

European Partnership for Action Against Cancer  
Joint Action

# CONFERENCE BOOK

Open Forum Madrid, 14 & 15 June 2011

Spotlight on Cancer Healthcare & Cancer Research (Work Packages 7 & 8)  
Hosted by the Spanish Ministry of Health, Social Policy and Equality



This conference book arises from the European Partnership for Action Against Cancer Joint Action, which has received funding from the European Union, in the framework of the Health Programme.





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Dear Readers and EPAAC Stakeholders,

Firstly, I would like to thank you for taking the time to read through the electronic conference book of the first Open Forum of the European Partnership for Action Against Cancer (EPAAC).

The Open Forum took place on 14 and 15 June and was hosted in Madrid by the Spanish Ministry of Health, Social Policy and Equality. It was a success, with participants spanning EPAAC associated and collaborating partners as well as other stakeholders in the cancer field. The themes of this Open Forum were Cancer Healthcare and Cancer Research, corresponding to Work Packages 7 and 8 of the EPAAC Joint Action.

This aim of publishing this e-book is so that all stakeholders who missed out on attending the Open Forum in person could be updated on the interesting presentations made and debates held, as well as get the opportunity of viewing the insightful posters that were also displayed there. I trust that this e-book will serve its purpose of updating you on the progress of the EPAAC Joint Action thus far. We look forward to hearing your comments and hope you will be able to attend the next EPAAC Open Forum in Rome in June 2012.

Marija Seljak  
Director, National Institute of Public Health

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# SUMMARIES

## PLENARY SESSION ON RESEARCH

ANNA ROUILLARD

Lack of coordination in cancer research at the EU level and amongst Member States has led to duplication of research efforts as well as to the creation of gaps that severely limit Europe's overall progress in the fight against cancer. A major bottleneck at European level is the lack of coordination and critical mass required to rapidly implement new discoveries into clinical applications. There is an urgent need to improve coordination of cancer research across Europe and in particular to identify gaps in the cancer continuum, as well as to highlight areas where further research is needed.

*“There is an urgent need to improve coordination of cancer research across Europe and in particular to identify gaps in the cancer continuum, as well as to highlight areas where further research is needed.”*

At the Open Forum, various key stakeholders were invited to present their views concerning the challenges ahead for coordination of cancer research within the European Research Area, with a focus on various instruments for coordination of funding and on the perspectives and expectations of stakeholders from the EPAAC partnership and beyond, including patients, industry and the European Commission.

The various instruments currently available for research coordination were presented, analysed with respect to the extent to which they serve the purposes of the respective projects, their shortcomings and their positive impacts on the research areas themselves.

One model for coordinating national programs through co-funding of joint calls for proposals is the **ERA-NET**. Another coordination structure is the **Network of Excellence (NoE)**

model, involving the implementation of a Joint Programme of Activities between research organizations willing to sustainably integrate a substantial part of their activities. There is no direct funding for research through this model, which, while stimulating co-funding, fundraising and collaboration, has been a major hurdle to the success of the instrument together with a lack of support for sustainability.

**Collaborative Projects** including Large-Scale Integrating Projects are objective-driven research projects co-financed by the EU, aiming at developing new knowledge, new technology, products etc. Possible improvements to the funding model could include co-ordination with national funding agencies, long-term investment in integration, and a focus on education and training.

Speakers pointed out that in some cases there is a need for collaboration beyond Europe, as is the case in research into numerous rare diseases, where there is a lack of patients in Europe to successfully perform research. Furthermore, collaboration between individual research groups may no longer be sufficient. Rather, bringing together Cancer Centres and basic/preclinical cancer research centres to guarantee the necessary infrastructure, expertise and resources as well as improving coordination are key to achieving momentum.

There was consensus that a global coordination strategy should be as inclusive as possible, and in particular involving patients through cancer leagues, patient organizations and patient support groups. New public-private partnerships should be explored with industry, while ensuring to build on previous mapping exercises and ensure open consultation.

# SUMMARIES

The panelists provided their views and recommendations on innovative partnerships towards coordinating cancer research at EU level, including the following (non exhaustive list):

- Address CT issues and opportunities
- Develop innovative access schemes (risk sharing)
- Address inequalities
- Build on research priorities and previous mapping exercises (both at national level - through cancer control plans- and European level)
- Exploit potential of Centres of Excellence/ Reference networks
- Standardize funding processes
- Coordinate infrastructure support and research
- Develop common research programs on 'omics' and data analysis at EU level
- Promote collaboration between Comprehensive Cancer Centres and basic research centers to structure translational cancer research
- Include prevention and social science in research priorities
- Integrate clinical cooperative groups at EU level
- Develop academic clinical trials based on the US CTEP public-private partnership model
- Focus on education and training

*“There was consensus that a global coordination strategy should be as inclusive as possible, and in particular involving patients through cancer leagues, patient organizations and patient support groups.”*

Further areas of research that may benefit from coordination at the European level will be gathered from the basic research community, the clinical community, the European Academy of Cancer Sciences, the epidemiology community, industry/SMEs and patient organisations through a questionnaire that is under preparation as part of the Work Package. Furthermore, the respondents will be asked to specify which models of collaboration would

be most useful for their prioritised areas. Based on the results of this questionnaire, a second questionnaire will be prepared, this time addressed to funders and industry, to present areas considered beneficial for collaboration and to ask for their opinions on the best and most appropriate ways of funding them.

# SUMMARIES

## PLENARY SESSION ON HEALTHCARE

JOSEP M. BORRAS

The Work Package 7, Health Care, organized a session in the Open Forum of the European Partnership Action Against Cancer (EPAAC). Presentations were made in two different panels, the first being Organisational Perspectives in Cancer Care, the second, From Diagnosis to Therapy, How to Improve Outcomes of Care.

The first plenary session began with a presentation made by Anita Margulies from the European Oncology Nursing Society (EONS) on the Challenges of implementing clinical guidelines in daily practice. In her presentation, the advantages of clinical guidelines as well as the barriers for implementing them were discussed using cancer nursing care as an example. EONS will lead the project in this WP7 on putting evidence into practice, which was described in the session, with several examples of the assessment of the evidence and recommendations.

The perspectives posed by the management of cancer patients in hospitals were presented by Pascal Garel. He showed data demonstrating clear differences in the management of cancer patients across European health systems and described the new perspectives for cancer management due to the consideration of cancer as a chronic disease and the implications of the need for a multidisciplinary approach in cancer care.

The Standards of care for children are a project developed under the leadership of the International Society of Paediatric Oncology (SIOPE), which was presented by Professor Jerzy Kowalczyk. The need for this project was explained using Polish pediatric oncology as an example. The consensus developed around the standards of care was presented, which is aimed at improving the equity of access to a high level of quality of care for all children with cancer in Europe.

The importance of bringing the patients perspective to the center of the cancer care was highlighted by Roswitha Britz from the Spanish Federation of Breast Cancer Patients Association in a beautiful presentation. Main proposals from the patients' perspective are to improve the

coverage of population based data from cancer registries, to support research and clinical trials as a way to improve knowledge as well as to promote multidisciplinary cancer care approach. The role of associations in the cancer field is clearly increasingly acknowledged. Their support for active policies against cancer and specific demands using breast cancer as a case study were shown as a way to improve the overall quality of cancer care.

The last presentation in this session showed the preliminary data and conclusions of a forthcoming OECD report on Health Policy Perspectives in Cancer Care. This study was based on the assumption that the utilization of resources devoted to cancer care and how it is organized and governed could result in better quality of cancer care and outcomes. The review of several indicators proposed by experts and the cross-country multivariate analysis showed that the main factors associated with a high performance from cancer care system were not only the input of resources but also the governance of the cancer control system. The countries with better performance using survival as outcome were defined by having established cancer policy priorities, implemented key elements of cancer control, introduced integrated care process and actively worked on the delivery of cancer services.

The second plenary session was focused on how to improve the outcomes of cancer care. Luzia Travado dealt with the way of integrating psychosocial care of cancer patients. First of all, the impact of cancer on the emotional, social and psychosocial area was reviewed, mentioning for instance that half of the cancer patients suffer from distress and some of them will develop psychopathological conditions. Psycho-oncology services have shown to be effective at preventing or reducing psychosocial distress and improving the capacity of the patient to cope with the therapy as well as his/her quality of life. Luzia then discussed the present status of psycho-oncology in cancer care and the proposed objectives of the WP related to the diagnosis of the situation and the improvement of communicational skills of health professionals in dealing with the cancer patient.

# SUMMARIES

The issue of the quality of cancer care and symptom control was discussed by Stein Kaasa, who is leading the related objective in the WP7. Stein discussed the different scientific contributions from the literature regarding the quality of care in patients with advanced disease, and the relevance of symptom control for their quality of life. There have been several projects carried out at EU level aimed at improving the research capacity in palliative care and, nowadays, the relevance of the assessment of symptoms in a standardized way is important in order to progress in the quality of palliative care. The need to review the evidence in this area and to implement guidelines in palliative care is one of the objectives included in the WP that was discussed in this presentation.

The third contribution to this session focused on the need to develop clinical guidelines based on the best scientific evidence in nutrition for cancer patients. The European Society for Nutrition (ESN) is leading and its representative, Alessandro Laviano, chairman of the Committee on Education and Clinical Practice, described the evidence supporting the need to take care of the nutritional status of the cancer patients because it is clearly associated with their prognosis and their quality of life. The contribution of the objective under the leadership of this Society is to develop an evidence based clinical guideline in order to improve this situation.

Finally, the last contribution was on the challenge posed by rare cancers. Paolo Casali from the European Society of Medical Oncology (ESMO) expressed that the involvement of patients with these diseases in clinical trials is essential in tackling with these cancers. In this regard, the need of networks involving clinicians and researchers is required in order to promote an effective interaction that will result in positive changes for the prognosis of the patients with rare cancers. The possible differences of existing clinical guidelines makes useful to assess the feasibility to harmonize the guidelines in order to improve equity of access to a similar quality of cancer care. Also, methodological challenges in order to undertake research in these diseases were discussed and possible ways of coping with them.

## Final comments

Several interesting proposals and ideas were made during the presentations and debate. Some of the points raised were the need to focus on implementation of clinical guidelines as well as to coordinate with other initiatives at international level, such as the GIN network. Also, the need to keep the balance between making guidelines and implementing them was highlighted, together with the importance of involvement of policy makers in order to hold the necessary political leverage. The issue of 'ownership' of clinical guidelines and its relationship with implementation was also raised.

Another set of issues discussed was related to the need for promoting the psychosocial perspective as an essential component of integrated cancer care, the implementation of which requires specific training from the professional involved. Also, the perspective of a high quality therapy of cancer patients requires a focus on symptom identification and control as well as approaches that focus on aspects like nutritional support during the care of cancer patients. Finally, the specific challenges posed by rare cancers' management as well as the opportunities offered in an EU context were discussed.

As a summary of the discussions, it could be said that organizational perspectives in cancer care were useful in order to assess the variability in the care offered, which is associated to a variety of epidemiologic, organizational and clinical factors. The performance of different health care systems was clearly shown by the OECD project and was considered highly relevant (once the final results will be available). This poses the question - what are the available policy options that result in the optimal organization of health care resources, using them in the most effective way, resulting in the best quality of health care outputs? The WP7 will allow different cancer plans, scientific societies and patient groups to share best practices and develop criteria to identify and improve quality of cancer care.



# ABSTRACTS



# WELCOME SESSION

## WELCOME SESSION

**JOSE MARTINEZ OLMOS**, Secretary General of the Ministry of Health, Social Policy and Equality of Spain

I am pleased to inaugurate this Open Forum and welcome you to our Ministry.

Cancer is a priority for the Spanish Ministry of Health. In 2006 our National Strategy on Cancer was approved and its first evaluation (in 2009) showed a significant reduction in mortality rates and improvement in survival rates.

One of the biggest strengths of the Strategy is that it involves participative work with all stakeholders: health professionals, patients, researchers, and public institutions responsible for the Strategy's implementation.

I should point out the relevance of gender perspective in the Strategy, considering the effect that biological and sociocultural—in contrast to sexual—characteristics can have on some related aspects of cancer and its risk factors.

Two of the pillars of the strategy are: multidisciplinary care and coordination with the Strategy of Palliative Care in the National Health Service.

Of special interest here is our commitment to public financing and development of cancer research and network resources.

We are dealing with a global problem that requires global efforts. "In unity lies strength," so the European Commission proposed the European Partnership for Action against Cancer (EPAAC) that provides Member States with a framework to share information and specialized knowledge on prevention and control of cancer, and avoids disperse actions and duplication of efforts.

As an associated partner of the EPAAC we are honoured to host the first Open Forum in Spain, and for our Ministry to be the setting that shows you the great opportunity that EPAAC represents for joint collaboration.

Taken from the speech given at the Open Forum, 14 June 2011





# WELCOME SESSION

## WELCOME SESSION

**Ivan Eržen, State Secretary of the Ministry of Health of the Republic of Slovenia**

Slovenia was proud to preside over the EU Council in the first half of 2008. Cancer and its ever increasing burden were emphasized by the Slovenian presidency as an area which could improve if Europe worked together to solve the complexities underlying this disease. In the European Council meeting in June 2008, the Council issued several conclusions on reducing the burden of cancer. The conclusions were that firstly, EU member states should develop comprehensive cancer strategies, secondly, that prevention should be highlighted as the most effective long-term strategy in the fight against cancer through the promotion of healthy lifestyles and early diagnosis through screening and thirdly, that the Commission present an EU action plan on cancer addressing the many aspects of cancer control, helping to promote the exchange of information and sharing of expertise.

The European Partnership for Action Against Cancer was born out of the Commission Communication on Action Against Cancer, in which they outlined its main principles. This communication of 2009 outlined the skeleton of the Partnership. The thread underlying the Commission's idea was synergy – a collective approach to one of the major health threats in Europe, cancer. By pooling all the resources available within the EU community, through sharing information, exchanging expertise, learning about best practices, we gain an important factor. This factor is added value.

The main premise of the European Partnership for Action Against Cancer is that it is a collective effort. Only through using the synergies available within our community can we avoid duplicating our efforts.

We know that there are inequalities in healthcare for cancer patients throughout the EU member states. We also know that these inequalities can be lessened. As the Commission has stated, it is feasible to anticipate that inequalities could be reduced by 70% by 2020.

The Partnership has indeed set itself high goals. But it is important to remember that these goals are achievable. We can only achieve them by working together and gathering as we did during the Open Forum, where health experts from all over Europe were able to share information and contribute to the improved health not only of their nation's citizens, but of the citizens of Europe.

Taken from the speech given at the Open Forum, 14 June 2011



# WELCOME SESSION

## WELCOME SESSION

**MARTIN SEYCHELL**, Deputy Director DG Sanco

The Partnership was initiated in 2009 to support Member States in their efforts to tackle cancer. The overall objective is to reduce cancer incidence by 15% by 2020, and to decrease citizens' suffering as a result.

This first Open Forum will highlight two important and closely linked areas: cancer research and healthcare. As a longstanding priority of the Commission, cancer research has three complementary objectives of promoting collaborative translational cancer research using a holistic approach, strengthening the infrastructure of cancer research in Europe by securing access to biological resources, and coordinating of cancer research at EU level and beyond.

In the area of cancer care, the objective at EU level is to tackle inequalities in cancer mortality, which can help reduce the disparity between the best and worst performing Member States. This can be facilitated by developing European benchmarks for best practice. Identification and dissemination of good practice on different models for comprehensive and integrated cancer care is essential. In the context of cross-border patient mobility and healthcare, this is of even greater relevance.

Cost-effective control of cancer and other chronic diseases is likely to become a key challenge for healthcare systems in the coming years due to increased life expectancy and ageing. Accordingly, another major health initiative at EU level, the first pilot Innovation Partnership, called 'Active and Healthy Ageing', was launched recently as part of the EU2020 Strategy.

Taken from the speech given at the Open Forum, 14 June 2011





# PLENARY INTRODUCTION

## CANCER IS A POLITICAL ISSUE OF THE HIGHEST IMPORTANCE

**ALOJZ PETERLE, European Parliament and Members Against Cancer**

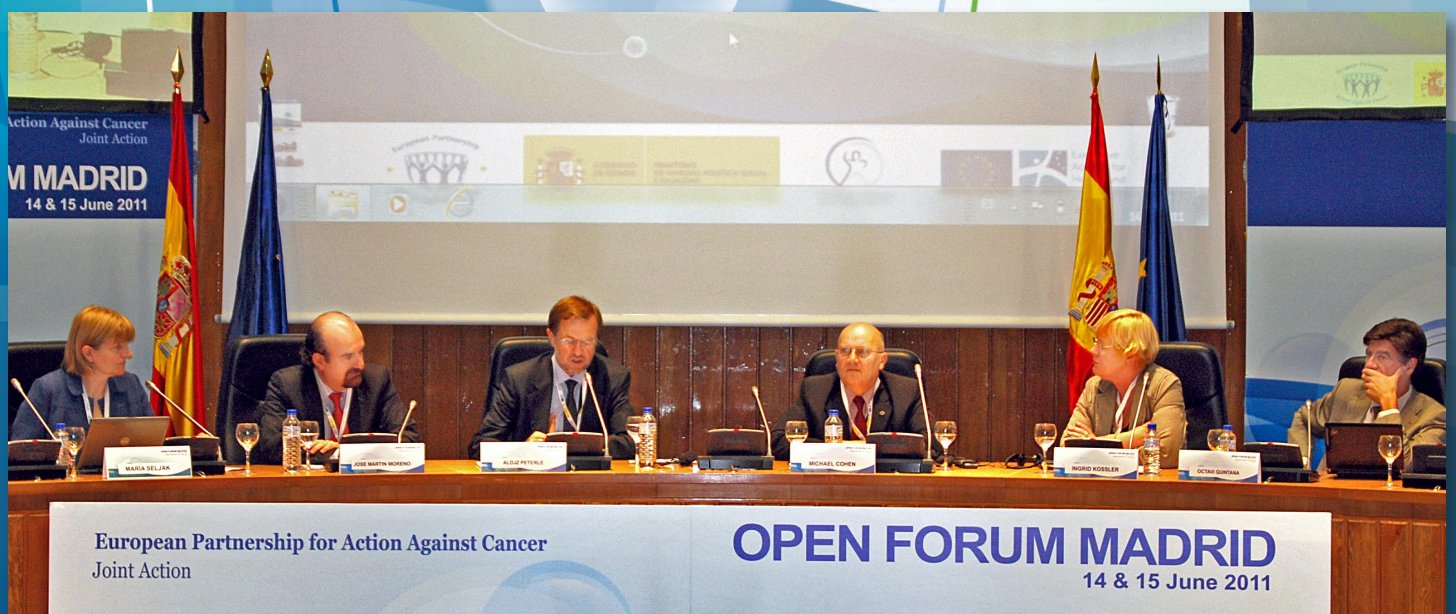
Cancer is a political issue of the highest importance. It has become a constant part of the European political agenda. EPAAC is an expression of this. Despite the progress of medicine and science, the incidence of cancer has been globally and constantly growing. We have not been able to respond to its dynamics with our measures so far.

*“Despite the progress of medicine and science, the incidence of cancer has been globally and constantly growing.”*

In order to diminish the inflow of new patients, we have to deal much more with reasons for cancer, with its social,

environmental and other determinants. The front against cancer has to be broadened from the symptomatic to the paradigmatic aspect. To invest more in prevention means to deal with healthy people as well. Member States spend on average only about 3% of their health budgets for prevention. A strategic shift is needed in this respect. In order to reach this objective we have to strengthen the political dimension of the fight against cancer at all levels.

In the current mandate, MAC (Members Against Cancer) pays particular attention to the prevention following objectives of the European Health Strategy, which demands health for all and is health in all policies.



# PLENARY INTRODUCTION

## HEALTH POLICIES FOR CANCER CONTROL: UNITING VERTICAL AND HORIZONTAL AXES FOR A COMPREHENSIVE APPROACH

JOSE MARTIN MORENO, World Health Organization

Cancer control is complex, spanning primary and secondary prevention, integrated care and research. It is also a health systems issue, where good governance, efficient financing, resource generation and effective service delivery must join together to meet citizen and patient needs. Given that the cancer burden is growing despite exist-

ments must be underpinned by proper training, service infrastructure and effective health systems management. On the other hand, cancer research must overcome the structural barriers, fragmentation and imbalances in funding which prevent European research from reaching its full potential.

*“EPAAC has a unique opportunity to bring together disparate stakeholders from all Member States to build on past successes and tackle present challenges.”*

ing knowledge to control it, it is vital that health systems invest in a comprehensive approach.

This presentation provided an overview of cancer control as a whole before highlighting the two focal points of the June Open Forum: integrated care and research. The first requires multidisciplinary care teams, evidence-based guidelines, a patient-centred approach and social support mechanisms within the community. These ele-

EPAAC has a unique opportunity to bring together disparate stakeholders from all Member States to build on past successes and tackle present challenges. WHO supports the Commission's approach

and hopes to pursue joint initiatives to fight cancer and other health threats, through integrated health security and health information systems; fluid exchanges of best practices and innovative policies; assistance to Member States in mitigating the effects of the financial crisis on health systems; and increased in-country cooperation.

# PLENARY INTRODUCTION

## MAKING THE CANCER PARTNERSHIP WORK The EESC Opinion on EPAAC

Ingrid Kössler, European Economic & Social Committee

Maria Prigorowski, Swedish Cancer Society

The European Economic and Social Committee is a consultative body of the EU, an assembly of 344 members representing main areas of economic, social and civic life of the 27 EU Member States.

Important areas and measures highlighted in the opinion:

- Joint EU action based on information sharing, exchange of expertise and best practice, to help Member States in their fight against cancer.
- Unacceptable differences between Member States in cancer incidence and mortality.
- Focus prevention on lifestyle patterns which increase the risk of getting cancer.
- Make the young generation aware that a healthy lifestyle reduces the risk of contracting cancer.
- All areas of the healthcare supply chain are important in reducing the burden and the suffering of cancer illnesses.
- As an initial step, put the focus on primary prevention and secondary prevention (screening) so that cancer can be detected and treatment begun early.
- Use the Structural Funds that are earmarked for training and infrastructure in the health sector. These funds are not utilised sufficiently in the Member States.

The EESC can make an active contribution through its contacts with civil society such as patient organizations in Europe: EUROPA DONNA and EUROPEAN CANCER PATIENT COALITION.

*“Make the young generation aware that a healthy lifestyle reduces the risk of contracting cancer.”*

PROCEEDINGS of the EESC:

Opinion adopted in the section with no votes against on 10 November 2009 and in the plenary session on the 16th of December, one vote against and with no abstentions. This shows a strong support for EPAAC.



# PRESENTATION OF EPAAC WP

## PRESENTATION OF EPAAC WORK PACKAGE

### Tit Albreht, National Cancer Plans, Work Package 10

Work Package (WP) 10 is dedicated to one of the horizontal topics in the Joint Action of the EPAAC. It deals with the topic of National Cancer Plans (NCPs), which have been explicitly defined as a commitment of all member states (MSs) of the European Union in the Conclusions of the Council of the European Union on reducing the burden of cancer, adopted on 10 June 2008. In their point 17 MSs are specifically called to develop comprehensive cancer plans or strategies that would deal with all aspects of cancer, thus leading to the development of an EU Action Plan on Cancer. This process should be completed by 2013. Led by these aims, in the JA on Cancer we decided that we would analyse the current state of the NCPs in the EU and explore the modes of developing a common framework for the future work on the NCPs.

Work on this WP is organised on several levels. The first operational level is the Core Working Group (CWG) consisting of the representatives of those MSs who expressed a particular interest in this topic: Belgium, Ireland, Italy, Malta, Netherlands and Slovenia. This group is intended to provide operational work on the deliverables, screen them, analyse them and propose improvements before the JA presents them for adoption. The next level is the Working Group on National Cancer Plans (WG on NCPs), which serves as the main discussion point for all MSs on the topic of NCPs. Finally, all deliverables as well as all open topics for discussion will be discussed and adopted at the Steering Committee (SC) of the JA. As the first step in this process we developed a questionnaire on NCPs and it was circulated it to all MSs, Iceland

and Norway in January 2011. By the end of June 2011 all MSs responded with filled-in questionnaires. The material was analysed by the JA's Consultant Dr Lydia Gorgojo and her team and the first draft report on the current state of NCPs was prepared. This was presented to the members of the CWG during the Open Forum in Madrid. It was provisionally approved by the Group. Still, at the point when the first draft was prepared several questionnaires were still outstanding. It was decided that all MSs would be given an opportunity to comment on the first draft report. This would then be amended with all the comments, corrections and additions received by the end of August 2011. A new draft would then be prepared for the discussion during the meetings of the WG on NCPs and the SC in Ljubljana end of September 2011. The next step in the process would be the work on the development of indicators, which would serve for the monitoring of the implementation of the NCPs in MSs as well as for the comprehensiveness and other qualitative aspects of the NCPs. This work is likely to extend itself over the following 12 months. During the WG meeting in Ljubljana the existing work on the indicator development will be presented and the initial discussion on the approaches to the desired and feasible categories of indicators will be carried out. The final deliverable is going to be a set of guidelines to serve in the preparation of good quality NCPs. The initial discussion shall be open during the meeting of the WG in Ljubljana in September 2011 and then the key activities on this deliverable will be carried out after the work on the indicators has been finished, i.e. late in 2012 and in 2013.



# CANCER RESEARCH

## EUROPEAN COORDINATION OF NATIONAL FUNDING: AN OVERVIEW OF THE STATE-OF-THE-ART

Rafael de Andres Medina, Instituto de Salud Carlos III – ISCIII and AALA Executive Board Treasurer

Country multilateral RTD Cooperation.

- The International Rare Diseases Research Consortium [IRDiRC] and the International Cancer Genome Consortium [ICGC].

Member states and associate states cooperation in ERA:

- ERANet and ERANets plus. Regarding cancer, it is
  - EUROCOURSES
  - Transcan [translational cancer research] has 25 partners from 3 Associate and 18 Member States and plans annual joint transnational calls above 10 M €.
- Art. 187 (ex 171) Treaty of the European Community [TEC].
  - Joint Technology Initiatives [JTI].
  - European Research Infrastructure Consortia [ERIC].
    - ESFRI initiatives have the possibility to get a legal personality according to the COUNCIL REGULATION (EC) No 723/2009 of 25 June 2009 on the Community legal framework for a European Research Infrastructure Consortium (ERIC). In the Biological and Medical Sciences Research, these are:
      - BBMRI – Biobanks
      - EATRIS – Translational research facilities
      - ECRIN – Clinical trials platform
      - ELIXIR – Bioinformatics
      - INFRAFRONTIER – Mouse models and archives
      - INSTRUCT – Structural biology facilities
      - EMBRC – Marine biology resources
      - ERINHA – High- security labs
      - EuroBioImaging – Cellular and medical imaging
      - EU- Openscreen – Chemical libraries and screening
      - ANAE – Analysis and experimentation on ecosystems
      - ISBE – Infrastructure for systems biology
      - MIRRI – Microbial resources
- Art. 185 (ex 169) TEC initiatives upon a Decision of the European Parliament and the Council, a Joint Undertaking with legal Personality and a bilateral Agreement with the European Commission for co-funding from RTD FP each:
  - EDCTP (clinical trials in SubSaharan African for HIV, malaria and TB) has 2 associate and 14 member states. For 2014-2020m expect a funding mobilization of 1 b €.

AAL JP (ICT applied research for ageing well) has 3 associate and 20 member states and launches an annual calls of 69 M €.

EUROSTARS

BONUS (Baltic Sea research)

Y toa gre copmon r`peirities an aldiegn funding EMNP (Metrology)

- Joint Programming Initiatives [JPI] pursue to agree on common priorities and align funding. Regarding Health and Health related, these are:
  - Neurodegeneration including Alzheimer [JP ND]
  - Healthy Diet for a Healthy Life [JP HDHL]
  - Anti-Microbial Resistance [JP AMR]
  - More Years Better Life [JP MYBL]
- European Innovation Partnership
  - e.g pilot on Active Healthy Ageing (AHA)

### Some Conclusions

- In ERA-Nets, AAL JP and JPIs
  - Scientific issues are managed at central level through the project consortium.
  - Central Independent scientific assessment of the proposals to be awarded.
  - One single legal frame work applied to each project partner and its funding is provided by a national body and within the corresponding national administrative regulations
- MSs' RTD funding legal and administrative framework needs simplifying and harmonization like.

Political, social and societal complicity and joining efforts with other RTD initiatives for lobbying, as well as A Win-Win Public - Private Partnership with Global Competition - Cooperation of scientists' efficient and fast speed driven.

- Benchmark-Feedback-Maturity: no new instruments but flexible & variable geometry comprehensive combination, common prioritizing & funding alignment for critical mass may make the difference.

# CANCER RESEARCH

## ERA-NET ON TRANSLATIONAL CANCER RESEARCH TRANSCAN

MARIA FERRANTINI, TRANSCAN

The objective of the ERA-NET funding scheme is to develop and strengthen the coordination of national and regional research programmes, e.g. by developing joint activities or by funding joint calls for trans-national research proposals. The participants in an ERA-NET consortium are typically funding organisations defining and/or managing research programmes.

The ERA-NET scheme has proven to be quite successful, based on the following figures: i) from 2002 to 2010 more than 100 ERA-NET actions have been funded with 340 million Euros; ii) all European Union Member States are highly involved in the current ERA-NETs; iii) more than 190 trans-national calls for proposals have been launched, resulting in more than 2.000 transnational projects being funded since 2004; iv) the annual volume of coordinated research is close to 300 million Euros, with substantial leverage effects on research coordination and an overall positive impact on structuring the European Research Area (ERA) as well as national programmes and their collaboration.

The ERA-NET TRANSCAN aims at linking translational cancer research funding programmes of 26 institutions in 20 Member States and Associated Countries. By concentrating transnational resources TRANSCAN is expected to provide a critical financial and scientific mass for tackling large scale problems, relevant for improving translational cancer research in each Member State or Associated Country as well as overall in Europe.

Major TRANSCAN objectives are to contribute to the building of the ERA through the coordination of national and regional translational cancer research funding organisations' activities, aiming at the integration of basic, clinical and epidemiological cancer research and facilitation of transnational cancer funding in Europe with the ultimate aim to streamline EU-wide cancer screening, early diagnosis, prognosis, treatment and care.

The launch, during the TRANSCAN lifetime, of three trans-national calls for proposals focused on cutting-edge topics in the field of translational cancer research is expected to greatly contribute to the achievement of these objectives.

TRANSCAN also strongly aims at the setting up of a sustainable European network for the funding of translational cancer research, by promoting integration and efficient use of resources concerning research policies. To this end, a long-term sustainability plan for the future beyond TRANSCAN will be elaborated and submitted to the consideration of both the national decision makers and the European Commission.

For details on the TRANSCAN project, please visit the website [www.transcanfp7.eu](http://www.transcanfp7.eu).

TRANSCAN is funded by the European Commission under FP7

# CANCER RESEARCH

## PLATFORMS CONTRIBUTING TO STRUCTURING THE ONCOLOGY FIELD AT THE EUROPEAN AND NATIONAL LEVELS

Ulrik Ringborg, Eurocan Platform

The growing cancer problem needs to be balanced by a predictive, personalized and preemive cancer medicine, as proposed by the NIH/US P4 medicine strategy. We need new translational research strategies to innovate prevention, early detection and treatment of cancer patients. EurocanPlatform is a project financed by the Eu-

*“The growing cancer problem needs to be balanced by a predictive, personalized and preemive cancer medicine, as proposed by the NIH/US P4 medicine strategy.”*

ropean Commission aiming at a platform for translational cancer research by linking basic/preclinical and clinical cancer research centres. Such a structure will improve the present suboptimal translational cancer research and increase the critical mass regarding patients, biological materials, technological structures and competences. There are 23 cancer research centres and five cancer organisations in the project. By using resources in a more efficient way strategies for a predictive and personalized cancer medicine have been outlined and are now in the implementation phase.

The EurocanPlatform may contribute to coordination of research and research infrastructures as well as to prioritization of research areas and strengthening of funding activities. Coordination of infrastructures involves

programmes for establishment and quality assurance of Comprehensive Cancer Centres, availability of patients, biological materials and specific technological resources. This means that infrastructures are shared in the consortium. EurocanPlatform offers possibilities to coordinate the cancer research by a specific work package on scientific coordination. Coordination and prioritization must build on competence and with the 28 participating centres/organisations, there is a substantial competence available. To further guarantee evidence based information as basis for giving priorities the newly established European Academy of Cancer Sciences will be consulted. The complete cancer research continuum will be covered and rational prioritizations for optimal balance of research in prevention, early detection and therapeutics will be a goal. Also within defined research areas, priorities will be given. EurcanPlatform will support funding activities. Coordination of present research support will be a challenge. A large number of researchers will be involved in planning of innovative grant applications. It will be possible to increase the interaction with funding bodies in the 11 participating countries and the EurocanPlatform should be of interest for collaboration with industry and SMEs. If the European Commission will succeed in allocating a larger part of the cancer research budget for international competition, a bottom-up process is needed from the cancer research profession. EurocanPlatform is one example of such a bottom-up process stimulating international collaboration aiming at innovative translational cancer research.

# CANCER RESEARCH

## PERSPECTIVES AND EXPECTATIONS OF DIFFERENT STAKEHOLDERS

FABIEN CALVO, Institut National du Cancer – INCa

As stated in the communication of June 24, 2009 by the European Commission on Action Against Cancer: European Partnership (COM(2009)291/4), a “comprehensive cancer approach should include all aspects of cancer research, from prevention to translational and clinical

*“The challenge ahead is to set a concerted agenda to gain momentum in the process of research translation toward the patients.”*

research... It should support the discovery and development of better medicines, including cancer therapies, and ... of clinical trials facilities and bio-banking to pave the way for a more harmonized European framework...” Hence, EPAAC provides the timeliest frame to support research coordination. The challenge ahead is to set a concerted agenda to gain momentum in the process of research translation toward the patients.

In France the fight against cancer has been endorsed at the highest level of the state and coordinates all players from across the cancer control continuum. The cancer control plan includes flagship activities for research (creation of multidisciplinary cancer research integrated sites, increased patient participation to clinical trials, full genome sequencing of 5 most common cancers, etc) and sets new ambitions that address health inequalities. International cooperation encompasses both networking (through the International Cancer Genome Consortium, the International Cancer Research Portfolio, the

Eranet Transcan, or the new program discussed with the NCRI on spontaneous tumour models in dogs) and bilateral initiatives (as the cooperation with the US National Cancer Institute in the CTEP– cancer therapy evaluation- program). Based on its current experience in various international cancer partnerships and as co-leader of the EPAAC research work-package, INCa is committed to help build coordination at the European level. Key areas could possibly include the integration of clinical cooperative groups, the development of academic clinical trials based on the US CTEP public-private partnership model, common research programs on « omics » and data analysis, and on prevention and social science.



# CANCER RESEARCH

## INVOLVEMENT OF RELEVANT EU INSTITUTIONS

Jan-Willem van de Loo, DG Research

The **Seventh Framework Programme** (FP7; 2007-2013), emphasizes the strategic importance of creating strong collaborative links within Europe. It

*“It combines coordination of research policies in Europe with better integration of research capabilities while focusing on topics of European or global significance.”*

combines coordination of research policies in Europe with better integration of research capabilities while focusing on topics of European or global significance. It supports transnational, collaborative research networks/partnerships involving cooperation between academic and industrial partners from several different European countries.

EU funding from the Health Programme has shown to leverage other funding. Overall, benefits are apparent regarding translational research outputs with direct benefits for patients, innovation activities as well as the creation of jobs and know-how. In the last 10 years, the Health Programme has already generated an estimated 50,000 jobs, 1,000 new SMEs and 1,200 licensed patents.

With the recent adoption of the Europe 2020, Innovation Union Policy, these efforts will increasingly be driven by **innovation** and **key societal challenges**, such as healthy ageing, with a clear shift towards closer-to-market exploitation and benefits at short to medium term. At the same time the EC continues

to strive to enhancing coordination of cancer research funding on a voluntary basis through different funding schemes and partnership initiatives.

All stakeholders in the EPAAC Joint Action were asked to reflect on a clear commitment at the end of this Joint Action following a thorough and transparent consultation process.

## CHALLENGES OF IMPLEMENTING CLINICAL GUIDELINES IN DAILY PRACTICE

Anita Margulies, European Oncology Nursing Society – EONS

**Clinical guidelines are important to standardize and improve the health care of patients with cancer.**

For nurses the goal is to educate and support european nurses to more widely utilise practice based clinical guidelines.

The EONS project aims to improve patient symptom management and care and will also show why it is relevant for all countries in the EU. We will be collaborating with various partner organisations e.g EHMA, ONS, and possibly with ESMO, trying not to overlap or duplicate their work.

*“For nurses the goal is to educate and support european nurses to more widely utilise practice based clinical guidelines.”*

### **Challenges and Barriers to implementation**

There are many known reasons why guidelines are a challenge and weighted down because of barriers. EHMA will be concentrating exactly on this topic and therefore an important part of the collaboration effort in the WP 7.

Challenges can be attributed to multiple problems in the health care setting as well as shifts and changes in cancer epidemiology. All this needs accordingly multiple options to approach these often very complex situations.

In the WP 7, EONS strategy activities will be focusing on the topic of “Enhancing Clinical Practice” with the introduction of the e-PEP guidelines. PEP = Putting Evidence into Practice and are resources originating from the Oncology Nursing Society (USA) which are designed to provide evidence-based interventions. These will be adapted to European needs, will be reviewed by experts and translated.

The development and implementation of 5 guidelines in 5 languages will be carried out in a two phase “plan of action” program and should be completed by 2013. An evaluation and analysis of the outcome is planned.

# CANCER HEALTHCARE

## CHALLENGES POSED BY THE MANAGEMENT OF CANCER PATIENTS IN HOSPITALS

Pascal Garel, European Hospital and Healthcare Federation – HOPE

When talking about new strategies and opportunities in management of cancer care, one has to take into account the impressive diversity and then should be careful with European averages. Differences in needs, resources and costs as well as differences in organisation and financing have to be taken into account when looking at this

*“Differences in needs, resources and costs as well as differences in organisation and financing have to be taken into account when looking at this issue.”*

issue. There are however major trends with an impact on management. Today more and more people recover their health after a cancer episode. Cancer is now becoming considered as a chronic disease. Patients now have new needs.

And there are new responses: it is not anymore only about cure and treatment but about providing global support, including nutrition, psychological, social and personal care. The patient has not anymore in front of him/her a single person specialized on the cure of the disease but a team of professionals focused on his/her global care.

To reduce morbidity and ensure early detection, better links with prevention, screening and early diagnosis are implemented. Ambulatory care is developed in most countries but with major differences. Hospital at home is growing but often set up by organizations other than healthcare institutions, sometimes integrated in hospital pathways but not always. Finally mechanisms of authorization to treat cancer patients are starting to appear. Yet, if there are official European cancer prevention guidelines, they do not exist yet for care.



# CANCER HEALTHCARE

## CO-DEVELOPING STANDARDS OF CARE FOR CHILDREN WITH CANCER: PARENTS AND PROFESSIONALS WORKING TOGETHER TO INFLUENCE HEALTHCARE

Jerzy Kowalczyk , European Society for Paediatric Oncology– SIOPE Europe

All paediatric cancers, both in children and adolescents are rare, with about 13,000 children newly diagnosed annually in Europe. Nevertheless paediatric cancer is still the 2nd most common cause of death in Europe in 1-14 year olds. Currently used treatment protocols result in high cure rates in most types of childhood cancers if patients are treated

*“Inequalities and barriers for these rare cancer patients in information, access to clinical trials, drugs, reimbursement and quality of treatment & care can be observed in Europe.”*

in specialised paediatric oncology/haematology centres. Inequalities and barriers for these rare cancer patients in information, access to clinical trials, drugs, reimbursement and quality of treatment & care can be observed in Europe. SIOPE Europe (SIOPE) is the only professional, multidisciplinary, pan-European organisation dedicated to childhood cancer and promoting optimal standards of treatment and care for children and young people with cancer. In May 2008 SIOPE concluded on emerging need to collect data on status and standards of paediatric cancer units in Europe and national regulations in each European country. To answer the question if any regulations related to standards for these wards are existing in their countries, a question-

naire on availability of national standards for paediatric oncology/haematology wards mailed to representatives of all European countries. In total, representatives of 27 countries responded. In summary only in 10 EU countries some regulations exist, but only in 5 countries these regulations are approved by legal authorities. Thanks to

partnership between SIOPE and Communication without Barriers Foundation, the Conference in Warsaw in 2009 was called to discuss European standards of care for children with cancer. For the first time, a multidisciplinary, multiprofessional care team came together - paediatric oncologists,

nurses, pathologists, psychologists, lawyers, survivors, parents, patients, lobbyists, interest groups - from at least 14 European countries (EU and non-EU). As a result a true consensus document was created. It describes an infrastructure for medical diagnostics as well as common work practices through multidisciplinary multiprofessional care team within a specialised unit and it includes Centres of Excellence, reflecting local population and geography, provision of both postgraduate training and consistent, continuous professional development for all staff concerned and psychological support, planned social and educational care as well as post-treatment assistance to ensure a child's reintegration.

# CANCER HEALTHCARE

## HEALTH POLICY PERSPECTIVES

Vladimir Stevanovic, Health Division, OECD

Fujisawa R., Health Division, OECD

This cross-national analysis of the performance of cancer care systems was undertaken within the OECD's Health Care Quality Indicators (HCQI) project. The aim of study was to explain the international variation in survival of patients with breast, cervical, colorectal and lung cancers by different cancer care policies.

*“The better-performing countries have also established cancer policy priorities, implemented key elements of cancer control, introduced integrated care processes and actively worked on the improvement of service delivery.”*

Data has been collected through a network of national cancer experts from 38 OECD member and non-member countries. Information on the main domains of the system of cancer care was gathered via a survey and follow-up interviews. Cancer survival data were obtained through the EURO CARE-4 study, US SEER programme and OECD HCQI data collection. Relations between health system characteristics in terms of resources, process quality and governance and cancer survival were investigated by fractional polynomials modelling.

The preliminary results indicate that survival is strongly related to country's income levels, investment in technology and innovative cancer drugs, and available human resources and infrastructure. The relationship between resources and outcomes is weaker once a reasonable re-sourcing level has been reached. Certain characteristics

of the access to services including screening and waiting time, and the reported availability of optimal treatment in terms of combined surgery, chemotherapy and radiotherapy, appear to be robust descriptors of evidence-based execution of cancer. The better-performing countries have also established cancer policy priorities, implemented key elements of cancer control, introduced integrated

care processes and actively worked on the improvement of service delivery.

The results of this work shed light on the underlying features of the cancer care system that are associated with cancer outcome variations and suggest which system characteristics are particularly important. The final report, including detailed information about different aspects of national policies, will be published in early 2012.

# CANCER HEALTHCARE

## HOW TO INTEGRATE PSYCHOSOCIAL CARE

Luzia Travado, NCOD, Portugal & International Psycho-Oncology Society

Cancer and its treatment have a tremendous psychological and social impact, alongside its physical impact. It is accompanied by a series of dramatic changes that involve the physical, emotional, spiritual, interpersonal and social dimensions of the person affected by cancer. As a result, at least 50% of cancer patients suffer from distress, and many of them develop more serious psychological conditions, such as anxiety, depression or

*“There is evidence that providing psycho-oncology interventions as part of standard regular care reduces the distress and psychosocial morbidity associated with cancer, improves quality of life and well-being during and after cancer treatment, re-integration to active life, and these are cost-effective.”*

maladjustment disorders. Psychological morbidity has significant clinical consequences, including poor compliance with treatment, reduced quality of life, higher perception of pain and other symptoms, shorter survival expectancy, longer hospital stays and increased costs, higher risk of suicide. There is evidence that providing psycho-oncology interventions as part of standard regular care reduces the distress and psychosocial morbidity associated with cancer, improves quality of life and well-being during and after cancer treatment, re-integration to active life, and these are cost-effective.

Despite this, provision of psychosocial care services are not routinely offered to all European cancer patients and in some countries, is scarce or absent. European Union recommendations state that “to attain optimal results, a patient-centered comprehensive interdisciplinary approach and optimal psychosocial care should be implemented in routine cancer care, rehabilitation, post-treatment and follow-up for all cancer patients” (Council Conclusions, June 2008). All Europeans should have equity of access to optimal cancer care to enable better clinical outcomes. The Psychosocial Oncology Action aims to survey service provision and training needs across Europe in psychosocial care and communication skills and plan the implementation of targeted training to skill up local teams who can then go on to provide

further country/region-specific training. This will constitute a train-the-trainers approach that should provide a cost-effective solution to disseminating out skills. This will move us closer to ensuring that high-quality psycho-oncology services can be included in all comprehensive cancer care programmes and national cancer plans in Europe.



## FROM NUTRITIONAL TO METABOLIC SUPPORT OF CANCER PATIENTS: CONTRIBUTIONS TO OPTIMAL CANCER PATIENT MANAGEMENT

Alessandro Laviano, European Society for Clinical Nutrition and Metabolism – ESPEN

The clinical journey of cancer patients is frequently characterized by the progressive deterioration of their nutritional status. A tumour itself, but anti-cancer therapies as well, is the main driver of the development of malnutrition, via the production of catabolic factors. Consistent clinical evidence show that cancer cachexia, i.e., malnutrition deriving from reduced food intake and derangement of host's metabolism, increases morbidity, mortality and impinges on quality of life. Despite this evidence, cachexia is frequently observed in cancer patients, whereas nutritional support to treat cachexia is generally considered by oncologists only in the palliative phase and for patients with advanced disease, thereby limiting the possibility to effectively prevent the development of cachexia. Surveys conducted by medical oncology societies show that oncologists are aware of the clinical relevance of preserving cancer patients' nutritional

*“The main reason reported by oncologists for suboptimal delivery of nutritional support is the lack of clear guidelines.”*

status, yet nutritional support is rarely considered in the daily practice. The main reason reported by oncologists for suboptimal delivery of nutritional support is the lack of clear guidelines. Therefore, ESPEN aims at developing

new clinical guidelines for nutrition support in cancer patients within the frame of the EPAAC project, and implementing their application in daily routine. Recent clinical data show that by integrating palliative care, which includes nutritional care, and active anti-tumour therapies, improved clinical response

is achieved. It is important to note that in such cases the enhanced efficacy of standard of care is brought about not by the development of a new drug, but just by the delivery of already existing treatments. Indeed, the greatest opportunity to increase the efficacy of anti-cancer treatment may come not from development of new therapies, but from more effective delivery of already existing ones.

# POSTERS





# Alcohol Consumption and Cancer

Marjetka Jelenc & Sandra Radoš Krnel

National Institute of Public Health, Ljubljana, Slovenia

## High alcohol consumption in Europe

The WHO European Region has the highest alcohol intake per capita of any WHO region and twice as high as the world average. It is the leading risk factor among young people. The burden of diseases related to alcohol in Europe is twice the world average. Mean yearly consumption in the countries with the highest alcohol consumption ranged from 10.8 L to 12.6 L of pure alcohol per head in 2003. The total tangible cost of alcohol in EU society in 2003 was estimated to be 125 bn Euros, equivalent to 1.3 % GDP.

## Alcohol intake and cancer

Alcohol consumption plays an important role in the causation of cancer. The more a person drinks, the higher the risk. A threshold level of alcohol consumption below which no increased risk for cancer is evident was not yet identified. There is evidence that men who have two or more drinks per day and women who have one or more drinks per day, have an increased risk of developing cancers of oral cavity, pharynx, larynx and oesophagus.

In a large meta-analysis statistically significant increases in risk also existed for cancers of the stomach, colon, rectum, liver, breast and ovaries. Colon cancer and breast cancer are the two most common types of cancer in developed countries after lung cancer. Even a moderate increase in risk may result in a relatively large number of additional cases and therefore have important public health implications.

The association between alcohol consumption and stomach cancer, pancreatic cancer, prostate and endometrial cancer is still controversial.

## Combined alcohol and tobacco use

The cancer risk increases exponentially when alcohol consumption and tobacco smoking are combined. Concurrent tobacco use is common among drinkers.

## Risks associated with different types of alcoholic beverages

Some studies found no apparent differences in the cancer risks associated with various beverages, whereas others have reported greater risks with spirits than with wine or beer.

## Mechanisms

Several mechanisms have been postulated through which alcohol may contribute to an increased risk of cancer. Nevertheless, the mechanisms underlying alcohol-related cancer development remain largely unclear. No experimental evidence indicates that alcohol by itself can cause cancer or that alcohol can act as a carcinogen. The main metabolite of ethanol, acetaldehyde and reactive oxygen species, produced by CYP2E1 activity can induce DNA lesions, which if unrepaired can initiate carcinogenesis. However, several animal studies have indicated that alcohol can have a cocarcinogenic or cancer-promoting effect. It means that when alcohol is administered together with other known cancer-inducing agents, it promotes/accelerates cancer development. Some researchers stated that slow oxidation of ethanol seemed to be associated with breast cancer risk. Genetic factors also may influence a person's risk-benefit balance. The association between alcohol consumption and female breast cancer may be limited to woman with a family history of breast cancer.

## Conclusions

Alcohol consumption seems to be an avoidable risk factor for cancer.

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This poster was prepared in the frame of European Partnership for Action Against Cancer Joint Action, which has received funding from the European Union, in the framework of the Health Programme.



**The pooled Relative Risk for the consumption of 2 standard drinks per day**  
(corresponding to approximately 25 grams of alcohol per day)



### Groups of Relative Risk (RR)

**RR 1.00 – 1.25:**  
stomach, colon, rectum, lung, endometrium, ovary, prostate, bladder

**RR 1.26 – 1.50:**  
oesophagus males, liver males, larynx, breast-females

**RR > 1.51:**  
oral cavity, esophagus females, liver females

Data from: Bagnardi V. Alcohol consumption and the risk of cancer.



# VARIATION IN "STANDARD CARE" FOR BREAST CANCER ACROSS EUROPE: A EURO CARE-3 HIGH RESOLUTION STUDY



Fondazione IRCCS Istituto Nazionale dei Tumori, Milano, Italy



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## BACKGROUND AND AIMS

The **EURO CARE-3 High Resolution (HR)** study on breast cancer collected detailed information on stage, diagnostic procedures, treatment and follow-up for a representative sample of about 15,000 women with a diagnosis of breast cancer during the 1996-1998 in 26 European Cancer Registries (CRs). The aim of the present study is to analyse the compliance with guidelines for treatment and staging.

## MATERIAL AND METHODS

We analysed data on **13,485** surgically-treated breast cancer patients from **26** European CRs in **12** countries: Denmark, Estonia, Finland, France (Bas-Rhin, Côte d'Or, Doubs, Isère, Tarn) Iceland, Italy (Firenze, Genova, Modena, Palermo, Ragusa, Varese), The Netherlands (Eindhoven), Poland (Cracow, Warsaw), Slovakia, Slovenia, Spain (Basque Country, Castellon, Granada, Mallorca, Navarra) and Sweden.

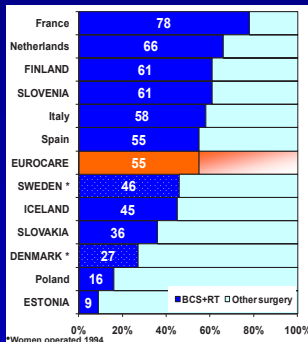
We examined the proportion of T1N0M0 patients receiving breast conserving surgery plus radiotherapy (BCS+RT); the proportion of N+ patients receiving chemotherapy; the proportion of ER+ patients receiving tamoxifen; and the proportion with 10 or more lymph nodes removed and examined during lymphadenectomy (minimum number of nodes for staging recommended by TNM during the study period). When the variable under study was not available for 20% or more of patients, the corresponding CR was excluded from the analysis.

The odds of being treated with BCS+RT (vs. other surgery) in T1N0M0 patients by country, adjusted for age and tumour size was estimated using a logistic regression model.

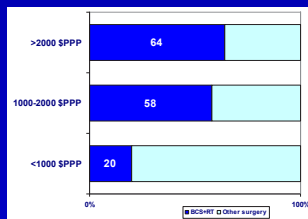
To investigate whether the use of "standard surgical care" for breast cancer was related to regional wealth, we analysed the proportion of BCS+RT (vs. other surgery) in T1N0M0 patients in relation to the mean total national expenditure on health (TNEH) in US dollars per capita purchasing power parity (\$PPP), in 1994-2000. TNEH was categorized as low (<1000 \$PPP), medium (1000-2000 \$PPP) and high (>2000 \$PPP).

## RESULTS

T1N0M0 patients (%) receiving BCS+RT



T1N0M0 patients (%) receiving BCS+RT, by total national expenditure on health (TNEH)



- T1N0M0 patients constituted 33% (4445) of the sample
- Overall 55% of T1N0M0 patients received BCS+RT 55%. Inter-country variation was marked (range: 9% in Estonia - 78% in France).
- Twenty% of T1N0M0 patients received BCS+RT in low TNEH countries (Estonia, Poland, Slovakia); 58% in medium TNEH countries (Finland, Italy, The Netherlands, Slovenia, Spain, Sweden); and around 64% in countries with high TNEH (Denmark, France, Iceland).
- Sixty-seven% of T1N0M0 patients who underwent lymphadenectomy had 10 or more lymph nodes examined (range: 24% in Estonia - 88% in Slovenia).

Odds of being treated with BCS+RT (vs. other surgery) by country, adjusted for age and stage at diagnosis

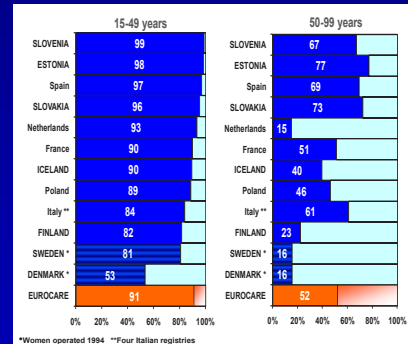
Country	No. cases	OR	95%CI
France	601	1	
Denmark	142	0.09	0.06-0.14
Estonia	85	0.03	0.01-0.05
Finland	207	0.43	0.30-0.60
Iceland	160	0.20	0.14-0.30
Italy	1000	0.37	0.29-0.47
Netherlands	526	0.56	0.43-0.74
Poland	276	0.05	0.03-0.07
Slovakia	121	0.14	0.09-0.21
Slovenia	190	0.42	0.29-0.60
Spain	774	0.32	0.25-0.41
Sweden	179	0.23	0.16-0.33
<b>Age (years)</b>			
15-39	215	1	
40-49	844	1.16	0.83-1.62
50-69	2399	0.96	0.71-1.31
70-99	803	0.33	0.24-0.47
<b>Tumour size</b>			
T1a	258	1	
T1b	1191	1.39	1.04-1.86
T1c	2812	1.08	0.82-1.42
<b>Total</b>	<b>4261</b>		

- Compared to France (reference) the odds of being treated with BCS+RT was lower in all other countries, even after adjusting for age and size of tumour. The lowest odds ratios (ORs) were found for Eastern European countries.
- Older women (70-99 years) had 67% lower odds of being treated with BCS+RT than younger women (15-39 years, reference group).
- N+ patients constituted 41% (5194) of total cases, 28% of whom were under 50 years and 72% were 50 years or more. Overall, 63% (3723) of N+ patients received chemotherapy but the variation by country was marked. Breakdown by age revealed that 91% of premenopausal (15-49 years) patients received chemotherapy.
- ER+ patients constituted 45% (5577) of total cases, 23% of whom were less than 50 years and 77% were 50 years or over. Overall, 56% (3094) of ER+ patients received hormonal therapy, 45% in premenopausal age (15-49 years) and 59% after menopause (50-99 years). There was marked variation across countries which was greater for premenopausal women (range: 4% in Denmark- 73% in Estonia and Spain) but still wide in older women (range: 33% in Finland - 91% in Estonia).

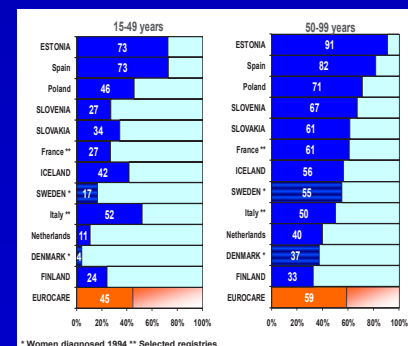
## DISCUSSION

The present study on breast cancers diagnosed mainly in 1996-98 has revealed large differences in care for this cancer across Europe. During the study period national protocols had been developed and disseminated, but standard European Guidelines were still not available. The effect of European guidelines should be evident for patients diagnosed more recently. High resolution studies on patients diagnosed and treated more recently should make it possible to assess the effect of guidelines and indicate whether the less-than-optimal allocation of resources for the treatment of breast cancer suggested by our late 1990s data has been remedied.

Adjuvant chemotherapy (%) in N+ breast cancer: women operated 1996-98, by age at diagnosis



Endocrine therapy (%), for ER+ breast cancer: women operated 1996-98, by age at diagnosis



# DEVELOPMENT OF EUROPEAN GUIDELINES FOR QUALITY ASSURANCE IN COLORECTAL CANCER SCREENING AND DIAGNOSIS



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## Background

Colorectal cancer (CRC) is a significant health problem that is getting worse in more-, and less-developed regions of the world [1]. Currently, CRC is the third most common cancer and the fourth most common cause of cancer deaths worldwide, with 1.2 million estimated cases and more than 600 000 estimated deaths in 2008 [2].

From demographic trends, the annual incidence of CRC is expected to increase by nearly 80% over the next two decades to 2.2 million cases. Nearly two-thirds of the additional annual incidence (62%) will occur in the less-developed regions of the world that are ill-equipped to deal with the increasing demand for cancer treatment. Concerted efforts to control CRC are therefore of major importance worldwide [1].

In the EU, the burden of CRC is particularly high; it is one of the most common newly-diagnosed cancers and is the second most common cause of cancer death [3].

The efficacy of CRC screening has been demonstrated in randomized controlled trials [4-7]. This was acknowledged by the Council of the European Union in 2003 when it recommended population-based screening programmes of appropriate quality using evidence-based tests for breast, cervical and colorectal cancer to the EU Member States [8].

Screening is performed on predominantly asymptomatic people; effective quality assurance is required to maintain an appropriate balance between benefit and harm in the large numbers of people eligible to attend cancer screening programmes [1, 9, 10]. European quality assurance Guidelines for breast and cervical cancer screening have been developed by experts and published by the EU [11, 12]. The new EU Guidelines for CRC screening and diagnosis [13, see also 14 and 15] now provide similar standards for CRC screening.

## Methodology of guideline development

The comprehensive, multidisciplinary guidelines were developed in an international collaborative project which started in 2006 and was coordinated by the Quality Assurance Group (QAS) at IARC. The collaborating institutions (Table 1) received co-funding from the EU Health Programme.

The editors developed a comprehensive, detailed guideline outline and recruited a multidisciplinary group of experts from across the EU that revised the outline in a series of workshops. Additional scientific support was provided by the coordination team at IARC and a literature group consisting of epidemiologists with special expertise in the field of CRC and in critical appraisal of clinical studies.

The authors and editors defined a list of key clinical questions based on the detailed outline of the Guidelines. The Literature Group then conducted systematic literature reviews based on this list. From the results of these reviews, the authors elaborated the draft chapters by describing the relevant issues, summarizing the evidence and formulating recommendations and conclusions. The strength of each recommendation and the applicable evidence was graded based on the results of the literature search and on the authors' clinical experience. The interim results were repeatedly reviewed and revised through multidisciplinary meetings of the authors, editors and the literature group. During the process, the principles, recommendations and underlying evidence in the Guidelines were discussed with experts and advocates from 49 countries including all EU and all IARC Member States. All but one of the chapters, (Introduction), underwent formal external review.

## Results

The Guidelines were launched shortly before World Cancer Day (4 February 2011). The printed version (400 pages) consists of 10 chapters (Table 2) each of which includes a list of key recommendations which are graded according to the strength of the recommendation and the supporting evidence. The respective evidence is summarized in the body of the chapters, with explicit citation of over 750 references. In total, over 270 recommendations are provided.

The entire screening process is covered, from invitation (Ch. 2, 10) to performance of the screening test (Ch. 4, 5), diagnosis and management of lesions detected through screening (Ch. 5, 7, 8) as well as surveillance (Ch. 9); overarching topics, i.e., efficacy and cost-effectiveness of screening tests (Ch. 1), organisation (Ch. 2), evaluation (Ch. 3), training (Ch. 6) and communication (Ch. 10) are also covered. The concept of screening and other general issues are also covered in the introduction (Ch. 1) and the Executive Summary. A Summary Table of key performance standards for usage in a pan-European setting is also provided.

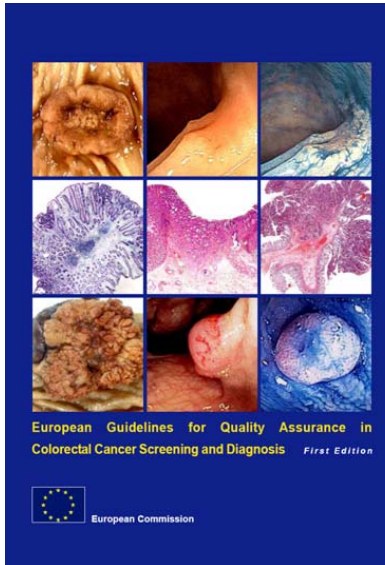
International Agency for Research on Cancer



**Table 1: Main collaborators and partner institutions**

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**Fig. 1: First Edition of EU CRC Guidelines, 2010**



**Table 2: Print version of the EU CRC Guidelines**  
274 graded recommendations  
772 cited references  
in 10 chapters:

- Introduction**
- Organisation**
- Evaluation and interpretation of screening outcomes**
- Faecal Occult Blood Testing**
- Quality assurance in endoscopy in colorectal cancer screening and diagnosis**
- Professional requirements and training**
- Quality assurance in pathology in colorectal cancer screening and diagnosis**
- Management of lesions detected in colorectal cancer screening**
- Colonoscopy surveillance following adenoma removal**
- Communication**

## Acknowledgements

Financial support of the European Communities through the EU Public Health Programme (Development of European Guidelines for Quality Assurance of Colorectal Cancer Screening (CRC), grant agreement No. 2005317), of the Public Affairs Committee of the United European Gastroenterology Federation, and from a cooperative agreement between the American Cancer Society and the Centers for Disease Control and Prevention, is gratefully acknowledged.

Special thanks are due to 102 experts serving as authors, contributors, editors or reviewers from 23 European countries (Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, the Netherlands and the United Kingdom) and 9 countries in Asia and North and South America (Argentina, Australia, Canada, China, India, Israel, Japan, Korea, and the United States) and IARC staff in the Cancer Information (CI) (M. De Camargo Canceled, J. Ren), Communications (COM) (J. Danielle) and Screening (SCR) (K. Gunot, E. Lucas, R. Mawanga, C. Sauvaget) Groups who provided additional technical support or assistance in reviewing the Guidelines' manuscripts.

The Web version of the Guidelines includes all of the elements in the print version, plus an extensive Appendix 1 in digital format (1000 pages) with a complete record of the key clinical questions and corresponding bibliographic searches conducted by the Literature Group. The search results are documented in table format, and in summary documents. Altogether summary documents for over 100 clinical questions and over 500 evidence tables are provided.

## Discussion

The potential harm caused by CRC screening includes the creation of unnecessary anxiety and morbidity, inappropriate economic cost, and exposure to the risk of invasive procedures for detection and diagnosis as well as for removal of lesions detected in screening. As demonstrated in implementation of breast and cervical cancer screening programmes, overall screening outcome and quality depend on the performance at each step in the screening process [1, 9-13]. To achieve the potential benefit of CRC screening, quality must therefore be optimal at each step in the process (Ch.1) [1].

The new Guidelines were specifically developed for screening of the average-risk population in which most CRC occurs. It should also be noted that the faecal occult blood test (FOBT - conventional guaiac or immunochemical) is currently the only test recommended for CRC screening by the EU. The purpose of the extensive new quality assurance Guidelines is not to recommend other modalities that might currently also be suitable for CRC screening in the EU. However, the evidence of the efficacy of other screening tests is also reported. Furthermore, the standards and recommendations provided in the Guidelines deal with all of the screening tests currently used in publicly mandated programmes in the EU: FOBT, flexible sigmoidoscopy and colonoscopy.

Organized, as opposed to "opportunistic" screening programmes are recommended because they include an administrative structure responsible for programme implementation, quality assurance and evaluation. Population-based programmes generally require a high degree of organization in order to identify and personally invite each person in the eligible target population. Personal invitation aims to give each eligible person an equal chance of benefiting from screening and to thereby reduce health inequalities. These efforts should be supported by effective communication for groups with limited access to screening, such as less advantaged socio-economic groups. This, in turn, should permit an informed decision about participation, based on objective, balanced information about the risks and benefits of screening (Ch. 1, 2, 10) [1, see also 9].

The population-based approach to programme implementation is also recommended because it provides an organizational framework for effective management and continuous improvement of the screening process, such as through linkage with population registers and cancer registries for optimization of invitation to screening and for evaluation of screening performance and impact. (Ch. 1, 2) [1, see also 10].

## Conclusions and future prospects

In a state-of-the-art process, wide consensus has been achieved on a comprehensive package of evidence-based recommendations for quality assurance in CRC screening.

Given the universally applicable guiding principles on which the Guidelines are based and the wide spectrum of cultural and economic health care settings in the EU, the recommendations are not only relevant to Europe, but also other regions of the world.

Widespread application of the Guidelines will facilitate quality management and promote the international exchange of information and experience between programmes that is essential for continuous quality improvement.

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# ECL: Together for Research

The Association of European Cancer Leagues (ECL) is an alliance of national and regional cancer leagues in the extended Europe. ECL provides a forum of exchange for information and best practices and connects the work and interests of cancer leagues in Europe.

Cancer leagues provide millions of Euros in funding for multiple research areas. The following areas are currently being funded or have been funded in recent years by leagues:

## PREVENTION



Primary and health promotion research focuses on the determinants of health, on strategies which can change not only lifestyles, but also the social, economic and environmental conditions that determine health.

Sample research

- ⇒ *The role of various food components of the Mediterranean diet in the prevention of certain cancers including breast, colon, endometrium, prostate, oral cavity*
- ⇒ *The effect of fruit and vegetables and plasma carotenoids, vitamin C and folate on the risk of high- and low-grade bladder cancer*
- ⇒ *Vitamins with antioxidant properties on oral cancers*
- ⇒ *Identifying genetic markers for certain cancers (Secondary Prevention)*
- ⇒ *Identifying quality indicators for screening and risk assessment (Secondary Prevention)*
- ⇒ *Effectiveness of screening campaigns (Secondary Prevention)*

## EPIDEMIOLOGICAL

Cancer epidemiological research investigates the populations with cancer; who gets specific types of cancer; and what factors (such as environment, job hazards, family patterns, and personal habits, such as smoking and diet) play a part in the development of cancer.

Sample research

- ⇒ *The increasing burden of second primary cancers in the Netherlands: trend in incidence, survival and causes-of-death since 1970*
- ⇒ *Improving and/or using cancer registries to identify geographic gaps in services*
- ⇒ *Mapping the prevalence of COPD in cancer patients and the impact of COPD on the choice of treatment and survival of cancer*

## PSYCHOSOCIAL AND BEHAVIOURAL

Study of psychological and social impact that a disease causes cancer patients and their families. This branch of research aims to improve psychosocial status of patients and patients and involves palliative care and continuum issues such as quality of life after cancer treatment.

Sample research

- ⇒ *Cognitive impairment in cancer treatment*
- ⇒ *Migrant populations' perceptions of cancer screening services*
- ⇒ *Improving personalized services*
- ⇒ *The impact of volunteers and support groups on cancer services*
- ⇒ *Energy for life in colorectal cancer survivors: how do physical activity and dietary factors affect their quality of life?*
- ⇒ *Enhancing patient communication during oncology follow-up visits: the design and testing of a computer-tailored pre-visit patient education program*

## TRANSLATIONAL

Translation research transforms scientific discoveries arising from laboratory, clinical, or population studies into clinical applications to reduce cancer incidence, morbidity, and mortality.

Sample research

- ⇒ *MicroRNA-profiling of renal cell carcinoma: tailoring individualised adjuvant treatment*
- ⇒ *Belgian/Australian Academic Translational Research Substudy: Investigating changes in estrogen levels for patients participating in the SOLE trial*
- ⇒ *Genetic biomarkers for anti-angiogenic therapies – a translational approach*

## BASIC

Study of molecular and cellular processes that may lead to the development of cancer. Basic research is generally performed in the laboratory and researchers work primarily on molecules or cells and carry out computer simulations.

Sample research

- ⇒ *Role of coregulated miRNA protein pairs in the development of colorectal cancer and in the cellular hypoxia response*
- ⇒ *Protection against graft versus host disease by IL-27 inhibition: comparison with IL-17A, IL-17F and CEACAM-1 and evaluation in graft versus leukemia reactions*
- ⇒ *Oxygen-sensing by professional antigen presenting cells in the tumor micro-environment and its impact on adaptive anti-tumor immunity*

## CLINICAL

Research on patients and patients, for example to test new and improved methods of diagnosis or treatment. Clinical research is permitted only if patients are informed in detail of the research project and are expressed agreement to participate.

Sample research

- ⇒ *Pharmacological immunomodulation of the tumor environment to promote vaccine-induced antitumoral T lymphocyte responses in patients with advanced melanoma*
- ⇒ *NEO-ZOTAC: A phase III randomized trial with NEOadjuvant chemotherapy (TAC) with or without Zoledronic acid for patients with HER2-negative large resectable or locally advanced breast cancer.*
- ⇒ *Mammaglobin as a marker for breast cancer*
- ⇒ *Phase III Intergroup Study of Radiotherapy versus Temozolomide Alone versus Radiotherapy with Concomitant and Adjuvant Temozolomide for Patients with 1p/19q Codeleted Anaplastic Glioma*
- ⇒ *Harmful side effects of treatments*

Leagues also support other areas of research such as **COMPLEMENTARY AND ALTERNATIVE CANCER TREATMENTS**, which are in addition to or which are not part of conventional medicine, and **EXPERIMENTAL TREATMENTS**, those being studied for their effectiveness.



# EUROPEAN SOCIETY OF ONCOLOGY PHARMACY

The European Society of Oncology Pharmacy, founded in 2000 in Prague, is the largest organization of oncology pharmacists in the world with 2400 members.



## Pharmacist Counselling Plan

### *Aim and Objectives*

ESOP supports optimal treatment for cancer patients with objectives to develop and promote clinical and oncology pharmacy practice through: 1. Education and training, 2. Safe handling and administration of drugs, 3. Quality management, 4. Research and development and 5. Pharmaceutical care. ESOP publishes its recommendations in the 4<sup>th</sup> edition of QuapoS (Quality Standard for the Oncology Pharmacy Service)<sup>1</sup>. Pharmaceutical counselling is described below as an example of these guidelines.

### Pharmaceutical counselling

The oncology unit of the hospital pharmacy continually strives to implement pharmaceutical counselling and give advice to therapy. A direct contact with patients on cytotoxic drugs and infusions are demanded. Information are communicated directly to the patient or indirectly by producing and distributing written information and documentation. In addition the oncology pharmacist is a partner to physicians and nurses on advice for best drug treatment.

For implementation of counselling and advice a structured approach by the oncology pharmacist is required. Communication of therapy-related data from the physician is a cornerstone as well as direct patient contact for information on drug handling and administration when arriving home.

A counselling plan results from a systematic analysis of all drug-related problems (DRPs) for a patient. Using SOAP method design, the plan will contain:

**S**ubjective: Complaints; **O**bjective parameters (e.g. weight, blood count, creatinine & liver values), **A**ssessment of problem(s) & identification of possible interventions and a **P**lan with therapy goals & control parameters.

Main advantages of such an approach are: (i) distinguish between medical & pharmaceutical DRPs, (ii) follow-up with measures & efficacy, (iii) continuous care within healthcare professionals, (iv) help the patient to be involved in his/her care (e.g. side effects' management).



Die Rolle der onkologischen Pharmazeuten ist es, für hochwertige hergestellte Arzneimittel und die Unterstützung für die Betreuung von Krebspatienten zu sorgen.



El farmacéutico especialista en oncología tiene como misión garantizar la calidad y seguridad de las preparaciones oncológicas así como proporcionar atención farmacéutica a los pacientes con cancer.



Aptekri roll on pakkuda vähihaigetele patsientidele nii kvaliteetselt valmistatud ravimeid kui ka kvaliteetset farmatseutilist hoold.



Le rôle des pharmaciens en oncologie est de fournir des préparations de médicaments de haute qualité et des soins pharmaceutiques aux patients atteints de cancer



Vloga onkoloških farmacevtov je skrb za zagotavljanje visoko kakovostnih zdravil in podporne terapije bolnikom z rakom.



De ziekenhuisapotheker is verantwoordelijk voor het op de juiste wijze voor toediening gereed maken van de chemotherapie en het verstrekken van de gewenste informatie aan kankerpatiënten.

### Reference:

<sup>1</sup> Quality Standard for the Oncology Pharmacy Service 4<sup>th</sup> edition. Available at [www.esop.eu](http://www.esop.eu)



# The burden of rare cancers in Europe



Gemma Gatta<sup>1</sup>, Jan Maarten van der Zwan<sup>2</sup>, Annalisa Trama<sup>1</sup>, Sandra Mallone<sup>3</sup>, Paolo G Casali<sup>4</sup>, Sabine Siesling<sup>2</sup>, Renée Otter<sup>2</sup>, Riccardo Capocaccia<sup>3</sup> and the RARECARE working group

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## Introduction

A major problem with rare cancers is that their overall burden on society has not been adequately estimated, although they are thought to constitute a major public health problem. Rare cancers are often inadequately diagnosed and treated in relation both to lack of knowledge and lack of clinical expertise. Improving the quality of care for these cancers is a public health priority. The project Surveillance of Rare Cancers in Europe (RARECARE) collected data on rare cancers from 89 population-based cancer registries (CRs) in 21 European countries, making it possible to study the epidemiology of these cancers as a whole in a large and heterogeneous population. Working from this database and the literature, a RARECARE working group produced a new list of cancers and developed a new definition of rare cancers (<http://www.rarecare.eu>).

**RARECARE aims:**  
 To provide a definition of "rare cancers" and a list of cancer  
 To estimate the burden of rare cancers in Europe  
 To improve the quality of data in cancer registration  
 To disseminate information on rare cancers to all key players

## Methods

Data from 89 CRs in 21 European countries were analysed to provide burden indicators for each of the rare cancers defined by RARECARE

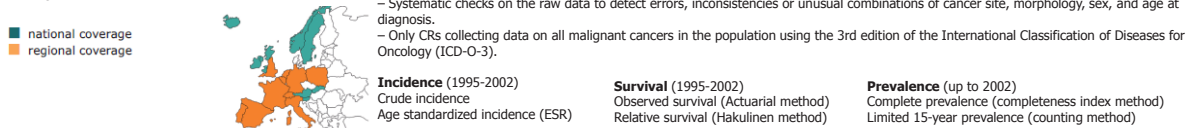


Figure 1. RARECARE database coverage

## Results

### Rare cancer list

The list of rare cancers is based on the ICD-O (3rd edition). The list was hierarchically structured in three layers based on various combinations of ICD-O morphology and topography to respond to different needs:

- layer 1) families of tumours (relevant for the health care organisation),
- layer 2) tumours clinically meaningful (relevant for clinical decision making and research),
- layer 3) WHO tumour entities.



### The burden of rare cancers in Europe

Based on the RARECARE definition (incidence <6/100,000/year)

**Incidence**  
**541,000** new diagnoses of rare cancers annually corresponding to **22%** of all cancer diagnoses

**Prevalence**  
**4,300,000** patients living today in the EU with a diagnosis of a rare cancer (**24%** of all cancer diagnoses)

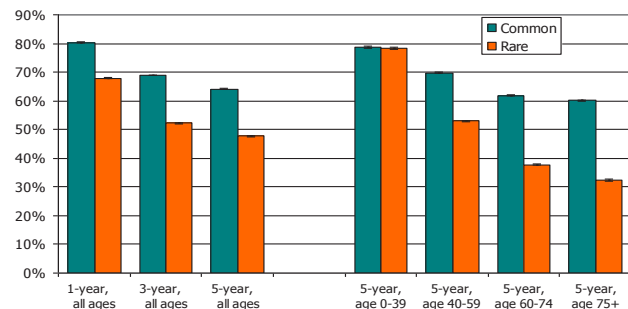
**Survival**  
 rare cancers (**47%**) versus common cancers (**65%**)

Surveillance of Rare Cancers in Europe						
Rare cancers are those with incidence <6/100,000						
C - common	R - rare	Layer	Tumour	Rate	Patients	Morphology code
	1	1	<b>EPITHELIAL TUMOURS OF NASAL CAVITY AND SINUSES</b>	<b>0.44</b>	<b>3,555</b>	C30.0, C31
R	1	1	<b>Squamous cell carcinoma with variants of nasal cavity and sinuses</b>	<b>0.31</b>	<b>2,498</b>	C30.0, C31
	2	1	Squamous carcinoma	0.24	1,913	C30.0, C31
	3	1	Venous carcinoma	<0.01	81	C31.0, C31
	3	2	Squamous cell carcinoma spindle cell	<0.01	311	C30.0, C31
	3	2	Papillary squamous cell carcinoma	<0.01	103	C30.0, C31
	3	2	Adenosquamous carcinoma	<0.01	181	C30.0, C31
	3	2	Squamous cell carcinoma, adenoid	<0.01	312	C30.0, C31
	3	2	Basaloid squamous cell carcinoma	<0.01	51	C30.0, C31
R	2	1	<b>Lymphoepithelial carcinoma of nasal cavity and sinuses</b>	<b>&lt;0.01</b>	<b>19</b>	<b>C30.0, C31</b>
R	2	2	<b>Undifferentiated carcinoma of nasal cavity and sinuses</b>	<b>0.02</b>	<b>139</b>	<b>C30.0, C31</b>
R	2	2	<b>Intestinal type adenocarcinoma of nasal cavity and sinuses</b>	<b>&lt;0.01</b>	<b>20</b>	<b>C30.0, C31</b>

Table 1. RARECARE estimates of incidence and prevalence for rare and common cancers by site in EU27

	Crude incidence per 100,000 per year	Standard error	Estimated incidence cases in EU27 per year	Incidence distribution (%)	Prevalence per 100,000	Standard error	Estimated prevalent cases in EU27 per year	Prevalence distribution (%)
Rare Digestive tract	17.5	0.1	87,280	15	50.9	0.4	294,479	11
Common Digestive tract	75.7	0.1	378,507	67	399.3	1.2	1,996,625	84
All Digestive tract	113.2	0.1	569,549	100	470.0	1.4	2,380,546	100
Rare Respiratory tract	13.6	0.0	68,147	21	60.0	0.4	300,193	46
Common Respiratory tract	31.5	0.1	157,445	49	56.0	0.3	279,942	43
All Respiratory tract	63.9	0.1	319,349	100	122.0	0.6	648,321	74
Rare Skin	1.5	0.0	7,649	2	14.8	0.3	73,949	2
Common Skin	60.8	0.1	304,186	96	744.0	1.5	3,724,477	96
All Skin	63.2	0.1	316,174	100	772.0	1.5	3,999,300	100
Rare Breast	4.1	0.0	22,041	7	60.2	0.7	300,759	9
Common Breast	47.5	0.1	237,929	74	619.0	4.1	2,999,432	74
All Breast	64.1	0.1	320,549	100	700.2	6.3	3,500,900	100
Rare Female genital tract	16.1	0.0	80,699	55	176.2	0.8	880,522	53
Common Female genital tract	9.5	0.0	47,639	32	126.7	0.6	613,280	38
All Female genital tract	29.5	0.1	147,433	100	333.9	1.1	1,659,991	100
Rare Male genital tract	4.4	0.0	23,872	8	93.1	0.8	465,363	23
Common Male genital tract	40.6	0.1	202,766	78	279.4	1.4	1,396,883	70
All Male genital tract	51.9	0.1	259,642	100	399.5	1.6	1,997,563	100
Rare Urinary system	2.6	0.0	12,740	8	18.3	0.4	91,683	8
Common Urinary system	25.8	0.1	129,796	70	202.1	0.7	1,010,735	65
All Urinary system	33.0	0.1	164,963	100	227.7	0.8	1,188,660	100
Rare Haematopoietic system	15.9	0.0	79,409	72	90.1	0.7	450,444	70
Common Haematopoietic system	4.8	0.0	24,991	22	32.3	0.3	161,618	25
All Haematopoietic system	22.0	0.1	109,738	100	120.5	0.7	647,596	100
Rare All sites	106.3	0.1	541,296	22	899.5	2.2	4,297,265	24
Common All sites	207.4	0.2	1,486,956	59	2368.3	4.8	11,941,853	66
All sites	502.1	0.3	2,510,662	100	3666.4	7.2	17,831,883	100

Figure 1. RARECARE estimates of relative survival for rare and common cancers in EU27, by year since diagnosis and age group. Error bars are 95% confidence intervals



## Conclusions

RARECARE has put numbers to a problem long known to exist. **Rare cancers in Europe are not so rare!**

RARECARE estimates constitute a useful base for further researches

To overcome rare cancers challenges is essential to establish centers of excellence for rare cancers or groups of rare cancers at the regional or national level and networking these centers across the EU

RARECARE will continue to encourage initiatives to put rare cancers on the map.

# IMPLEMENTATION OF CANCER SCREENING PROGRAMMES IN EUROPE – STANDARDIZING THE PROCESS

## BACKGROUND

From current estimates, cancer is the cause of approximately 7.5 million deaths/year worldwide and 1.2 million deaths/year in the 27 EU Member States [1]. Breast, cervical and colorectal cancer account for nearly one fifth of these deaths both (Fig. 1). Screening people of average risk for these cancers can lower the burden of disease in the population [2-5]. However, screening large segments of the population affects very many predominantly healthy individuals and consumes considerable resources. Hence quality assurance is required to maintain an appropriate balance between benefit and harm [5-8].

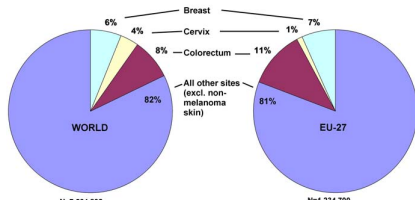


Fig 1: Estimated proportion of breast, cervix and colorectal cancer deaths worldwide (left) and in the EU-27 (right) in 2008. (Source [1])

## SCREENING PROCESS

EU experience demonstrates that overall screening outcome must be measured at the end of the screening process [5-8]. The screening process is comparable to the patient journey in a clinical setting, but includes procedures to identify and personally invite the eligible target population, followed by performance of the screening test. Then if necessary, a patient journey begins with diagnostic work-up, treatment and aftercare of screen-detected lesions. To achieve the potential benefit of screening, quality must be optimal at every step in the process [5-8]. Comprehensive, multidisciplinary guidelines for quality assurance covering the entire process of breast, cervical and colorectal cancer screening have been developed by experts and published by the EU [9-11] (Fig. 2).

## WHO AND EU RECOMMENDATIONS ON CANCER SCREENING

The World Health Organization (WHO) defined the first set of principles for population screening [12]. These principles are still valid today and are an integral part of the EU policy on cancer screening that is formulated in the 2003 Council Recommendation [13, see also 7]. The EU policy provides a comprehensive framework for evidence-based decision-making at the governmental level and invites EU Member States to take common action to implement breast, cervical and colorectal cancer screening programmes with an organized, population-based approach and according to European quality assurance Guidelines [9-11].

Population-based programmes aim to give each eligible individual an equal chance of benefiting from screening. The population-based approach to programme implementation is also recommended because it provides an organizational framework conducive to effective management and continuous improvement of the screening process, such as through linkage with population and cancer registries for optimization of invitation to screening and for evaluation of screening performance and impact.

The present analysis is relevant to efforts to make screening of high quality as recommended by the Council of the EU available to all who may benefit.

## RESULTS AND DISCUSSION

The EU experience demonstrates that the translational process by which an effective and appropriate screening programme is established can be standardized (Table 1) [7]. The generic elements of the implementation process shown here assume that a decision has already been taken to establish a cancer screening programme in the framework of an overall cancer control plan. After completion of rollout, continuous monitoring, evaluation and quality improvement of the routine service programme is required.

Understanding the process of quality-assured programme implementation facilitates efforts to ensure that screening is performed in a manner which is acceptable to the population and achieves maximum, appropriate benefit with the least possible harm and expense. Planning followed by feasibility testing, piloting and phased rollout across a country or region enables the responsible authorities to control the pace of implementation. This permits verification that requisite changes in current practice will effectively maximize benefits and minimize risks of screening, before substantial numbers of people are exposed to screening and before substantial resources are consumed.

In most EU countries the translational phase up to completion of rollout has taken 10 years or more. The duration can be reduced through international exchange of experience and collaboration to avoid pitfalls encountered in other programmes and to mobilize external resources for training and coaching [5, 7].

International Agency for Research on Cancer



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## Table 1: Process of quality-assured screening programme implementation

1. Comprehensive **planning** of screening process: feasibility of screening models, professional performance, organization and financing, quality assurance
2. Preparation of all components of screening process to perform at requisite high level (including **feasibility testing**)
3. **Expert verification** of adequacy of preparations
4. **Piloting** in routine settings and modification, if necessary, of all screening systems and components, including quality assurance
5. **Expert verification** of adequacy of pilot performance
6. Transition of pilot to service screening and geographically phased **programme rollout** in other regions of the country
7. Intensive **monitoring of programme rollout** for early detection and correction of quality problems
8. **Continuous quality improvement** of routine programme

## INTERNATIONAL MEETINGS AND WORKSHOPS

The need to translate the generic elements in the process of programme implementation outlined in Table 1 into a more detailed action plan tailored to the objective needs and capacities in a given country or region has been acknowledged at a number of international meetings and workshops co-financed by the EU (ECOC [14] network meeting in Warsaw in May 2010, EUSANH [15] workshop in Stockholm in February 2011) and coordinated by IARC and the WHO (expert advisory missions to Albania in June 2010 and Belarus in February 2011). Table 2 presents a typical plan that lists the main actions that are required in the implementation process from appointment of the steering committee to the country-wide roll-out and follow-up of a service screening programme.

The European experience shows that several factors are crucial to successful implementation of the process and plan outlined in Tables 1 and 2. They cannot all be mentioned here. The following points have been of particular relevance in the national consensus workshops held during the above-mentioned IARC/WHO expert missions.

## Table 2: Action plan for establishing population-based cancer screening programmes

1. **Governance**
  - Establish steering committee
  - Appoint responsible coordinator of pilot screening programme(s)
  - Establish expert advisory board (include representatives of civil society)
  - Develop proposal for financing phases 2 and 3
2. **Coordinator prepares work plans (for discussion with advisory board and approval by steering committee) including**
  - Feasibility testing followed by piloting
  - Budgeting
  - Organizational development (pilot leads, reference centres and other capacity for direct scientific and technical support)
3. **Feasibility testing in small scale studies**
  - Screening modalities (invitation, testing, diagnostic work-up, treatment)
  - Quality assurance
  - Revision of work-plans depending on results of feasibility testing
4. **Initial workshops and other training** for screening and other relevant staff (continuous process adapted to scale of programme activities)
5. **Pilot testing (large scale, "routine" setting)**
  - Designate suitable regions to pilot routine screening programme
  - Two rounds of breast screening, similar minimum pilot duration for cervical and colorectal screening
  - Screening modalities (invitation, testing, diagnostic work-up, treatment)
  - Monitoring and managing performance
  - Other aspects of quality assurance, including training
  - Reporting results
  - Revision of work-plans depending on pilot results
6. **Management and Evaluation (M&E) unit for the national programme (establish during the pilot phase)**
  - Establish organizational entity for M&E
  - Develop database for nationwide programme implementation
  - Monitor infrastructure for nationwide delivery of personal invitation
  - Monitor results of the programme, and develop performance indicators
  - Develop quality criteria for phased rollout and revise work-plans accordingly
7. **Countrywide roll out of the screening programme/after elaborating the same issues (see 5 and 6) in programmatic management.**
  - Phased rollout, beginning in a given region only after quality criteria are fulfilled
  - Monitor results of the programme, and further develop performance indicators

## AUTONOMOUS PROGRAMME MANAGEMENT

Adequate control of the process of screening programme implementation requires effective coordination of all activities, including quality assurance. Effective coordination requires an autonomous organization with managerial and budgetary control of programme activities, and appropriate governmental oversight

## LONG-TERM POLITICAL COMMITMENT AND SUSTAINABLE RESOURCES

Long-term political commitment is crucial to sustaining the dialogue and the institutional support for initiating and maintaining changes in current practice during the lengthy pilot and rollout phase of nationwide screening programmes. Sustainable resources are needed, not just to maintain all of the activities in the screening process, but also to coordinate the programme implementation process over a period of 10 or more years and in the subsequent decades in which the impact of screening becomes evident [16].

## CANCER REGISTRATION

The availability of accurate and complete cancer registry data for a target cancer is essential to quality assurance of cancer screening programmes, including the evaluation of programme impact.



Fig 2: The European guidelines for quality assurance in cancer screening INVOLVEMENT OF CIVIL SOCIETY

Involvement of public, patient and client representatives in the development of the programme and in monitoring and evaluation will help to take the perspective of the target population into account in delivery of screening services.

## ROLE OF GOVERNANCE

The role of the responsible authorities should be to provide oversight, political support and adequate, sustainable resources for the programme, including particularly coordination and quality assurance. As recommended by the WHO, these efforts should not be conducted in isolation, but integrated into an overall framework of comprehensive cancer control [17].

## CONCLUSIONS

In light of the projected increase in the burden of cancer in the coming decades, population-based cancer screening using evidence-based tests and with effective quality assurance is becoming an increasingly important tool of cancer control.

The experience in Europe shows that the process of implementing population-based cancer screening programmes across a country can be managed by coordinated planning, feasibility testing and piloting prior to geographically phased rollout.

It would be short-sighted, however, to assume that all of the problems of implementing screening as a tool of cancer control have been solved. Better understanding of the translational process of programme implementation has the potential to improve the effectiveness and the appropriateness of cancer screening.

Given the long time frame of ten or more years that is required to implement population-based cancer screening programmes of appropriate quality, and the even longer time frame required to effectively evaluate the results of service screening programmes, timely, sustainable investment in infrastructure in Europe to continuously improve the quality and effectiveness of service screening programmes should be high on the public health agenda.

## ACKNOWLEDGEMENTS AND REFERENCES

- Financial support from the EU Public Health Programme (project no. 2008022, European Cooperation on development and implementation of Cancer screening and prevention Guidelines (ECOC-ENP)) and from a bilateral agreement between the Republic of Belarus and WHO EURO (BAR-BOC award no. 05474) is gratefully acknowledged.
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# Belgian Cancer Plan

*Belgian Cancer Centre*  
*'A centre to optimise the fight against cancer in Belgium'*  
**TO FACILITATE, TO INVENTORY and TO ADVISE**

## Why a Belgian Cancer Plan?

### 1. An answer to policy issues:

- Recommendations WHO
- Recommendations European Union
- Belgian Oncological White Book published in 2007
- Discussion panels by the Belgian Minister of Health Care and Social Affairs, Laurette Onkelinx 2008

### 2. An answer to societal needs:

- Decrease morbidity and mortality
- Decrease cancer incidence
- Improve the quality of life of the patient and his family
- Support healthcare workers
- Facilitate the implementation of a qualitative oncological health system

The Belgian Cancer Centre is one of the initiatives taken in the Belgian Cancer Plan 2008-2010.

## Mission Belgian Cancer Centre

The missions of the Belgian Cancer Centre are

- (1) to formulate (evidence-based) proposals of measures for future Belgian Cancer Plans and
- (2) to evaluate and monitor the Belgian Cancer Plan and policies
- (3) to guarantee active involvement of all stakeholders in Belgium including patients
- (4) to centralise all relevant evidence, expertise and knowledge with regard to cancer and cancer-related issues.

## Working methods Belgian Cancer Centre

Working methods	Position of the Belgian Cancer Centre
Multilateral consultations / process facilitation	Consultation
Knowledge	Integration Centre
Impact analyses	Scientific advisory organism

## Creation of the Belgian Long-Term Vision in the fight against cancer

The Belgian Cancer Centre acts as a central facilitator between and within all relevant Belgian stakeholders in oncology. In order to guarantee a structural integration of the existing knowledge and expertise, different phases were identified in order to create the Belgian Long-Term Vision in the fight against cancer.

## Working methods overview



The Belgian long-term vision in the Action Against Cancer (2009-2010) was approved by all stakeholders and forms the basis for future proposals to be taken in a given Belgian Cancer plan.

## All Belgian stakeholders involved

In order to make sure that all Belgian stakeholders were involved in the creation of the long-term vision in the Action Against Cancer, the selection process of experts was divided into:

### 1. Selection criteria for content discussions:

- Expertise supplied by the coordination platform
- Scientific information within a given domain
- Experienced practitioner
- Equal distribution between the different institutions / organisations
- Balanced composition of the corpus medicus
- Equal composition in the experts and their mother language

### 2. Selection criteria for feasibility discussions:

These are the selection criteria for content discussions and two additional criteria:

- The presence of necessary social partners
- Equal representation of the necessary professionals

### 3. Four participation options:

For practical reasons the participation of the experts within the focus groups was limited to 20 persons per group and the participation was voluntary. To accommodate the busy schedules of the experts, 4 participation options were given:

- Getting information by reading reports
- Apply questions to the focus groups
- Active participation in the focus groups and Delphi rounds (face to face)
- Active participation in the Delphi rounds (electronic survey)

**In total, 237 different experts were involved and shared their expertise, 870 different recommendations were recorded.**

# The cure of cancer: a European perspective



Silvia Francisci, Claudia Allemani, Riccardo Capocaccia, Roberta De Angelis, Gemma Gatta, Maryska Janssen-Heijnen, Sandra Mallone, Daniela Pierannunzio, Silvia Rossi, Milena Sant, Andrea Tavilla and the EUROCARE Working Group

Main goals of cancer care are the **cure of patients** and the **gain in life expectancy** for fatal cases.

**Classical indicators** measure survival **improvements** of patients **at a given time** (5 years since diagnosis) without distinguishing cure patients from those bound to die for cancer.

**Mixture survival models** take into account information on survival over **the entire patients lifespan** and allow to identify the proportion of patients cured from the disease and the time to death for not cured patients.

## Aims of the present study:

1. to analyse and describe cancer survival in 18 European countries, for major cancer sites, using mixture survival models.
2. to summarise and interpret cancer survival differences on geographical patterns over the period 1988-1999 in terms of: **probability of cure (P)** **life expectancy for patients who can not be cured from the disease (T)**

### Data

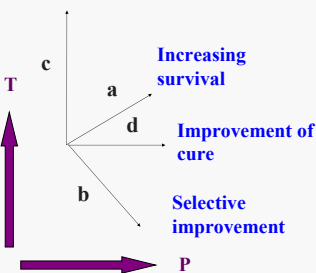
Cancer specific incidence and patients life status follow-up over the period 1988-1999 for 49 Cancer Registries, representing 18 European countries (source: **EUROCARE-4 study** data base); Life tables for the general populations over the same period 1988-1999 for the 18 European countries

→ **INPUT DATA: Relative survival**

### Results

The framework interpretation of changes in mixture survival model parameters in the T versus P plane

### Diagnostic anticipation



### Model

Estimates are specific by cancer site and country Input data are stratified by age

and period of diagnosis

$$RS(t) = P + (1-P)W(\lambda, \gamma, t) \rightarrow \text{estimates of } P, T$$

where

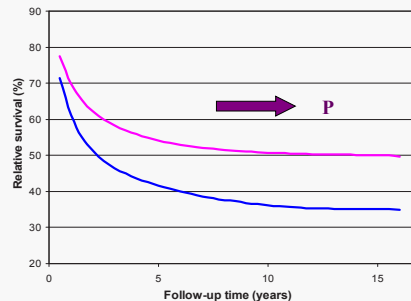
t = follow-up time

P = proportion of cured patients

(1-P) = proportion of *fatal* cases

W = Weibull distribution  $\exp(-\lambda t)^\gamma$

$\lambda, \gamma$  scale and shape parameters of the distribution



### GEOGRAPHICAL DIFFERENCES

A = AUSTRIA  
FIN = FINLAND  
S = SWEDEN  
CZ = CZECH REP.  
I = ITALY  
SCO = SCOTLAND

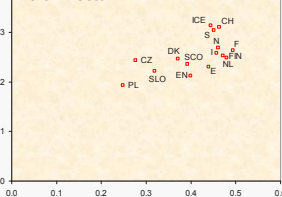
D = GERMANY  
ICE = ICELAND  
SLO = SLOVENIA

DK = DENMARK  
N = NORWAY  
CH = SWITZERLAND

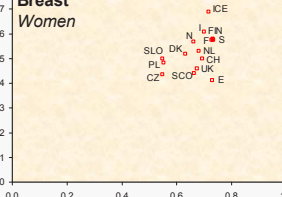
E = SPAIN  
NL = NETHERLAND  
UK = ENGLAND

F = FRANCE  
PL = POLAND  
WAL = WALES

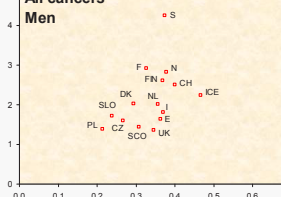
#### Colon Rectum



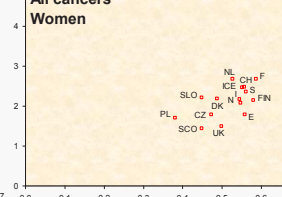
#### Breast Women



#### All cancers Men



#### All cancers Women

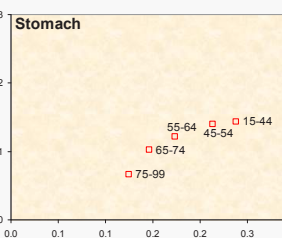
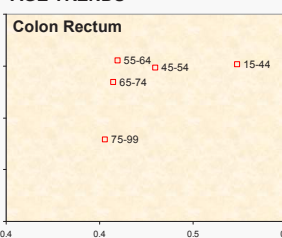


**Colon and Rectum** → real prognostic differences among countries due to combined effect of earlier diagnosis and more effective treatments

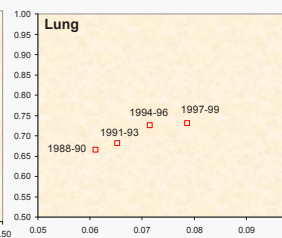
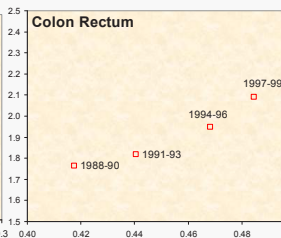
**Breast** → advantages on P of western European countries suggest positive effect of screening activities

**All cancers** → different case-mix by country, P can be used as indicator of cancer control, including diagnostic and treatment improvements and measures for cancer prevention

### AGE TRENDS



### TIME TRENDS



**P and T inversely related with age:** younger patients have more chance to be cured and survive longer than older patients

**Survival is improving overall in Europe** for major cancer sites here considered

### Discussion

Cure models provide summary survival indicators useful for **comparison purposes** and for **interpreting different survival patterns**

**Caution** should be taken when applying cure models to cancer sites for which an excess death risk for patients after many years still persist (i.e. **breast, prostate**)

**P and T indicators** can be addressed both: to **clinicians** (to improve understanding and communication with patients community) and **public health planners** (to better allocate health care resources)

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