deaths annually attributed to this cancer is 95 (49 for men and 46 for women).

Screening can either reduce incidence by removal of pre-malignant lesions or increase it by earlier detection of invasive cancer. One of the limitations that has so far been associated with the main method adopted in colorectal cancer screening, namely the Faecal Occult Blood test (FOB), is the preponderance for overdiagnosis. The detectable pre-clinical phase has been estimated as 2-6 years.

Faecal occult blood (FOB) testing is based on the detection of blood in stools. However, the most commonly used tests are not specific for human blood and may yield false positives in those who have eaten undercooked meat recently, and consequently the rate of false positive results is high. Diagnostic examination always involves colonoscopy, which allows for the

Table 13: Number of female respondents reporting having ever had a mammography by age group

Age groups	Had a mammography examination at least once (%)	Never had a mammography examination (%)
15 - 29	5.61	94.39
30 - 39	14.69	85.31
40 - 49	48.52	51.48
50 - 59	53.74	46.26
60 - 69	48.70	51.30
70+	32.29	67.71
Total	32.49	67.51

Of those who have had a mammography screening	%
Within the past 12 months	34.62
More than 1 year but less than 2 years	22.22
More than 2 years but not more than 3 years	18.84
Not within the past 3 years	24.15

removal of polyps, and histological verification of detected suspicious lesions.

3.1.4 Screening for other cancers

Screening tests are available for many other types of cancer, but their effectiveness has not been evaluated adequately to date or a lack of effectiveness has been demonstrated. Furthermore, for most of these, pilot studies are still required to demonstrate the feasibility of mass screening. These include: i) serum prostate specific antigen (PSA) levels and digital ultrasound rectal examination for prostate cancer; ii) chest X-rays with or without sputum cytology and spiral low-dose CT for lung cancer; iii) transvaginal or transabdominal ultrasound and serum CA125 levels for ovarian cancer; and iv) visual inspections for oral cancer and cutaneous melanoma.

For all the above, there is currently no evidence that shows that any of these tests have any applicable effectiveness in mass screening programmes.

3.1.5 Cancer screening guidelines

Several international and national organisations have made recommendations for cancer screening. In the EU, detailed quality assurance guidelines are available for breast cancer and cervical cancer screening while guidelines for colorectal cancer screening are under development.

3.1.6. Cancer screening activity in Malta

The first ever organised cancer screening programme in Malta was started in 2009 for breast cancer. However, opportunistic screening activity has been quite high for the past few years.

Results from the Health Interview Survey 2008 show that just over half of the women in the 50-59 year age group reported having had at least one mammography. Furthermore, half of the women aged 40-49 and 60-69 also reported having had a mammography examination. The majority of women who had undergone a mammography had done so less than two years

Table 14: Number of female respondents reporting having ever had a cytological smear by age group

Age groups	Had a cytological smear examination at least once (%)	Never had a cytological smear examination (%)
15 - 29	39.02	60.98
30 - 39	85.92	14.08
40 - 49	88.78	11.22
50 - 59	81.50	18.50
60 - 69	63.57	36.43
70+	30.37	69.63
Total	65.40	34.60

Of those who have had a cytological smear test	%
Within the past 12 months	42.33
More than 1 year but less than 2 years	21.00
More than 2 years but not more than 3 years	11.57
Not within the past 3 years	24.61

Table 15: Number of respondents reporting having ever had a FOB test by age group and gender

Age groups	Had a FOB at least once (%)	Never had a FOB (%)
15 - 29	2.44	97.56
40 - 49	4.57	95.43
50 - 59	5.68	94.32
60 - 69	8.51	91.49
70+	6.40	93.60
Total	4.71	95.29

Gender	Had a FOB at least once (%)	Never had a FOB (%)
Female	4.42	95.27
Male	5.57	94.08
Total	4.95	94.72

Of those who have had a FOB test	%
Within the past 12 months	30.69
More than 1 year but less than 2 years	12.87
More than 2 years but not more than 3 years	15.35
Not within the past 3 years	35.15

prior to the interview. These results are shown in Table 13.

Furthermore, from the same survey it was shown that the vast majority of women between the ages of 30 and 69 had undergone a cervical smear test at some point in their lives. Almost half of these women had undergone this examination less than one year prior to the interview. These results are shown overleaf in Table 14.

The usage of FOB testing appears to be generally low. The prevalence of FOB testing seems to rise with age, possibly due the use of this test for the investigation of suspicious symptoms (gastrointestinal cancers are known to increase with age). The use of FOB tests is largely the same in both genders. These results are shown overleaf in Table 15.

3.1.7 Cancer screening in Malta – The way forward

The national programme for breast cancer screening is the first national cancer screening programme to have been implemented in Malta. This programme started to operate in the last quarter of 2009. Women aged 50-59 are being invited to participate over a 3-year period and this age group may be expanded to include the 60-69 ages after an evaluation of the first cycle of screens is completed. The screening facility is situated in Lascaris Wharf, Valletta, and will allow for the administration of other screening programmes at the same facility in future. Implemented screening programmes need to attain the highest possible response rate and quality levels. They will be accompanied by the appropriate promotion campaigns and resourcing, including the initial and ongoing rigorous training of the staff operating the programmes.

For breast cancer screening, the target is to improve early diagnosis by implementing the national cancer screening programme, thereby reducing the percentage of women diagnosed at advanced stages of breast cancer (i.e. T3 or

higher) to less than 5% by 2012 in the screened age group. This will be achieved through the following measures:

- **Implementing a promotion campaign to encourage the population to take up cancer screening examinations especially when invited to participate in an organised cancer screening programme in order to ensure a high take-up. (The response rate for women invited to participate in the first full cycle of the breast cancer screening programme is set to exceed 70%.)**
- **Evaluating the breast cancer screening programme after the first three years of activity to ensure that the pre-set quality criteria are met, including a recall rate of 5% or less and a false positive rate of 3% or less.**

The introduction of an organized population-based screening programme for colorectal cancer will commence with the definition of a detailed roadmap that will include the acquisition of the required resources that will have been identified. These include the strengthening of the infrastructure needed such as medical equipment, time slots and supplies for the expected increases in endoscopic and surgical interventions and the adaptation of the IT system on the National Screening Unit to include new cancer screening programmes. The required capacity building and training and re-training of the relevant professionals will also be included in this roadmap. Furthermore, in 2011 there will also be further evaluation to establish the optimal screening methodologies and frequency of screening (important conclusions of international studies and the first ever EU Guidelines are expected to be published in early 2011) to be used in a national screening programme. It is expected that the first cohort of persons that will be invited for screening will include persons in the 60-64 year age group and will initially start with Faecal Occult Blood testing (FOB).

A full Health Technology Assessment will be performed in 2011 with a view to introducing a national programme of HPV vaccination. This programme will commence after the completion

of this exercise and the vaccines will be offered to a one-year cohort of girls between the ages of 11-16 years. The one-year cohort will be selected following the evaluation of the results of similar programmes in other EU Member States. Furthermore, during 2011 there will be further evaluation to establish the optimal screening methodology (important conclusions of international studies and an update of the EU Guidelines are expected during 2011) to be used in a national screening programme. There will also be an epidemiological assessment based on the incidence rates and characteristics of pre-malignant lesions of the cervix to establish the optimal one-year cohort of women over the age of 20 years that will be the first to be invited for screening.

- **Introducing an organized population-based screening programme for colorectal cancer, which will commence with the definition of a detailed roadmap that will include the acquisition of the required resources that will have been identified**
- **Introducing an organised population-based colorectal screening programme, as from 2012, that will invite persons in the 60-64 year age group for FOB test over 2 years**
- **Conducting a Health Technology Assessment exercise during 2011 with a view to introducing a national HPV vaccination programme**
- **Introducing a national HPV vaccination campaign, as from 2012, that will target a one-year cohort of girls - this one-year cohort will be selected from the age group of 11-16 year old girl population**
- **Introducing an organized cervical cancer screening programme, as from 2014, that will target a one-year cohort of women above the age of 20 years - the selected age group will be determined through an epidemiological evaluation of the incidence of pre-malignant lesions in 2011.**

3.2 Early diagnosis of suspected cancer cases

Apart from cancer screening, early recognition and investigation of possible cancer symptoms

and signs is the other effective strategy for controlling and reducing cancer mortality. There are many possibilities for delays in the pathway from the time a person acknowledges the presence of symptoms necessitating a visit to the doctor, and onwards to when a diagnosis has been made and a course of treatment has been initiated. These delays can be divided into three broad categories:

- **Patient's delay:** Patients often delay coming forward and seeking a diagnosis because of fears linked to the diagnosis of cancer and the difficulties associated with certain treatments.
- **Doctor's delay:** A doctor may take time to refer patients presenting with seemingly innocuous signs such as lumps, sores that fail to heal and abnormal bleeding, which may be the first warning signs of cancer.
- **System delay:** Patients often "get lost" in the system as they may require several diagnostic tests and procedures by different units and teams.

The national target is to minimize the time necessary for cancer patients to present and to start the necessary treatment. This will be achieved by:

- Raising awareness among the general public, through regular campaigns, about the early possible signs of cancer and the need to seek immediate medical attention – measurement of the level of awareness amongst the general public will be incorporated in the design of such campaigns. These campaigns will in part be based on the European Code Against Cancer²⁸
- Educating and supporting primary health care practitioners to ensure early referral of possible cancer cases by improved links between primary and secondary care and by nominating these professionals to act as the focal point for care coordination in cancer patients
- Improving the monitoring of the stage at diagnosis at which cancers are registered by the Malta Cancer Registry. This measure will be expanded further in Chapter 8 of this Cancer Plan.

References

- 24 In a study performed by the Malta National Cancer Registry (MNCR) on the female breast cancer cases diagnosed from 1998 to 2002, it was found that 11.8% of cases were diagnosed at an advanced stage of the disease (T3 or above) with tumours greater than 5 cm or with signs of advanced local extension within the breast. This data was compared with the stage at diagnosis of cases diagnosed during the same time period in Northern Ireland. In this series the number of cases diagnosed at stage T3 or higher was 4.4%
- 25 The MNCR performed a staging exercise on all the cases of colorectal cancer diagnosed from 1999 to 2003. The most common stage at diagnosis was Stage II (36%) followed closely by the cases diagnosed at Stage III (34%). In general, the cancers diagnosed in females were more advanced than those diagnosed in males. The lymph nodes of the cases diagnosed at Stage III are positive for metastases, while the lymph nodes of cases diagnosed at Stage II are still free from metastatic involvement.
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- 27 Council Recommendations of 2 December 2003 on cancer screening (2003/878/EC) advises Member States to initiate organised cancer screening programmes for breast, colorectal and cervical cancers.
- 28 European Code Against Cancer (2003)
<http://www.cancercode.org/>



Chapter 4

Ensuring quality in the diagnosis and treatment of cancer

Our overall goal is to ensure that all cancer patients have access to high quality care in the community or hospital in order to achieve the highest possible cure and survival rates, and to improve patients' quality of life.

The organisation and delivery of clinical services for patients diagnosed with cancer is complex. It involves a wide range of professional expertise and contributions from organisations at all levels of the health system.

The following are considered to be essential features for quality of care in cancer care:

- People who are suspected to have cancer need prompt access to appropriate specialists for accurate diagnosis and subsequent clinical management.
- Cancer specialists come from a range of medical disciplines and clinical professions. They need to work effectively together within a multi-disciplinary service if the best decisions are to be made about each patient's diagnosis, treatment and support, and if treatments are to be delivered safely and effectively.
- Diagnosis and treatment services are available at primary, secondary and tertiary care levels. Most cancer patients interact with services from more than one part of the health care

system and with different providers. It is imperative that the roles and operational practices of the entire system for delivering cancer services develop logically and fit well together.

- Effective communication and coordination of the delivery of services by healthcare professionals at every level is essential in order to ensure that each patient's pathway of care functions well.
- Patients' needs must be central to the organisation and delivery of services. Patients' views on different therapeutic options and expected outcomes should be part of the clinical decision-making process. Quality of life and psychosocial issues are important, and care plans should always take them into account.

Ensuring that our services come together to deliver quality cancer care requires certain changes in clinical services: how they function; how they relate to other services; and the staff and facilities required. Some changes may be welcomed whilst others may generate resistance because they signify a departure from the traditional way of doing things. The crucial question is "What arrangement is most likely to improve patient outcomes?", and it is this question that will drive our efforts to improve patient experience and care outcomes.

Transforming the delivery of cancer services to improve their performance for cancer patients requires changes in the following three fundamental areas so that:

1. All patients will have access to a uniformly high quality of care by developing and consistently implementing clinical guidelines;
2. An integrated cancer pathway is ensured by introducing the role of a 'key worker' for every cancer patient;
3. All patients have early access to the specialist services necessary for their diagnosis and treatment. This also requires access to specialised equipment, methods and treatment by promoting clinical

specialisation and by upgrading cancer services (facilities and pharmacotherapy provided by the public services).

Expert opinion overwhelmingly supports the principle of multi-disciplinary practice. Good teams take account of all important information within a collective process, although their methods vary. Teams need to develop defined membership and working arrangements with the ultimate aim of providing an integrated approach and continuity of care to the cancer plan of each individual patient.

An approach that encourages research into the performance of the cancer services and the ongoing evaluation of emerging and innovative methodologies for the management of cancer patients will prevail in all the above-mentioned sectors.

Furthermore, this plan is promoting the position towards the pursuance of the adoption of more intensive management practices for advanced cancers. This will become more possible as new expertise, drugs and equipment become available in each of the sectors mentioned below.

4.1 Clinical guidelines and the coordination of cancer care

In order to maintain a high standard of care and ensure that all patients receive high quality, evidence-based care in an equitable and reproducible manner, it is necessary to establish clinical guidelines. The guidelines, set up according to international criteria with the collaboration of experts in the field, will describe the recommended options for preoperative, peri-operative and postoperative care for various cancers, establishing important landmarks in the care of cancer patients such as evidence-based surgery, referral to adjuvant therapy and follow-up criteria and timelines. It has been documented that the use of clinical guidelines helps maintain and enhance quality, provided that such guidelines are implemented, complied with and actively updated.

Each guidance document needs to define the multi-disciplinary team necessary to deliver services, the roles and responsibilities of all components of the service, and how they fit together. For clinical quality to be monitored and improved, it is necessary to enhance the collection of data on identified clinical indicators. This could be achieved by active data collection at the departmental or hospital level and analysis of the data at the hospital, and finally, through the relaying of gathered indicators to the register of the National Cancer Registry. This would enhance the registry's role in cancer surveillance and quality assurance.

Patients with cancer are referred for investigation and management through a number of routes. The common factor is that whenever the suspicion of cancer emerges, the patient and her/his family want to feel confident that the subsequent stages of diagnosis and treatment will follow as soon as possible.

The development and introduction of a 'key worker' for every cancer patient stems from the view that s/he will be the lynchpin that will make sure that, where clinical guidelines are established, these are followed as rigorously as possible. At the same time, the key worker would also provide for the necessary flexibility to modify the cancer pathway as required for the specific needs of the individual patient. Patients' family doctors can assume the role of 'key workers' because they can oversee the whole process from suspicious presentation of symptoms and signs, through investigation, diagnosis and treatment and also palliative and terminal care. In this role, the family doctor will be a key team member of the multi-disciplinary team and will be better able to inform and reassure patients and their families.

Providing family doctors with increased access to diagnostic investigations, according to pre-defined protocols, facilitates confirmation and early diagnosis of suspicious cases without overloading specialist services. Likewise,

strengthening communication between family doctors and specialists facilitates consultation, as well as ensuring timely referral of patients with a high suspicion of cancer for specialist management.

Referrals of patients with a strong suspicion of cancer from primary to specialist care will be formally fast-tracked through a separate referral system, that is through the ticket of referral being delivered directly to consultants or resident specialists. The latter would in turn personally vet the cases and allot an early appointment within pre-designated cancer investigation slots in the outpatient appointment schedule. The urgency of appointments would depend on the strength of suspicion of cancer, according to clinical judgment or, better still, clinical protocols. It needs to be kept in mind that, apart from the classical referral from a family doctor to a specialist who then follows a sequential chain of events until cancer is diagnosed and treated, patients may enter this pathway through a number of alternative routes, and special care must therefore be taken to insert these patients into the symptoms-diagnosis-treatment pathway alongside other patients who are already progressing on it. For example, patients may also be diagnosed with cancer as a consequence of an emergency treatment for undiagnosed cancer, from participation in screening programmes or following referral from other hospital consultants. The important concept is that the patient should enter the appropriate pathway at the required level and that continuity of care is ensured *inter alia* by roping in the family doctor to coordinate the needed care services that would follow.

One ultimate goal will be to be able to offer a potential cancer patient referred by a family doctor to a specialist a waiting time for an outpatient appointment of 2 weeks or less. Another ultimate goal will be to offer a time span from an urgent referral for suspected cancer to the initiation of treatment of one month. In both cases, waiting times can be extended

either due to the specific needs of the diagnostic and therapeutic processes or to the patient's personal choices.

Measures that will help achieve this goal include the following:

- Increasing access to diagnostic investigations, according to pre-defined protocols, to facilitate early diagnosis of suspicious cases. Protocols to be finalised and implemented by end 2012
- In line with the implementation of the eHealth Strategy, providing family doctors with access to electronic clinical records of patients as necessary and following the patient's authorisation
- Formalising the fast-tracking of referrals of possible cancer patients from primary to specialist care
- Allocating dedicated slots in specialist outpatients clinics for urgent cancer investigations and establishing clinical protocols for prioritizing outpatient assessment of suspected cancer referrals by 2012
- Allocating slots for cancer diagnosis in medical imaging outpatient system and establishing clinical guidelines for the use of diagnostic imaging in the investigation of cancer by 2012.
- Allocating dedicated slots in surgery timetables for urgent diagnostic surgery in order to ensure that the time for diagnostic surgery is maintained at one week after the initial patient consultation in hospital by 2012
- Recruiting and training pathologists in order to increase the efficiency of cancer reporting (ongoing)
- Expanding oncological services to maintain a waiting time of less than two weeks from referral after definitive diagnosis and surgery to consultation with the oncologists and palliative care specialists - the latter professionals would then consider and decide on the adjuvant oncological treatment and palliative care required.

4.2 Clinical specialisation and upgrading cancer services

International evidence supports specialisation on the grounds that it is more probable that specialists will have wider experience of the diagnosis and staging of disease; be more aware of the full range of treatment options; be more experienced and proficient in appropriate technical aspects of treatment; and have a fuller understanding of the indications and potential adverse effects of the various treatment options. Furthermore, because cancer is a significant part of their work, they can participate more readily in multi-disciplinary working and should find it easier to remain up-to-date and to participate in audit, teaching and research.

The physical environment where care is delivered, together with the provision of modern equipment, are two essential elements that need to be considered when plans to improve cancer services are being designed. The conception of a new cancer facility which provides all the modern service modalities needed by cancer patients is a cornerstone of this plan. The integration and synergy of current services for the treatment of oncology patients is a key principle for the planning of future services. Furthermore, a marked shift in the types of agents used in the systemic treatment of cancer is occurring and will continue occurring. This means that the system needs to continually evaluate and assess the inclusion of new drugs with the possibility that they may also replace drugs that are currently in use.

4.2.1 Diagnostic Investigations

When a patient is seen by a specialist who decides to investigate further, a number of diagnostic modalities may be chosen in order to reach a definite diagnosis. The types of investigations selected vary between different cancers and between different patients. The setup of clinical guidelines for the use of

diagnostic procedures for the different cancer types, together with the consideration of relevant patient's individual characteristics, would ensure streamlining and equity in the diagnostic process, while curbing unnecessary investigation. The following diagnostic modalities and the time delay before and after such investigations may all contribute, individually or in concert, towards prolonging the time gap between the onset of symptoms and treatment. Every effort must therefore be made to curtail these time intervals.

4.2.1.1 Diagnostic imaging

Diagnostic imaging services carry the major weight of cancer diagnosis. With the emergence of new technologies and the increasing incidence of cancer, this demand is expected to be amplified. Exacerbating this is the fact that of all the cases investigated for cancer only a small minority are found to be actually suffering from this disease.²⁹

With the opening of Mater Dei Hospital, the utilisation of newer medical imaging equipment and technologies, and the development of the Picture Archiving and Communication System (PACS), clinical specialists can now access medical images in real time and with greater facility. All this has markedly improved the potential of medical imaging. This will be further augmented with further investments in the recruitment and training of dedicated radiologists and radiographers, as well as with the installation of new and ongoing replacement of diagnostic equipment.

The target will be the reduction and maintenance to not more than 10 working days of the waiting time from the first encounter of patients with the specialist physicians within hospital to the first diagnostic imaging appointment (which may involve surgical interventions), when indicated.

To reach this target, the following measures will be implemented:

- Establishing clinical guidelines for the use of diagnostic imaging in the investigation of cancer that will ensure the active involvement of radiologists in the cancer investigation process by 2012
- Continuing with the recruitment, training and specialisation of staff at all levels in the Imaging departments - this measure will tie in with the Human Resources strategic plan that will be developed for the healthcare services as an increase in capacity is required to ensure delivery of this plan
- Purchasing and modernizing of medical imaging equipment to include the installation of a PET/CT scanner by 2012
- Evaluating the feasibility of introducing new techniques that may be also performed with a therapeutic intent such as the Cyber and Gamma Knife
- Facilitating referral of patients whose treatment requires the use of specialized techniques to centres of reference abroad where such techniques are available by establishing and strengthening working relationships with identified centres and specialized teams in other Member States

4.2.1.2 Diagnostic surgery

Diagnostic surgery is necessary in order to reach a definitive diagnosis of cancer. It is the process of obtaining tissues or cells from a suspected cancer lesion which will be examined microscopically in order to determine the presence of cancerous cells and the cell types involved. This may be carried out in conjunction with diagnostic imaging.

Once a specialist decides to proceed to diagnostic surgery, it is recommended to carry out the procedure as soon as possible. Pre-planning slots in surgery timetables for diagnostic surgery ensures an avoidance of long waiting lists for these procedures.

Apart from contributing towards early intervention, reducing waiting time before diagnostic surgery also helps to significantly reduce the anxiety associated with having to wait for a definitive diagnosis after patients become aware that cancer is high on the list of possible causes for their symptoms.

The target will be the reduction and maintenance of the waiting time from the first encounter of patients with the specialist physicians within hospital to the first diagnostic surgery appointment (which may involve diagnostic imaging techniques), if indicated, to not more than ten working days.

To reach this target, the following measures will be implemented:

- Establishing clinical guidelines for the use of diagnostic surgery (with or without imaging techniques) in the investigation of cancer by 2012
- Continuing with the recruitment, training and specialisation of surgical staff - this measure will tie in with the Human Resources strategic plan that will be developed for the healthcare services
- Evaluating the feasibility of and the resources required for the introduction of new surgical and imaging techniques that may be also performed with a therapeutic intent
- Dedicating slots in surgery timetables for urgent diagnostic and other endoscopic surgery

4.2.1.3 Pathology

On average, two to three days elapse between the time a biopsy is taken, undergoes the necessary preparation in the laboratory and is seen and reported by a pathologist. In most instances this time delay cannot be shortened due to the necessary preparatory processes required prior to examination of samples. Once samples are reported, results must be confirmed by a consultant pathologist. Immediately after confirmation, results are uploaded onto the

Isoft Clinical Manager system and become easily accessible to the professional staff caring for the patient.

The target will be the reduction and maintenance of the time span from the time a sample of cells or tissues is taken to the analysis and reporting of the findings to not more than five working days.

To reach this target, the following measures will be implemented:

- Establishing protocols for the histo-, cyto- and haematological processes leading to the confirmation or otherwise of the presence of neoplastic/cancerous tissues in the pathological samples submitted in the investigation of a suspicious cancer lesion by 2012
- Continuing with the recruitment, training and specialisation of pathologists - this measure will tie in with the Human Resources strategic plan that will be developed for the healthcare services
- Evaluating the feasibility of and the resources required for the introduction of new pathology techniques, notably in the case of pathological samples which need specialized analytic techniques that will necessitate their referral to laboratories in centres of reference abroad. These referrals will be facilitated by establishing and strengthening working relationships with laboratories in identified centres in other Member States

4.2.2 Treatment of cancer

The treatment of cancer is complex and is often a prolonged process, involving the participation of various categories of healthcare workers, use of a vast range of resources and often of combinations of a variety of modalities of care. The ultimate aim of cancer treatment is that of abolishing cancer and offering a definitive cure. This may not always be possible and all efforts to prolong life or relieve suffering are offered through the various treatment modalities.

4.2.2.1 Surgical treatment

With the majority of cancer patients, surgical treatment is a decisive determinant of the overall treatment result. Surgery is used to cure more patients of cancer than any other intervention, and for the majority of cancers, surgery remains the principal treatment modality. Consequently, the overall demand for cancer surgery is likely to increase based on current trends, although the pattern varies between cancer types. The assurance of clinical quality through guidelines that set down optimal evidence-based patient pathways, surgical training and surgical clinical research are three important areas that need priority attention to ensure the continuous improvement of this important sector of cancer services.

The purpose of clinical guidelines is to ensure that patients are given the best evidence-based treatment. The guidelines describe the individual steps of the investigation, treatment and follow-up process and serve as a concrete tool for ensuring the quality of cancer treatment. The content of the guidelines can be clinically very concrete, for example, describing which diagnostic investigations should be performed or what treatment should be used. They can also contain a description of the pathway, for example, that the cancer patients have to be treated and monitored in an intensive care setting in the postoperative phase after extensive surgery.

It is vital for the various surgical specialities to have the possibility to work closely together on cancer surgery tasks. Surgical cooperation between gynaecological and gastrointestinal surgery can be relevant, for instance, for patients with gynaecological cancer. The specific surgical efforts do not stand alone but are based on broad, well-functioning cooperation with a large number of ancillary and supporting functions at the hospital. This is one of the pre-conditions for a good overall result. Regular clinical joint conferences about investigation and treatment decisions should be encouraged.

There is a particular need to promote the work on the use of guidelines and the definitions and development of indicators used for the monitoring of these guidelines. The processing of both incoming and outgoing data needs to be acknowledged as a decisive precondition for the maintenance and development of clinical quality and hence should be accorded the high priority it deserves.

The performance of cancer surgery necessitates that the surgeon has undergone special training after completion of the specialist education. The special needs for surgical training in order to be able to perform specific surgical procedures and techniques is to some extent met through participation in and supervised performance of operations. For surgeons working in Malta this training will have to be frequently done in centres abroad. Nurses and other professionals involved in the cancer surgery units also have to be able to participate in relevant continuous education programmes.

To ensure optimal quality of surgical treatment of cancer, the following measures will be implemented:

- Increasing, updating and implementing national clinical guidelines for as many different cancer types as possible - for the major cancer sites, such as female breast, lung, colorectal, prostate, uterine and urinary bladder cancer, these guidelines will be published by the end of 2012
- Establishing and utilizing indicators, that are suitably documented in patient administration systems, central registers and clinical databases, and in surveillance findings, as a basis for continuous quality improvement
- Promoting more multidisciplinary team cooperation in surgical departments on the treatment of cancer patients, including the organisation of regular clinical joint conferences to discuss individual cases
- Specifying levels of competence and the content of continuing medical education for each type of cancer for specialists who perform surgical treatment of cancer patients, including

specific goals for all cancer surgery areas -suitable trainee surgeons for specialised cancer surgery training abroad should be identified. Training updates should also be planned.

4.2.2.2 Pharmacotherapy (including the introduction of new drugs)

Over the last 20 years, a huge amount of fine detail has been amassed about the basic biological processes that become disturbed when there is cancer. These have proved to be fertile areas to hunt for rationally based anti-cancer drugs and have produced a record number of novel compounds, several of which are currently undergoing cancer treatment trials. Clearly there will be a marked shift in the types of agents used in systemic treatment of cancer over the next decade and this will impose huge financial pressures on all healthcare systems. Investment will also be needed in more sophisticated diagnostics in tissue pathology and specific biomarkers.

The new therapies that are being or will be developed will be more selective, less toxic and given for prolonged periods - sometimes for the rest of the patient's life. Future cancer care will be driven by the least invasive therapy consistent with long-term survival and, although still desirable, it is envisaged that the eradication of the disease will no longer be the primary aim of treatment. This radical overhaul of cancer care will make it more like the delivery of diabetes care.³⁰ Community nursing and patient education will be as important as the chemotherapy protocols devised by the cancer centres.

During 2008 the total expenditure on drugs used solely for cancer patients amounted to €4.9 million, while the expenditure on a list of other drugs that are often given to cancer patients (as in palliative care) but can also be indicated for other patients reached €1.6 million.³¹ The incorporation of newer, more

sophisticated chemotherapeutic agents into the national formulary, together with the rising demands for these drugs as a consequence of rising trends of cancer incidence and heightened public awareness and expectations, is expected to lead to significant increases in the necessary expenditure on medicinals needed in the management of cancer patients.

Prior to accepting new drugs as standard treatment, an evaluation process needs to be accomplished. Depending on needs, the evaluation will encompass the drug's quality, safety and side-effects, as well as the health, economic (cost-effectiveness and 'added value'), patient-related and organizational consequences of the implementation of a treatment. In addition, the evaluation should consider how the added medicines will supplement or replace existing treatments. Once a drug is accepted as an established standard treatment, it should thereafter be provided on the basis of specific clinical guidelines. Compliance with the guidelines should be monitored, as should also the efficacy of the treatment.

All the above processes require the strengthening of the structures that perform the evaluation, the drawing up of clinical guidelines and the monitoring of compliance with these protocols and efficacy of treatment.

In order to achieve the above, the following measures will be implemented:

- **Developing the capacity of the Directorate of Pharmaceutical Policy and Monitoring to be able to take up the duties of evaluation of new drugs, assistance in the development of the clinical guidelines needed for their use once they are approved, and monitoring of their use and efficacy - this will involve the engagement of one full-time appropriately qualified professional to be fully dedicated to work on cancer drugs**
- **Developing further a detailed financial control system that identifies the use of drugs used in cancer treatment and accurately monitors their cost - this will involve the strengthening**

of the structures that are responsible for the monitoring of procurement prices

- Continuing with the phased expansion of the Government formulary in the area of cancer drugs, especially to proven new medicines -the aim is to decrease the time frame between the awarding of the marketing authorisation license of the product and the availability of the licensed drugs to the patients for whom they are indicated
- Proposing and developing new methodologies for the financing of new emerging cancer drugs in order to increase patients' access to innovative drugs, while safeguarding the financial sustainability of the system - one such methodology is the 'risk sharing' procedure, whereby the first cycles of a drug/ regimen are financed by the industry/ importer, and, if the drug is shown to be effective with an improvement in the prognosis of the patient, the subsequent cycles are then referred for funding from public funds.

4.2.2.3 Radiotherapy

Radiotherapy has an important role in the treatment of many different forms of cancer. This treatment modality can be used in a curative, adjuvant and palliative manner. For some cancers, radiotherapy may be the main form of treatment, such as for cancer of the larynx, where preserving the voice-box may be a high priority. For other cancers, radiotherapy is often used alongside surgery,

as in breast conserving procedures for breast cancer, or alongside chemotherapy such as for oesophageal cancer. Radiotherapy is also extensively used to alleviate symptoms of advanced cancer, such as pain from bone metastasis. It is estimated that at least half of all cancer patients require radiotherapy at some point in their cancer pathway. In addition to this, radiotherapy is being used with increasing frequency for the treatment of non-malignant diseases as well.

The need for radiotherapy has increased considerably in recent years due to the increasing incidence of cancer and is expected to grow even further over the next decade as new treatment recommendations encompass more treatments which are often more complicated. The trend towards more complicated and technologically demanding radiotherapy imposes requirements for technologically updated equipment (including additional and replacement equipment), for more personnel to operate the equipment and for more specialised training.

An EU-wide exercise that worked towards the establishment of estimates for the appropriate level of radiotherapeutic infrastructure in 25 EU countries concluded with a recommendation for five linear accelerators per one million population.³² For Malta, this can be translated into two linacs for the whole nation.

In order to improving radiotherapy services, the following measures will need to be adopted:

- Replacing old and adding new radiotherapy equipment - two linear accelerators will be in operation by 2012
- Reviewing and further developing clinical guidelines for the radiotherapeutic treatment of specific cancer types, together with the corresponding monitoring systems, by 2012
- Evaluating the feasibility of and the resources required for the introduction of new radiotherapy techniques, including methodologies that will combine radiotherapeutic and surgical (radio-surgery) expertise, such as intra-operative radiotherapy and radio-frequency ablation of liver secondaries
- Investing in the training of the professionals critically needed in the operation of the Radiotherapy Units: oncologists, radiographers and physicists - this will include the retention of existing staff and the recruitment of new staff. This measure will tie in with the Human Resources strategic plan that will be developed for the healthcare services
- Re-structuring the training programme for radiographers at the University of Malta by continuing with the plans for the assimilation of therapeutic radiographer training in the present diagnostic radiographer courses (ongoing)
- Extending the time/hours during which the Radiotherapy Unit is operating. This Unit should be operating for more than 12 hours daily.

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Chapter 5

Improving the quality of life of persons living with cancer

5.1 Our overall goal is to attenuate the impact of cancer on quality of life

5.1.1 Physical impact

Cancer and its treatment have significant effects on the body and its functions. The anatomic site of cancer may influence the patient's emotional response to the disease, especially when cancers arise in visible areas of the body. The type of cancer therapy employed may also affect the patient differently at the physical level. Such effects can be transient, namely symptoms such as pain and fatigue, or permanent, that is physical impairment or disability. These effects often limit the patient's ability to carry out activities of daily living.

Symptoms like these are especially common in cases of advanced cancer, with patients' symptoms, including pain, breathlessness, fatigue, anorexia, insomnia and depression being especially common in virtually all patients on admission to palliative care services.³³

5.1.2 Psychosocial and economic impact

A diagnosis of cancer brings about a great deal of psychological distress in patients and their loved ones. This includes an increased uncertainty about the future, emotional instability, increased dependence on others, reduction of self-esteem and the perceived threat of possible death. Such distress puts

cancer patients at increased risk of developing psychological disorders. Furthermore, these disorders may cause *inter alia* a less effective response to treatment as well as a higher risk of recurrence and decreased survival from cancer.

The spiritual beliefs of patients and relatives can also be badly shaken by the disease, which aggravates their state of mind. Those close to cancer patients, namely family and friends are particularly vulnerable at the final bereavement stage of the disease process.

A patient who is suffering from cancer may have an altered sense of belonging to and communicating with their families and society in general. They may feel lonely or abandoned, as well as marginalized or stigmatized.

Following treatment, cancer patients may encounter problems returning to their working lives. Informal carers of cancer patients bear the economic brunt of the disease during the care process as they may be forced to curtail or halt their occupational activities in order to tend to a cancer patient.

5.2 Alleviating the impact of cancer

According to WHO, the goal of palliative care is to improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement. Palliative care is often associated with cases of advanced cancer. However, WHO has recommended that palliative care should begin early in the course of the illness, thus forming part of the overall intervention protocol.

5.2.1 Alleviating the physical impact of cancer

Much of the adverse impact of cancer on the patient's body can be effectively managed and attenuated by means of symptom management techniques, such as pain management methods, and rehabilitative protocols, such as prosthetic and orthotic devices. Such care is typically administered by palliative care specialists.

5.2.2 Alleviating the psychosocial impact of cancer

The provision of professional psychotherapeutic support to patients and their loved ones throughout the course of the care process is a vital component of palliative care. The need for such support should be formally assessed by the relevant professionals. Spiritual support tailored to the individual's personal beliefs and/or religious affiliation can be especially important in the context of end-of-life palliative care.

Table 16: Estimates of cancer-related morbidity among cancer sufferers in Malta³⁴

	No. of cases (per year)	Estimated burden on the Maltese population (per year)
Cancer deaths	2,800	800
Pain	2,400	685
Trouble breathing	1,300	370
Nausea/ vomiting	1,400	400

5.2.3 Home and community supportive care services

Providing supportive care to patients in their everyday setting is in itself a form of support that helps to palliate the adverse psychosocial impact of cancer. Such an arrangement can be especially significant in cases of terminal cancer requiring end-of-life care.

5.3 The situation with regard to palliative care in Malta

5.3.1 The need for palliative care

The table below provides a scientific estimate of the proportion of cancer patients who would suffer from pain and other distressing symptoms before death. These estimates can thus be used as the indicative annual burden of cases in Malta for which specialised palliative care is necessary.

5.3.2 Cancer palliative and supportive care services in Malta

Malta's health care system offers a wide range of formal palliative care services mainly to adult cancer patients. Integration between all the services involved in the provision of palliative care to those affected by cancer is ensured by means of a multidisciplinary team approach that has been adopted both in the public sector and in the private voluntary sector which is partially funded by Government. Furthermore, there is also good coordination between the respective multidisciplinary teams of the two sectors.

5.3.2.1 Alleviating the physical impact of cancer

The physical impact of cancer on cancer patients in Malta is palliated by means of the following healthcare professional services:

- palliative care o oncology o pain management
- medical services
- nursing
- pharmacy
- physiotherapy
- occupational therapy
- complementary therapy.

Relative to the year 2008, the level of activity of Malta's palliative care services is illustrated by the activity of the Oncology and Palliative Care Physiotherapy Services. These catered for 247 outpatients, 112 of which being new referrals (752 sessions were carried out), and 154 inpatient cancer cases. The Occupational Therapy Department at Sir Paul Boffa hospital (SPBH) catered for a similar number of cancer patients.

A 10-bedded specialist palliative care ward has been recently inaugurated at SPBH. These are dedicated for inpatient palliative care for oncology patients. In addition, an outpatient palliative care clinic is held once a week. Patients are usually referred to the clinic from the Oncology Department. There is continuity and overlap of the oncology and palliative care services, allowing patients who attend palliative care outpatient visits to receive services, such as radiotherapy or chemotherapy, on the same day.

Like curative oncological medical care, palliative care is free of charge for all those who are entitled to free health care in Malta. Drugs provided for palliative care (prescribed for use outside hospital) are made available through the National Health System either as regular or special items.

The available specialist palliative care setup currently concentrates its work on adult cancer patients. Likewise, paediatric cases (cancer or otherwise) do not to date have appropriate or adequate access to specialist palliative care inpatient or outpatient support. Paediatric cancer patients currently receive oncological treatment as well as palliative care from a specific setup that is led by a paediatric oncologist.

5.3.2.2 Alleviating the psychosocial impact of cancer

These include the following professional services offered to patients and their families:

- psychotherapy/counselling (including bereavement therapy with a special focus on children experiencing bereavement due to the loss of significant adults)
- family support
- spiritual support (manned by chaplains and available upon request also to patients from religious denominations other than the Catholic faith)
- social work
- respite care.

5.3.2.3 Home and community palliative care services in Malta

Psychosocial home and community palliative care services are provided mainly through the voluntary sector. Outreach palliative care services provided through the public sector consist mainly of home visits by an occupational therapist, accompanied by a social worker, that are aimed at assessing the home situation and provide guidance for the necessary adaptive changes in the home environment.

Nevertheless, provision of home and community palliative care services through the public sector is still underdeveloped. This is in part reflected in figures of the Malta National Mortality Registry, which show that between the years 2005 and 2007, the vast majority of patients who died as a direct consequence of cancer passed away within a hospital setting (80%), while only 12% and 8% respectively passed away in their own home or in a long-term care institution. The proportion of all deaths occurring in a hospital setting is also high at 65% but it is worth noting that the proportion of cancer deaths is markedly higher. While other factors may be contributing to this scenario, such as the fear associated with dying at home, the incomplete coverage of palliative care services within the community is likely to play an important part in this trend.

5.4 Improving palliative care services for cancer patients in Malta – the way forward

It is clear that the current offer of palliative care services, as measured by the number of beds earmarked for this purpose within the public sector, does not match the scope of the demand for such services. Using the estimates suggested by the experience in the UK, it has been estimated that the local need of palliative care in-patient beds for cancer patients would amount to approximately 16-20 beds.

Unless remedial action is taken, this mismatch will worsen as the need for palliative care increases owing to the increasing incidence of and improving survival from cancer. At present, the mismatch is likely leading to long waiting times for access to inpatient palliative care services which are unsustainable given the reduced life expectancy of cancer patients and the insufficient overall supply of home and community-based palliative care services. The latter requires upgrading while, more generally, palliative care needs to be brought closer to cancer patients and their families.

Upgrading the human resource infrastructure is a major prerequisite for addressing all the above needs. This issue is explored in greater detail in Chapter 7.

Apart from extending provision of palliative care, there is also the need to broaden its scope that is to offer cancer patients newer palliative care methods including more pharmacotherapeutic methods for palliative care.

The target will be to provide superior palliative care to more people affected by cancer in a timely and humane manner.

To reach this target, the following measures will be implemented:

- Setting up a 16-bed dedicated in-patient facility for specialized palliative care
- Allocating a number of beds within existing long-term care facilities for use only by cancer patients
- As part of the preceding measure, increasing the provision of planned respite care to help the informal carers of cancer patients
- Expanding and better coordinating community palliative care services
- Offering round the clock access to advice and assistance for palliative care to cancer patients, their families and doctors both in the community and hospital settings
- Conducting a review of the Government formulary with a view to including essential drugs required for symptom control that are currently not included
- Developing specialised palliative services for paediatric cases
- Enhancing the capacity for providing psychological and spiritual support
- Conducting a study of the feasibility of including an amendment to the Social Security Act that will provide for the right to social assistance to carers of cancer patients receiving active palliative care, irrespective of the age of the patient
- Establishing better coordination between the rehabilitation services offered from the cancer hospital and the services offered in the community.

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Chapter 6

The patient's perspective

Our goal is to make patients' and carers' experiences as positive and empowering as possible.

The process of providing cancer care should not be aimed solely at treating the cancer patient's disease but should equally be geared towards making the patients' and their carers' experience as positive and empowering as possible. This can in turn have a beneficial effect on the outcome of the care process.

This chapter draws on the experience of cancer patients during the care process collected in the consultation carried out during the drafting of this National Cancer Plan.³⁵

Four main dimensions of the care process have been identified as being capable of enhancing the cancer patient's experience. These are:

- the physical and social context of care delivery
- patient information and education
- patient involvement and choice
- continuity of care.

A diagnosis of cancer is traumatic. The patient is confronted with a life-threatening illness on which they may well know very little about. There are wide variations in the needs for information and in information-seeking

behaviour among patients with cancer. For a variety of reasons, patients may also have difficulty in discussing their concerns in the consultation setting. The difficulties associated with asking for and accessing information must be recognized and overcome.

6.1 Physical and social context of care delivery

The physical environment where care is delivered must not only meet the appropriate standards of comfort and hygiene but should also inspire a sense of warmth, security and tranquility in the patient, especially given the debilitated state of mind which cancer patients tend to experience. The physical environment must provide the patient with personal space and privacy.

Care must be delivered in a friendly and sensitive manner by all those who work in care environments and come into personal contact with the patient. Cancer patients need their preoccupations and personal values to be listened to and taken into consideration. Feelings of loneliness or abandonment, problems with returning to work and an active lifestyle and, consequently, financial difficulties, marginalisation and even stigmatisation are common issues reported by cancer patients. The capacity of patients to cope with the multiple losses caused by cancer should be constantly monitored in clinical practice. The impact of cancer on psychosocial well-being, which include the physical, emotional, spiritual and interpersonal dimensions, must be taken into account when delivering care.³⁶ This underscores the utility of the liaison between cancer care and psychosocial care professionals. It also highlights the need for inter-sectoral collaboration with employment and social security services to devise measures to help cancer patients retain and return to their employment once the more acute phase of their cancer treatments is over.

6.2 Patient information and education

The benefits of good and properly communicated information have been shown to contribute towards the experience of a higher degree of control by the patient. Acquiring information about cancer, its treatment modalities and possible complications may help patients and their carers overcome senses of helplessness and uncertainty associated with this disease. The information imparted to patients must be thorough, truthful, timely and easily comprehensible to the patient in relation to their particular intellectual competencies and cultural background (including patients' expressed choices on how much they want to know). According to the patients who contributed to the above-mentioned consultation process, at present local practices concerned with the dissemination of information to cancer patients are considered to be generally inadequate.

In the course of the consultation, some patients reported receiving excellent care in a friendly way, with sensitive and thoughtful communication, clear information about their disease and its treatment, and good support when needed. However, others reported being given 'bad news' in a deeply insensitive manner (especially in the acute general hospital facilities, where most of the diagnoses are performed and 'bad news' is often communicated), being left in the dark about their condition and being badly informed about their treatment and care.

The ability to communicate information to patients in the correct manner (i.e. empathically, respectfully, humanely) entails specific training of healthcare professionals and the allocation of sufficient time to communication with patients. Sufficient time must be allocated in order to ensure that the information provided is properly understood and that patients are able to ask questions about it. This is especially important

when a healthcare professional is called to deliver potentially disturbing news to the patient, such as an ominous diagnosis or an unfavourable prognosis. Informing patients in an environment that respects their privacy is equally necessary.

6.3 Patient involvement and choice

Patients should be informed but, more importantly, educated about cancer and its management. Patient education has been found to empower the patient to take part in her or his care plans and to engage more in self-care. Healthcare professionals should not only inform their patients but also listen to what they have to say about their care. Patients should also be more empowered to access their medical records. Studies have shown that patients who are involved in clinical decisions are more satisfied, exhibit better treatment compliance and experience better treatment results than patients who have not been so involved. Where possible, patients should thus be allowed to choose between different care options on the basis of reliable information that is effectively communicated to them. In end-of-life care, for instance, the healthcare system should be able to accommodate the patients' choices especially if they prefer to die outside a hospital environment.

It is important to determine the role of carers and relatives in the patient's cancer pathway early on after the detection of disease. It is often helpful for the patients to involve their loved ones in their experience of cancer as this would help them acquire support and understanding during these difficult times. However, the patient has a right to privacy and to decide to whom this personal information can be disclosed. The choices of patients to refrain from informing other family members and friends must be understood and respected. Conversely, patients may choose to opt out of

receiving information regarding diagnosis and prognosis and to appoint a carer or healthcare worker as a decision-maker with respect to the management of their condition. These choices must also be respected.

Furthermore, although rapid treatment is necessary for improving prognosis, patients may at times prefer to postpone treatment by a few days to be able to assimilate the information and understand the process.

In short, the motto of the European Cancer Patient Coalition (ECPC)³⁷, 'Nothing about us without us', succinctly expresses the need of patients to be consulted.

On a broader scale, regular consultation with cancer patient groups imparts knowledge regarding how patients are experiencing their care. A formal structure through which regular and systematic dialogue with groups of cancer patients and informal carers can be maintained needs to be set up.

6.4 Continuity of care

The care received by cancer patients typically involves the input of a multitude of health care professionals. Without adequate collaboration between all care providers, the care process can easily become disjointed and discontinuous to the detriment of the patient's satisfaction with both the process and the outcome of care. For these teams to be effective, they need to be coordinated and have administrative support. This process will be strengthened by the introduction of a 'key worker' for each cancer patient, whose primary role will be the assurance of an integrated care pathway.

It needs to be acknowledged that the multi-disciplinary approach in the cancer care sector in Malta has been developing over the last few years. Currently teams made up of

a hospital doctor, a nurse, an occupational therapist, a physiotherapist and a social worker hold regular meetings to discuss individual cases. The provision of palliative care is also carried out on a multi-disciplinary team basis. The palliative care and oncology teams work closely together. Similarly, the Malta Hospice Movement functions by means of a multi-disciplinary team which is backed by administrative staff and a group of volunteers. Domiciliary nursing care (which also includes personal care and administration of treatment to cancer patients) is provided by the Primary Healthcare Department's CommCare Unit, through the Malta Memorial District Nursing Association (MMDNA). Service provision is preceded by an assessment of the patient's needs, followed by the formulation of a customized care plan. Patients requiring occupational therapy and physiotherapy are followed up at the hospital's rehabilitation departments and in their homes.

However, it is still evident that there are certain communication barriers that need to be further managed between the secondary and primary care service providers. These shortcomings were the focus of several of the comments received during the consultation. The need to strengthen the coordinating role of the family doctor in order to ensure continuity of care, provided that they are given the necessary support and training to help them meet the basic medical needs of cancer patients living in the community was also highlighted.

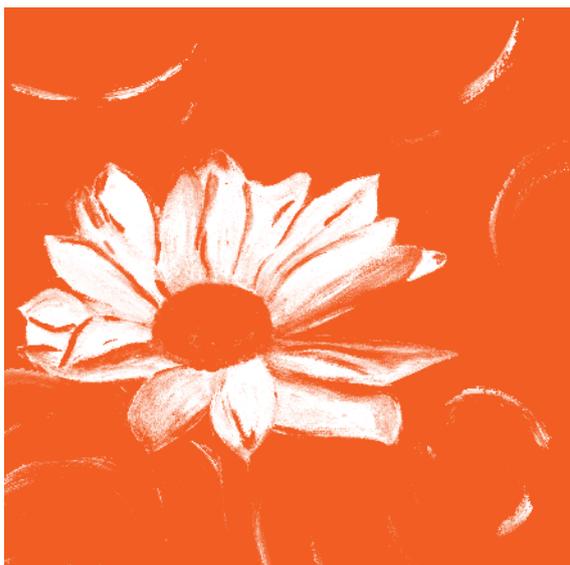
The target is to ensure that the experience of patients and their carers is as positive and empowering as possible.

In order to reach this target, the following measures will be implemented:

- Creating brighter atmospheres in places as part of the interior design plans of the new oncology and palliative care facility that will be built adjacent to Mater Dei Hospital
- Determining what psychosocial support is required by patients as well as by members of the multidisciplinary team working in the cancer sector. The recruitment of providers of psychosocial care and support will be included in the Human Resources strategic plan that will be developed for the healthcare services
- Facilitating inter-sectoral collaboration with employment and social security services with a view to devising measures to include the extension of absence from work in order to allow for the often prolonged treatment and rehabilitation process according to the recommendations submitted by their treating physician
- Providing training at under-graduate, post-graduate and CPD levels in communication skills, including face-to-face communication, to all health care staff working directly with cancer patients, with particular emphasis on training in breaking bad news to patients and their families in a sensitive and humane manner
- Enhancing personalised patient information through the formulation and enforcement of minimum process standards for the allocation of time for information provision and communication with patients and relatives within consultations
- Proceeding with the publication of legislation laying down patient's rights with regard to adequate provision of information about the patient's condition and care, and the patient's right to choice and involvement in clinical decisions
- Developing referral guidelines and protocols concerned with the assessment of cancer patients' psychosocial problems and needs in order to provide more responsive services
- Enhancing access of patients and informal carers to information about cancer and the services available to cancer patients through various media, such as paper brochures, email and telephone access and ehealth facilities - the latter will include links to reputable and accountable sites on cancer and will be implemented in accordance with the national eHealth strategy
- Developing care protocols encompassing all professionals involved in the delivery of services to patients within hospital, at the Hospice and in primary/ community care settings - these protocols will include the assignment of the family doctor as the 'key worker' for each cancer patient as an essential element.

References

- 35 The experience of cancer patients during the care process has been compiled using two basic groups of data. This included objective and factual data from structures and processes in place and more subjective data based on the personal experiences of cancer sufferers and their relatives. The latter were collected during a consultation process conducted between July and December 2007 with a number of patient groups.
- 36 Luigi Grassi & Lucia Travado, 'The Role of Psychosocial Oncology in Cancer Care', in Michel P. Coleman, Delia-Marina Alexe, Tit Albreht & Martin McKee (eds.), *Responding to the challenge of cancer in Europe*, Institute of Public Health of the Republic of Slovenia, -Ljubljana, 2008
- 37 European Cancer Patient Coalition; <http://www.ecpc-online.org/>



Chapter 7

Human resources

Our overall aim is to strengthen the capacity of the skilled and flexible healthcare workforce needed to implement this Cancer Plan.

The professional speciality of the workforce that works with cancer patients is very diverse. While a number of personnel, such as oncologists, work exclusively with cancer patients, others, such as surgeons, dedicate only part of their time to cancer patients while also caring for other patient groups.

Rising trends in the prevalence of cancer, as a consequence of increased incidence rates and prolonged survival, together with the development and request for new services, result in an ever-increasing call for more human resources. On the other hand, inflexible demarcations between different groups of staff prevent the most effective use of the skills and potential of this most valuable resource from being made. Experience in other countries, however, shows that, even though substantial improvements in the efficiency of services can be achieved by re-organising and streamlining care, a significant change in the size of the cancer workforce is needed. This is the main rate-limiting factor in the improvements to cancer services set out in this plan. In order to ensure the attainment of the targets of this strategy, a needs analysis to identify gaps

in the supply of healthcare professionals, both from the perspective of the number of professionals and from that of the level of expertise, will be carried out in the early phases of implementation of this strategy.

7.1 Investing in all the members of the cancer workforce

As has been described elsewhere in this document, demands on human resources by cancer care go far beyond those involved in supplying distinct oncology and palliative care services. Considerable human resources are engaged in the process of investigating and diagnosing cancer, as well as providing cancer treatments, such as surgery which is mainly performed at Mater Dei Hospital. Healthcare professions mostly involved in these processes include radiologists, radiographers, pathologists and surgeons, among others. Recognising the demand for the cancer services provided by these groups and ensuring adequate human resources in this sector, as well as providing continuous professional development with respect to cancer to these professionals, is paramount.

Working with cancer patients may at times present emotional difficulties. It is important to recognize these challenges placed upon the workforce and to be ready to provide workers with the recognition and psychological and emotional support they may need.

Although not directly involved in delivering care to cancer patients, health promotion initiatives play a role in decreasing the incidence of cancer. It is thus important to recognize the role of prevention in the implementation of a national cancer strategy and to support this facet of dealing with cancer by ensuring an adequate human resource complement, together with providing necessary funds for carrying out such efforts.

7.1.1 Generic Training

In order to ensure a sufficient supply of healthcare professionals entering the cancer workforce, this career pathway has to be promoted among prospective students in a stepwise fashion. Efforts should be made to encourage young students to opt for becoming healthcare professionals and, once qualified, to progress onto specialisation in cancer care. A career in the cancer workforce has to be seen as rewarding. A truly appealing career pathway needs to present a realistic opportunity for career progression.

Apart from attracting more individuals to specialise in cancer care, it is important to provide the necessary training to those who deal with cancer patients as part of their work but are specialised in other areas. This training must commence at the undergraduate level. Apart from the clinical aspect of cancer care and concepts of palliative care, teaching of personal and communication skills are also required. This training will continue through the Foundation Programme for newly qualified doctors, and will also be extended to all healthcare professionals who have direct contact with cancer patients in the clinical setting.

Generic training will continue to be provided to healthcare professionals already receiving such training, and will be enhanced where necessary. This is especially important with regard to the training and continued professional development of general practice doctors. Training in cancer care will provide general practitioners with the necessary skills and tools which would enable these doctors to act as the 'key worker' for individual cancer patients. This will contribute towards improving the quality of care received by these patients.

7.1.2 Specialisation in the context of multidisciplinary teams

Evidence shows that patients managed by specialist surgeons have better outcomes than those who are operated on by general surgeons. This evidence has been best illustrated in breast cancer surgery.³⁹ The evidence on the impact of specialisation overlaps with the evidence of the importance of caseload, since specialists normally have higher cancer caseloads than generalists. There is consistent evidence that specialisation in diagnostics is also important.³⁸

Expert opinion supports specialisation on the grounds that it is more probable that specialists will have wider experience of the diagnosis and staging of disease; be more aware of the full range of treatment options; be more experienced and proficient in appropriate technical aspects of treatment; and have a fuller understanding of their indications and potential adverse effects. Furthermore, because cancer is a significant part of their work, they can participate more readily in multi-disciplinary working and should find it easier to remain up-to-date and to participate in audit, teaching and research.

Through the setting up of a human resources plan, individuals who require highly specialised training in order to obtain the necessary competency will be selected. This competency would, in most cases, be obtained through training abroad by means of twinning initiatives with centres specialised in cancer. Candidate professionals for such training include surgeons, radiologists, radiotherapy scientists, physicists, and palliative care specialists. The human resource plan, which will include the number of individuals required for specialist training, will also include appropriate career pathways and incentives to retain these specialists in the cancer workforce. Collaboration with reference centres as well as cross-border and twinning incentives shall be actively sought in the carrying out of such training programmes.

The ultimate objectives of providing specialization and continued professional development are those of ensuring that specified levels of competence are obtained by specialists who perform and interpret diagnostic interventions and carry out surgical treatment of cancer patients, and of keeping these healthcare professionals up to date with knowledge about the latest technologies and possession of new skills required for effectively managing cancer.

Specialization, and expanding the number of specialists, is important in the five medical specialties where the work is often to a large extent cancer-related: clinical radiology, histopathology, haematology, oncology and palliative medicine.

Posts have already been issued for surgeons with a particular interest in breast and colorectal cancer surgery. This trend of issuing such posts for surgeons with interest in the cancer surgery for a particular organ or system shall be continued and will be expanded to include other specialities such as gynaecology and orthopaedics.

7.2 Investing in staff providing oncology and palliative care

Staff currently providing oncology and palliative care at Sir Paul Boffa Hospital (SPBH) is highly specialised and dedicated. Apart from staff members who offer extremely valuable work but who are not directly involved in administering cancer treatment (such as administrative staff, health assistants and cleaners), the clinical staff complement comprises: i) three consultant radiotherapy (clinical) oncologists, ii) a consultant in palliative care, iii) medical doctors supplemented by General Practice trainees and housemen (availability of the two latter categories depends on rotational attachments to the department), iv) a complement of nurses manning the two in-patient oncology wards, out-patients and the day ward, v) physicists, vi) radiotherapists who are dedicated to cancer

services, vii) physiotherapists, viii) occupational therapists, ix) a psychologist, x) social workers and xi) a pharmacist.

This small contingent of healthcare professionals offer sterling service to our cancer patients but, clearly, expanding these very limited human resources is required in order to cater for the increasing requirement for these services, and to become able to offer a higher level of personalised care and human contact to each and every cancer patient, especially within the new planned Cancer Hospital.

Increasing the number of specialised staff to the required complement takes time. It takes a total of fifteen years to train a consultant, including five to six years specialist training. For Maltese medical officers, a good proportion of this training has to be performed in centres abroad. Other professions, such as nurses and radiographers, also need several years of training.

The inclusion of Medical Oncologists within the upgraded complement of specialists for the new Cancer Hospital is important. This new speciality has more extensive knowledge in the use of chemotherapeutic agents and is a recognized, new and rapidly developing speciality abroad. This speciality will complement the clinical oncologists as the latter is becoming more oriented towards specialist practice in radiotherapy. The necessary changes in the Healthcare Professions Act to remove the speciality “oncology and radiotherapy” and substitute with “clinical oncology (or radiotherapy)” and “medical oncology” will be needed in this respect.

The specialist medical and nursing complement of the Paediatric Oncology Unit must be maintained and strengthened as necessary, especially when staff replacement is required. This will require long term planning as this staff is not easily replaceable. A lacuna that needs addressing is in the field of oncology for the adolescent/ young adult age group.

A number of measures will be adopted to achieve the target of strengthening the healthcare workforce for the implementation of this National Cancer Plan:

- Drawing up a human resource plan - this strategy will be developed by end 2011
- Widening expertise on cancer, both at the specialist level and by strengthening generic training of all healthcare professionals providing care to cancer patients, at undergraduate and post-graduate levels and also in CPD programmes
- Increasing collaboration between the Paediatric and Adult oncological services and addressing the current gap in the adolescent/ young adult age group
- Continuing with the practice of issuing posts for surgeons with a special interest in the cancer surgery for a particular organ or system - this will be expanded to include specialities such as gynaecology
- Changing the Healthcare Professions Act to remove the speciality “oncology and radiotherapy” and substitute with “clinical oncology (or radiotherapy)” and “medical oncology” in order to allow for the inclusion of a Medical Oncologist within the upgraded complement of specialists within the new Cancer Unit

References

- 38 Bachmann MO et al. (2003), Influence of Specialization on the Management and Outcome of Patients with Pancreatic Cancer', in *Br J Surg*, 90(2):171-177.



Chapter 8

Surveillance and research

Our overall goal is to establish a national infrastructure for the coordination of cancer research and to strengthen surveillance in order to monitor disease prevalence and survival, and to document the quality of cancer services and their outcomes.

8.1 Surveillance in the cancer field

The purpose of surveillance in the cancer area is to obtain data that can be used to monitor disease incidence, prevalence and survival and to document the quality of treatment efforts in order to be able to take preventative measures and make improvements. Survival data are important for monitoring the final effect of cancer treatment.

Considerable amounts of data can be gathered and processed in the cancer area. The Malta National Cancer Registry³⁹ collects cancer statistics on incidence, survival and mortality and publishes them on its website. However, it is recognised that more data, especially in the hospital information and clinical sector, is being or can be collected, analysed and published. There is a need to develop a repository or site to allow for a more coordinated collection of all this information with the aim of providing an overall picture of the quality and effect of cancer healthcare services.

Coordinated surveillance needs to be introduced in order to:

- Monitor the occurrence and trend in population health habits and lifestyle factors of significance in the development of cancer (smoking, diet, exercise and alcohol) with a view to evaluating prevention programmes;⁴⁰
- Document disease prevalence and treatment results in the cancer area based on both cancer register-based documentation and data from clinical and clinical quality databases;
- Monitor the quality and impact of the cancer healthcare services by gathering data on the activities throughout the patient pathway in both the primary and secondary sectors and use the data to make improvements in the services provided;
- Ensure that up-to-date data is available and disseminated to healthcare planners, clinicians, researchers, patients and others who need to use it.

Nationwide, the population-based registers that are utilised in the surveillance of the prevalence and treatment of cancer are the Cancer Register and the Cause of Death or Mortality Register. Both these registers are housed within the Directorate of Health Information and Research (DHIR). Cross-referencing between these two registers is necessary for deriving cancer survival statistics and also for the assurance of the quality of the data in both registers. Efforts are continually being made to improve the quality of the central registers. However, experience has shown that data from the hospital information systems such as the Patient Administration Systems and Pathology registers can also be successfully used to supplement surveillance information especially if electronic submission of information to the cancer register is enabled.

The number of clinical and clinical quality databases in the cancer field in Malta is unknown. The creation and maintenance of these databases needs to be encouraged and supported. They can be developed for specific

cancer site areas and can be supported through a fund that would finance applications for databases, provided, for example, that an annual report is published.

In 2002, the WHO⁴¹ published a report on national action programmes in the cancer area. The report recommended the designation of a central unit to coordinate the surveillance activities and to draw up an overall surveillance report at regular intervals. At the same time, the report recommended that this central unit should establish cooperation with all the parties that provide cancer data so that planning of the surveillance activities and analysis of the data are coordinated. The importance of joint evaluation of the selected surveillance model in order to enable it to be regularly adjusted is also stressed. Responsibility for establishing such coordinated surveillance could be placed centrally.

A number of user groups are interested in the cancer data available in the registers, e.g. clinicians wanting to monitor the quality of their treatment efforts, healthcare planners wanting to clarify questions relating to prevention or planning tasks, and researchers needing data for research projects. Journalists may also want available key figures about cancer and patients. Attempts should be made to ensure that the user groups requesting information about healthcare efforts in the cancer area have access to the information requested and that it is presented to them in understandable and usable formats.

The process that cancer patients undergo is physically and psychologically demanding. Patients and their relatives have expectations about quality of the treatment and care provided by the healthcare professionals. In order to be able to develop and improve the quality of the patient pathways, it is necessary to know the patients' expectations and their actual assessments of the pathway they are on or have been through. Questionnaire surveys are only one of several possible methods for

gathering information about the patients' perspective and assessments. Qualitative methods such as focus groups or user panels should also be employed in order to obtain as qualified a basis as possible for making improvements for the patients.

The following measures will be adopted in order to strengthen surveillance, to monitor disease prevalence and survival and to document the quality of cancer services and their outcomes:

- Coordinating the regular and coherent monitoring and dissemination of disease trends and treatment quality, through DHIR - efforts will be made to ensure that the national registers, patient administration systems and clinical databases cover the whole cancer area. The feasibility of including an area on patient assessment of cancer treatment will be studied in the planning of nationwide patient satisfaction studies that will be conducted by DHIR
- Implementing and publicising electronic data submission methods for sending information about cancer from the hospital information and the clinical setting to the cancer registry - this would enable the collection of more accurate and complete data in real time
- Increasing participation of the National Cancer Registry in national and international research, both as an independent body and as a collaborator with other entities, such as other governmental departments, university, or private researchers.

8.2 Cancer Research

In order to be able to provide future modern treatment that meets the highest international quality standards, it is necessary to conduct research in all relevant aspects of the cancer area.

Research will aim towards an ongoing evaluation of the progress and effectiveness of the implemented activities proposed in this Plan.

However, it is important that an analysis of all ongoing cancer research and research projects that can be embarked on in Malta is carried out. In particular, there needs to be an assessment focusing on whether the necessary research resources and structures are available so that the activities proposed in the Plan can be implemented.

There is also a need to introduce and maintain researcher networks that coordinate research efforts at the national level. There is also a recognised need to strengthen and step up the promotion of the support that can be given to help potential researchers to access project funds and to establish working relationships and partnerships with international collaborators, such as through EU funds, the Malta Council for Science and Technology and the University of Malta.

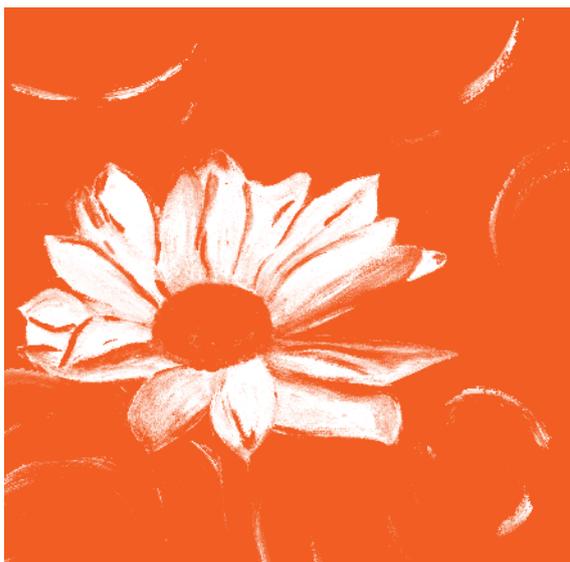
Thanks to widespread international high quality research, the pace of change in cancer can be rapid. It is therefore vital that Malta develops the capacity for effective and good quality 'horizon scanning' to enable the identification of and planning for the opportunities and challenges of the future. For example, this is necessary to ensure that new potentially beneficial technologies (such as drugs or other treatments) are identified and that an evaluation into their therapeutic effectiveness and cost-effectiveness is carried out in a timely manner.

Research on cancer will focus on the following identified aspects:

1. Promoting molecular, genetic and pathology laboratory-based research, and research into the development and implementation of structures in order to develop and utilize adult stem cells sources from and for the use of patients in Malta - this will primarily require the development of cell and tissue culture facilities. This specifically includes the development of particular streams of cellular and para-cellular therapeutics which are becoming and will continue to become mainstays of cancer therapy in future, e.g. immunotherapy, whereby tumour cells grown from the patient are re-injected into the patient as tumour vaccines, and viral therapy, whereby viruses are cultured in vivo (in cell cultures) and are then delivered to the patients as therapy for cancers.
2. Assessing the benefits of offering new therapies such as cellular therapies and support therapies for terminally ill patients by participating in clinical trials and conducting research into the therapeutic effectiveness and the cost-effectiveness of expensive new treatment - this work will facilitate the development and evaluation of clinical guidelines for new treatment modalities.
3. Conducting epidemiological and public health-based research (this was also dealt with in detail in the Surveillance section) and research into causation of the commonest cancers occurring in the Maltese population

References

- 39 Malta National Cancer Registry; https://ehealth.gov.mt/HealthPortal/strategy_policy/healthinfor_research/registries/cancers.aspx
- 40 This information is being regularly collected in the national Health Interview Survey which is carried out every 5 years.
- 41 National Cancer Control Programmes: Policies and Managerial Guidelines', 2nd edition, World Health Organisation (2002).



Chapter 9

Implementation of the plan

9.1 Financing the implementation of the strategy

Tackling cancer aggressively and holistically over a five-year span (i.e. 2011-2015), as is being proposed in this strategy, is a formidable challenge that entails a hefty financial investment in the required material and human resources. Nevertheless, in view of the serious social and economic impact of cancer on Maltese society, Government is determined to deploy all the necessary financial instruments and resources at its disposal towards implementing this strategy.

A comprehensive exercise was performed to establish the expenditure requirements for the measures that have been included in this plan in order to determine the cost for the implementation of the whole strategy. Over a five year period, Government will invest over ten million Euros in delivering the measures outlined in this plan, foremost among which is the introduction of screening programmes for colorectal and cervical cancer and of new medicines, including the HPV vaccine.

This plan is therefore an important instrument to complement the formidable investment that Government has committed to undertake with the construction of a new cancer treatment facility within the grounds of Mater Dei

Hospital. Work on this facility has already commenced. It is estimated that the total cost for this project will be around 60 million Euros, for which cost Government is seeking assistance from the European Regional Development Fund.

Apart from this investment, Government has already committed itself to fund the procurement and installation of the PET/CT scanner at Mater Dei Hospital with the assistance of funds from the Swiss Government, at a total projected cost of €2.8 million.

9.2 Steering the implementation of the strategy

Such is the scope of the strategy and the multitude of players involved in its implementation that a central body to monitor and coordinate the strategy's implementation is necessary to ensure timely and robust action across the strategy's various strands.

A committee with the following mandate will thus be set up to:

- steer the process of implementation of the strategy's measures,
- monitor progress in relation to the implementation of the strategy's measures and the reaching of the strategy's targets, and to
- monitor expenditure from the implementation of the strategy.

The committee will conduct its work on behalf of the Minister responsible for Health. All entities falling within the Ministry's remit will thus be bound upon request by the committee to submit reports on the progress achieved and/or on action plans and/or financial accounts in relation to any of the measures of the strategy. The committee will also commission scientific studies of the status of the strategy's key indicators with a view to monitoring the achievement of the strategy's targets.

All information gathered by the committee will be used to compile and issue a mid-term review and end-of-term evaluation of the progress achieved in relation to the cancer strategy and the general cancer situation in Malta.