



Fighting against cancer today: A policy summary

Written by

Jose M. Martin-Moreno, Meggan Harris,
Eva Garcia-Lopez and Lydia Gorgojo

Edited by

Tit Albreht and Radivoje Pribaković Brinovec



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Trubarjeva 2
1000 Ljubljana
Slovenia

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CIP - Kataložni zapis o publikaciji
Narodna in univerzitetna knjižnica, Ljubljana

616-006(4)(082)

FIGHTING against cancer today : a policy summary / written by Jose Maria Martin Moreno ... [et al.];
edited by Tit Albreht and Radivoje Pribaković Brinovec. - Ljubljana : Institute of Public Health of the
Republic of Slovenia, 2009

ISBN 978-961-6659-52-9

1. Moreno, Jose Maria Martin 2. Albreht, Tit
246392832

Printed and bound in the Republic of Slovenia by Tiskarna Radovljica

Further copies of this publication are available from:
Institute of Public Health of the Republic of Slovenia
Trubarjeva 2
1000 Ljubljana
Slovenia

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**Main conclusions arising from the comprehensive cancer control analysis
carried out under the Slovenian Presidency of the European Union
(January–June 2008)**



European
Observatory
on Health Systems and Policies



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List of abbreviations

AFP	Serum alpha-fetoprotein
CCC	Comprehensive cancer centre
CME	Continuing medical education
COPD	Chronic obstructive pulmonary disease
CT	Computed tomography (scanning)
DALY	Disability-adjusted life year
DCO	Death certificate only
DG-SANCO	(European Commission) Directorate General for Health and Consumer Protection
DNA	Deoxyribonucleic acid
EAPC	European Association for Palliative Care
ECAC	European Code Against Cancer
ECI	European Cancer Initiative
ECPC	European Cancer Patient Coalition
ECRIN	European Clinical Research Infrastructures Network
ECRM	European Cancer Research Managers Forum
EFTA	European Free Trade Association
EHSS	European Health Survey System
EJC	European Journal of Cancer
EMA	European Medicines Agency
EPIC	European Prospective Investigation into Cancer
EU	European Union
EUnetHTA	European Network for Health Technology Assessment
EUROCHIP	European Cancer Health Indicator Project
EUROSTAT	Statistical Office of the European Communities
EU15	Member States belonging to the EU prior to May 2004
EU25	Member States belonging to the EU prior to January 2007

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FACT	Fighting Against Cancer Today
FCTC	Framework Convention on Tobacco Control
FOB	Faecal occult blood
FP6, FP7	Sixth/Seventh Framework Programme
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
HMA	Homovanillic acid (urinary catecholamine metabolites)
HMP	Health monitoring programme
HP	Helicobacter pylori
HPV	Human papilloma virus
HRT	Hormone replacement therapy
HTA	Health Technology Assessment
IAEA	International Atomic Energy Agency
IARC	International Agency for Research on Cancer
ICMJE	International Committee of Medical Journal Editors
ICRP	International Commission on Radiological Protection
IMI	Innovative Medicines Initiative
IVZ	Institute of Public Health of the Republic of Slovenia
LSHTM	London School of Hygiene & Tropical Medicine
MAC	MEPs Against Cancer
MEP	Member of European Parliament
MRI	Magnetic resonance imaging
NCCN	National Comprehensive Care Network
NCCP	National Cancer Control Plan
OC	Oral contraceptives
PET	Positron emission tomography (scanning)
PM	Particulate matter
POM	Polycyclic organic matter
PSA	Prostate-specific antigen
UNSCEAR	United Nations Scientific Committee on the Effects of Atomic Radiation
UV	Ultraviolet
VMA	Vanillylmandelic acid (urinary catecholamine metabolites)
WHO	World Health Organization
WISE	Water Information Systems for Europe

Foreword

During the first half of 2008, and under the co-ordinating role of the Slovenian Ministry of Health, the Slovenian Presidency of the Council of the European Union centred its health objectives on policies directed at reducing the burden of cancer. To achieve these objectives, a comprehensive cancer control approach was proposed based on four main pillars of action: primary prevention, secondary prevention (screening), integrated patient care and research.

Although European citizens account for only one-eighth of the world population, one quarter of all cancers occur in Europe. Projections of the future burden of cancer in Europe show us that further dramatic increases are expected in the next two decades. Apart from the devastating human toll these figures imply, there is the underlying concern that health systems are not well prepared to meet the rapidly increasing demand for health services this epidemic will bring about.

Additionally, the expansion of the EU has provoked a spirited discussion over the basic rights of equity guaranteed to all Europeans, and how to provide them in heterogeneous settings marked by disparities in economic development, unequal resources, different capacities for effective government action, and variable cultural factors.

In June 2008, at the Employment, Social Policy, Health and Consumer Affairs Council meeting in Luxembourg, the Council of the European Union articulated its solid support for the work carried out during Slovenia's six-month term in the EU Presidency. The Council Conclusions urge the Commission to take vigorous action wherever they can, including lending direct professional support to Member States in order to modernize their

screening programmes and cancer registries, implement volunteer accreditation schemes, coordinate health technology assessment evaluations and foster international research cooperation. In addition, Member States are encouraged to develop and implement national cancer control plans, paying close attention to all aspects of cancer care, including health promoting activities, screening programmes, cancer registries, innovative health technology and appropriate equipment, palliative care, psychosocial support and research.

Following these Conclusions and the European Parliament's resolution on combating cancer in the enlarged EU from April 2008, the European Commission proposed (in June 2009) the communication on Action Against Cancer: European Partnership for the period 2009-2013. The Partnership is aimed at supporting the Member States in their efforts to tackle cancer by providing a framework for identifying and sharing information, capacity and expertise in cancer prevention and control. The partnership would also engage relevant stakeholders across the European Union in a collective effort. Areas and actions of comprehensive policy response would include health promotion and early detection, health care, research, data and information.

Ivan Eržen
State Secretary
Ministry of Health, Slovenia

Acknowledgements

The policy summary *FIGHTING Against Cancer Today* has been written as part of the Fighting Against Cancer Today project, funded by the European Union's Public Health Programme. It summarizes the main conclusions and policy lessons arising from the cancer control activities held under the Slovenian Presidency of the European Union in 2008.

We are extremely grateful to all the authors for the enthusiasm they have brought to this project and their hard work in meeting tight deadlines.

We very much appreciated the helpful comments and suggestions from the project's partners, Michel P Coleman (Professor of Epidemiology and Vital Statistics at the London School of Hygiene and Tropical Medicine) and Tanja Čufer (Professor of Oncology at the Medical Faculty, University of Ljubljana, as well as Senior Consultant at the Institute of Oncology, Ljubljana).

This volume is produced by the European Observatory on Health Systems and Policies and published by the Institute of Public Health of the Republic of Slovenia. We are especially grateful to Jonathan North and the production team at the European Observatory, and to Nicole Satterley and Pat Hinsley for their work on the editing and typesetting of the publication.

We would like to thank Mojca Gruntar Činč, Vesna Kerstin Petrič and Nataša Hace at the Slovenian Ministry of Health, along with Marija Seljak (formerly Director General of the Directorate of Public Health at the Ministry of Health) at the Institute of Public Health of the Republic of Slovenia, for their tireless support and enthusiasm for the project.

Finally, we would like to thank Josep Figueras, the Director of the European Observatory, and members of its secretariat in Brussels, for their endeavours in this project.

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Executive summary

This report summarizes the main conclusions and policy lessons arising from the cancer control activities carried out under the Slovenian Presidency of the European Union (EU) in 2008. We reflect the key evidence in two publications arising from these activities: *Responding to the challenge of cancer in Europe* (Coleman et al., 2008) (published by the Slovenian Institute of Public Health (IVZ)) and a special issue of the *European Journal of Cancer* (EJC). To enrich the final synthesis, we also include ideas that emerged from the policy dialogues, conferences and workshops that were held under the Slovenian Presidency. The cancer control approach endorsed by participants rests on four main pillars of action: primary prevention, secondary prevention (screening), integrated care and research.

Primary prevention is the first step any society can take to reduce the incidence of cancer, with positive effects on other noncommunicable diseases. Addressing certain lifestyle choices (tobacco cessation, decreased alcohol consumption, healthy diet and physical activity) through education and policy has been shown to improve population health and reduce cancer deaths. Environmental and occupational risk factors should mainly be tackled by traditional health protection activities, such as maintaining air and water quality and improving safety at work. Initiatives such as the European Code Against Cancer (ECAC) could be exploited better, both by the EU and by individual Member States, to prevent the occurrence of cancer in many EU citizens. Finally, ensuring progress in prevention in the future requires more investment in research in the present.

The ECAC covers important public health programmes, encouraging citizens to participate in specific vaccination programmes and in regular screening for those cancers amenable to it. At a policy level, population-based mass screening programmes, which have been proven to reduce cancer mortality substantially,

must be clearly distinguished from opportunistic screening, for which there is insufficient evidence of population benefit. Screening programmes must be based on solid evidence. At the time of writing, the European Commission recommends screening only for breast, cervical and colorectal cancers. Other types of cancers, such as those of the lung and the prostate, may be detected early, but there is as yet scant proof that this improves either the patient's chance of survival or quality of life. Research should continue, however, so that we can identify treatable cancers as early as possible, thus increasing the possibility of a shorter and more successful pathway to cure.

Once cancer has been diagnosed, truly integrated care should be the goal of the health system. The care pathways between diagnosis, treatment (including chemotherapy, radiation and surgery), psychological support, palliative care and rehabilitation need to be well organized in order to optimize outcomes (including quality of life) for all patients. Given the high number of stakeholders involved in this process, it is important to forge a consensus between them, including patients, physicians and other health professionals, policy-makers and industry. Clear ground rules to foster accountability and transparency and a well-articulated framework of action are necessary to ensure access, quality and efficiency.

Significant investments in research are required across the board. European research is strong in the basic sciences, but domains such as epidemiology, health system management, translational research, prevention and palliative care have consistently been underfunded. This impedes progress in cancer control. Coordination between funding sources, universities, industry and Member States is inadequate, leading to overlaps in some research fields and gaps in others. Finally, European regulations, intended to harmonize some processes between countries, such as in clinical trials and the transfers of personal data, have had the opposite effect, hindering important advances. Strong leadership and a more coherent European infrastructure are both vital if the EU is to make the most of its strengths and take a worldwide lead in cancer research.

The best model identified to tackle these four domains of action is a comprehensive National Cancer Control Plan (NCCP). Such initiatives are already developing in various Member States. However, existing NCCPs have been formulated ad hoc, without European leadership. Many lack basic elements, such as financing and accountability mechanisms. This offers an opportunity for the EU to create an organized framework of action across Europe, guiding Member States in the development of cancer plans and integrating lines of action (such as cancer registries and European reference centres). Strong European leadership in cancer control is vital if we are to tackle the growing cancer burden effectively. Both health systems and patients will reap the benefits of united action.

Introduction: Responding to the challenge of cancer in Europe

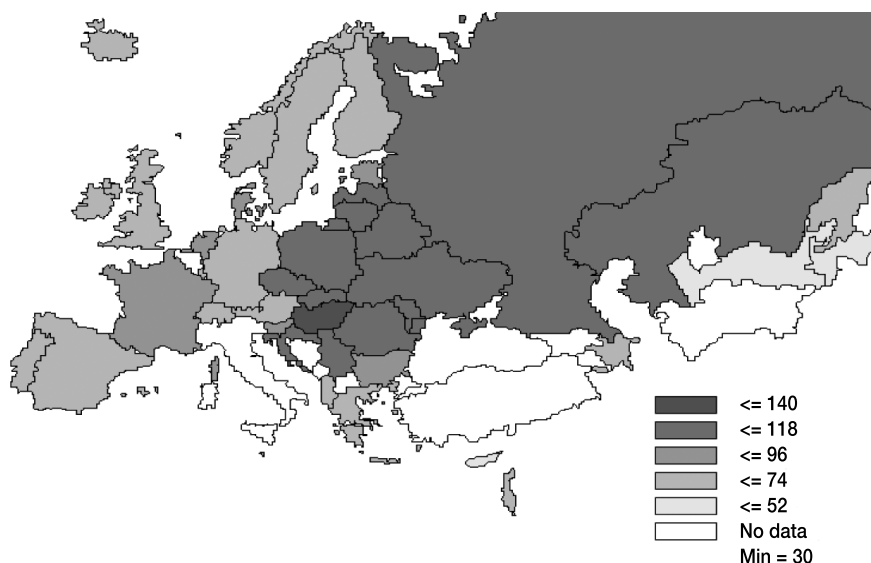
1.1 The rationale of the Slovenian initiative on cancer: Four pillars of cancer care

During the first half of 2008 and under the direction of the Slovenian Ministry of Health, the Slovenian Presidency of the Council of the European Union (hereinafter “the Slovenian Presidency”) centred its health objectives on reducing the cancer burden. The endorsement and energetic advocacy of this cause are welcome signs of leadership in a field which has generally suffered from intense fragmentation, both within and between Member States. The increased focus is also an acknowledgement of the very real challenges that Europe and its national health systems will face in the coming years, as demographic change increases the age – and health problems – of European populations.

Projections of the future burden of cancer in Europe circulate among oncology, public health and health management specialists without interlude; the victims are already numbered in millions. Further dramatic increases are expected well into the late 2020s. Even if the age-adjusted incidence rates were to remain unchanged, there would still be significant increases in the overall incidence and prevalence of cancer, mainly due to the intense process of ageing. Although European citizens account for only one eighth of the world population, a quarter of all cancers occur in Europe. Apart from the devastating human toll these figures imply, there is the underlying concern that health systems are not prepared to meet the rapidly increasing demand for health services.

In addition, the expansion of the European Union (EU) has provoked a spirited discussion over the basic rights of equity guaranteed to all Europeans, and how to provide them in heterogeneous settings with unequal resources, different capacities for effective government action, and variable cultural factors. At the time of writing, the asymmetrical incidence and mortality rates relating to cancer in European populations is largely a reflection of these fault lines (Figure 1-1). This is most evident from the examination of mortality data for cancers amenable to screening and cure, such as cervical cancer (Figure 1-2).

Figure 1-1 Standardized death rate per 100 000, all malignant neoplasms, 0–64 years

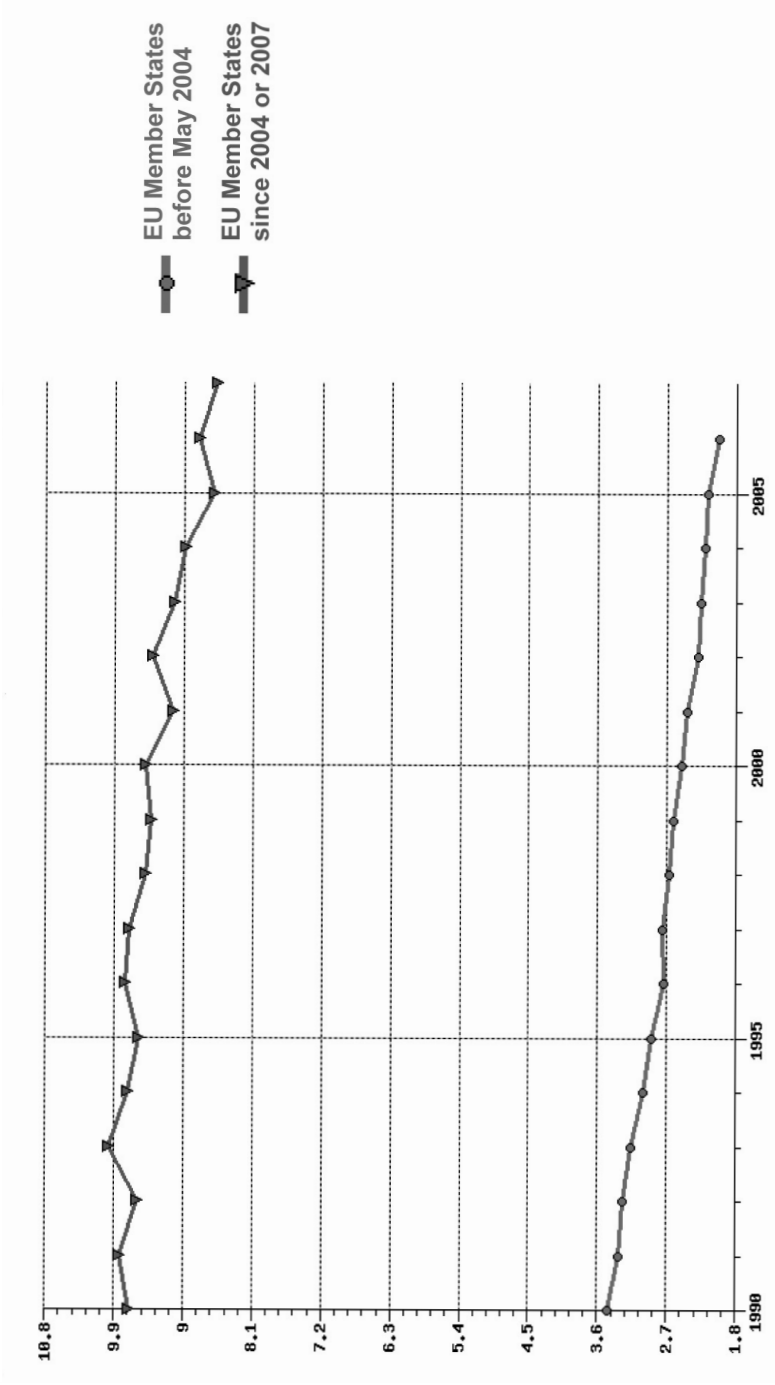


Source: WHO Regional Office for Europe 2009

However, the patterns of cancer incidence, mortality and survival across Europe vary particularly widely, and much work is still to be done. For example, in the conclusions presented by Drs Freddie Bray, Franco Berrino and Riccardo Capocaccia in *Responding to the challenge of cancer in Europe* (Coleman et al., 2008), Romania, Bulgaria and Greece are shown to have the lowest incidences of cancer in Europe, while the highest can be found in Hungary, Belgium and France. However, cancer patients in Belgium and France are more likely to survive than in most other countries in the EU (with no data available for Romania, Bulgaria or Greece). Sweden has the lowest incidence of lung cancer, but the highest of prostate cancer.

These disparities could arise from several interconnected factors, beginning with the variable quality of cancer registries, which hinders the comparability

Figure 1-2 Standardized death rate per 100 000, cancer of the cervix, all ages



Source: WHO Regional Office for Europe 2009

of data between countries. The data from Sweden illustrate a major contrast: the low incidence of lung cancer reflects the great investment that has been made in terms of prevention, while the high incidence of prostate cancer reflects great efforts in early diagnosis. In any case, it is clear that we must gauge the effect of other cultural factors and targeted government action on quantitative outcomes. Reducing persistent health inequities and the huge differences in the cancer burden between Member States is another challenge we must face together, as Europeans.

It was with this in mind that the Slovenian Presidency decided to tackle the issue ambitiously and purposefully, in a way which belied the small size of the country. Setting out a formidable programme of activities, including a book, several policy dialogues and workshops, and eventually a special issue of the *European Journal of Cancer (EJC)*, Slovenian leaders invited a wide range of European experts to exchange ideas and to forge a consensus among policy-makers regarding the next operational steps to be taken in tackling the cancer burden.

This policy summary aims to synthesize the cancer-related publications and events carried out during the 6-month Slovenian Presidency, producing a concise and functional guide for policy-makers. The Fighting Against Cancer Today (FACT) book and the aforementioned *EJC* special issue represent the bulk of the evidence-based information on the four main areas of cancer management, and we summarize the main points that should be taken into account by health system planners. In addition, this summary also examines the lessons learned during the process, highlighting the evolution of the conclusions and focusing on future operational steps.

The approach rested on four pillars of action: primary prevention, secondary prevention, integrated care and research. The first of these focuses on influencing citizens' lifestyles and fostering a healthy environment in a way which promotes good health. Objectives include preventing people from starting to smoke or encouraging them to quit, decreasing alcohol intake, increasing physical activity and encouraging a healthy diet. These measures, along with other efforts to ensure a clean and safe environment (including occupational safety) could prevent up to a third of all cancers as well as positively influencing other health indicators, such as ischaemic heart disease. The European Code Against Cancer (ECAC), which itemizes the most effective primary and secondary preventive measures in an accessible format, contributed with great success to a coherent strategy during the Europe Against Cancer programme in the 1980s. However, prevention efforts in Europe today should ideally be more coordinated and evidence based.

Secondary prevention, or screening, is the first step that the health system can employ, by detecting cancer before it gives rise to symptoms. Patient survival is closely related to the stage of the tumour at diagnosis, so health systems are strongly encouraged to pursue screening programmes for those cancers amenable to screening: at the time of writing, these include breast, cervical and colorectal cancers. Educating the public about symptoms and risk factors of other cancers, such as melanoma and liver cancer, could also be important. An effective population-based screening programme, especially targeting the most vulnerable populations and subgroups, dramatically increases the chances of survival and reduces the overall duration of treatment, thus proving a key to an economically efficient and clinically effective strategy. A population-based approach to screening programmes is gaining ground in most European countries, but there is still much progress to be made in increasing the efficacy of such programmes and providing equitable access to them.

Integrated care is perhaps the most complex of the four areas, encompassing virtually all cancer services from the moment of diagnosis until the end of the patient's life – whether death is due to cancer or not. A multidisciplinary approach is vital, to ensure that fluid lines of communication are open between primary care physicians, oncologists, surgeons, palliative care specialists and other health professionals involved in patient care. A trusting and open relationship between physicians, patients and their families is also important. Services to patients include diagnostic techniques (such as positron emission tomography (PET), magnetic resonance imaging (MRI), and so on); treatment options, including surgery, radiotherapy, chemotherapy and other drugs; rehabilitative care; palliative care; and follow-up to detect recurrence. In order to choose most effectively from the spectrum of possible treatments available for a given cancer, physicians must have the appropriate training and professional support, including treatment guidelines that they trust. When treatment requires the specialties of more than one discipline, doctors must also feel comfortable seeking the collaboration of their colleagues. Quality treatment for rare cancers is especially challenging, because many physicians will not have an adequate case-load to provide a proper learning curve. Comprehensive cancer centres (CCCs) and/or European reference centres offer one possible solution to this conundrum, pooling human and material resources to ensure the best care for patients, irrespective of the country in which they live. Finally, when curative treatment is no longer necessary and the patient enters into the rehabilitative or palliative phase, the continuity of care should be as seamless as possible. The capacity to provide integrated care varies widely across the EU; there should be an increased focus not only on allocating resources, but also on planning the most efficient way to bring benefits to suffering patients.

Research, the last pillar of an effective strategy for cancer management, underpins all cancer control activities. It provides the evidence to ensure that action, when taken, is as effective as possible. European cancer research has many strengths, but it is weakened by lack of coordination between stakeholders across and within the Member States, including funders, managers, patients, researchers and the public sector. While the pharmaceutical industry invests a large amount of resources to develop new pharmaceuticals, the public sector does not always match this investment in other areas. Streamlining processes and encouraging a holistic approach to cancer research, combined with more public outreach to engage and educate patients and the population, are the main priorities articulated for the future of European cancer research.

1.2 Building a consensus. Key stakeholders in the fight against cancer

In order to develop a coherent approach to this incredibly complex issue, a number of stakeholders were invited to participate in policy dialogues and workshops, documented in the book *Responding to the challenge of cancer in Europe* (Coleman et al., 2008), as well as in the special issue of the *EJC*. These overtures elicited very positive reactions from a wide spectrum of the European cancer community. The process was thus enriched by the active roles of the European Cancer Patient Coalition (ECPC) and Members of European Parliament (MEPs) Against Cancer (MAC), as well as the trio Presidency of Germany, Portugal and Slovenia. Researchers from across Europe, with the support of the European Observatory on Health Systems and Policies and the London School of Hygiene & Tropical Medicine (LSHTM), also took part.

One central partner in the Slovenian Government's cancer initiative was the ECPC and its president, Ms Lynn Faulds Wood. The ECPC's chapter in *Responding to the challenge of cancer in Europe* (Sundseth & Faulds Wood, 2008) and their presentation (Faulds Wood 2008) in the conference in Brdo, Slovenia, *The burden of cancer: how can it be reduced?* provided a powerful reminder to all participants of the central protagonist in the fight against cancer. This fresh perspective was welcome, not only because ECPC is an advocate for patient rights, but also because it tirelessly stresses the importance of comprehensive and equitable cancer care in Europe, with special attention to be paid to prevention. ECPC presented the human face of cancer, and in so doing staked out the role of the patient today as the natural partner of doctors and policy-makers. In addition, as the umbrella organization for hundreds of national and regional cancer patient groups

across Europe, it stands as a model of European integration that governments, researchers and health care systems would do well to imitate.

The ECPC was a natural partner in the cancer-related activities under the Slovenian Presidency. Its advocacy role has already exerted great influence in Europe and within individual Member States. By supporting and acting as the secretariat for the MAC group, the ECPC has been able to cooperate directly with high-level policy-makers. It has been an active proponent of the Warsaw Declaration and a partner to both the European Medicines Agency (EMA) and the World Health Organization (WHO) Clinical Trials Registry Platform. Moreover, the ECPC is in a unique position to support creative national programmes, such as Mamazone (which educates patients to be experts on their cancer) in Germany and to perform a benchmarking function to spread knowledge among national member organizations.

Medical professionals play a multifaceted role in the fight against cancer. They are involved in almost all phases of the cancer treatment and management cycle. In this role, they need to be involved in all developmental activities that include transfer of knowledge and efficient leadership in medically led teams. Medical oncology societies offer one good interface for policy-makers, but a better forum is required to encourage physicians from the entire spectrum of cancer care to take part in these activities.

Information systems increasingly provide more evidence-based, consistent, reliable and internationally comparable data. Developing a pan-European set of cancer indicators is a difficult task. It is that much more commendable when such efforts actually lead to productive outcomes, as in the European Cancer Health Indicator Project (EUROCHIP). Similarly, the EURO CARE programme, a stable and well-harmonized collaboration based on reliable data from national and regional registries, provides a well-balanced and clearly evidenced insight into the most crucial data about cancer – incidence, prevalence and survival by country, type of cancer and age group.

One initiative that Slovenia promoted in deciding to bring cancer to the forefront of EU health policy was the continuous effort of the MAC group. They inspired some of the approaches used to coordinate with the ECPC and participated widely in the conference *United against cancer: Making cancer a priority for action*, in Ljubljana in November 2006.

The pharmaceutical industry has an important role to play in cancer control. While the public sector has a clear responsibility in most aspects of health care services (including ensuring access to pharmaceuticals), private enterprises carry out vital research and development of new pharmaceuticals, which greatly contribute to treating cancer and improving patients' quality of

life. Given the ever-increasing cost of developing effective anti-cancer drugs, it is important to foster partnerships and coordinate the use of resources. Establishing fair ground rules and including considerations for the pharmaceutical industry in the cancer management process are pragmatic and strategic necessities.

Germany, Portugal and Slovenia formed the trio Presidency, which adopted a joint framework agenda. The efforts of Portugal and Slovenia were of special mention in this context as they worked in a complementary fashion. During the Portuguese Presidency, a conference on health strategies took place in Lisbon with cancer at the forefront of its agenda. All the four aspects, or pillars, of the Slovenian approach to cancer were elaborated and outlined (primary prevention, screening, integrated care and research). This effort was further developed with a strong Portuguese presence in all the events of the Slovenian Presidency, most notably at the conference in Brdo in February 2008.

1.3 Responding to the challenge of cancer in Europe

The book *Responding to the challenge of cancer in Europe* (Coleman et al., 2008) was launched at the conference in Brdo, Slovenia, in February 2008. Work on the book began well before the Slovenian Presidency began, as part of the project FACT, sponsored jointly by the European Commission's Directorate General for Health and Consumer Protection (DG-SANCO) and the Slovenian Government. Other partners in the FACT project included LSHTM, the European Observatory on Health Systems and Policies and the Slovenian Institute of Oncology, closely collaborating in all phases of publication.

The purpose of the book was to review current efforts to control cancer in Europe and to provide an evidence-based guide for effective policies within EU Member States and beyond. Much of the book is dedicated to the four pillars of action that form the basis for cancer control. The review of evidence and the conclusions in the book comprise the main source of data for this report. The book goes further, however, with chapters that delve into health system management as it relates to cancer control, including cancer registries and national cancer control frameworks. This broad operational focus was designed to produce a new reference for national and European policy-makers who seek to address the challenges that the cancer burden brings to citizens and health systems.

Contributors to the book come from all corners of Europe, from Iceland to Poland and from Portugal to Slovenia. While some authors are oncologists or epidemiologists, others are health system planners or policy experts. Still

others are cancer survivors who have dedicated their energy to advocating for other victims. The collaborators come from vastly different backgrounds, but they share a personal and professional commitment to improving cancer control and cancer services for all citizens.

1.4 Policy dialogue

Policy dialogues have developed into a well-established method of sharing and exchanging views about different approaches, proposals, ideas and solutions in a forum that combines representatives from all EU Member States. This is probably the only efficient method by which all Member States can be involved in discussing such important topics.

Under the FACT project, two policy dialogues were organized. The first, in April 2007, involved a number of European experts in the different domains of cancer, ranging from primary prevention to health technology assessment (HTA). The aim was to discuss the approach proposed by the Slovenian Presidency, particularly the four key pillars, well in advance. It was important to identify any omissions in the proposed approach and to collaborate with a broad community involved in cancer control and cancer management from the start. The event became a brainstorming session in which full support was given to the Slovenian approach. The second dialogue took place in November 2007, with two sessions forming part of a single event. Given the large number of Member States, it was essential to divide participants into two groups which shared the same agenda and the same aims of the event. Most countries were represented by their health attachés in Brussels, while some delegations also included public health and cancer experts. A more elaborated, policy-driven approach for each of the four pillars was proposed to participants. It became clear that there was more ease in discussing the issues of primary prevention and screening, which both belong to the broader spectrum of EU affairs, while there was some reluctance to include integrated care and cancer research in the EU agenda. The conclusions nonetheless covered all the four domains proposed, and they were all taken forward to the EU Cancer Conference in Slovenia.

1.5 Conference and its workshops

The European conference, *The burden of cancer: how can it be reduced?*, was the main health event during the Slovenian Presidency of the EU. The Conference was organized around epidemiology, overall cancer burden, old and new Member State differences, outlooks for the future, panel policy

discussions and workshops focused on the topics of the four pillars (Albreht & Pribaković, 2009).

The Conference workshop on primary prevention and health promotion emphasized the importance of effective policy implementation, concluding that a horizontal approach to cancer as a chronic disease is essential in addressing health determinants.

Cancer screening proponents recommended that Member States organize population-based screening programmes. Professional, organizational and scientific support from transnational bodies needs to be provided for countries with weaker infrastructures.

The workshop on integrated cancer care stressed the convenience of national cancer plans in providing a comprehensive approach to cancer. Development of European reference centres for cancer was also supported by many participants.

Finally, participants in the workshop on cancer research acknowledged the fragmentation and heterogeneity of European research and recommended closer collaboration between research centres. Activities need to be undertaken to encourage translational and public health-related research.

The conference created an inspiring atmosphere, in which leading European experts and policy-makers presented diverse pictures of cancer in Europe. The keynote speakers provided an evidence-based perspective on what had already been carried out and what is yet to be done, while the conference workshops generated operative ideas and conclusions regarding how to strengthen cancer control in the EU.

1.6 Council conclusions

In June 2008, at the 2876th Employment, Social Policy, Health and Consumer Affairs Council meeting in Luxembourg (Council of the European Union, 2008), the Council of the European Union articulated its solid support for the work carried out during Slovenia's 6-month term in the EU Presidency. The conclusions applauded the initiative shown during the conference in February 2008 and echoed many of its conclusions. Although the competencies of European authorities in health matters are subject to the prerogative of Member States, European bodies do have a considerable role to play in the cross-border coordination of many cancer-related issues, especially in the areas of public health and research.

The Council Conclusions urge the European Commission to take vigorous action wherever they can, including lending direct professional support to Member States in order to modernize their screening programmes and cancer registries, implement volunteer accreditation schemes, coordinate HTA evaluations and foster international research cooperation. In addition, Member States are encouraged to develop and implement National Cancer Control Plans (NCCPs), paying close attention to all aspects of cancer care, including health promotion activities; screening programmes; cancer registries; innovative health technology and appropriate equipment; palliative care; psychosocial support; and research. Finally, civil society and the wide range of stakeholders in cancer care are encouraged to work together in order to optimize the results.

1.7 Special issue of the European Journal of Cancer

As a special tribute to the joint efforts of the Slovenian Presidency and the European Commission, the *EJC* dedicated an entire issue to the main topics and outcomes of the FACT project. The issue included:

- a critical foreword with direct thoughts about the shortcomings of the previous European activities addressing cancer at the transnational level;
- two papers on trends in cancer survival in European countries;
- an appraisal of European activities in the field of cancer prevention;
- evidence and practice on cancer screening in Europe;
- the cancer situation in central and eastern Europe;
- improving cancer control in Europe – conclusions from the Lisbon round table during the Portuguese EU Presidency;
- identification of obstacles to European research projects;
- policy approaches on how to make progress against cancer in Europe.

This variety of topics dealt with all the most important issues related to cancer control and management in Europe.

Chapter 2

Primary prevention: Avoiding cancer before it appears

Health promotion and disease prevention activities, which are relevant not only to cancer but also to a wide range of communicable and noncommunicable diseases, are the first line of defence in reducing the disease burden in the long run. This is especially true for cancer; it is estimated that up to a third of all cancers can be prevented simply by modifying lifestyle and environmental factors. This section reviews the main risk factors associated with the development of cancer – as summarized by Martin-Moreno and colleagues in the FACT book (Martin-Moreno & Magnusson, 2008) and the *EJC* special issue (Martin-Moreno, Soerjomataram & Magnusson, 2008) – as well as proposing policies to combat them.

2.1 Lifestyle risk factors

Current research indicates that lifestyle factors are the leading cause of avoidable cancer incidence in Europe. While it is distressing to realize that the incidence of cancer in so many thousands of citizens could have been prevented, it is also a sign of the enormous potential for progress in the field of preventive medicine. By energetically using and improving the implementation of existing tools, such as the ECAC (Box 2-1), and developing new ways to encourage healthy lifestyles, the expected rise in cancer incidence rates into the late 2020s could be at least partially counteracted.

2.1.1 Tobacco smoking

Smoking is by far the largest avoidable risk factor for disease – not only for cancer, but also for heart disease, stroke, chronic obstructive pulmonary

Box 2-1 *The European Code Against Cancer*

Many aspects of general health can be improved, and certain cancers avoided, if you adopt a healthier lifestyle

- Do not smoke; if you smoke, stop doing so. If you fail to stop, do not smoke in the presence of non-smokers.
- Avoid obesity.
- Undertake some brisk, physical activity every day.
- Increase your daily intake and variety of vegetables and fruits: eat at least five servings daily. Limit your intake of foods containing fats from animal sources.
- If you drink alcohol, whether beer, wine or spirits, moderate your consumption to two drinks per day if you are a man and one drink per day if you are a woman.
- Care must be taken to avoid excessive sun exposure. It is specifically important to protect children and adolescents. For individuals who have a tendency to burn in the sun active protective measures must be taken throughout life.
- Apply strict regulations aimed at preventing any exposure to known cancer-causing substances. Follow all health and safety instructions on substances which may cause cancer. Follow advice of national radiation protection offices.

There are public health programmes that could prevent cancers developing or increase the probability that a cancer may be cured

- Women from 25 years of age should participate in cervical screening. This should be within programmes with quality control procedures in compliance with European Guidelines for Quality Assurance in Cervical Screening.
- Women from 50 years of age should participate in breast screening. This should be within programmes with quality control procedures in compliance with European Union Guidelines for Quality Assurance in Mammography Screening.
- Men and women from 50 years of age should participate in colorectal screening. This should be within programmes with built-in quality assurance procedures.
- Participate in vaccination programmes against hepatitis B virus infection.

Source: Boyle et al., 2003.

disease (COPD) and stillbirth. It is responsible for approximately one quarter of all cancers in developed countries and for a 12.3% decrease in disability-adjusted life years (DALYs) in the WHO European Region (Boyle et al., 2004; Mucha et al. 2006). Incidence figures for cancer of the lung, trachea, bronchus, oesophagus, larynx and oral cavity are particularly striking. Just under nine out of ten lung cancers are attributable to smoking, as are approximately half of cancers of the oesophagus, larynx and oral cavity (Boyle et al., 2003). Smoking

is also a serious risk factor for cancers of the urinary tract and bladder and the pancreas, and a contributing factor to the development of cancers of the kidney, stomach, cervix and nose, as well as myeloid leukaemia.

For these diseases, the latent period usually spans two or more decades, so an analysis of the efficacy of preventive measures is only possible by examining anti-tobacco campaigns in one decade and the incidence figures for cancers that are closely related to smoking in another. Such analyses show a notable decrease in mortality rates for smoking-related cancers in men in the 1990s, a reflection of the vigorous anti-tobacco measures implemented in the early 1980s in many European countries, which led to a decrease in smoking prevalence among men. However, this trend also highlights the fact that smoking-related cancers are rising in women, a fact which can be attributed to the increase in smoking among women during the 1980s. Male manual workers are more likely to smoke than their professional counterparts; one study found that lung cancer mortality was five times greater among blue-collar working men than among white-collar professionals (European Commission, 2003). In all countries, there is an inverse relationship between smoking prevalence and educational level, signalling the urgent need to find effective ways to reduce tobacco use among all strata of society.

2.1.2 Alcohol

Alcohol is the third greatest risk factor for the burden of disease in Europe (after high blood pressure and tobacco smoking), and the most significant among young people. Its influence on the developing fetus and its role in traffic accidents are well known, but it also contributes to cardiovascular disease and to the development of cancer, including cancers of the oral cavity, pharynx, larynx, oesophagus, breast, liver and large bowel. Although alcohol intake is in itself a risk factor, the danger increases exponentially when alcohol is combined with smoking (European Commission, 2003; Pöschl & Seitz, 2004).

It is particularly worrying that Europe consumes more alcohol than any other WHO Region in the world, and research shows that consumption is increasing (European Commission, 2007). As a result, Europe's alcohol-related burden of disease is twice the world average (WHO Regional Office for Europe, 2006). While efforts to promote abstinence are highly unlikely to be effective, moderation should be actively encouraged. At the time of writing, the accepted threshold for "safe" consumption is two drinks a day for men and one for women.

2.1.3 Diet, nutrition and physical activity

Some studies suggest that up to a third of cancer mortality could be related to diet, but many open questions remain in this dynamic research area. Results

of investigations into the relationship between the intake of animal fats and cancer incidence are – so far – inconclusive, although they seem to indicate a positive association. Similarly, some European studies have found that whole-grain cereals and high-fibre foods reduce the risk of cancers in the digestive tract, but these results have not always been duplicated in investigations involving a large cohort.

However, research has found that fruits and vegetables seem to have anti-carcinogenic properties, though scientists cannot yet explain what these properties are or in which fruits and vegetables they are found. Diets rich in fruits and vegetables appear to reduce the risk of epithelial cancers, such as pancreatic, stomach, colon, rectal and oesophageal cancer, but no effect is apparent for hormone-related cancers. The so-called “Mediterranean diet” comprising large quantities of fruits, vegetables, fish and grains is largely credited with the relatively low rate of incidence of many types of cancer in Spain, Greece and Italy, but more research is needed to confirm these outcomes.

There is great potential for progress in this research area. DNA chip technology and functional proteomics will eventually help to explain nutrient-gene interactions, which in turn will shed light on the pathophysiological mechanisms of cancer causation and prevention, as well as improving cancer surveillance abilities.

The association between physical activity, body composition and cancer is much clearer. There is consistent evidence that overweight and obesity are responsible for up to 11% of colon cancers, 9% of breast cancers, 39% of endometrial cancers, 37% of oesophageal adenocarcinomas, 25% of kidney cancers and 24% of gall bladder cancers (Boyle et al., 2003). This is due, in part, to an increased production of oestrogen and insulin, which can trigger cancer growth. Physical activity, which of course can help to reduce obesity, also seems to have a positive effect on cancer incidence, regardless of weight (Melzer, Kayser & Pichard, 2004). Like other risk factors mentioned here, overweight increases the risk not only of cancer, but also other pathologies, such as heart disease and diabetes.

In recent years, European populations have seen an accelerated increase in obesity and overweight, most frighteningly in children, who are 10 times more likely to be obese today than they were in the 1970s. By 2010, WHO estimates that obesity will affect 150 million adults and 15 million children in Europe (WHO Regional Office for Europe, 2007). This is a serious public health concern and it should be vigorously combated by public policy and health professionals.

2.2 Occupational and environmental factors

Conservative estimates attribute 5% of cancers to occupational and environmental factors, but the percentage is probably somewhat higher (Boyle et al., 2003; Siemiatycki et al., 2004). Although lifestyle factors are unquestionably the risks that are under the most personal control, workplace settings and circumstances in the environment can also contribute to the development of cancer. These areas are more directly the competences of public authorities and the producers and users of carcinogenic chemicals, but in order to effectively lower cancer incidence caused by environmental factors, civil society should consistently demand accountability from their elected leaders and industry representatives, to reduce carcinogens at work and in the water, air and food supply.

2.2.1 Occupational risk factors

There are a host of cancers and carcinogens linked to the workplace, many of which can be isolated to a few professions (Pukkala, 1995). While the situation has improved substantially since the 1990s, when it was estimated that up to 23% of workers (or 32 million people) in the EU were exposed to dangerous levels of known carcinogens, there are still workers who spend their day dealing with these dangerous chemicals, including asbestos, diesel exhaust and radon. National and European authorities, as well as labour unions representing workers, still have a long battle ahead before these highly avoidable cancers can be prevented.

2.2.2 Environmental contamination

There is still much we do not know about the connection between pollution and cancer. However, research has suggested that there is an elevated risk of some cancers for people living in urban areas with low-level air pollution or near industrial production centres. Contaminants include combustion products, such as polycyclic organic matter (POM), particulate matter (PM), radio nuclides, 1,3-butadiene and aldehydes, organic fibres (mainly asbestos) and radon. These have been associated with a slightly increased risk of lung cancer (approximately 1.35-fold, relative to the level in residents of non-polluted areas) as well as a higher risk of heart disease and other acute, short-term health effects. Our drinking water also contains trace levels of several known or suspected carcinogenic substances (Cantor et al., 2006). However, it also contains important minerals such as magnesium and calcium, which provide protection against some types of cancer.

2.2.3 Solar, ionizing and non ionizing radiation

There is a large body of research documenting the dangers of radiation, especially solar ultraviolet (UV) rays and ionizing radiation. The former is probably the most common cause of concern, but also the simplest to avoid (by moderating exposure and the use of sunscreens). The latter, on the other hand, is not considered a risk in natural terrestrial doses but can be catastrophic in the context of nuclear power and a genuine cause of concern in medical contexts when it is used in diagnostic or therapeutic procedures. The risks of nonionizing electromagnetic fields are not so evident, but research continues.

The relationship between UV light and skin cancer is analogous to the link between smoking and lung cancer: overexposure to sunlight is responsible – solely or in concert with other factors – for virtually all squamous cell carcinoma, basal cell carcinoma and cutaneous melanoma. The first is the most common among outdoor workers and organ recipients (due to the combined effects of rapid HPV (human papilloma virus) growth in their skin, caused by immunosuppression or exposure to sunlight), and the second is the most prevalent of the three. Carcinomas account for 95% of all skin cancers; they are very rarely fatal, but treatment is a serious financial burden for individuals and the public health system. Melanoma, on the other hand, is significantly more dangerous, and has been the object of numerous public health campaigns encouraging the use of solar protection and reduction of exposure.

High doses of X-rays, gamma rays and neutrons are also a significant risk. Although today only approximately 1% of cancers worldwide are attributable to ionizing radiation, the risk inherent in nuclear power plants, testing and accidents should not be ignored. In addition, the benefits of therapeutic and diagnostic procedures, such as X-rays, should be weighed against the possible risks.

2.3 Other cancer determinants: Infections, hormones and immunological factors

Infections, hormones, and immunological factors contribute to a significant percentage of some cancers. Infections may offer the greatest potential for rapid advances, because vaccines exist for HPV (which causes cervical cancer) and hepatitis B virus (HBV, which increases the risk of liver cancer). Vaccine development is under way for *Helicobacter pylori* (HP), which may cause up to 65% of stomach cancers. HPV vaccination is being incorporated into the vaccine calendar in a number of European countries, but HBV vaccination has not yet been incorporated as widely as it should be, despite its low cost and

proven efficacy. Hepatitis C virus (HCV), which can be much more serious than HBV, is also an important risk factor for liver cancer, but at the time of writing, supervising blood transfusions and avoiding the re-use of hypodermic needles are the best approaches to limit the spread of this disease.

Exogenous hormones are known causes of cancers in the reproductive organs. Oral contraceptives (OCs) and hormone replacement therapy (HRT) both contribute to some cancers and prevent others. Both hormone therapies increase the risk of breast cancer in current or recent users. OCs also increase the risk of liver cancer and of cervical cancer in HPV-positive women, and HRT is positively associated with ovarian cancer and cancer of the uterus (when taken with unopposed oestrogens). By contrast, OCs reduce the risk of ovarian cancer by 30% and probably reduce the risk of endometrial cancer and colorectal cancer. HRT also protects against colorectal cancer, although time-related factors have not yet been fully examined.

Finally, the impact of immunological disorders represents a promising area of new research. These disorders can be acquired, for example, after an organ transplant or with an HIV (human immunodeficiency virus) infection, or they can be inherited. Acquired immunosuppression increases the risk of skin cancer, non-Hodgkin lymphoma and Kaposi sarcoma, and inherited forms are associated with lympho-proliferative malignancies. It is estimated that only approximately 5% of cancers are hereditary, but more is being learned about the role of genetic factors in common cancers. If future investigations can identify the “problem” genes which contribute to the development of cancer, the potential for creating powerful tools to prevent and fight them is enormous. More investment in multidisciplinary research, including the use of biobanks and large-scale population based studies, will be necessary to optimize results.

2.4 Prevention policies

The challenges we face in formulating effective preventive activities are numerous, multifaceted and complex. Most interventions are the competence of Member States, but the EU and worldwide organizations such as WHO have a role in funding research, drafting guidelines, building networks and advocating effective policies at a population and decision-making levels. Here, we briefly review some general health promotion activities aimed at reduction of cancer incidence in the EU and its Member States, before narrowing our focus to measures undertaken against specific risk factors.

In Europe, one of the most relevant instruments is the ECAC. This short and simple set of recommendations (covering prevention and early detection) is

highly accessible to the general public, and it provides an excellent tool for encouraging a proactive and preventive approach for individuals' health. First formulated in 1987, it has since been updated twice by international experts in order to maintain its scientific base and relevance. The evolution of the ECAC has seen an increasing emphasis on individual behaviour and lifestyle choices, which aims to raise awareness of the responsibility each of us has in terms of our own health.

At the end of the Slovenian Presidency, the support of the European Commission was also reiterated, with its encouragement to Member States to act in the cancer management field, particularly in prevention. The Council Conclusions (see Subsection 1.6) stress that prevention remains the most effective long-term strategy to reduce the increasing cancer burden. Consistent approaches to health promotion and primary prevention, using – where appropriate – measures in a range of policy areas across sectors, would have a positive influence not only on cancer but also on other significant chronic noncommunicable diseases.

There is a need for national cancer plans to effectively coordinate cancer management activities in both a horizontal and a vertical way, involving related sectors such as agriculture, education and tourism. Some key tools include **legislative measures**, which can have immediate results such as reducing smoking; **advocacy**, which builds support, funding and capacity; **partnerships**, which can coordinate efforts between the EU and individual Member States; and **health impact assessment**, which can help policy-makers decide which are the most effective programmes to pursue. See Table 2-1 for proposals to combat the major risk factors at the Member State level.

2.4.1 Tobacco

Worldwide, the most potent formula put into place to fight the scourge of tobacco is a legally binding treaty spearheaded by WHO. The groundbreaking Framework Convention on Tobacco Control (FCTC) (World Health Assembly, 2003) – which took effect in 2004 for the 168 signatories (including the European Community) – is a comprehensive plan to reduce both the supply of and demand for tobacco products. The document calls for strict dissuasive pricing mechanisms, laws to reduce or eliminate tobacco smoke in public places, restrictions on advertising, full disclosure of product contents and regulation thereof, public awareness and education campaigns, and smoking-cessation activities. On the supply side, signatories must confront and oppose contraband or counterfeit products, encourage alternatives for those connected to the tobacco industry, and eliminate sales to and by minors.

Table 2-1 *Policies to address cancer risk factors at the national level*

• Tobacco	Implement FCTC
• Alcohol	Limit sales of alcohol by pricing policies and/or regulations Educational campaigns on the connection between alcohol and cancer Work to eliminate alcohol in some settings (work, sports activities, driving)
• Diet, nutrition and physical activity	Follow the models proposed by the Global Strategy on Diet and Physical Activity Regulate food labels and advertising of unhealthy products Increase access to sports facilities
• Occupational risk factors	Foster partnerships between the health sector, workers and industry Implement Global Plan of Action on Workers' Health 2008–2013
• Environmental factors, including radiation	Develop and improve the EU Water Framework Directive and WISE Educate population on dangers of solar radiation and X-rays
• Other factors	Introduce HBV and HPV vaccinations into the national vaccination calendar Educate women on the risks of HRT Invest in genetic research

Source: Authors' own compilation.

Notes: FCTC: Framework Convention on Tobacco Control; EU: European Union; WISE: Water Information Systems for Europe; HBV: Hepatitis B virus; HPV: Human papilloma virus; HRT: Hormone replacement therapy.

The enormous success of the FCTC is, in many ways, a reflection of the growing consensus that exists, not just in the health sector, but also across civil society, that smoking is a dangerous and unhealthy habit. Some Member States have acted aggressively on this front for several decades, and sufficient time has passed for the effects to be apparent. In the Nordic countries, for example, where strict controls on tobacco have been in place since the 1970s, the incidence of lung cancer is now low, at the time of writing. The United Kingdom and France have also seen decreases in tobacco consumption (by 46% and 11%, respectively) since anti-tobacco measures were put into place.

The most effective measures are those listed in the FCTC, in particular restrictions on smoking indoors and dissuasive pricing and taxes on the purchase of tobacco. For each 10% increase in price, a 3–5% increase in the cessation rate is achieved, while laws on clean indoor air can be responsible for up to a 38% decrease in smoking. These results, achieved by legislation, are by far the most cost-effective measures that can be taken to decrease smoking, but a coherent strategy which includes health education and support for cessation is also necessary.

2.4.2 Alcohol

While legislative measures are more appropriate for tobacco smoking, regulatory approaches to limit alcohol consumption are usually combined with a focus on safety (on the road and during pregnancy, for example) and culture. Both tactics aim to reduce or eliminate alcohol use in certain contexts (on the road, at work, during pregnancy, and so on), while encouraging interaction with healthy environments that are not usually connected to alcohol, such as sports and other leisure activities. There have been numerous initiatives at a European level to reduce alcohol consumption, including two consecutive action plans (1992–1999 and 2000–2005) and two ministerial conferences – the European Charter on Alcohol (1995) and the Declaration on Young People and Alcohol (2001). Furthermore, a policy instrument was provided in 2006 in the form of the European Commission's *EU strategy to support Member States in reducing alcohol-related harm* (European Commission, 2006a).

Action to control alcohol consumption in individual Member States has, with a few exceptions, been less spectacular. Sweden pursued a similar strategy with alcohol as with tobacco, limiting sales on the basis of pure alcohol content and seeing a 15% decrease in consumption as a result. However, most countries do not have a strategy to limit alcohol intake, and there is little awareness in the population of the link between alcohol and cancer. Vigorous education efforts should be combined with appropriate regulatory consequences (for drink driving, for example) to combat the culture of alcohol in adults, and further efforts should be made to offer young people alternative healthy social activities.

2.4.3 Diet, nutrition and physical activity

A key strategy in modifying diet is to reduce or counteract publicity and propaganda that tout unhealthy foods with public campaigns encouraging fruit and vegetable intake and low-fat choices. Clear food labels and itemizing the nutritional content of packaged products are also important, as is

multisectoral collaboration in areas such as education and agriculture. Children and parents should be the main target of these measures, given the fact that eating habits are developed primarily during childhood.

Other measures are necessary to induce physical activity. Point-of-decision signs have been proven effective at elevators, prompting an increase of 54% in stair-climbing in one study. Investigators have also shown that easy access to exercise facilities is also extremely effective, leading to an increase of nearly 50% in activity frequency. Finally, social counselling, including interventions in the workplace, can make up to a 20% difference in how often people exercise (Kahn et al., 2002).

While some countries have taken action in this area, a great deal remains to be done. The rising prevalence of overweight and obesity proves that effective formulas must be found quickly before overweight and obesity become a European epidemic, as has already been declared in the United States. A non-binding Global Strategy on Diet and Physical Activity was adopted by EU Member States in 2003. This blueprint provides models and advice on future action for Member States.

2.4.4 Occupational safety

WHO has been very active in supporting the rights of workers to a safe environment. Participants at the 60th World Health Assembly in 2007 endorsed the Global Plan of Action on Workers' Health 2008–2017 as an update to a previous programme, and the WHO Regional Office for Europe has pledged to work with governments, trade unions, employers, professional associations and other stakeholders to implement the measures outlined in the Plan. In Member States, Nordic research is the most advanced in finding formulas to track and control carcinogens in the workplace, and it could be an effective model for other countries to follow. Their strategy includes optimal use of cancer registries, as well as agreements between the health sector, workers and industry regarding confidentiality issues, access to data, and consent.

2.4.5 Environmental factors, including radiation

While air and water pollution are not considered highly significant causes of cancer in Europe, more research should be carried out to learn about the precise causal relationship. In addition, water safety initiatives, such as the EU Water Framework Directive (Directive 2000/60/EC of the European Parliament and Council) and the Water Information System for Europe (WISE) should be developed and improved in order to explicitly link water safety and public health in the minds of policy-makers and the public.

Radiation is more clearly linked with a large number of cancers, and it should be tackled with more resolve. Fortunately, many of the tools for this action are already in place. The United Nations Scientific Committee on the Effects of Atomic Radiation (UNSCEAR) has produced statistical models to track the health effects of ionizing radiation, and regulations and recommendations have been produced by the International Commission on Radiological Protection (ICRP) and the International Atomic Energy Agency (IAEA), as well as European Council Directives 96/29/EURATOM and 2003/1227/EURATOM. Information on the risks of solar radiation should also continue to be promoted, urging all fair-skinned individuals to sunbathe with caution and to use solar protection.

2.4.6 Policies to respond to other risk factors, including infections, hormones and immunological factors

The best advice to reduce cancers caused by the remaining known factors is largely a question of common sense. Infections should be reduced with traditional public health strategies, including increased surveillance, prevention and control of communicable diseases and the use of vaccines when available (such as for HBV or HPV). Similarly, the cancers caused by exogenous hormones, particularly by HRT, could be avoided by recommending moderation in their use; this is a message which must be transmitted first from doctor to patient, and reinforced by other sources, including the pharmaceutical industry. Finally, a greater European commitment to research on immunological risk factors for cancer is the best way to progress in this field.

It is conservatively estimated that one third of cancers could be prevented by adopting a healthier lifestyle, making wiser choices in terms of risk factors such as solar radiation or exogenous hormones, and by living and working in a clean and safe environment. With projections of future cancer incidence rising rapidly, it is vital that we begin to work on reducing the impact of cancer before this occurs. Additional research to deepen our knowledge and increase our understanding of known risk factors and to discover new ones is part of this commitment to society. If Member State governments pursue these policies aggressively, we will see dramatic decreases not only in cancer incidence, but also in respiratory disorders, heart disease, diabetes, stroke, hepatitis and many other communicable and noncommunicable diseases. Healthy societies are happy societies, and there is no better, more efficient way to promote health than to inform and counsel citizens to be responsible for their own well-being.

Chapter 3

Secondary prevention: When early identification makes a difference

For some of the most common cancers, screening asymptomatic individuals is the best method of discovering malignancies before they grow or metastasize. It is generally recognized among oncologists that early diagnosis is the biggest factor underlying the wide differences in cancer survival across Europe. This conclusion is based on the survival trends from the EUROCORE project, which show that international differences in survival are minimal for rare, treatable cancers and cancers with poor prognosis, such as testicular cancer, pancreatic cancer and Hodgkin's disease, but disparities rise sharply for common cancers that are susceptible to screening, such as breast or colorectal cancers. At the time of writing, only cervical, breast, and colorectal cancers present sufficient reasoning to justify population-based screening programmes, while screening for other cancers, such as ovarian, lung or prostate cancer, shows inconsistent results or a lack of effect on mortality. However, there could be opportunities to reduce mortality in oral cancer, cutaneous melanoma and liver cancer if selective programmes are carried out effectively. Using as its main sources the evidence put forward by Hakama and colleagues in the FACT book (Hakama et al., 2008a) and the *EJC* special issue (Hakama et al., 2008b), with survival data presented by Berrino and Capocaccia in the same volume (Berrino & Capocaccia, 2008), this section reviews the main conclusions on secondary prevention measures reached by participating researchers and policy-makers in the first half of 2008.

Screening programmes are often used as a proxy for secondary prevention policies in cancer management. However, while these diagnostic procedures are central to any secondary prevention programme, the concept should be more broadly considered to include all measures aimed at early diagnosis,

including educating the population on risk factors, symptoms and the effect of earlier diagnosis on survival. Secondary prevention must begin with a strong focus on gathering and disseminating solid information. Only when citizens understand the importance of prompt diagnosis will mass screening programmes obtain sufficiently wide participation to be effective.

3.1 To screen or not to screen: Which cancers can (and should) be detected early?

Screening is widely celebrated as the best way to reduce mortality for some cancers, but it is not always appropriate. If the quality is not assured and the effects are unproven, screening can be ineffective. It is also important to note that along with the positive effects, there can be negative ones, both for the patient (distress due to false positives, overdiagnosis, exposure to radiation) and the health system (increased use of economic resources). Therefore, planning an effective screening programme should be carried out with these considerations in mind. Most health organizations worldwide also make the distinction that screening should only be carried out when it could have a positive effect on prognosis and/or quality of life, and not for largely fatal malignancies such as lung cancer. Early diagnosis in these cases could add years of unnecessary suffering and stress to the patient's life as well as sap the resources of the health system, without significantly affecting chances of survival or improving quality of life. Overdiagnosis refers to the use of very sensitive technology that can detect even the smallest lesions, which might otherwise go unnoticed for the rest of the patient's life. The risk of this has been suggested for cancers of the prostate, breast, kidney, lung, melanoma and childhood neuroblastoma.

3.1.1 Breast cancer

Breast cancer is the most common cancer among women in Europe (approximately 430 000 new cases in 2006). Mammographic screening has been shown to reduce mortality by 20–35% in women aged 50–69 years, as well as improving quality of life by providing more treatment options and the opportunity to avoid radical surgery. While digital examinations and MRI do take place, these procedures do not have the same evidence base as traditional mammography. This is carried out by radiological imaging of the breast and is most beneficial for women with small lesions and dense breast tissue. Two views increase the sensitivity and efficacy by 20% and 10%, respectively. Women whose scans show abnormalities are then requested to return for a biopsy or excision.

Although there is some overdiagnosis (3–5%) and some added risk from the limited exposure to ionizing radiation (1–3%), the benefits are widely

understood to outweigh the risks. Virtually every respected health authority in the world (WHO, International Union Against Cancer, EU, American Cancer Society, International Agency for Research on Cancer (IARC)) recommends a population-based breast cancer screening programme, usually every two years for women aged 50–69 years. The American Cancer Society and some medical specialty societies tend to urge more screening (beginning at age 40 and once a year) than European institutions, but the very detailed EU guidelines on quality assurance have been proven to be highly effective.

3.1.2 Cervical cancer

Cervical cancer, usually caused by oncogenic strains of HPV, follows breast cancer as the most common cancer among European women and the success rate of periodic screening is remarkably high, with an 80–98% reduction in the risk of cancer (Olesen, 1988; WHO, 1986). In part, this is due to the slow development of the disease and a long latent period of approximately 12–16 years in the pre-clinical phase, for most lesions. While many of these lesions disappear on their own, others will eventually develop into cervical cancer. Removing all lesions does carry some risk of overtreatment (there is a 10–15% chance that an abnormality will be detected, compared to a 3% risk of cervical cancer), but the spectacular drop, not only in cancer mortality but also in incidence, justifies a population-based screening programme.

Detecting these lesions is usually carried out by the Papanicolaou cytology (Pap smear), but other screening techniques exist, such as visualization of the cervix, liquid-based cytology and HPV screening. Interestingly, cytological smears have not been established as effective with modern and methodologically strict evaluation criteria; however, the reduction of incidence in cervical cancer experienced after the introduction of screening programmes in countries such as Finland (60% after 10 years (Nieminen, Kallio & Hakama, 1995)), Norway (22% after two years (Nygard, Skare & Thoresen, 2002)) and the United Kingdom (33% between the period 1991–1993 and 1998–2000 (Canfell, Sitas & Beral, 2006)) is very clear. Furthermore, Denmark saw an increase in invasive cervical cancer incidence in a region where cytology had been discontinued (Lyng, 1998).

Most Member States have cervical screening programmes in place; however, the methods are remarkably heterogeneous, and target populations vary. In Slovenia, for example, only 30% of the population is covered by the screening programme, while in the Nordic countries the level is 100% (Anttila et al., 2004). The EU guidelines state that cervical screening should begin no earlier than at 20 years of age and no later than at 30 years, with a frequency of every 3–5 years (Council of the European Union, 2003). Screening can be discontinued after 60 years of age. It is important to target the entire female population

under 60 years old to avoid excluding some of the most vulnerable groups, but this recommendation will change over the next 10–20 years as the HPV vaccine is introduced into the vaccination programme of many European countries.

3.1.3 Colorectal cancer

Most cases of colorectal cancer have their origin in flat or polypoid adenomas, which are collections of growths (usually benign) that become a cause of concern if their diameter exceeds 1 cm and they exhibit dysplasia. Colorectal cancer is the second most common cause of cancer death in Europe, accounting for approximately 20% of all cancer deaths in 2006. There is a relatively long detectable pre-clinical phase (2–6 years), making regular screening a good option which can significantly reduce mortality.

At the time of writing, faecal occult blood (FOB) testing has the strongest evidence base as a screening technique, although there are several alternatives, which could eventually take its place. FOB tests check for the presence of haemoglobin in stools (two specimens are obtained over three days) by means of a guaiac-impregnated patch that oxidizes after contact with a positive sample, producing a visible colour change. The leading test, Hemocult II®, has some risk of false positives, but it is more cost-efficient than its competitors, despite expense of the follow-up diagnostic exams caused by false positive results. Randomized tests consistently report a reduction in mortality of approximately 15% with biennial screening (Towler et al. 1998).

Alternatives to FOB include flexible sigmoidoscopy, screening colonoscopy and faecal DNA analysis. The main problem with the first option is a lack of reliable data to justify its use in population-based programmes, although some preliminary data suggests that it could be up to 60–80% more sensitive than FOB. A large randomized trial is under way in Norway. Screening colonoscopy might detect up to one third more cases than FOB; however, it is more stressful and more expensive, and no clinical trial has yet proved its efficacy. Faecal DNA analysis has been introduced recently and shows some promise, but it is too early to draw definitive conclusions.

FOB remains the best approach to colorectal cancer screening at the time of writing. It is the method used in population-based programmes in Finland, France, Italy, the Netherlands, Poland and the United Kingdom. It is also recommended by the Council of Europe, which advocates screening for men and women aged between 50 and 74 years (Council of the European Union, 2003). FOB screening is underutilized at the time of writing. European support for new quality-assurance guidelines, being drafted at the time of writing by specialists, could help expand the use of this important procedure.

3.1.4 Selected screening for other cancers

A few cancers can be detected relatively easily (even by visual examination), leading to significant reductions in mortality, but they do not warrant population-based screening interventions. Oral cancer, cutaneous melanoma and liver cancer are all associated with very specific risk factors: tobacco chewing or smoking, fair skin or excessive exposure to solar radiation, and HBV infection, respectively.

Oral cancer can be detected upon visual inspection, showing a 20% reduction in mortality in a recent cluster-randomized trial of nearly 200 000 subjects (Sankaranarayanan et al., 2007). Similarly, it is known that chances of survival increase if melanoma is detected early and that pre-malignant lesions can be detected upon visual inspection, but no randomized trials have been carried out to produce scientific evidence on the results of melanoma screening. Finally, a large randomized trial for liver cancer screening (by means of combined tests of serum alpha-fetoprotein (AFP) levels and ultrasound) has recently been conducted in China among 18 000 chronic carriers of hepatitis B, finding a reduction of one third in 5-year mortality rates.

For these cancers, it may be useful to disseminate information to the general population on risk factors and symptoms, and primary care physicians could visually screen – or recommend screening – based on individual cases. However, more research should be carried out before incorporating these recommendations into guidelines for primary physicians; previous attempts at selective screening for breast and cervical cancer were not considered successful.

3.2 Other screening techniques

While there is a decisive body of evidence for population-based screening programmes for breast, cervical and colorectal cancer, and some complementary screening for oral, liver and skin cancer is justified for risk groups, research must still be conducted in order to refine other procedures. Development is under way for diagnostic processes to detect prostate, lung and ovarian cancer, as well as neuroblastoma and gastric carcinoma, but evidence has not yet shown improvements in mortality or quality of life.

Studies are under way in Europe and the United States to measure the effect of prostate-specific antigen (PSA) screening on prostate cancer mortality, but the final results of these large randomized trials are not yet available at the time of writing. Other ecological and time-series analyses have produced contradictory results. Prostate screening carries a high risk of overdiagnosis, as it is estimated that approximately 30–45% of prostate cancers found during screening would

not be diagnosed during the man's lifetime. Side-effects of treatment are common and very serious, including erectile dysfunction, urinary incontinence and persistent inflammation of the rectum and bladder following radiation therapy.

Lung cancer and neuroblastoma (a rare childhood tumour) can be detected through screening, but with little benefit. The rate of 5-year survival for lung cancer (12%) is one of the lowest in Europe (Berruno & Capocaccia, 2008). Three diagnostic modalities have been proposed as screening procedures: chest X-ray, sputum cytology and spiral low-dose computed tomography (CT). The first two procedures have no effect on mortality, and the effect of the third is unclear. Screening urine for the catecholamine metabolites HMA and VMA to detect neuroblastoma can increase the recorded incidence between 2- and 6-fold over that seen in unscreened individuals, but this does not reduce either mortality or the incidence of advanced disease.

Screening for ovarian cancer is not considered useful at the time of writing, either. Results from preliminary, non-randomized studies are not promising; a number of false positives, combined with low sensitivity in the various methods (transvaginal or transabdominal ultrasound for imaging and CA-15 as a biochemical marker) make further research necessary before routine screening can be seriously considered.

Finally, photofluorography and endoscopy can be used to screen for stomach cancer, but again, several case control and cohort studies have demonstrated inconsistent results, and no randomized trials have been carried out.

3.3 Population awareness and secondary prevention: The case of colon cancer in Europe

While screening is extremely useful, it can be underutilized unless it is combined with public campaigns to foment participation among the population. A perfect example of this fact is illustrated by the experience of Lynn Faulds Wood, the president of the ECPC. She was diagnosed with advanced colon cancer a full year after beginning to experience symptoms. This led her to find that there was no evidence-based guidance on the symptoms for this cancer, leading to a lack of awareness by patients and doctors alike.

Since then, the ECPC has worked in a pan-European context to prevent this disease, encouraging countries to adopt screening programmes but also carrying out extensive public awareness campaigns to encourage populations to participate in them. In addition, the ECPC is working to formulate reader-friendly guidelines on symptom detection and is partnering with the European Commission to produce quality assurance guidelines for screening.

The role of the population should not be dismissed in secondary prevention policies. Disseminating information on the most common types of preventable and/or treatable cancers is an essential complement to any screening programme, increasing the participation of – and therefore the benefits to – all of society.

3.4 The role of European Union guidance in cancer screening

Most Member States have already adopted screening programmes for one or more of the most common cancers. However, there is great disparity in the quality and effectiveness of these interventions. Therefore, EU guidance on quality standards and screening guidelines would be an excellent way to ensure that resources are used wisely to optimize their efficacy.

The ECAC does contain recommendations to participate in screening programmes for breast, cervical and colorectal cancers. Quality assurance guidelines exist for breast and cervical cancer and guidelines are being developed for colorectal cancer. In addition, European Council recommendation of 2 December 2003 urged Member States to implement population-based screening programmes according to rigorous standards. The Council Conclusions of June 2008 reiterated this advice and invited the Commission to provide medium- and long-term professional and scientific support in order to facilitate this task within the Member States.

These initiatives are very positive, but more can still be done. The Workshop on Cancer Screening identified several key priorities, including:

- emphasizing the ineffectiveness of opportunistic screening as compared with population-based interventions;
- discouraging the use of screening methods that are not evidence based, such as PSA screening for prostate cancer;
- generating evidence on how to improve existing programmes and to develop new ones.

Additional recommendations include implementing a European accreditation and certification scheme for screening programmes and a European school for screening management, as well as investing funds to carry out these measures and developing a process of oversight and monitoring. The information and recommendations on cancer screening in this section are summarized in Table 3-1.

These measures would help to ensure that screening programmes are implemented systematically and in line with the available evidence. As with any public health intervention, planning the appropriate execution is the first vital step to success.

Table 3-1 Current evidence and recommendations on cancer screening

Type of cancer	Method	Standards	Quality control	Complementary or further action
Population-based campaigns screening recommended at time of writing	Breast	Mammography every 2 years for women aged 50–69	Compliance with guidelines published by the Council of the European Union (2003)	Awareness to encourage participation (due to higher survival rates) and reduce stigmatization Support continued research Incorporate HPV vaccination into vaccination calendar
	Cervical	Cytology every 3–5 years for women aged 20 (or 30 at the latest)–60 years		
	Colorectal	FOB testing for men and women aged 50–74 years.	Guidelines under development by the European Commission	Awareness campaigns Continued research into other methods, including screening colonoscopy, flexible sigmoidoscopy, and faecal DNA analysis
Some evidence of efficacy for opportunistic screening available	Skin (melanoma)	Visual; skin biopsy		
	Oral	Visual screening for subjects with high-risk behaviour (i.e. tobacco chewing)		
	Liver	Serum alpha-fetoprotein (AFP), and ultrasonography for HBV-positive subjects on a bi-annual basis		Incorporate HBV vaccinations into vaccination calendar
Screening not advised (more research necessary)	Prostate	Serum PSA or digital rectal examination. No effect on mortality shown.		
	Lung	Chest X-rays with/without sputum cytology and spiral low-dose CT. Unclear effect of spiral CT on mortality. No effect on mortality observed due to chest X-rays.		
	Ovarian	Transvaginal or transabdominal ultrasound. No effect on mortality shown.		
	Neuroblastoma	Urine test for catecholamine metabolites. No effect on mortality shown.		
	Gastric carcinoma	Fluoroscopic imaging or endoscopy. Inconsistent or non-existent evidence of efficacy.		

Source: Authors' own compilation.

Notes: AFP: Serum alpha-fetoprotein; CT: Computed tomography; FOB: Faecal occult blood; HBV: Hepatitis B virus; HPV: Human papilloma virus; PSA: Prostate-specific antigen.

Integrated care: A patient-centred approach for those affected by cancer

The most visible facets of cancer care for patients fall into this extremely challenging pillar of cancer control. Integrated care spans certain preventive activities, diagnosis, treatment, professional training, psycho-oncology, clinical trials, palliative care and rehabilitation. Each of these elements depends on a wide range of health care professionals and stakeholders, including physicians in primary care, oncology, surgery, physiotherapy, palliative medicine, radiology, psychology and research; nurses; social workers; professional and non-professional caregivers; pharmaceutical companies; health system planners; quality monitors, and so on – the list goes on and on.

Thus, as experts increasingly advocate the importance and effectiveness of multidisciplinary care for patients, health systems are faced with the task of finding new formulas to provide a clearly articulated cancer care structure as well as continuous care pathways and fluid communication channels between all members of the care teams, including patients and their families. Meeting this challenge depends on effective health system management, whereby the administrators of cancer care are responsible for the structural organization which favours cooperation and collaboration among all involved.

Policy-makers must consider questions of access, quality and efficiency at all levels of care in their strategic planning, as well as health systems issues such as proper governance, use of resources, and professional training. In this section, we briefly describe how these aims can be met alongside the traditional clinical goals that seek quality of life and recovery for patients, identifying important issues and recommendations which were proposed over the course of the cancer events and activities undertaken during the Slovenian

Presidency of the EU. We also focus specifically on two fields – psychosocial oncology and palliative care – which are relatively new in cancer care (and virtually absent in many EU countries) and therefore merit closer examination.

4.1 Equitable access to cancer care

The first thing to which citizens and patients need access is information. This should begin with education about risk factors, both for those who have no history of cancer and those who wish to avoid a recurrence. This is especially important at the lower socioeconomic levels of society. The need for information continues at the level of secondary prevention; as explained in Chapter 3, there is a strong correlation between the stage of tumour at diagnosis and patient survival. Therefore, it is important to inform citizens about possible symptoms and the availability of screening, and to emphasize that survival is much higher if cancer is detected early. During the treatment process, access to information is at least as important as in the previous stages; doctors and patients must form a care partnership, in which patients can take part in decisions about their treatment in an informed way and can communicate new symptoms to the receptive ear of their doctor. They should also have access to information on clinical trials and be aware of any new treatments.

Secondly, prompt access to diagnostic procedures and multidisciplinary specialist care is essential. Most patients will be diagnosed by their family physician, who should quickly be able to identify which tests to perform, including blood tests, X-rays, ultrasounds, endoscopies or other methods of diagnosis. If appropriate, specialist care is ideal even at this early stage; evidence relating to lymphoma has shown that specialists tend to provide a more accurate diagnosis (Lester et al., 2003). Once a patient knows she or he has cancer, however, access to specialist care should be offered quickly. A wide body of evidence supports this recommendation, reporting higher survival for patients treated by specialists than by physicians who are not specialized in the cancer in question (Gillis & Hole, 1996; Bachmann et al., 2003; Grilli et al., 1998; Junor, Hole & Gillis, 1994; Sainsbury et al., 1995; Selby, Gillis & Haward, 1996). Specialist care should be multidisciplinary in nature, in order to address all the patient's needs, including pain management, psychosocial needs and physical rehabilitation. Some of these needs can be addressed at local health centres, but others, such as radiation therapy, are best dealt with at centralized cancer management centres (see Section 4.2). Clear care pathways are vital for this approach to be effective.

4.2 Ensuring quality

CCCs are repeatedly cited as an effective and efficient means of providing high-quality treatment. These facilities allow the concentration of expensive resources and scarce skills, such as radiotherapy installations and the expertise of medical radiologists, while increasing the cancer case-load per centre, which has been shown to lead to higher quality care and better chances of survival (Hillner, Smith & Desch, 2000). In addition, the centralized structure means that multidisciplinary teams are better articulated, as they are in constant contact with each other because they share many patients. Treating rare cancers is also more feasible in this setting; a general hospital would have difficulty maintaining the expertise needed to treat these diseases effectively, but CCCs can accept cases from a wider geographical area, gaining more extensive experience and skills. As a logical centre for cancer care innovation, CCCs also tend to produce good results for complex procedures in common cancers, such as radical surgery for cancers of the oesophagus or pancreas.

One idea that emerges as a potentially useful option is the concept of European reference centres. For small countries, especially, this could be an excellent solution for dealing with rare cancers, because this type of facility would raise the clinical case-load and would help establish well-funded research networks with close contact with regional populations. Such centres would foster an integrated approach, from prevention to research, representing an important resource to the region they cover (Ringborg et al., 2008a). The opportunities for knowledge transfer, telemedicine and the fostering of networks with general hospitals and other regional cancer treatment facilities are also very exciting. Several thorny issues arise, however, namely the principle of cross-border health care and other territorial concerns, but the idea was endorsed by policy dialogue participants as a creative approach to implement a Europe-wide approach to comprehensive care.

The need to provide most cancer services in local health centres or hospitals does not disappear with the comprehensive cancer care model. With the exception of radiotherapy, most common cancers can be adequately treated nearer to the patient's home. Local or district health care facilities also have more natural channels of communication with other social and health services in the community. Thus, the highest quality cancer care will be the result of networks, rather than isolated excellence in specific centres. This requires an explicit commitment from all involved parties (from policy-makers to service providers) to coordinate care pathways and share information such as patient records, communications and decisions.

Quality assurance requires good governance of an effective framework to maintain and improve performance at every level. Guidelines for clinical actions (clinical procedures, surgery, pharmaceutical prescription, and so on) are now common, but service guidance can also help staff by explicitly stating what multidisciplinary team members are necessary for a specific type of cancer, as well as the responsibilities of each and how to coordinate action. Rigorous evidence-based methodology was used to create these guidelines in England and Wales (Bentzen et al., 2005; Haward, 1998; Haward, 2003; Slotman et al., 2005), with notably positive effects. Continuing education and training for staff can prepare practising physicians to use innovative techniques and procedures, and encouraging the development of new research networks can vastly increase the number of patients who take part in clinical trials. Finally, staff at the service level can offer a real contribution to the decision-making process, using their deep knowledge of the workings of each facility to tailor the solutions to individual centres.

4.3 Making the most of available resources

Resources and the efficiency with which they are used are central to the effectiveness of service provision. Effective cancer care requires substantial investment in human and financial resources, and any coherent cancer plan will need to include specifications on how that money will be allocated. However, the high cost of cancer care – including pharmaceuticals, radiotherapy equipment, staff ratios, surgical costs and so on – raises huge concerns about the sustainability of the system. A study in the United Kingdom estimated that in 2007, each cancer patient expended £25 000 of health system resources. As the cancer epidemic evolves into the late 2020s, this annual cost is conservatively estimated to quadruple (Bosanquet & Sikora, 2006). The increase in costs will mostly be due to technological advances and rising development costs, but the cost per annum does not tell the whole story. By 2030, cancer will join the ranks of other chronic diseases such as diabetes and hypertension, leading to a much higher prevalence and subsequent care costs (Sikora, 2008).

Many health systems have already responded to financial strains by introducing rationing measures for expensive treatments. This is especially common for cancer drugs. Doctors may deny the existence of a treatment, or patients may be required to make a co-payment or even be referred directly to the private sector. These measures are not equitable, however, and they directly contradict the equally important goal of ensuring access to treatment. In the long term, the cost-controlling mechanisms aimed at improving efficiency

(such as HTAs) will be the most effective in improving outcomes for all patients. Many treatments are costly, and health systems face challenges in sustainability as a result. However, in addition to considering individual utility (quality of life for individual patients), concerns of societal utility – including upholding basic principles of social and health equity – must also be borne in mind. The traditional tenets of proper strategic planning, attention to accountability, monitoring and evaluation of results are essential in optimizing a national (or European) strategy for cancer control.

HTA is one of the key approaches to making important national policy decisions on cancer control. Such decisions must be firmly evidence based, regardless of the pressures to base them on other criteria. Cancer is a highly resource-intensive discipline in health care, and it is therefore even more important to consider all the available evidence in order to make sound decisions. Some of the most recent advances in cancer care, especially in the field of medical treatment, further stress the importance of a reliable mechanism for implementing HTA into everyday decision-making. This should not be limited to national or regional decisions in individual Member States but should also include decisions at international levels.

Many countries do not have the technical capacity or resources for independent HTA procedures. Even wealthier countries can recognize the usefulness of a unified European structure, such as the EMEA, to handle HTA for all diagnostic procedures and treatments. The European Network for Health Technology Assessment (EUnetHTA) could prove to be a valuable tool for cancer care, and should be fully exploited. However, it is also important to learn from past experiences: while the EMEA has simplified some processes, most countries still maintain a separate stage of approval before “technologies” (including pharmaceuticals) are incorporated into the public health care system. This is often – though not always – due to price negotiations or cost-efficiency assessments between health system planners and health technology producers. These processes, as well as administrative procedures, can delay the uptake of medicines and diagnostic equipment for up to two years – far longer than the 180-day uptake limit stipulated by the EMEA (Jonsson & Wilking, 2007). Obviously, this leads to further inequalities among European countries, where some administrations act more rapidly than others. Cost-efficiency analyses are an area which might be addressed by EUnetHTA, although much attention should be paid to the peculiarities of cancer, its treatment and the overall impact on society.

4.4 Psychosocial oncology and palliative care: The increasing importance of holistic cancer care

Psycho-oncology and palliative care are two fields of emerging importance in cancer control. They are not aimed at reducing incidence or mortality, nor are they primarily concerned with cure. Instead, they address quality-of-life issues, not only for patients, but also for their families and loved ones. Both fields have gained recognition since the mid-1980s and are now recognized by many countries as vital elements of a comprehensive cancer strategy. Grassi and Travado (2008), along with Higginson and Costantini (2008), devote two chapters of the FACT book to psycho-oncology and palliative care, respectively. These are two of the most perennially misunderstood and underresourced areas of cancer management. This is perhaps due in part to the lack of neat statistical figures (such as mortality data) to show progress, and in part due to a separation between clinicians trained to focus on curing disease, and patients and family who suffer from less-tangible disorders such as clinical depression, social alienation and spiritual turmoil. If the cancer is amenable to curative treatment, psychosocial well-being is an important factor of success. On the other hand, if there is a limited prognosis, the role of the medical team irrevocably shifts towards more humanistic actions, whereby caregivers are primarily responsible for relieving pain, ensuring quality of life, and preparing the patient for death.

4.4.1 The psychosocial consequences of cancer

The physical effects of disease on a patient do not occur in a vacuum. Rather, the emotional, spiritual and social context of the disease has profound effects on patients, as well as their families and caregivers. Without professional support, stress and psychological disorders, including anxiety, insomnia, fear and depression, are present in at least half of all cancer patients. Spiritual concerns also arise: changes in faith, personal values, and the perception of being and meaning all affect the sense of self and spiritual stability. The thoughts provoked by illness and physical deterioration are often experienced in addition to very real social problems, such as money issues and concerns for the partners and children, loneliness and stigmatization, and problems returning to work. When curative treatments have been abandoned, these problems become even more acute. Families also face a heavy psychosocial burden, as members are strained emotionally, physically, financially and socially. Finally, professional caregivers are susceptible to psychosocial distress, as the emotional toll of caring for the ill and the dying accumulates and deepens with time.

Identifying these feelings is the first step in dealing with them, but many clinicians do not have training in the psychological and social aspects of cancer care, and up to 40% of cancer patients suffering from psychological problems are not properly diagnosed (Grassi et al., 2005b). The National Comprehensive Care Network (NCCN) began formulating clinical practice standards for psychosocial distress in 1997, and almost every year a new update is published (NCCN, 2007). Their panel of multidisciplinary experts has devised a straightforward instrument for recognizing patient distress, which they recommend incorporating into routine interventions in order to carry out real multidisciplinary care more effectively. The “distress thermometer” mirrors the manner in which clinicians measure pain, on a scale of 1 to 10, and includes a list of possible causes of anxiety, such as physical symptoms, practical problems and emotional upset, which can help to articulate what help is needed. This instrument – if used properly and routinely by oncologists, nurses and other members of the care team who have been trained to recognize the psychosocial effects of cancer on their patient – could facilitate interventions from psychologists, faith leaders, and/or social workers that are essential to a holistic approach to cancer.

It must be stressed that caregivers and the cancer patient’s family are emotionally and socially vulnerable as well. Many family members give up social contact in order to care for the patient and they can face financial strain related to health care costs (68% of family members pay for some treatment). Financial problems are exacerbated by employment difficulties stemming from time devoted to caregiving. These issues do not disappear even with the death of the patient, and families need access to bereavement counselling and further social assistance to help them to adjust.

4.4.2 Psycho-oncology

Once feelings of stress are identified, the patient should have access to the appropriate support, whether this is given by traditional caregivers (oncologists and nurses) or by other members of the multidisciplinary team, including psychologists, psychiatrists, faith leaders or social workers. In the first case, it is important to ensure adequate training for all care team members in the psychosocial aspects of cancer care. There are widely accepted online curricula available in a number of languages (IPOS, 2006) and successful precedents in hands-on training workshops (Grassi et al., 2005a). Improved communication between physician and patient has been found to improve patient satisfaction, symptom control, treatment adjustments and final outcomes (Fallowfield & Jenkins, 2004; Maguire, 1999). If the problems are more complex, the role of the psycho-oncologist and/or other professionals

becomes more salient. Specialized interventions, such as group therapy, can be positive for both patients and families, improving both the quality of life and symptom perception, as well as guiding them through numerous social adaptations involved over the course of the illness. Personal counselling and psycho-pharmacological intervention may also be required.

Evidence supporting the idea that psychological well-being results in longer survival and a better chances of cure has reinforced the importance of the field of psycho-oncology (Rowland, 1997; Gunnars, Nygren & Glimelius, 2001; Jacobsen, Davis & Cella, 2002). As patient-centred care strategies become the gold standard for cancer services, psycho-oncology and quality of life assessments will presumably grow more consolidated. At the time of writing, these services are offered in many centres across Europe,¹ but the accepted instruments for assessing patients' quality of life – EORTC QLQ-C30 and FACT (Sloan et al., 2006) – are not mandatory, and this vital aspect of care is often relegated to advocacy groups and charities.

4.4.3 Palliative care

The field of palliative care faces similar circumstances to those described for psycho-oncology. Although growing steadily across Europe, the hospice movement is still lacking the explicit financial and institutional support of all but a handful of European countries. Palliative care, like psycho-oncology, addresses quality-of-life concerns, but the field is broader and usually associated with terminally ill patients, although palliative care experts advocate early inclusion in the multidisciplinary team. The two main pillars of this discipline are pain management and psychosocial support for the patient and their family. The former requires optimal identification of symptoms and adequate opioids with which to relieve pain, while the latter is mostly accomplished by training the care team and good articulation and communication among caregivers, patients and families. Palliative caregivers are responsible not only for assuring physical comfort, but also for guiding patients and loved ones through the process of dying and grief. Although differing from psycho-oncology in that it spans all diseases and not just cancer, palliative care is nonetheless overwhelmingly significant in terms of its use as a resource for cancer as opposed to other pathologies.

Care structures are varied in this discipline, with a wide range of possibilities and choices, dependent on the cultural and economic circumstances of the patient and family. Care can be provided in the home (where most Europeans tend to prefer to die), in hospitals, hospices, day-care centres, nursing homes

¹ www.psycho-oncology.net/index

and many options which mix these settings. Similarly, the care team may include oncologists, palliative care specialists, psychologists, faith leaders, nurses, social workers and volunteers. Different countries in Europe have developed these services somewhat haphazardly (Martin-Moreno et al., 2008), without sufficient attention to population needs, highlighting the urgent need for better epidemiological research and evidence-based assessment to guide development and inform decisions.

However, from a policy standpoint, there are several measures which can be taken immediately to ensure high-quality end-of-life care for citizens. The most important measures include providing at least some training for all physicians and health professionals (including primary care practitioners and nurses) and guaranteeing the adequate availability of opioids.

Training is especially important because it gives doctors a better understanding of both physical and psychological symptoms and hence better tools to address them. Most European cancer patients still receive most treatment from their family doctors, even if some treatments are performed by oncologists or other specialists. Thus, while a strong base of palliative medicine specialists is a powerful engine for the overall development of the field, basic training in pain and psychosocial distress management is essential to quickly improve care for European cancer patients. Three levels of training are recommended: one for primary care physicians and nurses, a second for related specialists such as oncologists, and a third for palliative care specialists.

Availability of opioids, including the legal framework to regulate their use, is also important. While most of the main pain-relieving drugs are theoretically available in European countries, bureaucratic entanglements and legal limitations often restrict their use and, as a result, many European cancer patients still die in pain. Laws may include restrictions on where and when an opioid can be dispensed, who can prescribe and receive it (with special licences for physicians and patients), or how much can be prescribed at any one time. The regulations are aimed at limiting abuse and addiction by those who do not need the drugs, but often they result in unacceptable difficulties for dying patients to access essential drugs that they need. These limitations, combined with prejudice on the part of both patients and physicians, lead to poor quality-of-life outcomes for patients, which are easily avoidable.

Until the time of writing, the palliative care field has advanced almost exclusively on a national level, with every country deciding ad hoc how best to approach end-of-life issues within their territory, based on cultural factors, economic capacity and the strength of advocacy from national stakeholders. To date, there has been little support for research, training, or strategic

planning from the EU. However, there are several measures which could be implemented to guide further development without imposing solutions. In addition to supporting horizontal efforts in multidisciplinary training and research across the entire cancer field, including psycho-oncology and palliative care, the EU could actively contribute by formulating standards of care for hospital units, home care, and palliative support care teams. Furthermore, encouraging the adoption of the Budapest Commitments, led by the European Association for Palliative Care (EAPC), could strengthen palliative care policy in many countries in which this field is still poorly developed.

4.5 The challenge of good training: Specialization and multidisciplinary clinical practice

As stated in the previous sections, adequate training is essential for a quality-based approach to cancer management and its components. This is true not only of the clinical disciplines involved in managing cancer but also, to a similar degree, in all those which contribute to overall cancer management and control, including epidemiology and health promotion, as well as rehabilitation. Cancer is too complex to depend only on the current skills of generally trained staff, as these will soon prove to be insufficient to meet all the complexities of cancer management. It is worth noting that professional training and development in cancer management is necessary for all professionals involved in cancer care, which extends far beyond medical professionals at all levels.

Incorporating effective training requires a multidimensional approach to professional education, combining four dimensions of cancer medicine, as described here.

1. *The role of universities as the main seats of education and training in medicine.* The university is the natural focal point for all aspects of cancer information, including training doctors and nurses; providing a setting for research ventures; and acting as an intermediary between policy-makers, industry, hospitals and health care professionals. A vibrant university culture is necessary for any comprehensive cancer plan, and should be strengthened with grants and leadership from both the European and national levels.
2. *The need for clinical experience.* Only a hands-on learning environment gives the adequate competence and clinical excellence needed to successfully manage cancer. Multidisciplinary clinical training in health promotion, screening, diagnostics, surgery, chemotherapy, radiotherapy,

psychosocial care and palliative medicine is necessary to foster true cooperation and comprehension among all team members, including primary care physicians and nurses.

3. *Continuing medical education (CME)*. Medical knowledge is quickly advancing and the need to continually update knowledge to include the most recent findings and experience is vital to the continued development of scientific knowledge in cancer management. Mandatory research programmes for clinicians and courses designed to update knowledge are vital. Experienced physicians are an enormous asset in any cancer management programme, but without the most modern training tools, their years of clinical experience cannot be taken advantage of to the fullest extent possible.
4. *The independence of teaching*. This is one of the cornerstones of independent science and its development, as well as a powerful motor of innovation. Independence can be fostered by offering open-ended or flexible renewable grants, separating (to the extent that it is possible) the vested interests of funding sources from objectives, and fomenting a meritocracy in universities, teaching centres and research institutions.

Like all elements of cancer management, the relevant training should be in line with the needs of the population and should take into account the national structure of education and health care. With this in mind, as well as a holistic, multidisciplinary and multisectoral approach, countries can work on strengthening their professional workforce to deal with the growing cancer burden.

Chapter 5

Research: Finding new solutions for prevention and cancer care

The complexity of cancer requires further innovative approaches to tackle this extremely diverse set of diseases. This goal is complicated by the fact that all the resources necessary to deal with cancer are particularly costly, irrespective of whether the process concerns experts involved in treating cancer, technology invested in screening, genetic testing or the diagnostic and therapeutic set-up of an individual's cancer management programme. Paradoxically, research is both the main driver of cancer cost – resulting from the costs of investigation itself and especially the expense of new technologies and pharmaceuticals which emerge from it (The Economist, 2004) – and the only real means to improve the quality and efficiency of cancer control. Therefore, a serious commitment to tackling the cancer burden will require the allocation of significant resources to cancer research in all its dimensions, both at national and European levels.

Neither Europe nor the individual Member States can afford to pour resources into any area without reflection on priorities. At the time of writing, European cancer research is intensely fragmented in its structures, funding and cooperation. There is an urgent need to articulate goal-oriented strategies to reduce overlaps without sacrificing competition and to fill gaps in research domains that do not receive sufficient attention or resources. Improving information on cancer is essential to assess needs and to identify trends, risk factors and vulnerable populations. Moreover, Europe lacks balanced research aims; plenty of research concentrates on innovative pharmaceuticals and treatments, but other important fields are perpetually underfunded, such as epidemiology, public health and health promotion, psycho-oncology and palliative care, translational research and health systems management (relating

to chronic disease management). Finally, the research community (in both the public and private sectors) needs to increase communication with patients and society, setting ambitious but realistic goals on such key issues as clinical trials and philanthropic support.

Europe has a key role to play in this endeavour – perhaps much larger than in the areas of cancer service delivery or public health. Indeed, Europe is in a unique position to formulate a coherent and flexible structure for cancer research within its territory, while striving to maintain a major strength which differentiates it from, for example, American cancer research – a wide variety of academic structures which favour creative and original approaches to similar problems. Achieving this requires unification at some levels (such as standardized information systems and regulations) and coordination at others (such as funding mechanisms). In this section, we briefly describe the main priorities identified for European cancer research, especially those summarized by Cufer and Sullivan in the FACT book (Cufer & Sullivan, 2008). We also touch on the biggest challenges and opportunities we face at structural, regulatory and funding levels.

5.1 European priorities in cancer research

5.1.1 Cancer registries and information systems

High-quality and evidence-based information on cancer is the first step to successful promotion of all the issues related to cancer, ranging from health promotion, risk reduction or elimination and secondary prevention to effective cooperation in planning disease management strategies, including rehabilitation and palliative care.

Every patient diagnosed with cancer has two crucial questions: “What would be the most effective treatment of choice for my cancer?” and “What are my chances of survival, given the disease stage and the specific cancer characteristics at diagnosis?”

In answering these two questions, the role of epidemiology provided by cancer registries is irreplaceable. The existence of national cancer registries needs to be promoted for several reasons:

- for data collection and production of valuable analyses on national cancer epidemiology – current and projected trends in incidence and prevalence;
- for cancer survival;
- for studies of regional and other differences in cancer incidence;

- for the evaluation of clinical practice and treatment outcomes at the national and local (hospital) levels, whenever applicable;
- as a resource base for studies of the relationship between cancer and exposure to carcinogens in different environments.

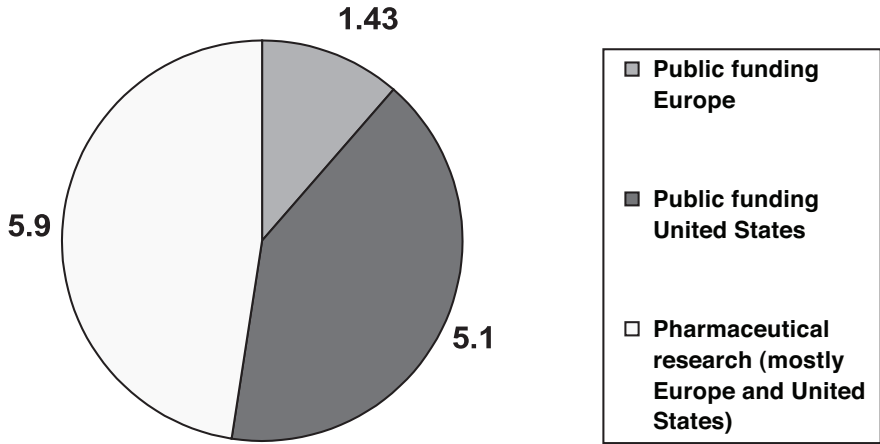
Building a good national cancer registry is a costly investment, but many countries with registries that function well have shown that the registry very soon proves to be a highly cost-effective and valuable investment that cannot be replaced by any other comparable resource. Countries that do not possess any type of organized cancer registry should seek to establish one as soon as possible. This is particularly true for countries with plans to introduce organized screening programmes. Only a fully operational cancer registry can provide adequate evidence for the monitoring of such a programme. Similarly, a functioning cancer registry is also required to monitor a national cancer programme which aims to include different strategies and activities in tackling cancer at the national level (Rachet et al., 2009).

At European level, cancer information systems are equally important, especially if progress is to be made on tracking and reducing inequalities within the EU. The most important elements of this concept are the expansion of territories covered by registries and the unification of criteria used in collecting information. Great strides have been made in both areas. From the public health monitoring programme (HMP) initiated by the European Commission in 1997, EUROCHIP has emerged to track a number of cancer-related health indicators throughout the EU, including lifestyle and environmental risk factors, patient survival, access to screening, treatment and clinical aspects, and socioeconomic variables. The IARC has analysed the quality criteria of cancer registries (Curado et al., 2007) to improve their internal consistency, the histological verification of cancer diagnosis, and the percentage of cases registered by death certificate only (DCO). Finally, the Statistical Office of the European Communities (EUROSTAT) is developing a European Health Survey System (EHSS) to facilitate the standardization of health surveys, ensuring that data (on health problems, status and needs; prevalence of health indicators; health care consumption; and trends) will be comparable across the continent. These endeavours are all crucial to tracking incidence, mortality and survival across Europe.

5.1.2 Balanced research priorities

At the time of writing, European cancer research has less than one third of the public resources of cancer research in the United States. By contrast, a high percentage of financing is provided from the pharmaceutical and health technology industry (Figure 5-1).

Figure 5-1 *Public and private sources of cancer research funding per year in the United States and Europe, in €billions*



Source: Jonsson & Wilking, 2007.

As a consequence, cancer drug output is rising faster than output in other areas: approximately 2000 pharmaceuticals were ready for clinical trials in 2007, and by 2010 projections indicate that this will reach approximately 5000. On the other hand, other relevant fields in cancer care, such as epidemiology, chronic disease management and palliative care lament the fact that insufficient resources are available. It is illustrative to note that in the United Kingdom, less than 0.2% of the public research budget is devoted to palliative care. Similarly, the number of cancer patients participating in clinical trials in Europe is very low. According to the American and Canadian National Cancer Institutes, the figure stands at just 3% worldwide; although no precise figures are available for the EU, this is – in and of itself – an indication of the low priority given to patient participation in most EU countries.

European policies on cancer research provide a very useful platform for financing research efforts. The increased awareness of cancer and its rapidly growing incidence and prevalence further strengthen the arguments in favour of a continued effort at EU level to support diverse research activities relating to cancer. A special need must be noted in trying to balance out the different issues related to the diversity of cancerous diseases. This also includes the relationship between basic and applied research. Because of its nature, cancer needs to be studied through basic research, but applied research is required in translating the basic research findings into practice and monitoring changes in practical situations. The issues to be taken into account are described here.

- Research directed at studying health promotion activities to prevent and reduce the problem of cancer in the future. A special problem in that respect is the issue of measuring the efficiency and efficacy of the promotion activities.
- Follow-up and research of the impact of screening on developments in the epidemiology of cancer; development of new screening tests for cancers, which are currently not amenable to screening; and evaluating the existing screening tests and programmes.
- Clinical research (including clinical trials) is a particular priority as it has immediate relevance for current patients – research should include all aspects of clinical management of cancer in order to support an evidence-based decision-making process at the patient's bedside.
- Research should also cover complementary aspects and concepts that support the implementation of research findings into practice – a particular case is HTA; in itself this also requires further research in order for decision- and policy-makers to be able to make informed decisions based on the state-of-the-art knowledge available in the field.
- Joining efforts between the clinical and research communities on the one hand and the pharmaceutical industry on the other, in order to facilitate a stronger independent research input on the part of the academic community. CCCs could be the key interface in this endeavour (Ringborg et al., 2008a).

To accomplish these goals, it is necessary to strengthen and coordinate (in terms of financing, regulations and structures) European academic research infrastructures. Research from public institutions, especially when interlinked through combined international efforts, is particularly important as it connects basic research findings with practical work and contributes to the independent nature of cancer research. Private research initiated by the pharmaceutical industry plays a vital role in developing innovative treatments for cancer. However, commercial ventures should complement – never replace – independent investigation on the part of public sources. Only by increasing public commitment to cancer research in all its facets will we be able to manage the cancer burden in a comprehensive way.

5.1.3 Disseminating information

In addition to broadening our focus to take a more holistic approach to cancer research, there is a need to broaden our base of public and population support. This implies engaging patients and citizens in the process, disseminating

results to a wide audience, and conducting outreach activities in order to “sell” the importance of cancer research, so that we are prepared as a society for the consequences of the growing cancer burden. This effort will have positive impacts both in the short and long term. Patients and patient organizations who feel informed, with fluid communication channels between them and the relevant health care services and research structures, will be more likely to know about and participate in clinical trials, which will contribute to improving outcomes. Patient satisfaction will presumably rise as well. In addition, support among the lay population (and subsequent pressure on policy-makers) will work towards ensuring sustainable funding for research ventures well into the future. Moreover, approximately a quarter of public European research funding already originates in philanthropic sources; fostering support in the population could help to consolidate and even increase this figure.

There are some concrete measures which could be taken both by Europe as a whole and individual Member States to improve communication and the dissemination of information relating to cancer research. In the United States, for example, the National Library of Medicine sponsors a comprehensive web site in English² for patients and the public, with up-to-date information on virtually all clinical trials in the country, as well as some carried out abroad, including in Europe. A similar structure here, available in the main European languages, would be an excellent step. Similarly, the EMEA maintains a database on current pharmaceutical development clinical trials (EudraCT), but unfortunately this reference resource does not allow access for patients or lay people, limiting the potential for information sharing. Reversal of this policy would be particularly positive for patients and their families. Finally, the results of clinical trials are often published asymmetrically, with a strong emphasis on disseminating only the positive results. Negative results are then published with significant delays, or not at all (Krzyzanowska, Pintilie & Tannock 2003). Some action to correct this has been taken by the International Committee of Medical Journal Editors (ICMJE), which implemented a new policy in 2005 to reject submissions of trial results unless they had been registered in a publicly accessible database at the outset. Reinforcement of this position from national health ministries and regulatory agencies would greatly contribute to expanding access to information for all stakeholders, especially patients.

² www.clinicaltrials.gov

5.2 European research policies and regulations

In order to achieve the goals we have identified, national and European health authorities must pursue actions on three levels: structural, regulatory and financial. While all three of these are intertwined, regulatory mechanisms and policies constitute the foundation, as they actually create the national and international infrastructure for research. At the time of writing, there are both bright spots and shadows in this area, with some very positive, well-planned initiatives, and other less successful and even counterproductive policies which urgently need reform.

Among the positive efforts, one initiative has been the new Paediatric Regulation, which has made a Paediatric Investigation Plan obligatory during the pharmaceutical development process (Dunne, 2007), increasing the incentives offered to the pharmaceutical industry for conducting clinical trials in a paediatric setting. The creation of a European Research Area during the sixth Framework Programme (FP6) also stands out. Both the FP6 and FP7 attempt to correct some of the shortcomings identified in previous iterations, namely the divide between socioeconomic objectives and technical aims. The Innovative Medicines Initiative (IMI) is one positive aspect of this framework, as it fosters public/private partnerships in an effort to produce more independent research. However, other important fields are also in need of support from the FP7, including clinical trials (such as the European Clinical Research Infrastructures Network, ECRIN³), epidemiology (such as the CONCORD Working Group, 2007), prevention (such as the European Prospective Investigation into Cancer, EPIC) and paediatric research (such as Innovative Therapies for Children with Cancer).

Regulatory schemes have not always been so successful. Indeed, European countries offer a blurred amalgam of regulations, directives and laws at the EU, national and even regional levels, requiring a Herculean effort to overcome bureaucratic entanglements in order to carry out cross-border research initiatives. This is especially distressing with regard to rare cancers and small countries, as only transnational exchanges of tissue through biobanks can realistically tackle the investigation of these cancers. The European Data Protection Directive (1995) paved the way with good intentions, aiming to harmonize Member States' use of personal data by imposing protective ethical regulations. However, the result has in fact been detrimental for the research community, with each Member State interpreting the ambiguities of the Directive in a different way and disrupting or impeding

³ www.ecrin.org

the collection of important data (on gender, age, ethnicity and race) which could provide evidence on risk factors without any plausible invasion of privacy (Van Veen, 2008).

The Clinical Trials Directive (2001/20/EC) is another example of what most researchers decry as severe overregulation. Aiming to regulate clinical trials while protecting patients, it imposed stringent rules regarding reporting and monitoring, and fees to be paid to ethics committees and authorities, as well as increasing the related administrative burden. These factors have combined to reduce dramatically the number of clinical trials being carried out, especially in the non-commercial sector. Prior to the implementation of the Directive, clinical trials were steered by the *Guidelines for Good Clinical Practice*, an international quality standard consistent with the Helsinki Declaration and good practice throughout Europe, North America, Japan and Australia. As a European Directive, however, it failed to distinguish between investigations taking place in the private and public sector, leading to a host of complications. This further highlighted the communication gap between policy-makers and the academic research community they regulate and it has caused a rapid deterioration of the clinical trials infrastructure. Reforming the Clinical Trials Directive, this time with the endorsement of the research community, is absolutely necessary to encourage growth in this essential area.

5.3 Funding cancer research in Europe, including at Member State level

As seen in Subsection 5.1.2, Europe lags far behind the United States in public financing for cancer research. The European Cancer Research Managers Forum (ECRM)⁴ tracks expenditure on research, its sources and its output. The data reveal extremely diversified sources of funding in Europe in comparison to the United States, with a decentralized approach within and among Member States. One task would be to coordinate these sources to reduce overlaps and fill gaps. In terms of per capita spending on public cancer research, the ECRM reports that the United States spends nearly €18 per person per year, compared to just €5.79 in the EU25 (countries belonging to the EU before January 2007) + EFTA (European Free Trade Association) (€8.20 in the EU15 – countries belonging to the EU before May 2004). Interestingly, research output – as measured by publications on cancer – tells a different story, with Europe producing 4–5% more publications than the United States since 1997. Europe also publishes more clinical research than our

⁴ www.ecrmforum.org

American counterparts (Mowery, 1998), and trends show a gradual move towards translational studies (Cambrosio et al., 2006). However, the funds allocated to basic research are not matched by funds available for other fields, creating an imbalance which future policy should work to correct – not by decreasing financing for the former, but rather by increasing financing for the latter.

European policy has an important role to play in this endeavour. Recently, the IARC sponsored a 2-year project with the participation of hundreds of cancer experts from all over Europe to assess cancer research activities. EUROCAN aimed to identify weaknesses and propose operational solutions at the European level. The centrepiece of their recommendations was a unified European Cancer Initiative (ECI) which would take advantage of European infrastructures to sponsor cross-border initiatives, including European reference centres (Boyle, on behalf of the EUROCAN+PLUS Study Team, 2008). Of course, policy and funding issues were central to this approach, as they are the two key areas in which policy-makers can make a real difference.

Before 2007, it was debatable whether European sources had a great impact on cancer research within EU Member States. However, the FP7 (2007–2013), with a budget of nearly €6 billion, has a greatly expanded mandate to guide the direction of European research in the future. The key to the success of this initiative lies in the commitment to move beyond joint ventures with industry. Some of these, including the IMI, are very positive for cancer research and subsequently for patients. This type of collaboration also helps to foster transparency and independence in pharmaceuticals research. However, the public sector must also commit resources to tackle cancer control issues which are unlikely to garner profits, including cancer registries, paediatric research networks and health promotion. Indeed, a European Council report (European Commission, 2006b) has already acknowledged the need for European infrastructure funding. The document notes the ease with which European support could bolster existing cooperative structures.

At the Member State level, priorities depend greatly on the circumstances of each country. Clearly, some countries have more resources than others, and when these are scarce, policy-makers rightly focus on investing in cancer services rather than investigation. The Warsaw Declaration (signed both by participants of the Slovenian Cancer Summit in November 2006 and from the ECPC) echoed these priorities. One clear exception, of course, is the absolute necessity to maintain a broad and accurate cancer registry covering as much of the national population as possible.

Other countries seeking to strengthen their research infrastructure should consider investing more funds in public health research on cancer in order to

foster more balance as a whole. This approach would support those activities which benefit the specific situation in a particular country, especially in view of the adaptation of patient pathways and clinical protocols. Some elements of the FP7 could steer this process, such as the Specific International Scientific Cooperation Activities, but the heterogeneity of national institutions and research cultures makes this a decidedly national competence.

Another source of funding which should be taken into account both by Member States and Europe as a whole is charitable donations. At a policy level, it is problematic to consider philanthropy as a static or reliable source due to the inherent and unavoidable fluctuations. As the ECRM has discovered, however, philanthropy is a vital source of funding for cancer research. In many countries, including the entire Nordic region (except Finland), Hungary, the Czech Republic and Italy, charitable organizations devote more resources to cancer research than the governments. While policy-makers should not see this as a reason to allocate less funding from government sources, efforts should be made both to encourage this type of activity (for example, through tax deductions or information campaigns) and to foster real cooperation in terms of scientific collaboration and budget allocations.

In conclusion, the situation of European cancer research illustrates both extremely positive and particularly negative aspects, consistent with the geopolitical, economic and cultural realities of the continent. We have an extremely competent professional workforce, with the ability to produce a large quantity of research output in proportion to the resources invested. Europe also remains an attractive territory for industry investment, and collaboration between public and private enterprise is growing stronger. This will continue to foster a large body of basic research on cancer treatments and diagnostics.

On the other hand, there have been several regulatory and administrative mishaps that have weakened European capacity for clinical research, including cross-border tissue exchange and clinical trials. These bureaucratic obstacles become even more acute within Member States, which have developed institutions and structures at national level, either without EU guidance or with inconsistent interpretations of guidance. The political and social unity of the EU remains a work in progress, so the fragmentary nature of cancer research is not unexpected, but it nonetheless needs to be addressed. Furthermore, Europe should take advantage of the opportunity it has within the context of the FP7 to bring coherence to the cancer research paradigm, assessing the areas that are in need of the most stimulus and identifying where transnational commonalities and differences can be exploited.

Chapter 6

Recommendations and conclusions: Establishing a road map for National Cancer Control Plans

The complex task of integrating the many disparate and connected elements of cancer care can only realistically be accomplished with a structured approach to the disease as a whole. In recent years, NCCPs have emerged as the most common strategy to address cancer issues. The first attempt to formulate a coherent approach was the United Kingdom's 1995 policy framework, which was successful at bringing cancer issues to the forefront of political and institutional action. Since then, at least 19 national plans have emerged, proving that this strategy has already been widely accepted as effective.

However, great heterogeneity can be observed in both the planning and the implementation of these plans (Atun, Ogawa & Martin-Moreno, 2009). This is partly due to cultural, economic and political variables in each country, but it indicates a need for an EU-wide framework for strategic analysis of cancer services and for the development of cancer plans. A comprehensive framework for cancer control is necessary at the national level. This is true also in countries in which there is no consensus in favour of a national cancer plan. Such a framework should aim first to improve outcomes for patients, combining the vertical elements of cancer care which have been covered in this report, as well as the horizontal health systems elements that will ensure its success (governance, financing, resource generation and service delivery). The broad lines of this approach are summarized in Table 6-1.

Table 6-1 *Horizontal and vertical elements in cancer control health policy*

↓ →	Governance	Financing	Resource generation	Service delivery
Primary prevention	Authority responsible for planning, implementing and evaluating effectiveness of services; multisectoral cooperation with other ministries or authorities	Specific revenues generated and reserved for each service identified in planning stage	Issues of training and provision of material resources (facilities, equipment, etc.), including distribution at regional/local/centre levels	Inventory of specific, evidence based services required (and where)
Secondary prevention (screening)				
Integrated care				
Research				

Source: Authors' own compilation.

6.1 The four pillars of cancer care

The bulk of this report sets out the evidence base and detailed concept of improving cancer care based on four pillars (tackling both primary and secondary prevention, as well as integrated care and research). The consultation process led by the Slovenian Ministry of Health has cemented our conviction that elements from all of these areas must be included in cancer policy in all Member States if we are to address the increasing cancer burden adequately while increasing health equity within our borders.

Primary prevention. At the national level, measures should include (a) integrating cancer prevention into public health and health promotion activities; (b) implementing lifestyle interventions, such as the FCTC and the Global Strategy on Diet, Physical Activity and Health; (c) encouraging use of the ECAC in multiple settings across sectors (health, education, labour, and so on); and (d) exploiting other population-based measures, such as HPV vaccination, to reduce incidence.

Secondary prevention. National, population-based screening programmes should be in place for breast, cervical and colorectal cancer. These should be evidence based and accompanied by the appropriate awareness campaigns, especially targeted towards the most vulnerable populations.

Integrated care. The priorities in this area should be geared towards ensuring access and quality with a multidisciplinary approach, including special efforts towards training professionals at all levels of care (primary, secondary and tertiary). Specific areas such as psycho-oncology and palliative care, which have historically been neglected, should be given appropriate attention.

Research. All countries should invest in modern cancer registries that cover the largest territory possible. Without this key foundation, further epidemiological and public health research to track incidence, survival and the results of national health policy will be ineffective. Countries with vibrant research cultures, or those developing new programmes, should seek balance in funding mechanisms that ensure a holistic approach, with special attention to non-commercial areas such as public health and health policy, psychosocial and palliative care, and translational research. Bureaucratic and administrative obstacles should be identified and minimized.

6.2 Horizontal issues to consider

Like all health policy management, proper attention should be paid to health systems functions. Formulating a plan to address the four pillars of cancer control is positive, but without the mechanisms to implement, carry out, monitor and evaluate activities and results, goals will not be achieved. The elements detailed here, grouped by the health systems framework functions, should be considered.

- *Governance/Stewardship*

Leadership. Experience in the United Kingdom and France has shown that a specific body or person should be responsible for managing the plan. This reduces fragmentation, favours the selection of qualified staff and increases accountability. It is important to involve community leadership in this endeavour, engaging local stakeholders – including doctors – in individual programmes and centres. An inclusive process will ensure that all points of view are considered and transparency is fostered.

Multisectoral action. The leaders of the national cancer plan should actively seek collaboration with other sectors, including education, urban planning, and industry and labour. This public health approach is especially important for primary and secondary prevention activities, but it also helps to build general community participation in cancer issues.

Benchmarking. This is an instrument that can be useful in comparing the effectiveness of different staffing or equipment arrangements and in evaluating the performance of cancer centres.

Targets. These should be used sparingly, and always in selected areas that address specific problems, such as waiting times or quality-of-life issues. The more specific the target, the easier it will be to address: for example, reducing mortality is the effect of multiple and interrelated policies, while improving

quality of life for patients is possible through a few selected measures (training courses for personnel, psychological assessment of patients and access to psycho-oncology or palliative care staff).

Monitoring. Evaluating population-based information, such as incidence, mortality and survival trends, is required to assess the overall success of cancer programmes and the performance of specific hospitals; well-designed cancer registries are essential for this.

Peer review and accreditation. This process can provide valuable lessons and maintain high standards of care, exposing problems and acting as a constructive force to optimize performance.

- *Financing*

If the NCCP is to be feasible, proper financing mechanisms must be in place. It is important to specify where the funds go, making sure that all required services have the proper resources to function optimally. Limiting discretionary funds will increase accountability and transparency. On the other hand, some flexibility is appropriate for costs that might emerge. Innovative medicines and diagnostic techniques are a good example, as they are expenses that cannot be precisely predicted. In an ongoing project that has been submitted for publication, Atun and colleagues analyse European NCCPs, discovering that the financing aspect is particularly weak, with only four countries (Belgium, England, France, and Poland) (from a spectrum of 19) that allocate specific funds for their NCCP (Atun, Ogawa & Martin-Moreno, 2009).

- *Resource generation*

Four types of resources should be explicitly allocated for the plan, in line with national needs and priorities.

1. **Human resources**, properly trained and distributed across the territory.
2. **Physical resources**, including equipment, facilities and pharmaceuticals.
3. **Information resources**, including access to research and evidence-based guidelines for practice and treatment.
4. **Social resources**, such as long-term community support.

- *Service delivery*

Implementation. Specific structures should be in place to oversee and manage the implementation process, with attention to transparency and clearly defined responsibilities at all levels, including for service providers.

Service delivery is the culmination of the health system's activities and the most visible face of cancer care for patients and citizens. However, its success in achieving effective cancer management for patients and cancer control for society is closely related to the health systems infrastructure which supports it (financing and resource generation) and above all the stewards who oversee it.

6.3 The role of Europe in supporting National Cancer Control Plans and cancer management in Europe

The EU health strategy represents an excellent opportunity to implement many of these principles, which are not limited to the problem of cancer. The comprehensive nature of the EU health strategy offers the necessary space and momentum to enhance the development of Cancer Plans. We can learn from past experience, when these plans did not develop as intended. The most important problems were in the lack of commitment and the lack of appropriate monitoring mechanisms, which might have steered the implementation of a plan so as to avoid inadequacies. In the future, greater commitment to implementation must be founded on explicit ground rules that ensure ethical principles and aim for health equity. These precepts will, in turn, underpin the planning of research and development activities and reinforce an open and transparent model of operation. Optimal coordination should be a fundamental element, not only for national actions, but also in the sphere of the EU.

In its Conclusion of June 2008, the Council of the European Union endorsed many of the recommendations that emerged during the Slovenian Presidency. Several measures were mentioned that could contribute to improving cancer control and supporting NCCPs at the European level (Council of the European Union, 2008). The first of these was the Conclusion itself, which encouraged Member States to develop comprehensive NCCPs. It also invited the Commission to maintain support for research structures and develop infrastructures for information exchange, including HTA and related public health and health policy investigation. The European role in quality standards was also highlighted; the EU is the only political body with the necessary legitimacy to formulate accreditation schemes and clinical guidelines for screening and treatment that would be accepted throughout the continent. Perhaps most importantly, the Council encouraged the Commission to develop an EU Action Plan on Cancer. This document would establish a framework for national cancer plans which would include all aspects of care (from prevention to palliative care and rehabilitation) integrated in coordinated multidisciplinary action.

The body of work on European cancer control continues to grow, advocating patients' rights and the pursuit of excellence in the care of cancer patients. Throughout this endeavour, the same themes emerge that somehow characterize the EU as a whole, for better or for worse. Europe is heterogeneous, with diverse health care structures that favour innovation but also foster inequality. We strive to uphold the basic principles of solidarity and we are intrinsically opposed to inequities in health, yet we remain competitive, and reluctant to prioritize European development over national development. United but separate, we take part in a constant tug-of-war in various policy areas, including cancer control policy. However, the tendency in Europe (slow and halting, but never stopping completely) is to increase cooperation, as we have learned that division brings no benefits.

The cancer control activities carried out under the auspices of the Slovenian Presidency have shown that, by cooperating, we can in fact formulate a coherent plan to reduce the cancer burden. Our next challenge will be implementing that plan, together, to achieve more tangible results both for European citizens who want to prevent cancer and for the many patients who suffer from it.

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This report summarizes the main conclusions and policy lessons arising from the cancer control activities held under the Slovenian Presidency of the European Union in 2008.

Key evidence from these activities was reflected in two publications: *Responding to the challenge of cancer in Europe* (published by the Slovenian Institute of Public Health) and a special issue of the *European Journal of Cancer*. To enrich the final synthesis, ideas that emerged from the policy dialogues, conferences and workshops that were held under the Slovenian Presidency have also been included.

The cancer control approach endorsed by participants rests on four main pillars of action: primary prevention, secondary prevention (screening), integrated care and research.

This policy summary has been produced under the Fighting Against Cancer Today (FACT) project. FACT is co-funded by the Government of Slovenia and the European Commission's Health and Consumer's Protection Directorate, with additional support from the European Observatory on Health Systems and Policies.

ISBN 961-6659-52-9



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