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# Improving cancer control in the European Union: Conclusions from the Lisbon round-table under the Portuguese EU Presidency, 2007

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ABSTRACT

Cancer is a major cause of morbidity and mortality in the European Union (EU), and a public health burden. Improving cancer control in the EU will require implementation of efficient strategies within Member States and better policy coordination between them. In cooperation between the rotating EU Presidencies of Germany (2007), Portugal (2007) and Slovenia (2008), special attention was devoted to an integrated approach to cancer control in EU policies and programmes. A round-table focussed on national cancer plans, population-based cancer registries and cancer screening programmes was held during the *Health Strategies in Europe* meeting in Lisbon in July 2007, under the Portuguese Presidency. These three topics were selected as critical for improving cancer control at both national and European levels. The round-table was designed to produce a set of recommendations to inform EU cancer policy. This paper provides a résumé of the conclusions and recommendations, to stimulate wider discussion and policy development.

The conclusions of the meeting were presented at the Employment, Social Policy, Health and Consumer Affairs Council in December 2007 and cancer was included in the Council Conclusions for the new European Health Strategy. Success in cancer control will require consistent attention from future EU Presidencies, such as the initiative of the Slovenian EU Presidency in early 2008.

## 1. Introduction

Germany, Portugal and Slovenia have collaborated on an 18-month health policy programme during their consecutive 6-month Presidencies of the European Union (January 2007–June 2008). Special attention has been given to improving EU policies and activities on cancer control. A round-table on cancer was included in the *Health Strategies in Europe*

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meeting in Lisbon in July 2007, under the Portuguese Presidency.

The Lisbon round-table was designed to advance European policy for improving cancer control, treatment and care in all EU member states. Cancer will be the main health topic of the Slovenian Presidency, in the first half of 2008. It was considered important to establish continuity with future EU Presidencies, in order (a) to ensure that progress in cancer control in the European Union comes under active surveillance, (b) to develop cancer control strategy in the EU, and (c) to make cancer control strategy a standing item on the EU health agenda.

The main conclusions of the round-table were that cancer must be recognised as a European public health priority, and integrated into wider European public health strategy. Improving cancer control in Europe will require sharing of expertise and best practice, continuous dialogue among all involved parties and better coordination of health policies between Member States.

We present the background, conclusions and recommendations of the Lisbon meeting, and its outcome in the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council in December 2007, to stimulate further discussion and policy development.

## 2. Background

Cancer is one of the major causes of disease and death in Europe. An estimated 3.2 million people were diagnosed with cancer in 2006, and there were 1.7 million cancer deaths.[1] The annual number of new cases has increased by 300,000 since 2004. Ageing of the European population will cause these numbers to increase still further over the next few decades, even if the chances of being diagnosed with cancer at each age do not continue to rise.

European institutions have collaborated in many cancer control initiatives in the last few decades, keeping cancer high on the European health policy agenda[i]. Despite considerable progress, cancer remains a huge public health challenge. It affects millions of individuals, their families and society at large, and it places a huge and growing burden on national health care systems in both human and financial resources.

Inequalities in cancer incidence, mortality and survival among EU Member States represent a major health challenge in their own right. Cancer mortality is rising in most of the ten Member States that joined the EU in 2004, and trends in survival have generally been less favourable than in the rest of the EU.[2–4]

Cancer is a complex health problem: it requires multi-disciplinary approaches that range from health promotion and prevention to screening, diagnosis, treatment, rehabilitation and palliative care. Strategic action is still required in most EU Member States to develop or improve national cancer control plans, mass screening programmes and population-based cancer registries, all of which play a key role in cancer control.

The EU recently expanded from 15 to 27 Member States. Reduction of avoidable inequalities in life expectancy, in health status and in access to high-quality health services will contribute to the development of a more cohesive Europe.[5] In the name of solidarity and equity, it is essential that all Europeans have the same opportunities to access services for cancer prevention, screening and treatment, to reduce the risk of developing cancer and to improve survival, mortality and the quality of life for those who do develop cancer.

The objectives of the Lisbon cancer conference were (a) to discuss the most effective approaches for developing national cancer plans, population-based cancer registries and cancer screening programmes, in order to foster cancer control, reduce inequalities in health and in healthcare, and promote solidarity among EU Member States; (b) to ensure that progress in cancer control becomes a regular item on the agenda of every EU Health Ministers meeting, and (c) to contribute to the development of an overarching strategic framework for health gains in Europe.

Brief overviews of national cancer plans, cancer registries and cancer screening programmes were drafted by the authors, with recommendations for EU health policy. The three drafts were revised by *rapporteurs* at a meeting in London in May 2007. Some 40 cancer specialists across Europe were then invited to comment on the drafts, and on a résumé of cancer control structures in Europe. At the round-table in Lisbon[j], an overview of the cancer burden in Europe was followed by presentations on cancer plans, cancer screening and cancer registration. Each topic was actively discussed in a plenary session by more than 80 cancer experts from 16 EU countries, with representatives from international organisations[k], health ministries and national cancer authorities of EU member states. The three documents and draft recommendations were amended in the light of the discussions and reviewed by the authors at the conference. Finally, the conclusions were posted on the web for further consultation and comments from participants. The following recommendations were proposed as a result.

## 3. Cancer plans

The cancer burden can be influenced by interventions of all kinds, from primary prevention to end-of-life care. It is an ex-

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[i] Among others, these include the Europe against Cancer programme (1987–2002), the European Network of Cancer Registries (1989–), the EUROCARE studies (1989–), the Charter of Paris against Cancer (2000), the EUROCHIP Network (2001–), the European Code against Cancer (1994), the European Council Recommendation on Screening (2003), the European cancer network (2003–), EUNICE (2003–), the EUROCAN+Plus Project (2005–2007), the Eurocadet project (2005–), the European Alliance Against Cancer (2005), the WHO resolution on Cancer and Global Cancer Control Strategy (2005), the WHO Framework Convention on Tobacco Control (2005), the Warsaw Declaration on Cancer (2005) and the statement issued by the Members of the European Parliament's MEPs Against Cancer group (2005).

[j] More information on the round-table (agenda, presentations, list of participants) can be found at: http://www.acs.min-saude.pt/2007/12/18/health-strategies-in-europe-workshop-sobre-cancro?r=16

[k] European Cancer Patient Coalition (ECPC), European Commission Health and Consumer Protection Directorate-General (DG SANCO), European Society of Medical Oncology (ESMO), International Agency for Research on Cancer (IARC), World Health Organisation (WHO).

tremely complex social undertaking to organise and deliver public health programmes that are designed both to reduce cancer incidence, with preventive services, and to improve cancer outcomes and reduce cancer mortality, with clinical services. It involves a wide range of professional expertise, and input from organisations at all levels within the health system.[6] Relevant outcomes include incidence, prevalence, survival, quality of life (reflecting morbidity both from the disease and its treatment), and patient satisfaction with the care they receive and their experience of that care.[7]

There is good evidence that significant European variations exist, both in outcomes and in the delivery of services.[8,9] International differences in the adequacy of cancer control may reflect past decisions on funding, policies for prevention or screening, and the availability of, and access to, interventions for the investigation or treatment of cancer. Important unexplained variations in service delivery remain between and within countries in different healthcare settings, which are often reflected in the quality of care given to individuals. These differences require research to identify both the causes and the necessary remedial actions, including appropriate investment both in resources and training.

There is growing evidence from epidemiological studies about the relationships between the structures and processes of service delivery and outcomes. Cancer outcomes could be improved in all or most countries if the entire range of activities and services for cancer were performed at anywhere near the levels achieved by the better health systems.

### 3.1. *The basis for action*

We know from research and from the opinion of experts and patients that the following provide a sound basis for action:

- All populations need an effective, integrated cancer plan for prevention, screening, early diagnosis and treatment, as well as research: these are vital if we are to achieve long-term reductions in cancer morbidity and mortality.[10]
- People who may have cancer need prompt access to appropriate specialists for accurate diagnosis and subsequent management. A multidisciplinary approach to cancer care is required to make the best decisions about each patient's diagnosis, treatment and support.[11,12]
- Complex interventions for diagnosis or treatment should be concentrated where all the necessary expertise can be assembled cost-effectively and the results audited consistently.[13–15]
- Services for diagnosis and treatment are found at primary, secondary and tertiary care levels. Most cancer patients will need care at each of those levels. Ways must be found to ensure that all parts of the service are developed logically, that they communicate effectively, and that care for the patient is well coordinated.
- The value attributed by patients to the different therapeutic options and the expected outcomes should be considered in the clinical decision-making process.[16] Quality of life and psychosocial issues need to be addressed at all stages in the cancer pathway.[17] The specific needs of long-term survivors must also be considered.[18]
- Patients' involvement in the management of their disease increases their satisfaction with care and their partnering in strategic planning assures that their expertise and needs are included.[16]

A number of EU Member States have implemented - or are in the process of developing - a national cancer plan (or regional plans) as a strategy to raise the profile of cancer and to manage the developments required to improve cancer control. Progress will require systematic assessment of the operational strengths and weaknesses of all cancer services. The results of such an assessment must be used to identify specific priorities - and the necessary resources - in order to highlight areas for improvement and to address weaknesses. WHO has developed guidelines for the development and implementation of cancer plans,[10] and these guidelines could be used as a reference.

## 4. Cancer registration

Population-based cancer registries collect data on all new cases of cancer occurring in a well-defined population, with the goal of improving cancer control. By 1955, cancer registries were operational in England, Germany, all five Nordic countries and Slovenia. Elsewhere in Europe, cancer registration started in the 1970s or later, with regional registries covering usually about 30% of the national population, though less in Eastern European countries.[19] Today, 15 of the EU-27 Member States have national cancer registration coverage, and eight have regional coverage. Various bodies provide national, regional and Europe-wide coordination.[20–23]

Two main roles can be described for population-based cancer registries.

### 4.1. *Measuring the burden and the public health impact of cancer*

The minimal role of any cancer registry is the provision of timely and robust data on cancer incidence, survival and prevalence.[21] Many registries also analyse cancer mortality. The European Network of Cancer Registries has developed recommendations for the standard data set to be routinely recorded for all cancer patients,[20] while additional data, such as details on treatment, quality of life, hospitalisation or average cost per case are optional, and are usually restricted to representative samples of registered cases.

The two main strategies for cancer registration (national registries in Northern Europe, networks of regional registries in Southern Europe) seem unlikely to change. Eastern European countries that do not already have national registries may opt for the regional rather than the national approach because of limited resources. Good statistical techniques are now available to obtain national estimates of cancer incidence, prevalence and survival from networks of regional registries.[1]

A number of cancer registries in EU Member States already contribute to the efficient evaluation of screening programmes.[21] Others could do so by providing the following data:

- early indicators: screen-detected incidence as a proportion of general population incidence, number of interval cases, follow-up of cases after migration or lapsed attendance at the screening programme
- impact indicators: down-staging of incident cases; reversal of the initial prevalent wave of cases after the introduction of screening; trends in mortality and survival among screened subjects and the general population[24,25]

### 4.2. *Cancer survival*

Cancer registries can also provide data on population-based survival.[3] Survival patterns and trends by age, geography, socio-economic status (etc.) can provide useful indicators of the overall performance of a nation's health system. Detection of survival that is too low should stimulate more in-depth studies to determine whether this is due to late diagnosis or to inadequate availability of (or poor access to) effective treatment.[26–28]

These activities are sufficient to justify the establishment and operation of a cancer registry or network of registries in any country. Cancer registration is not an expensive activity, but the benefits of national investment in the human and capital resources required can be further enhanced by the role that registries play in basic, epidemiological and clinical research, through bio-banks, aetiological research, and studies of molecular or genetic epidemiology and the quality of life.'

### 4.3. *Constraints on cancer registration*

Over one hundred cancer registries operate in Europe today, playing a key role in public health. Yet in several EU Member States, severe constraints on registry operation have been imposed by statute law or professional regulations. These constraints were intended to improve patient confidentiality, but in each case they failed to take account of the public health impact. Such constraints caused the closure of several cancer registries in the former West Germany (1991), former East Germany (1991) and Hungary (1992), and very nearly did so in the UK (2000). Constraints have also prevented some registries from linking death certificates with cancer records. In Estonia, this has created an absurd paradox: cancer registration and death registration are both statutory, but cancer survival analysis is illegal.[29]

Statutory support for cancer registration in all Member States would remove legal constraints in the wider public health interest. It would facilitate harmonisation of cancer registry procedures across Europe. It would also facilitate monitoring the progress of cancer control in Europe.

## 5. Cancer screening

The ultimate purpose of cancer screening is to reduce cancer mortality, and to reduce the incidence of disease that is too advanced for curative treatment, thus improving the quality of life. The basic approach is early detection of disease that is not yet clinically detectable.

Screening has been shown to reduce cancer mortality in regional comparisons for cervical cancer (with the cervical smear or Pap test),[30] and in randomised controlled trials for breast cancer (mammography)[31] and colorectal cancer (faecal occult blood or FOB test).[32] Reductions in mortality of the order of 25% can be envisaged for breast and colorectal cancer, and up to 75% for cervical cancer. Up to 50,000 cancer deaths could be prevented in the European Union each year by effective screening for these cancers. Routine public health implementation of cancer screening is effective, but evaluation is more difficult.[33]

This summary focuses on the public health aspect of cancer screening programmes. A mass screening programme must be seen as a linked chain of actions, from identification and invitation of the target population (especially lower socio-economic groups), to the more successful treatment of cancer patients because they are detected at an earlier stage by the screening test. The overall effectiveness of a screening programme is determined by the weakest link in the chain. Routine evaluation of each step is therefore crucial in order to demonstrate effectiveness at the population level.

Organised screening programmes are likely to be more effective, to provide more equal access and to produce less harm and lower costs than spontaneous (opportunistic) screening. Mass screening programmes can be more thoroughly evaluated than spontaneous programmes and, if ineffective, they can be stopped or changed more easily. Thus mass screening for neuroblastoma in Japan was shown to be ineffective,[34] and it was stopped.[35] Such evaluations have also shown that for cervical cancer, less intensive screening for a broader age range is more cost-effective, and causes less harm.[36]

The decision to start a routine mass screening programme should be based on evidence of its predicted health benefits at a population level. Only cervical, breast and colorectal cancer screening meet this standard at present. It is crucial to predict the effects, side-effects and costs of such a programme in the specific country or setting before screening is implemented.

It has been shown that indirect or non-experimental evidence of the efficacy of screening is often misleading, due to a wide range of biases. Randomised controlled trials are under way in Europe to establish whether screening for prostate cancer[37,38] or lung cancer in high-risk subjects[39] may lead to important health benefits, especially a reduction in mortality. The results of those trials should be awaited before any decision is made to implement screening for lung or prostate cancer.

Ideally, an organised screening programme should be prepared in such a way that continuous evaluation is possible during the implementation phase, including compliance with the invitation, efficiency of referral for further investigation, sensitivity of the programme and its effectiveness in reducing cancer mortality. Attention should also be given to informing eligible persons invited for screening about both the favourable and unfavourable effects anticipated from screening, so that they can make an informed choice.

### 5.1. *Recommendations*

#### 5.1.1. *Cancer plans*

1. EU Member States should develop (or continue to improve) their cancer planning, using an integrated approach and evidence-based strategies in each of the following domains:

- Primary prevention and screening programmes
- Rapid access to diagnosis and multidisciplinary clinical care, using the full range of appropriate therapies
- Focus on patients' needs and inclusion of their preferences in management of their disease
- Coordination of cancer care throughout the process from diagnosis to therapy, including palliative care
- Concentration of diagnostic and therapeutic procedures of low frequency or high complexity in clinical services with an adequate caseload, to maintain quality, with regular audit of results
- Adequate management of patients' quality of life and provision of psychosocial care services
- Use of existing treatment guidelines
- Involvement of cancer patient organizations in strategic development and evaluation of the plan
- Evaluation of cancer outcomes
- Ensure support for research
- Ensure support for training of healthcare professionals
- Evaluate the performance of the plan itself

### 5.1.2. *Cancer registration*

2. Cancer registries should contribute to evaluating the impact of cancer prevention, screening and treatment programmes
3. The EU Directive (1995) on data protection should be updated explicitly to enable population-based cancer registration.
4. The EU should recommend that all Member States make cancer registration a statutory requirement, to protect a key public health instrument for the evaluation of cancer control, including incidence, screening and survival.
5. EU-wide standards should be defined for the minimal and optimal sample size and design for establishing cancer registration in countries where it is currently absent.

### 5.1.3. *Cancer screening*

6. Nationwide screening programmes should be implemented in timely fashion for breast cancer in women aged 50 and over, for cervical cancer in women aged 30 and over, and for colorectal cancer in persons aged 50 and over.
7. Nationwide screening programmes should not be implemented for other cancers unless and until the evidence is strong.
8. The public health effects of a screening programme, and its costs, should be carefully predicted before screening is implemented, and the programme should be continuously evaluated after implementation.
9. Opportunistic screening should be discouraged.

## 6. Summary and conclusions

Not all EU Member States have a national cancer plan, or a population-based cancer registry, or mass screening for cancers of the breast, cervix and large bowel. Member States that do have one or more such programmes still need to improve them in a number of areas.

All populations need an effective, integrated cancer plan for prevention, screening, early diagnosis and treatment of cancer, as well as cancer research. These activities are vital if we are to achieve long-term reductions in cancer morbidity and mortality. EU Member States should develop (or continue to improve) their cancer planning, using an integrated approach and evidence-based strategies on a number of domains.

A cancer registry provides timely and robust data on cancer incidence, survival, prevalence, mortality and the efficacy of screening, and can play a key role in basic, epidemiological and clinical research. EU Member States should make cancer registration a statutory requirement, to protect and regulate this key public health instrument for the evaluation of cancer control.

There is evidence that cancer screening reduces mortality for cervical cancer, breast cancer and colorectal cancer, but not yet for other cancers. Nationwide screening programmes should be implemented in timely fashion for those cancers.

The conclusions of the Lisbon cancer round-table were presented to the EU Member States at the Employment, Social Policy, Health and Consumer Affairs Council (EPSCO) meeting in December 2007, as part of the conclusions of the Lisbon meeting on *Health Strategies in Europe* organised by the Portuguese Presidency in July 2007. These conclusions contributed to shaping the European Commission's White Paper *Together for Health: a strategic approach for the EU, 2008–2013* and developing an EU Health Strategy, which was approved by the Council of the EU (EPSCO Council–Health) and thus became the first EU Health Strategy. The Council Conclusions stressed the need for development of a new European strategy to tackle the major communicable diseases and to prevent non-communicable diseases, including cancer.[40]

Some progress has been made - but the European Commission will need to develop and implement a comprehensive strategy for cancer control, prevention and care, to promote health, to ensure access to high-quality health services in all Member States and to reduce inequalities in life expectancy. Success in cancer control will require consistent attention from future EU Presidencies, such as the initiative of the Slovenian EU Presidency in early 2008.[41]

## Conflict of interest statement

None declared.

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