**European Partnership for Action Against Cancer**Joint Action

# **CONFERENCE BOOK**

Open Forum Rome, 19 & 20 June 2012

**Spotlight on Health Promotion & Prevention and Cancer Data & Information** (Work Packages 5 & 9)



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.



Editors Marija Seljak, Sandra Radoš Krnel, Marjetka Jelenc

Proofreading and Editing Tina Lipušček

> Authors Riccardo Capocaccia, John Dalli, Yana Dimitrova, Gauden Galea, Rute Horta, Luc Joosens, Susan Knox, Sandra Radoš Krnel, Susanna Leto di Priolo, Francesco de Lorenzo, Ciarán Nicholl, Renée Otter, Aloiz Peterle, Michel Richonnier, Ulrik Ringborg, Stefano Rosso, Milena Sant, Stefan Schreck, Reinhold Stockbrügger, Marie-Christine Wilmink, Martin

> > Wiseman, Wendy Yared

N. Alcaraz (CSISP, DGISP), Giuseppe Banna (Medical Poster Authors

Oncology and Breast Unit, Cannizzaro Hospital, Catania/ Italy), A. Molina-Barceló (CSISP), E. Capelletto (University of Turin, AOU San Luigi/Italy), S. Castán (CSISP, DGISP), B. Crida (University of Turin, AOU San Luigi), Domenico Galetta (Medical Oncology, Cancer Institute "Giovanni Paolo II, Bari/ Italy), F. Giner (CSISP), Marjetka Jelenc (IVZ), Sandra Radoš Krnel (IVZ), M. Giaj Levra (University of Turin, AOU San Luigi/Italy), M. Longo (University of Turin, AOU San Luigi/ Italy), C. Mantovani (University of Turin, AOU San Giovanni Battista/Italy), J. Miranda (CSISP, DGISP), J. Moreno (CSISP), S. Novello (University of Turin, AOU San Luigi/Italy), M.V. Pacchiana (University of Turin, AOU San Luigi), R. Peiró-Pérez (CSISP, DGISP), S.G. Rapetti (University of Turin, AOU San Luigi), R. Ronchetta (Medical Oncology, Cancer Institute "Giovanni Paolo II, Bari/Italy), D. Salas (CSISP, DGISP), M. Talavera (Universidad de Valencia), G. Vallés (Universidad de Valencia), S. Vallone (WALCE/Italy), M. Vanaclocha (CSISP), T. Vavalà (University of Turin, AOU San Luigi/Italy),

Aurora, Bristol-Myers Squibb Foundation

Publisher National Institute of Public Health of the Republic of

Slovenia (IVZ)

Graphic design template Motiviti. d.o.o.

Address of the Editorial Office European Partnership for Action Against Cancer (EPAAC) and Administration Joint Action

National Institute of Public Health, Republic of Slovenia.

Trubarjeva 2, 1000 Ljubljana, Slovenia

E-mail partnership.cancer@ivz-rs.si

Internet home page www.epaac.eu

### **Contents**

Annexes - How Europe Went into Public Health in 198780
Posters
Cancer Data and Information Abstracts60
Cancer Data and Information Summary54 Milena Sant, WP 9 Leader
Health Promotion and Prevention Abstracts40
Health Promotion and Prevention Summary35 Wendy Yared, WP 5 Leader
Media Training
EPAAC Update
25th Anniversary of Europe Against Cancer
Welcome and Introductory Remarks
Marija Seljak, Acting Director, National Institute of Public Health Slovenia

### Introduction



### Introduction

#### Dear Readers and EPAAC Stakeholders,

Thank you for reading this e-conference book of the second Open Forum of the European Partnership for Action Against Cancer (EPAAC).

The Open Forum took place on 19 and 20 June and was hosted in Rome by the Italian Ministry of Health. This year's Open Forum was a bit different from the inaugural Open Forum last year – alongside an interesting conference programme focusing on Cancer Prevention and Health Promotion (WP 5) and Cancer Information and Data (WP 9), we also held a Media Training Session for journalists from across the EU with informative sessions on how to report on cancer. A press conference also took place immediately prior to the Open Forum and we are extremely grateful to Commissioner Dalli, Italian Minister of Health Balduzzi, Slovenian Minister of Health Gantar and Member of the European Parliament Peterle, for their attendance and contributions both at the press conference and for welcoming the Open Forum guests in the first session

We would like to also thank all of the speakers at the Open Forum for delivering informative presentations. For all those who could not attend the Open Forum in person, we have prepared this e-book with summaries, speaker abstracts and posters from the Open Forum Rome.

I would like to take this opportunity to invite all stakeholders in the EPAAC and cancer fields to attend the final EPAAC Open Forum, which will take place at Brdo pri Kranju, Slovenia in November 2013, focusing on the final results and outcomes, as the event is scheduled to take place two months prior to the official end of the EPAAC Joint Action.

Marija Seljak

Acting Director, National Institute of Public Health Slovenia

### **Welcome and Introductory Remarks**



### Welcome Speech

John Dalli, European Commissioner for Health and Consumer Policy

On the occasion of our second Open Forum of the European Partnership for Action against Cancer, we also celebrate the 25th anniversary of the EU action against cancer.

We have come a long way since EU action on cancer began, 25 years ago. Together with Member States and stakeholders, the Commission has supported many actions on cancer. The present European Partnership for Action Against Cancer is one such outcome and is a demonstration of our collective commitment.

We count on our Partnership to support Member States in establishing and implementing national cancer control plans, by fostering exchange of knowledge and developing guidelines and indicators to help them in this process.

Despite our achievements in the past decades, a lot remains to be done as cancer still claims the lives of well over 1 million citizens every year. We need to do more - together - to better prevent and control cancer across the whole of the European Union. I am committed to supporting actions that add value to national endeavours in cancer prevention and control in a sustainable manner.

The two themes of this year's Open Forum are cancer prevention and cancer information.

Primary prevention is the first step that can reduce the incidence of cancer. Let us not forget that one in three cancers is preventable! What people eat, drink, and do, and whether or not they smoke are the key factors in building prevention. Together with Member States, we share the responsibility to inform our citizens on how to improve their health and avoid certain cancers, by making healthier choices as early in life as possible. This is precisely what European action on promoting good health seeks to achieve, together with the European Partnership for Action Against Cancer and working through key tools such as the European Code Against Cancer.

Smoking is the biggest preventable risk factor for cancer. My aim is to make tobacco products less attractive for young people, and to discourage them from getting addicted to nicotine in the first place. It is in this spirit that I plan to propose a revision of the Tobacco Products Directive later this year.

The second theme on the Open Forum Agenda is cancer information. Accurate and comparable data on cancer is vital for planning, implementing and evaluating programmes for cancer prevention, control and care.

Registries on cancer are more advanced than for any other disease. Those Member States that have up-to-date national or regional cancer registries harbour a rich resource of valuable information. This information is essential to compare the incidence and burden of cancer at European-level and to plan, implement and evaluate effective cancer prevention and control strategies.

The EU has supported many projects to enable the provision of comparable data and has encouraged high quality standards and networking of cancer registries. A key purpose of the European Partnership for Action Against Cancer is to contribute towards building a shared comprehensive cancer information system for the European Union. The European Commission is committed to fostering sustainable long-term cooperation in cancer data and information. It is with this in mind that we are now co-operating with the European Commission's Joint Research Centre and with key stakeholders in this area. I appreciate and admire the dedication of all of you that have spared no effort in taking action against cancer and I look forward to future co-operation, and future successes, in tackling the challenges that lie ahead.

Based on the speech from the Open Forum, Rome, 19 June 2012



# Raising Awareness for Cancer Prevention in the EU and Beyond

Alojz Peterle, Member of the European Parliament

The European Week Against Cancer (EWAC) takes place from 25 to 31 May each year. This Week has been relaunched as one of the actions of the Joint Action "European Partnership for Action Against Cancer" (EPAAC) 2011-2014 and an is initiative of the Association of European Cancer Leagues (ECL), the leader of the Work Package on Health Promotion and Prevention.

During EWAC, health promotion and prevention messages are stepped up all over Europe, with special attention to populations which can benefit from targeted communications such as youth, women, or the ageing society. European citizens are reminded that they can prevent at least 33 to 40% of all cancers by adopting healthier lifestyles as outlined in the evidence-based European Code Against Cancer (www.cancercode.eu), including tobacco control, increasing physical activity, limiting alcohol consumption, adopting a healthier diet, avoiding excessive UV exposure, participating in screening and vaccination programmes, etc.

The Members of the European Parliament (MEPs) Against Cancer (MAC) group is dedicated to the actions of the European Partnership and supports the work of its work packages through various ways such as the hosting of meetings on related themes. As the European Parliament's Rapporteur on the Commission Communication on Action Against Cancer: European Partnership, I have pointed out that in the time of financial crisis, the European Partnership has a great opportunity to encourage Member States to invest more in the prevention and healthy lifestyle. To more effectively coordinate activities and actions that are taken within different policy areas by Member States and other stakeholders, we have to consistently cooperate more closely with employers and employees.

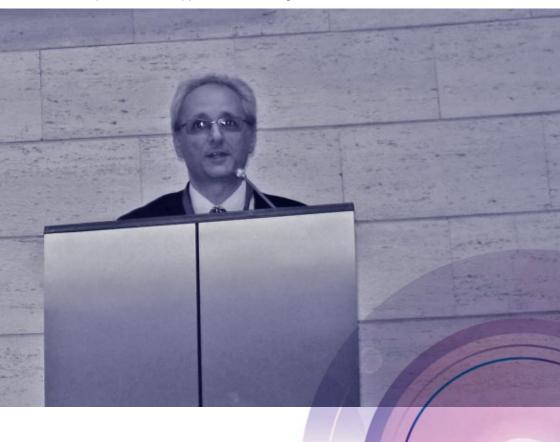
In 2011 when the Partnership started, MAC hosted a meeting on colorectal cancer screening to raise visibility for the new EU colorectal cancer guidelines, and later in the year on an update of the Partnership Against Cancer actions. I was invited to represent MAC during the Open Forum of the Partnership in Madrid where I reiterated our dedication to support all work package actions toward the long-term aim of the Partnership in reducing cancer incidence by 15% by 2020.

While it is important for politicians and policy-makers to support the work of this Joint Action Partnership, we can increase awarness of health promotion and cancer prevention in other ways. The Partnership gathers stakeholders to work together at the European level. The opportunity exists to engage policy-makers at the national level to advance cancer prevention. One way is to support the development and/or the implementation of national cancer control plans. Another is to encourage the implementation of EU screening guidelines in our countries. Most importantly we should support tobacco control efforts- for instance, by increasing taxes on tobacco products (5% above inflation) and by supporting effective pictorial health warnings covering 80% of the back and front of tobacco product packaging.



# Public Health Policy Makers Gauden Galea, World Health Organization Europe

The key implications for public health policy makers of the Political Declaration of the United Nations (UN) High Level Meeting, the developing European Health Policy (Health 2020), and the European Noncommunicable Diseases (NCD) Action Plan will be reviewed. While the policy environment is rich in support for the NCD agenda, there remain major barriers to the development and implementation of cancer control programmes in many European Member States. The presentation has reviewed current demand for development of national policies, and opportunities for regional collaboration.



### 25th Anniversary of Europe Against Cancer



### How Europe Went into Public Health in 1987 History of a Beginning: Europe Against Cancer

Michel Richonnier<sup>i</sup>, Pioneer of the Europe Against Cancer Programme

To answer the above question, one has to go back thirty years ago: Europe (10 countries) was, as today, confronted by a serious crisis with unemployment rates close to 10% in France and Germany and 15% in Belgium, the Netherlands and Ireland. A major change took place in 1985 as a result of the then newly appointed European Commission.



Jacques Delors

Its President, Jacques Delors, succeeded in convincing the Heads of State and Government, as well as both sides of industry, that establishing a true Internal Market, before the end of 1992, would boost growth and employment. To that end, the Member States would have to abandon their right of veto, which they had so often used in the past, and move to majority voting in order to lift the many barriers that were hindering the Common Market. This revolutionary change was introduced in a new Treaty, the Single European Act of July 1st 1987...and this would, indirectly, make it possible for Europe to make a big leap forward into Public Health. In parallel, the European Council and the European Commission and Parliament were well aware of the fact that Europe could not limit itself solely to the Internal Market!

#### From the Common Market to Social Europe and People's Europe

Already in 1972, at the European Summit in Paris, French President Georges Pompidou underlined that Europe could not confine itself to a Common Market and he called for a Social Europe. This took shape in 1974 with an ambitious Social Action Programme built around two axes, legal and financial. In ten years, some ten European directives (to be implemented through national laws) were adopted, for instance in the area of occupational health. In parallel, the resources of the European Social Fund (ESF) "exploded" from ECU 30 million to circa ECU one billion in 1984\*.

Twelve years later, at the initiative of another French President, François Mitterrand, the European Council in Fontainebleau (June 1984) called for the setting up of a People's Europe. This would lead subsequently to European symbols such as the European flag and anthem (1986) or the European passport (2002) and programmes such as Erasmus as well as Europe Against Cancer. These pioneer programmes opened up the way, in 1987, for Europe to move into education and public health.

\*Editorial Note: ECU refers to "European Currency Unit", an artificial currency used by EU MS for internal accounting purposes and a predecessor of the single EU currency, the Euro

#### A People's Programme : Europe Against Cancer

Launching Erasmus in 1987 was not that easy but the European Commission was then supported by existing European networks of students, professors, and universities ready to implement it. In contrast, for Europe Against Cancer, things were more complex. On one hand, many of the key players in the fight against cancer were not organised at European level. On the other hand, the EEC Treaty did not directly cover public health<sup>iii</sup> and, indirectly there were no other legal alternatives to decisions requiring unanimity<sup>iv</sup>.

A strong political push was therefore necessary. This would happen at the initiative of both French President François Mitterrand and Italian Prime Minister Bettino Craxi, in June 1985 in Milan, when the European Council called for "a European action programme against cancer". As early as November 18, 1985 the Commissioner in charge of Social Affairs, Peter Sutherland, from Ireland, proposed to the European Commission a Council Resolution describing the main action areas for a "European Community Action Programme Against Cancer". On 07.07.1986 the newly appointed Commissioner for Social Affairs, Manuel Marin from Spain, would succeed in getting the Council of Health Ministers to adopt this Resolution after a positive opinion from the European Parliament (OJ C 184 of 23.07.1986): A budget of ECU18 million was granted for 1987-1989 (ECU 10 million for cancer were already available under the Research budget).





François Mitterrand (1916-1996) and Bettino Craxi (1934-2000)





Peter Sutherland and Manuel Marin

#### Drafting a 1987-1989 Action Plan: A Speedy and Concerted Process (1986)

In parallel, the European Commission prepared an action plan with the support of all the external partners contributing to the fight against cancer in Europe. It was not appropriate indeed to invent from "Brussels" what was best for European citizens. Consultation was necessary. Several networks were thus set up, consulted, and mobilised at the beginning of 1986.

- The Committee of Cancer Experts which first met at the end of January 1986. Professor Maurice Tubiana (France) and Umberto Veronesi (Italy) who were at the origin of the Milan European Council proposal were naturally appointed Chairman and Vice Chairman respectively<sup>v</sup>;
- A Group of Senior Officials was also set up to involve all the Health Ministries since they had key responsibilities, notably in the area of training or screening;
- Non-governmental networks were also put in place such as: Associations and leagues against cancer and tobacco and a group of Medical TV programme producers;
- Finally, an internal task force was set up within the Commission<sup>vi</sup> to produce, with the other networks, the first action plan 1987-1989 of the programme.





Prof. Maurice Tubiana and Umberto Veronesi

At the beginning of 1986, a broad consultation was launched to find an attractive name for the programme. Europe Against Cancer was found to be the best label, being understood that Europe was not only the European Institutions and the national Ministries but also those NGOs fighting cancer ... as well as the citizens themselves! During the whole of 1986, this extensive consultation also led to the development of both the programme (not limited in time) and its first action plan (limited to 1987-1989). For the programme, the following objective, strategy and factics were selected:

The objective was to reduce cancer mortality by 15% between 1985 and 2000 (after correction for population ageing);

The strategy was built around two axes, as for Social Europe: The legal one, notably for controlling tobacco and other carcinogenic products and for improving training or screening and the financial one, to support European cooperation;

The tactic was to rely on partnership, internally (to involve all Commission services concerned) and externally with all partners, public or private, at all levels (national, regional or local) mainly through European networking.

This programme was implemented according to the ISO 9001 standard (Say what you do = Action Plan, Do what you say = Implementation, Assess what you do = Eurobarometer survey and Evaluation report). Adopted by the European Commission in December 1986, the first action plan (1987-1989)<sup>vii</sup> was built around four pillars: prevention (tobacco control, nutrition improvement, protection against carcinogenic substances, screening and early detection of cancer); awareness raising and health education notably through the diffusion of the European Code Against Cancer; training of medical staff; epidemiological studies and medical research. Seventy five actions were thus identified for implementation.

This first action plan was the birth certificate of Public Health Europe. The Europe Against Cancer taskforce was transformed, in January 1987, into an administrative division first attached to Vice-President Marin in 1987, then to Jean Degimbe, Director General for Social Affairs, before joining, in 1999, an autonomous DG. In between, the Rome Treaty was modified in Maastricht (1992) to introduce a Public Health chapter "excluding any harmonization of the laws and regulations of the Member States". The European Commissioner in charge of Public Health cannot therefore be considered as a European health Minister when it comes to laws and regulation.

## Breakthrough in Awareness Raising and Health Education: The European Code Against Cancer (1987)

Drafted by the Committee of Cancer Experts, these Ten Commandments, covering cancer prevention and early detection, were adopted by all NGOs fighting cancer and also all Ministries of Health. This short document (see Annex 1) was all the more important as the European Council in London (December 1986), with the strong support of Margaret Thatcher, selected 1989 as the "European Year of Information on Cancer" The European Code was its cornerstone. It would be formally handed over to the European Council in Copenhagen in December 1987.

This text was extremely cautious, due to the scientific uncertainties that prevailed at the time, notably in the nutrition and screening areas. This 1987 European Code was distributed and broadcast throughout Europe by all partners of Europe Against Cancer. Several European TV programmes were produced and broadcast in the first European Week Against Cancer (1-7 May 1988) and in 1989, the European Year of Information on Cancer. For example, in May 1988 "Lifestyle and Cancer in Europe" was broadcast by 11 TV channels with a large number of viewers (6 million in Germany). 1989 was closed by a "Eurovision Against Cancer" broadcast by 12 channels across Europe that attracted positive reviews by the press.

Further other information and health education support was provided and disseminated by all partners of Europe Against Cancer, notably posters illustrating the European Code Against Cancer with maps showing differences in mortality by cancer across different European regions and linking them with differences in lifestyle (for example, high mortality from oesophageal cancer in Normandy and Brittany due to high alcohol consumption)<sup>ix</sup>.

The impact of these awareness raising campaigns was regularly assessed by Eurobarometer surveys. Thus, the % of Europeans having heard about the European Code against Cancer increased from 16% in 1988 (after the European Week against Cancer) to 25 % in 1990 (after the European Year). Also, 38% of Europeans knew about the existence of Europe Against Cancer at the end of the first three year action plan!



Autumn 1986: 10 Downing Street

### Breakthrough in European Laws on Tobacco Control: Thanks Twice to the Milan European Council (1985)

The European Council in Milan, in June 1985, played a key role in initiating Europe Against Cancer. What is less well known is that this European Council also played a major role in implementing the programme's legal axis. Indeed Prime Minister Bettino Craxi made a revolutionary move by getting the European Council to vote for the first time in its history. The issue at stake dealt with the opportunity to convene an Intergovernmental Conference for modifying the Rome Treaty in order to set up a true Internal Market by 1992, thanks to majority voting. Since Mrs Thatcher was reluctant to go that way, Bettino Craxi called for a vote which the Iron Lady lost<sup>x</sup>. The Intergovernmental Conference was set up and the new Treaty entered into force on July 1st 1987. This fast decision was essential for tobacco control. Indeed, the former article 100 EEC (unanimity) was replaced by article 100A (qualified majority) that, moreover, stated that: "the Commission, in its proposals envisaged in paragraph 1 (internal market) concerning health, safety, environmental protection and consumer protection, will take as a base a high level of protection, taking account in particular of any new development based on scientific facts. Within their respective powers, the European Parliament and the Council will also seek to achieve this objective." The legal puzzle was resolved - one had simply not to speak about "tobacco control and public health" but about "lifting the obstacles to the functioning of the internal market for tobacco products". In other words, when it comes to European laws, the national wording "public health" had to be translated into "internal market". This allowed a speedy process for the adoption of the first two directives<sup>xi</sup>.

#### CERTAINS CANCERS PEUVENT ÊTRE ÉVITÉS:



Votre santé bénéficiera des deux commandements suivants qui peuvent aussi limiter les risques de certains cancers





CONSCIMINATION DE



S. CONSCIONEZ QUESTIONES FELTS DES LÉCUMES FRAIS ET AUMENTS RICHES ES







#### N PLUS GRAND NOMBRE DE CANCERS SERONT GUÉRIS S'ILS SONT DÉTECTÉS PLUS TÔT

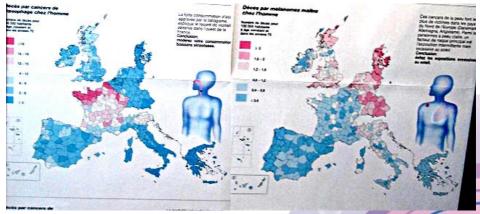








#### Poster on the European Code Against Cancer (1987)



Death by oesophageal cancer: "Moderate your consumption of alcoholic beverages"

Death by melanoma:

"Avoid excessive exposure to the sun"

For the maximum tar content directive, the ceiling of 15 mg by the end of 1992 was recommended by the Committee of Cancer Experts. The task force added the 12mg ceiling by the end of 1995 to emphasize that it was a dynamic process that would not end in 1992. Also, several cancer experts and NGOs requested a limit for CO content. For both tactical ("do not overload the boat") and statistical reasons (the two variables are highly correlated, see Annex 2), it was not done. This was well understood by the external partners of the programme. The second directive on the labeling of tobacco products was inspired by the Irish law. A general warning "Tobacco seriously damages health" was to be printed on the most visible surface of all unit packets of tobacco products. With regard to cigarette packets, the other large surface of the packet had to carry alternating warnings such as "Smoking causes cancer" or "Smoking causes heart disease". Here again, the task-force had to limit the enthusiasm of external partners, many of them willing to have extensive health warnings, whereas the surface of a cigarette packet was necessarily limiting the length of such warnings. The task force also suggested limiting as much as possible the length of health warnings to five words ... which was not always possible (see Annex 2). Manuel Marin, Vice President in charge of Social Affairs, had these two proposals approved by the European Commission at the end of 1987xii. The tobacco lobby was furious since it was convinced that such proposals could only be based on unanimity voting. Mrs. Thatcher was also furious because she considered that such issues should be dealt with through voluntary agreements. As in Milan, in June 1985, voting was called for in the Council of Health Ministers and the tobacco lobby was defeatedxiii. Indeed, the labeling directive was adopted on 13.11.1989 and the maximum tar content directive on 17.05.1990xiv (cf. Annex 2).

Finally, even the non binding resolution of 18 July 1989 on the ban of smoking in public places<sup>xv</sup> would be enforced in several countries through national laws.

## Overview of the First Action Plan Implementation: The European Council Expresses its Satisfaction (December 1989)

In parallel to these breakthroughs in health education and tobacco control, numerous other achievements could be mentioned in the area of prevention, training or research as indicated in the report of the European Commission: "Europe Against Cancer- Report on the implementation of the 1st action plan"xvi . For instance several other European laws were adopted such as Directive 89/677/EEC on the protection of consumers against dangerous substances, or Directive 90/394/EEC on the protection of workers from carcinogens at work or Recommendation 89/601/EEC on the training of health professionals. Also, Europe against cancer co-funded European network of studies and actions in several domains, for instance EPIC (European Prospective Investigation into Cancer and Nutrition) that followed up on a few hundred thousand Europeans, ENCR (European Network of Cancer Registries) with some fifty cancer registries to begin with, EBCN (European Breast Cancer Network) that started with nine European countries, or EUROCARE (EUROpean CAncer REgistry-based study on survival and CARE of cancer patients)

Such achievements were praised by the European Council which, in December 1989, in Strasbourg, expressed "its satisfaction at the conduct of the Europe against cancer programme and at the agreement of principle reached on adoption of the second action plan 1990-1994". Indeed, the second Europe Against Cancer action plan (1990-1994) was adopted in May 1990\*\*with a budget of ECU 55 million to support cooperation in the fight against cancer throughout Europe.

#### Twenty-five Years Later (2012)

This overview demonstrated that the People's Europe concept was very fruitful for launching a Public Health Europe (and also an Education Europe with Erasmus). With its pioneer programme, Europe Against Cancer, the European Community, European Union today, has strengthened its human dimension and it has come closer to its people. In 2000, it has been estimated that 92.500 deaths by cancer were avoided (a 9,2% reduction instead of the 15% target)xix thus preventing many people from lengthy suffering and consequently reducing the burden of public health expenditures. Only Austria and Finland reached the 15% target. The UK, Luxembourg and Italy came close. However, Spain, Portugal and Greece did not meet the objective and, even more worrying, their increase in the number of deaths by cancer was larger than the one due to their ageing population. If one now looks at the whole 16 year period (1987-2002), and in the hypothesis of a smooth evolution, 850.000 deaths by cancer were avoided<sup>xx</sup> thanks to the joint effort of all those that fought under the banner Europe Against Cancer: European institutions, Ministries of Health, medical doctors and nurses, epidemiologists and researchers, NGOs fighting against cancer and tobacco ... and of course the people who have implemented the European Code Against Cancer.

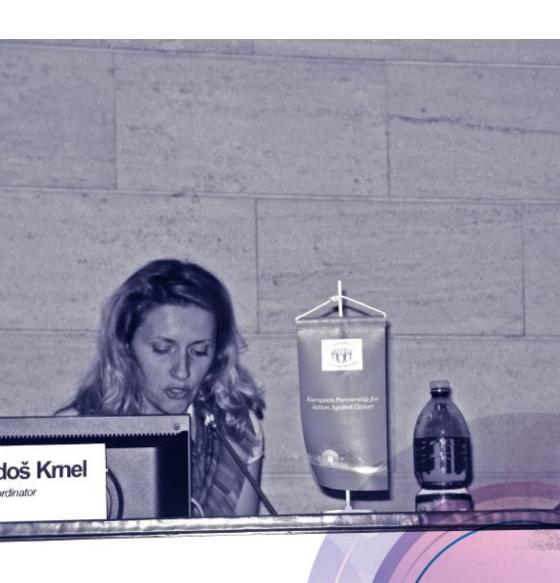
With the first (2003-2008) integrated Public Health programme<sup>xxi</sup>, when many new challenges had to be coped with (SARS, bioterrorism, bird flu)<sup>xxii</sup>, in a period of severe financial constraints, the funding of Europe Against Cancer<sup>xxiii</sup> was severely cut<sup>xxiiv</sup> and it lost momentum and visibility until 2009. Thanks to the joint impulse of the European Parliament, that set up in 2006 a group MEPs Against Cancer, and of some new Member States, notably Slovenia during its Presidency in 2008, the European fight against cancer was re-launched by the European Commission in 2009<sup>xxv</sup> under a new name "European Partnership Action Against Cancer" (http://www.epaac.eu) and with a similar objective i.e. reduce by 15% the number of new cancers detected by 2020. It is thanks to this initiative, and to its three year (Feb. 2011- Feb. 2014) EPAAC Joint Action (EPAAC JA), that we had the chance to meet in this European Cancer Prevention Conference in Rome. Many thanks to the Italian Health Ministry and to the National Health Institute of Slovenia (coordinator of EPAAC JA) for having organized such a successful event.

## Final Thoughts Following Debates or Questions Raised during this EPAAC Open

- 1) The label European Partnership for Action Against Cancer is the new name given to the European cooperation in the fight against cancer. The former label, Europe Against Cancer, was quite successful (38% of Europeans knew about it in 1990) and there is no copyright... Partners of the EPAAC JA could use it if they so wish.
- 2) It would be wise to formulate the 2020 objective in terms of both incidence and mortality and monitor the two variables at shorter intervals. As 25 years ago, European legislations have a key role to play in reaching this objective.
- 3) Thus, it would be appropriate to update the Screening Recommendation of 2003 under the aegis of a scientific committee such as the former Committee for Cancer Prevention. The interesting and conflicting debates during the screening session of this conference prove that there is a real need for that.
- 4) Also, consideration should be given, when updating the Tobacco Product directive of 2001, to reintroducing, in the list of alternating warnings, two short and punchy ones from the 1989 directive: "Smoking Causes Cancer" and "Smoking causes heart disease". The scientific relevance of these warnings is as high today as in 1989xxvi.

- 5) All EPAAC partners should recall that the European institutions have no direct legal powers in Public Health. To forget this opens the way to serious pitfalls. Thus, in 1990, under the pressure of NGO fighting cancer and tobacco, the European Parliament voted in favor of a total ban of tobacco product advertisement. In the euphoria of this vote, the European Commission submitted in May 1991 a directive proposal for a total ban. It was adopted ... seven years later by the Council (98/43/EC)... and was rejected by the European Court of Justice in 2000 (cf. Annex 2): All three European institutions are strictly bound by the Internal Market legal articles when it comes to producing European laws for improving Public Health. This ECJ message was, of course, aimed at all partners fighting cancer in Europe.
- 6) To call for interventions of the European Structural Funds in the area of Public Health, as announced by Commissioner John Dali in introducing this Open Forum, is an excellent and timely idea. Obviously, the fight against cancer is a perfect candidate for mobilizing Structural Funds in order to improve both the training of health professionals and the screening or treatment infrastructures in countries that are the least advanced in the fight against cancer, such as Greece, Portugal or Spain. This will help to avoid lengthy individual suffering, reducing the pressure on public health expenditure in these countries, and humanizing Europe that is, today, perceived as austerity prone and lacking solidarity.

## **EPAAC Update**



# **European Partnership for Action Against Cancer – Update**

Sandra Radoš Krnel, European Partnership for Action Against Cancer Coordinator

Having in mind that 1/3 of all cancer cases are preventable and that prevention offers the most cost-effective long-term strategy for the control of cancer, Work Package 5 - Health Promotion and Cancer prevention led by ECL is focusing its work on the objective to raise awareness about health promotion and cancer prevention by disseminating the European Code Against Cancer, by re-launching the European Week Against Cancer (EWAC) 25-31 May each year and by engaging policy-makers at the European, national, and subnational levels.

The re-launch of EWAC occurred in Brussels in 2011; in 2012 the second EWAC conference was held in Rome, organized by the Italian Cancer League on the themes of Tobacco Control, Screening and Healthy Lifestyles.

Since youth presents one of the target groups for health promotion, there were a few activities in supporting this objective: flash mobs were executed in different European cities as a specific action that attracts youth and additionally the youth competition was organized, targeting youth from the ages of 11to 18. Groups from all over Europe prepared posters and videos with messages on the Code against Cancer.

The activities from Work Package 6 on Screening and Early detection lead by FCS are organized around four major objectives:

- 1.To support the achievement of establishing an intensive comprehensive training course in management of cancer screening programs. The next actions were achieved: Meeting of the senior management team on 8 May 2012 for designing the course and to make the curriculum preparations. It was decided to have a first week module on 19-23 November 2012, at IARC, Lyon, France and a 2nd week module on 11-15 Mar 2013, venue tbd. First announcement and invitations were already released in June 2012. Additionally, a report on pilot audit of a screening management programme conducted in January 2012, was completed in June.
- 2. The second objective is to identify inequalities in cancer screening programmes, therefore the analysis of results of cervix and breast cancer screening were done. There is ongoing preparation of the report on the literature review on participation and compliance and it is targeted for completion in July 2012. At the same time there were activities on preparation of survey design and plan and it is targeted for completion in September of this year.
- 3. To facilitate expert advice to regions seeking to implement or improve cancer screening programmes, the first workshop on colorectal cancer screening programmes was held in March in Liverpool, the report is completed. The second screening workshop on cervical cancers is planned to be in October 2012 in Italy. The draft programme has been developed, the keynote speaker and other speakers have already been invited. The cervical cancer screening programme survey was drafted (now it is in testing phase with selected experts); 26 regions/Member States are identified to receive the survey.
- 4. The last objective in the WP6 is on health checks to develop a pan-European consensus on quality criteria for health checks. A survey on the applicability of the Netherlands' experience to other Member States was prepared. The deadline for the completion was moved to May 2012. The NEN is exerting further efforts to disseminate and follow up responses to the survey. The project team met on 23-25 May 2012, the draft report has been circulated.

Work Package 7 on Cancer Healthcare is led by ICO and its work is organized around 3 major objectives with many specific actions. Listed here are ongoing activities that are planned to be finished by the end of this year:

To set criteria for identifying and assessing best practices focusing on organizational approaches, the actions on the literature review on multidisciplinary care and qualitative review of networks of cancer care are ongoing and expected to be finished by September 2012.

Criteria for literature review on assessing evidence and use of Complementary and Alternative Medicine (CAM) in cancer care are in development, expected by the end of 2012.

The review of experiences on implementing clinical guidelines with focus on addressing inequalities such as access to healthcare is expected in October 2012.

Activities that are planned and achieved until June 2012 are:

International conference to increase policy awareness on Standards of Care for Children with Cancer was organized in October 2011 in Poland and currently these Standards are being disseminated.

To improve treatment, symptom assessment and follow-up of palliative care through a standardized methodology and evidence based guidelines, the expert meeting was held in January 2012, a report is in preparation with a scientific publication expected.

Work Package 8 on Coordination of Cancer Research, led by ECCO, has been acting on 3 levels:

The first level includes input from the scientific community on areas of cancer research that would benefit from coordination.

On the second level, input was received from cancer research funders on the funding landscape.

On the third level, the meeting with Member States was organized on cancer research coordination. It was hosted by the German Ministry of Health and held in March 2012.

This WP is preparing a Research Forum to be held on 2nd of July in Brussels. This meeting will involve cancer research funders, researchers, patients and policymakers to enable them to discuss and agree on potential areas for coordination between Member States, e.g. public-private partnerships for early phase clinical research, platform for outcomes research and innovative approaches for improving coordination and collaboration.

Since Cancer information and Data (WP9) is one of the main topics of this Open Forum, only basic information on what was done in past 16 months will be presented.

This WP led by INT is ahead with the proposed work and the draft proposal for a future European Cancer Information System (ECIS) has been discussed in meetings with representatives from IARC, European Network of Cancer Registries, European Commission, Joint Research Center, and other European institutions and projects.

In contribution to the 2nd objective of the WP 9 – unification of cancer burden indicators under the common platform – the preparation of cancer survival data of patients diagnosed in 2000-2004 to be included in HEIDI and the future ECIS has been achieved as well as establishment of contacts with HEIDI in order to investigate the feasibility of posting cancer indicators.

Additionally, the Ispra meeting between EUROCHIP, EUROCARE and EPAAC WP 9 was held aiming to connect EPAAC WP9 with other European activities.

Knowing that cancer incidence is increasing and that cancer costs are increasing even faster than the available resources, it is very important to have standardized and comparable data on cancer costs on the European level. In this regard, OECD activity on System of Health Accounts (SHA) was connected with EPAAC WP 9.

Besides the mentioned activities, the collection of socio-economic data for the regression analysis already started and data collection for national cancer registry areas is nearly concluded.

Regarding the Work Package 10 on National Cancer Plans (NCP), led by IVZ Slovenia, much work was done on preparing the questionnaires on NCPs, these were sent to all MS, Norway and Iceland, we achieved a 100% response rate. The first draft report on NCPs was discussed at the SC meeting in Ljubljana in 2011.

At the Core Working Group (CWG) on NCPs meeting in Malta (February 2012) it was decided to prepare two types of report: a technical report (focused on the response analysis of the questionnaires) and a full analysis of the questionnaires with the background, methodology, conclusions and recommendations. The final version of the technical report has been completed in June and the main topics in this WP at the moment are the guidelines for high-level NCPs as well as respective indicators.

At the end I would like to mention dissemination activities which are very important for us since it is the face that the Partnership is showing to the different stakeholders and interested public.

On our website there are 2 major improvements achieved in May 2012:

- The Open Forum and Steering Committee sections were prepared with all information relating to these events and the conclusions,
- The EPAAC GANTT chart was published; it contains the latest updates on project milestones and deliverables with links to available documents.

This autumn we are starting with the EPAAC social campaign on Facebook. It will be a special Facebook social game application to be used as a platform to promote cancer prevention. We will motivate users through 'gamification' to engage with our mission and values and perform actions. Facebook users will become our activists and recruit their friends to also perform actions for a good cause and have fun.

At the end, I would like to thank all of our partners for the great job they have been doing, a special thanks goes to all Work Package Leaders.

## **Media Training**



### Media Training Off-The Record: Can Europe Cope with the Rising Burden of Cancer?

Kathy Redmond, European School of Oncology

Twenty two journalists from 17 EU member states and neighbouring countries participated in a two-day training course.

On day one the group looked at the statistics showing how your chances of getting and surviving cancer vary considerably across European countries, and looked at all the things that have to be done right to minimise the number of new cases and maximise survival with a good quality of life.

On day two the journalists heard from the man who was called in to sort out the UK's cancer services in 1999, after a set of Europe-wide statistics had convinced the government that the UK's results were in the bottom half of the European league table. The journalists then took a look at how far other European countries have been taking up the idea of a 'cancer plan' or programme to improve services, and this was followed by a panel discussion on "Delivering high-quality cancer care in an age of austerity", with views from the clinic, from policy making and the pharmaceutical industry.

The journalists appreciated the chance to get new information and ideas. They said they would put this to use by focusing more on the context behind the stories they cover on individual patients, to "act as a bridge between the patient and the policy makers."

# **Innovative Approaches in Cancer Prevention and Health Promotion**



# Summary: Health Promotion and Prevention

Wendy Yared, Association of European Cancer Leagues, WP 5 Leader

The Association of European Cancer Leagues (ECL), as the leader of the EPAAC Work Package 5 on Health Promotion and Cancer Prevention organized a session on "Innovative Approaches in Cancer Prevention and Health Promotion" to showcase how some organizations and companies are forwarding prevention in original ways.

The President of the Italian Cancer League, Francesco Schittulli, presented on the various prevention campaigns and actions of the League, as it celebrates its 90th anniversary this year. Its actions in primary prevention are in information campaigns, publication of brochures, and health education interventions in schools and at events. Secondary prevention is through the clinics of the provincial departments. The Italian League's actions in tertiary prevention focuses on caring for patients with home care, physical rehabilitation as well as psychosocial rehabilitation. The Italian League recently hosted the Official Conference for the European Week Against Cancer in May at the Ministry of Health, and an entire day was devoted to tobacco control and EU policies.

Gauden Galea of the World Health Organization's Regional Office for Europe stressed the importance of cancer prevention in the context of their non-communicable disease strategy, namely in the areas of nutrition, obesity and physical activity. Cancer prevention is seen in the larger context of health promotion at WHO.

An update was provided for the Work Package 5 by Wendy Yared of ECL. The 2012 Official Conference for the European Week Against Cancer was hosted by the Italian Ministry and organized by the Italian Cancer League end of May. The overarching themes were tobacco control for 31 May, World No Tobacco Day, where there was a debate on EU tobacco control policies. A scientific seminar followed the next day on Screening and Healthy Lifestyles where national case studies were presented. Presentations would be made

available on the ECL website.

Martin Wiseman of the World Cancer Research Fund presented "Evidence on Cancer Prevention and Health Promotion" to lead into the case studies by organizations and companies. It was stressed that that a third of the commonest cancers could be prevented through improved patterns of diet and activity, and healthy body weight. A dietary pattern which is high in fibre-rich plant foods and low-energy, relatively unprocessed foods, and low in red and processed meat, alcohol, salt and high energy foods, together with being physically active, will also prevent other noncommunicable diseases

Luk Joossens of ECL followed with a presentation on "How to Put Pressure on Your Politicians" using a country ranking scale. Governments are very sensitive to their image and rankings. The Tobacco Control Scale quantifies tobacco control policies at country level. Last year, ECL published for the fourth time the ranking of tobacco control policies in 31 European countries. The top five countries (UK, Ireland, Norway, Turkey and Iceland) all have policy on tobacco control with high prices for tobacco products and complete smoking bans, including in bars and in restaurants. These measures are considered to be the top two of the most effective policies and are therefore rewarded with the highest scores. Four of these countries recently decided to ban the display of tobacco products at the point of sale by law. The top five countries represent a good example for all countries in the European Region.

Yana Dimitrova of the French Cancer League shared information on the "You Kill, You Pay" initiative. The French League is a main actor of the social and health democracy and is highly involved in tobacco control at all levels: health, economic, social and political. The objective of its tobacco control programme is to stub out tobacco in France and to raise the tobacco issues as a societal question, with for central concern the victims from tobacco and the

protection of persons, in particular the most vulnerable.

In the context of its active commitment to stub out tobacco in France, the French League against cancer continues its mobilization in one of its main tobacco control projects: supporting the implementation of a tobacco solidarity levy as a source tax paid by the tobacco companies. **Europa Donna's Breast Health Day was presented by Susan Knox.** She pointed out that due to the increasing number of studies showing that lifestyle factors play a big role in breast cancer incidence, Europa Donna (the European Breast Cancer Coalition) launched Breast Health Day in 2008 to raise awareness, disseminate information and ensure that women, mothers, families educating and raising young women in our society today know about the importance of a healthy lifestyle to avoid breast cancer later in life.

Reinhold Stockbrügger of the United European Gastroenterology (UEG) presented on "Colorectal Cancer Screening in Closed Communities." He argued that whereas the European Council recommendation from 2003 clearly indicates a need for populations-based screening for colorectal and other cancers, this type of CRC\_SCR is still only realized in a minority of the 27 EU Member States (and in most of them only covering parts of the population). Opportunistic CRC\_SCR is offered in a number of EU countries and had a documented success particularly in Germany. Despite all Public Health activities, adhesion to all types of CRC\_SCR programs is disappointingly low. In a number of examples it was demonstrated that CRC\_SCR offers in 'closed communities (companies, associations, hospitals, health insurers, etc) are mostly well accepted, particularly in regions, where governments/Public Health have not been able to establish population-based screening. Screening in 'closed communities' can therefore parallel public and opportunistic screening and achieve a considerable gain in the fight against colorectal cancer.

Information on an HPV Vaccination Campaign in pharmacies was shared by Rute Horta, Associação Nacional das Farmácias. Community pharmacists are in a unique position to improve vaccination rates and reduce the burden of vaccine-preventable diseases on the population. Concerning HPV infection, pharmacists are well positioned to inform the target population about HPV infection and cervical cancer and the benefits of immunization, to immunize patients with a HPV vaccine prescription, as well as in reinforcing adherence to the vaccine 3-dose series, thus contributing to optimizing immunization rates.

Susanna Leto di Priolo showed how Novartis as a company was forwarding Cancer Prevention in the Corporate Setting. The Novartis Corporation set up the "Be Healthy" global standards in 2011 which included information and encouragement of worldwide employees to have more healthy habits including appropriate physical activities, healthy food, checkups, preventive measures: the first Novartis Be Healthy celebration week took place on September 19-23, 2011. This week coincided with the "United Nations/World Health Organization/World Economic Forum Be Well week". Starting from 1997 periodical prevention campaigns are ongoing to preserve the health of employees who can have access free of charge to them in the site of Origgio, near Milan, Italy.

The European Week Against Cancer Youth Competition was presented by Marie-Christine Wilmink of Pfizer, who has volunteered her time to ECL to help with the organization and management of the competition. She presented the winning submissions from students in Italy and Slovenia. These submissions can be seen on the ECL website.

In the discussion facilitated by ECL Vice-President Joan Kelly, a notably lively discussion took place when some countered the presentation made by UEG and pointed out that the vision of screening in "closed communities" is a misleading title for offering opportunistic colonoscopy to whoever can afford to pay for it, with no monitoring of quality control, equality of access or overall effectiveness. The proposals made in the presentation run directly counter to the European Union's formally adopted policy for each Member State to implement mass screening programmes for colorectal cancer, a policy that is based on a considerable volume of scientific evidence. A member of the audience pointed that all published official recommendations at the European level state that cancer screening must be organised and that opportunistic screening is not an acceptable strategy and that, furthermore, a screening policy must be based on scientific evidence and it must be evaluated.

**In conclusion,** organizations and private companies are investing in cancer prevention and health promotion in different, innovative ways. While some actions have been evaluated, others have not. Simply committing to actions and campaigns in health promotion is not enough. It is clear that more experience and evaluation of actions in this area are needed.

# **Update of Work Package 5: Prevention and Health Promotion**

Wendy Yared, Association of European Cancer Leagues

The overall aim of Work Package 5 on Health Promotion and Prevention is to raise awareness about health promotion and cancer prevention, especially among target groups in Europe (youth, migrants, ageing, etc) by disseminating the European Code Against Cancer messages (www.cancercode.eu); by relaunching the European Week Against Cancer 25-31 May each year; and by engaging policy-makers at the European, national, and subnational levels.

This work package aim to communicate to the general public that at least one-third of all cancer cases are preventable by adopting healthy lifestyles, by immunization against cancer causing infections, and by early detection. Policy-makers and member states should be aware that prevention offers the most cost-effective long-term strategy for the control of cancer.

Advances made since end of last year to achieve the above aims include a) the involvement of partners in an Advisory Council meeting; b) the launch of a Youth Competition, c) call for European Week Against Cancer (EWAC) Flashmobs to take place across Europe, d) organisation of the 2012 EWAC Official Conference in Rome in May and coordination of other EWAC events.

#### **Consultation with WP5 Partners**

WP5 Partners met in an Advisory Council meeting in November 2011 at ECL to discuss actions to advance cancer prevention awareness before and during the European Week Against Cancer (EWAC) 25-31 May 2012, including reaching the general public and youth with the flashmob and youth competition campaigns. Partners also provided advice on themes and presentations for the Official Conference for EWAC at the Italian Ministry in Rome in May, as well as ideas for presentations for the Health Promotion and Prevention session of the Open Forum in Rome in June.

#### Reaching Youth as a Target Audience.

In order to generate interest in the area of cancer prevention among the young European populations, a Youth Competition was launched this year. Invitations were made to students between the ages of 11 to 18 years to create a poster or video communicating one or more messages of the European Code Against Cancer. In order to generate discussion and research, submissions had to be made by teams of 3 to 5 students, within or outside the classroom. Teachers were also encouraged to facilitate the interest and discussions and prizes were also offered to educators. The winning entries were posters submitted by a school in Slovenia and two schools in Italy. Students won iPads, iPods, and digital cameras. Teachers won cash prizes to be used for the classroom. Prizes were sponsored by the Italian Cancer League who also hosted the Official EWAC Conference at the Italian Ministry.

#### Reaching the General Public with Flashmobs

ECL made a European-wide call for countries to organise Flashmobs to raise cancer prevention awareness. A dance classs at the European School in Brussels provided the music and choreography on Youtube for other dance groups in Europe to replicate in their own cities, ahead of the European Week Against Cancer. The main flashmob took place in front of the very crowded Spanish Steps in Rome. Spectators were handed copies of the European Code Against Cancer to be informed of the steps they can take to prevent cancer later in life.

Official Conference for the European Week Against Cancer (EWAC) An official conference for EWAC was organised by the Italian Cancer League and hosted by the Italian Ministry of Health on 31 May to 1 June in Rome. The theme was tobacco control, appropriate for 31 May which is World No Tobacco Day. Distinguished speakers included representatives of the Italian Ministry of Health, the Board of the Italian Cancer League, ECL Past President, the European Commission, the Vice-President of the International Olympic Committee, the World Health Organization, the European Parliament, and a patient's voice by a sports celebrity. Appropriate for an event taking place in Rome, the audience was graced by special guest appearances - designers from the Italian fashion industry houses of Biagiotti and Fendi. The second day was a scientific conference with presentations related to screening and healthy lifestyles.

Other notable events which took place for the European Week Against Cancer were organised by partner organisations. Member of the European Parliament and MEPs Against Cancer (MAC) champion Mr Pavel Poc facilitated the event European Colorectal Cancer Days in Brno in the Czech Republic. The European Institute of Women's Health organised a meeting on cervical cancer prevention at the European Parliament in Brussels. The European Liver Patients Association organised an event to raise awareness on liver cancer also at the European Parliament. More information on these events are posted on the ECL website as well as on these partner organisations' websites.

#### **Next Steps**

Steps for immediate future actions to advance cancer prevention within this work package will be discussed with WP5 partners after the summer, especially in relation to the Official Conference of the European Week Against Cancer to be hosted by the Irish Cancer Society in Dublin in 2013, during its 50th Anniversary and while Ireland holds the EU Presidency.

## **Physical Activity, Nutrition, Obesity**

Stefan Schreck, DG Health and Consumers

Europe is facing an unprecedented epidemic of chronic diseases. These diseases put a high burden on health systems, and in addition to human suffering, represent a significant social and economic cost. They are the leading cause of mortality in the world, representing 63% of all deaths. In the EU there are over 4 million deaths a year from chronic non-communicable diseases, representing over 87% of all deaths. Much of this burden is preventable, by taking action on the key common risk factors - nutrition and physical activity, tobacco, alcohol-related harm. This has received high political priority through the recent UN High Level Meeting on non-communicable diseases in September 2011.

The European Union has policy approaches in place to address these health determinants. Nutrition and physical activity is a good example of our approach: we work closely with Member States, with stakeholders across society and across EU policies to improve diets and promote physical activity.

## Food, Nutrition and Physical Activity: Evidence on Cancer Prevention and Health Promotion

Martin Wiseman, World Cancer Reseach Fund

About a third of the commonest cancers could be prevented through improved patterns of diet and activity, and healthy body weight (Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective; 2007). This dietary pattern, high in fibre-rich plant foods and low-energy, relatively unprocessed foods, and low in red and processed meat, alcohol, salt and high energy foods, together with being physically active, will also prevent other non-communicable diseases. People's behaviour is shaped by their physical environment, and their social and economic circumstances as well as their personal knowledge, beliefs and attitudes (Policy and Action for Cancer Prevention; 2009). Broad policy action is needed to make these factors more conducive to health. The independent expert panel responsible for these reports, convened by World Cancer Research Fund (WCRF), made recommendations to nine groups of actors across society. Coherent action by all actors is needed, and leadership should come from health professionals and government.

### **How to Put Pressure on Your Politicans**

Luc Joosens, Association of European Cancer Leagues

Monitoring of tobacco control policies is essential to put pressure on politicians. Ranking of countries might also be useful. The fourth edition of the European Tobacco Control Scale (TSC), a report by the Association of European Cancer Leagues (ECL), was published in 2011. The top five countries (UK, Ireland, Norway, Turkey and Iceland) all have policies on tobacco control comprising high prices for tobacco products and complete smoking bans, including bars and restaurants. These measures are considered to be the top two of the most effective policies and thus receive the highest scores. Four of these countries recently decided to introduce legislation to ban the display of tobacco products at the point-of-sale. As in the second TCS in 2007, the UK scores best in all six categories for a comprehensive and (cost)effective tobacco control policy. The five countries with the lowest scores were Austria, Greece, Luxembourg, the Czech Republic and Hungary. The benefits and risks of rankings were discussed during the presentation.

## "You Kill You Pay"

Yana Dimitrova, La Ligue (French Cancer League)

The French League Against Cancer supports the implementation of a tobacco solidarity levy as a source tax paid by the tobacco companies. Tobacco industry makes huge profits by selling a poison that kills each year 6 million people (first risk factor that deals with all non-communicable diseases). The French league wishes to raise political responsibility to support the implementation of a levy on the profits made by tobacco companies based on the "polluter pay" principle in order to finance tobacco control worldwide.

The "tueurs-payeurs" campaign based on advocacy, mobilisation and media events contributes to strengthening the fight for a solidarity levy on tobacco profits and raising awareness among society and the political sphere.

## **Breast Health Day**

Susan Knox, Europa Donna

Due to the increasing number of studies showing that lifestyle factors play a big role in breast cancer incidence, Europa Donna (ED) -The European Breast Cancer Coalition launched Breast Health Day in 2008 to raise awareness, disseminate information and ensure that women, mothers, families educating and raising young women in our society today know about the importance of a healthy lifestyle to avoid breast cancer later in life.

Studies from the International Agency for Research on Cancer (IARC) show that as much as one third of breast cancer can be attributed to increased weight and physical inactivity. As the cancer burden increases across Europe and the world with resulting rising costs to our national health systems we know it is essential to provide a major educational awareness programme to prevent more disease from occurring. Breast Health Day now takes place annually on 15 October and seeks to educate people about prevention, early detection and especially lifestyle factors connected to breast cancer incidence. It informs girls and women that from an early age, there are steps they can take to lower their risk of getting breast cancer over their lifetime.

Europa Donna carries out an extensive campaign each year that includes a digital campaign on Facebook, Twitter and YouTube to reach a wider audience of younger women and girls. In addition all information and materials are available on the Breast Health Day website ( www.breasthealthday. org), National activities are conducted in many of ED's 46 member countries ensuring that a significant number of women receive positive messages through media and local events that stress the importance of making healthy choices. Our efforts include the dissemination of Breast Health Day materials to women on all continents with the aim of making 15 October Breast Health Day across the world.

# Colorectal Cancer Screening in 'Closed Communities': A European Experience

Reinhold Stockbrügger, United European Gastroenterology

The key topics of this presentation were:

- The difference between "population-based" and "opportunistic" colorectal cancer screening.
- -All colorectal cancer screening started as opportunistic screening (and most of it still is!).
- -The characteristics of a 'closed community'.
- -Examples of colorectal cancer screening in 'closed communities' in Europe.
- -Advantages and disadvantages of "patchy" colorectal cancer screening.

Conclusion: START with the "spirit" of opportunistic screening NOW, and hope to END UP with population-based and population-wide prevention of cancer (and not only colorectal!).

# Pharmacy-Based HPV Vaccination Campaign

Rute Horta, Associação Nacional das Farmácias

Following the new legislation allowing pharmacies to provide immunization services, published in November 2007, the Campaign "Get immunized against HPV infection in your pharmacy" was the second nationwide initiative developed in this field (after the first Pharmacy-Based Influenza Immunization Campaign 2008/2009). The overall aims were to contribute to the prevention of HPV infection as a tool in the battle against cervical cancer in Portugal and to raise awareness of the availability of immunization services in community pharmacies.

Although the information campaign targeted females aged 13 through 26 years, the vaccine administration in pharmacies was targeted to young women with prescribed HPV vaccine not included in the national immunization schedule (woman aged 19 through 26 years). The campaign was preceded by evening sessions for pharmacists held in the 3 major cities. Pharmacists documented the vaccine administration service in a spreadsheet which was then later sent to ANF. The evaluation was performed by CEFAR (Centre for Health Evaluation & Research - ANF Group) from April to July 2009.

844 pharmacies (31.6% of ANF pharmacies) participated in the campaign, out of which just 39 (4.6%) have sent data to ANF. A total of 113 patients were immunized, in 39 pharmacies, based on data received. All of the patients were female, 65.1% were aged 19 through 26 years and average age was 24.9. Approx. 97% of all pharmacy-based immunizations were performed by pharmacists. The % of HPV vaccines administered in pharmacies was 29% (of vaccines dispensed only in pharmacies that sent data).

Community pharmacists are well positioned to inform the target population about HPV infection and cervical cancer and the benefits of immunization, to immunize patients with a HPV vaccine prescription, as well as to reinforce adherence to the vaccine 3-dose series, thus contributing to optimizing immunization rates.

Compared with other campaigns, few pharmacies have sent data to ANF. Financial constraints could be the main obstacle for patients, not included in the national immunization schedule, to get immunized in pharmacies.

# Cancer Prevention in the Corporate Setting, Novartis Be Healthy Activities

Susanna Leto di Priolo, Novartis

Novartis Oncology region Europe is the European Oncology Unit of Novartis, a Swiss pharmaceutical company, born in 1996 from the merger of Ciba Geigy and Sandoz, with its headquarters in Basel. The European Offices of Novartis Oncology are based in Italy, in Origgio, a small village near Milan.

In September 2011 the Novartis Group launched a wide range of internal activities aimed at improving knowledge of employees about healthy lifestyle: Be Healthy.

Be Healthy was composed of 4 main pillars: Move, Choose, Know, and Manage. Under these pillars several components of a cancer prevention campaign can be identified:

MOVE: physical activity is recommended to prevent cardiovascular events as well as cancer (an example is the Breast Health campaign by Europa Donna) CHOOSE: healthy food is recommended to prevent colon and breast cancer KNOW: screening and smoking cessation programme

This campaign which the Novartis Italian affiliates implemented in all the local sites in Italy which are in various regions and locations (Novartis, Sandoz, Vaccines, and Alcon) was added to several activities in terms of health of the employees which Novartis Italy started since 1997, in particular in its site in Origgio.

Starting from 1997 periodical prevention campaigns are ongoing to preserve the health of employees who can have access free of charge to them in the site of Origgio. In some case the campaigns have been offered also to external employees (the so called Field Force).

In particular the following cancer prevention campaigns are ongoing:

- Breast Cancer: Every year, Novartis women can access a control visit, to prevent breast cancer, the senology visit is done by an expert of LILT, the Italian League Against Cancer. In 2012 we rolled out the 4th edition of breast cancer prevention. 279 colleagues were visited. (> 60% of the total women in Origgio site) Moreover this year a mammary ultrasound examination was also offered.
- Prostate Cancer: Every year men in Novartis who are at least 45 years old can get a simple blood test to measure PSA. In the 2011 Campaign (IV edition) 50 colleagues requested the exam
- Cervical Cancer: All over the year women 25 to 64 years old, can do Pap tests.
- Skin and Oral Cancer: A simple visual inspection, done by an expert oncologist, is the prevention measure offered to all colleagues, independent of gender and age.
- 2009 campaign (skin and oral cavity): 337 visits
- 2011 Campaign (skin): 386 visits in collaboration with the Italian League section of Varese (approximately 60% of the site population)
- Leaflet "Behavioural code in the sunshine"
- Smoking Cessation during the "know your numbers campaign" in 2010 and the "Be Healthy" program in 2011, an intensive information campaign was run on smoking as a cardiovascular and cancer risk with suggestion on "How to stop smoking"

CONCLUSIONS: The health and well-being of associates is a top priority for the Novartis Group and a natural extension of our purpose to "care and cure. Novartis Italy is one of the Novartis affiliates with the longest commitment to improving the health of its associates. Part of the activities are specific to cancer prevention.

## **Youth Competition Winners**

Marie-Christine Wilmink, Pfizer

This session has focused on the European Week Against Cancer Youth Competition, which has been organised by the Italian Cancer League and the European Cancer Leagues as one of the actions of the EPAAC Work Package on Health Promotion and Prevention for the European Week Against Cancer. The competition was launched to encourage youth in Europe to learn about how cancer can be prevented, and to think about how they would communicate the importance of cancer prevention to their peers by focusing on the evidence-based messages of the European Code Against Cancer. Besides addressing the objectives and process of the competition, the winning posters and/or videos have been announced and are:

1st Place: Istituto Mazzini-Da Vinci of Savona, Italy

Student: Claudio Pavione Teacher: Angela Caprino

2nd Place: Secondary School of Nursing, Ljubljana, Slovenia

Students: Helena Miklavčič, Viktorija Dimovska, Marta Cigale, Jaka Rogelj

Teachers: Jana Jakša, Aleksandra Soršak

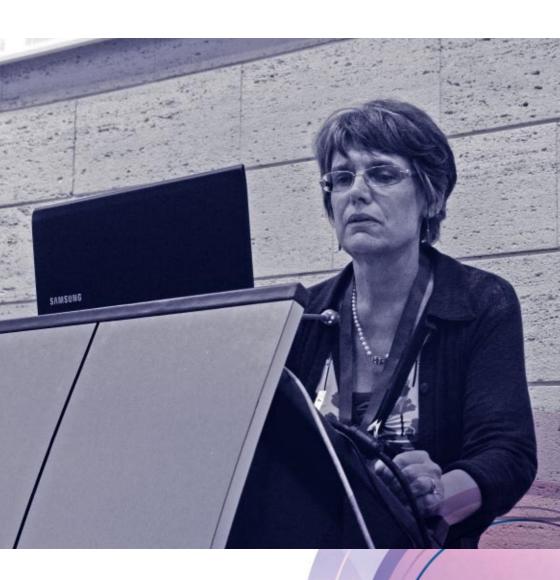
3rd Place: I.I.S 'M. Guggenheim' school, Italy

Students: Davide Bettin, Riccardo Trevisan, Denisa Mihaela Zetu

Teacher: Enzo Blivoli

We warmly congratulate all of the winning entries and thank all of the participants from across Europe.

# **Cancer Data and Information**



## **Summary: Cancer Data and Information**

Milena Sant, Istituto Nazionale dei Tumori, WP 9 Leader

The Work Package 9, on Cancer Information and Data organized the afternoon session of the 2nd day of the Open Forum 2012 of the European Partnership Action Against Cancer (EPAAC).

WP 9 session was devoted to illustrating the drives of the Package, hence framing the cancer data context in Europe, the actors involved, their visions and how, together and thanks to EPAAC, we are getting to make them a reality, by also introducing the innovative approach of working on the cancer data flow in Europe together. This requires involving cancer patients, cancer registration experts and policy makers, both at EU level as well as locally, in each one of the EU member states.

**Milena Sant Leader of the EPAAC WP 9**, presented the WP 9 session topics, summarized WP 9 objectives in the Partnership and provided the audience with an update of the package activities. Milena is scientific coordinator of the cancer registry- based project on survival EUROCARE, now in its 5th round, and of the EUROCARE High Resolution Studies, aimed at interpreting interregional and overtime cancer survival differences, starting a second round in 2013.

The session aim was to share experiences with the wide EPAAC consortium on the uses of cancer information for all cancer stakeholders, from health policy planners, to researchers, health professionals, industry and patients, with concrete ideas for the future, stressing the benefits of evidence-based effective actions, if Europe wants to tackle inequalities in cancer outcomes.

The programme of the day included specific highlights on the role of cancer registries, on the successful experience of the UK, on the cancer epidemiological data available in Europe at population level, on the possible integration of population based and clinical approach and on the point of view of patients. The concluding part of the session consisted in an open discussion on the WP 9 proposal for coordinating all expertise already existing, including all data banks, (i.e. aggregated data on risk factors, early diagnosis, health care resources and socio-economic variables from various sources -HIS/HES, OECD, Eurostat) for the constitution of a European Cancer Information System.

First of all, an overview was given on cancer information in Europe today, since the creation of the first population based registry in Finland in the 1940s. Thanks to cancer registries, incidence and mortality were analyzed and published in 9 successive volumes over the last 45 years in CI5 by IARC, and survival data is available through the EUROCARE CR- based studies since the '90s. Europe now needs population based data on the extent to which survivors are reintegrated in to society, on needs in the area of palliative care and on the cost effectiveness of care. Since the year 2001, cancer indicators have been studied by the DG SANCO-funded EUROCHIP (with a specific focus as of late on the availability of patterns of care indicators) and a review of the capacity of the EU CRs was developed in the recent years by the DG Research-funded EUROCOURSE.

Longtime CEO of the Comprehensive Cancer Centre IKNL, Renèe Otter talked of population based cancer information and the key role of cancer registries. Renèe contributed to the Dutch National Cancer Plan as well as in creation and improvement of several registries in Europe. Her presentation explained how cancer registries are essential for building National Cancer Plans if they wish to be well integrated with clinical, permanent and high quality data.

UK Cancer Director, Professor Sir Mike Richards, talked about the "National Cancer Intelligence Network" initiative for cancer strategy, monitoring cancer indicators and outcomes in the UK since over a decade, as well as about the successes of the International Benchmarking Partnership (Lancet, 2011) comparing population level data from cancer registries in Australia, Canada, Denmark, Norway, Sweden and the UK and about what policy can do with quality and comparable data.

The Director of the Descriptive Studies Unit of IARC, Dr. David Forman, provided a picture of what population based data is available in Europe today and illustrated the European Cancer Observatory website, going public in August 2012, for user-friendly, interactive access to: incidence, mortality, survival, prevalence, estimates for 40 countries (and EU-27), all registry data as provided and updated and preparation of research data sets.

Professor Ulrik Ringborg, from the Karolinska Institute in Stockholm, presented the EUROCAN PLATFORM vision of the "4 Ps" approach of a Preventive, Personalized, Preemptive, Participative Medicine. Ringborg especially talked of the EUROCAN PLATFORM WP 11, on the possible integration between cancer registry data to the clinical registries, thus creating an Outcome Research Platform able to monitor the whole of the cancer research continuum, including patients' needs and cost effectiveness of treatments.

The patients' point of view and the important role of ECPC both at EU and local level was illustrated by Francesco De Lorenzo, Vice President of the European Cancer Patient Coalition, who matched the information on cancer data in Europe with data on the social security benefits, on the chronic and late physical and psychological symptoms brought by the cancer experience and on data about job loss and returning to work for cancer patients. The experiences of the 7th Integrated Cancer Programme and that of the CAREMORE project were illustrated as well as the involvement of patient groups in the progress reached in the NCP in Italy and in the Non Communicable Disease United Nation Summit Declaration of 2011.

After the break, the discussion moved specifically on the subject of the WP 9 mission of guiding the different initiatives in Europe to work together towards the constitution of a European Cancer Information System, ECIS. Suggestions, amendments and comments on ECIS will be welcome from all EPAAC partner untill September 2012, a revised version will be circulated before the end of 2012, and the document will be an official deliverable of EPAAC at the end of the Joint Action's second year.

The proposal, which had already been circulated among all EPAAC partners, was presented to representatives of all EU cancer registries and EU Health Ministries by Dr. Riccardo Capocaccia, head of Cancer Epidemiology and main manager of the EUROCARE cancer registry data base at the Public Health Institute in Rome.

The system proposed by WP 9 is intended to function as the sum of institutions, persons, procedures and resources dealing with cancer information and data, and coordinated to provide the necessary knowledge to optimize cancer control activities and operate as a research infrastructure in public health. Running an information system means connecting people - providers, analysts, users. Cancer control, as a part of the health care system, is mostly up to Member States or regions, but health care research should be focused at the European level. Although legal constrains exist, ECIS is designed for the widest possible use: a vision of data coming from and to citizens, for the citizens, for an overall cost <  $0.01 \in x$  citizen x year is expected.

Before a round table was opened for discussion, moderated by **two high profile international cancer epidemiology experts, Professor Michel Coleman and Timo Hakulinen,** the floor was given to two key players, the European Commission Joint Research Centre (JRC), and the European Network of Cancer Registries (ENCR), to inform participants on their contributions to ECIS.

The European Commission JRC is the European Commission's in-house science service and since September 2011, its Institute for Health and Consumer Protection (in Ispra) has received the EP mandate to assist the WP 9 steps towards providing a sustainable solution for harmonising, improving and using population-based cancer information in Europe. The ENCR established in 1989 within the framework of the 'Europe Against Cancer' programme of the European Commission, provides regular information on the burden of cancer in Europe, improves quality, comparability and availability of cancer incidence data, helps to monitor cancer incidence and mortality in Europe and promotes the use of cancer registries in cancer control, health-care planning and research.

#### **Conclusions**

The discussion gave the opportunity to confirm the importance of the different perspectives in health decisions by various Member States and at the same time, the importance of ensuring that ECIS involves sustainable data accuracy and comparability. The governance of ECIS and the structural involvement of the JRC is yet to be determined, but what is clear is that Member States are supported by the EC through JRC assistance and that EPAAC is the ideal platform for coordinating the different players at this stage.

# **Update of Work Package 9: Cancer Data and Information**

Milena Sant, Instituto Nazionale dei Tumori

#### The Objectives of WP 9 are:

- (Obj 1) to map the main sources of cancer data in the EU and identify priorities
- (Obj 2) to unify cancer data under a common platform
- (Obj 3) to investigate population based cancer cost data
- (Obj 4) to investigate population based survivorship data
- (Obj 5) to develop an inventory of methods to analyse population based data

The developments of the Package since the EPAAC Open Forum in 2011 are:

#### (Obj 1)

The WP 9 availability of cancer health indicators in the EU is available through EPAAC. The key indicators are: incidence, mortality, survival, prevalence. More must be done for data on stage, tumour characteristics, diagnostic investigations, treatment and follow-up, as they inform us on the reasons for differences in time and in places and help us improve outcomes. Moreover, sources of data on survivorship and costs are being investigated. WP 9 was involved in the EUROCARE-5 survival analyses, in order to provide updated cancer survival estimates. The first EUROCARE-5 results were illustrated in the EUROCARE plenary working group meeting which was held on 28 February 2012 in Ispra.

#### (Obj 2)

A writing committee for the ECIS proposal was created and a document was proposed to all partners before the OF 2012.

#### (Obj 3)

Socio-economic variables for the regression analysis were defined, a collaboration was started with the OECD (SHA), a discussion on the European Deprivation Index was initiated in 5 EU countries.

#### (Obj 4)

Aims and documents have been set also in collaboration with the EUROCHIP-3 group.

#### (Obj 5)

Contacts with European experts in population-based analyses were established. The possibility to organize a meeting dedicated to methodological issues and recent developments is under consideration.

# What is Needed: Illustration and Discussion of the Most Important Needs on Population-Based Information The Role of Cancer Registries

Renée Otter, Comprehensive Cancer Centre

Untill the end of the '90ths, most of the cancer registries only provided data on Incidence and mortality in a comparable way, through the International Agency for Research on Cancer (IARC) (CIFC). Meanwhile, the European cancer registry-based study on survival and care of cancer patients (EUROCARE) provided the first data on relative survival in the different countries of Europe and the cancer survival in five continents: a worldwide population-based study (CONCORD) compared relative survival between the five continents of the world.

Huge differences within Europe and within the world became visible. However, understanding the reasons seems difficult although many suggestions concerning quality of care, the availability of participating in screening programmes, presence of primary prevention were put forward. But no comprehensive data on all these issues was present, nor was data on comparability present.

The European Cancer Health Indicator Project - 3 (EUROCHIP-3) and Europe Against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research (EUROCOURSE) projects try to get more information on the availability and barriers of getting of data from the cancer registries in the EU concerning topics such as quality of care, based on the experiences of previous EU projects like ECHI, EUROCANPLUS+, EUROCHIP-1&2 and the ENCR.

Out of the questionnaire sent to all the EU Cancer registries (CRs), most of the major variables to understand differences in survival (such as stage, delay in treatment and treatment in accordance to guidelines) were not all available in the registries, even in the CR regions where a screening programme was organised, CRs were not involved in the evaluation of this programme!!

Out of 2 other EU projects, CRs were mostly not used to evaluate or to monitor national comprehensive cancer plans (NCCPs).

Cancer registries, the most reliable population-based databank over years, seem to be used mainly for information on the cancer burden of the countiy through incidence, mortality, survival and prevalence indicators. But CRs are not used in an efficient way for the evaluation of screening programmes, for the evaluation of monitoring NCCPs or many other possibilities.

It is necessary to considering the fact that:

- more effort has been made in primary prevention in many EU countries,
- that implementation of screening programmes only make sense when optimal cancer care is available for the population,
- that education of the professionals involved in cancer diagnosis,treatment and support is of major importance,
- that due to better survival, survivorship and rehabilitation programmes should be implemented, and
- that all these activities should be considered under the umbrella of a NCCP and even under an EU NCCP guideline.

CRs should be used in a much more efficient way than they have been up to now, through linkage with different national databanks, through providing a dataset at EU level with well defined items in order to have comparable data on all the domains covered by a NCCP, etc. These items should be defined in the next year and the MOH of the EU countries should make it possible to gather this information. Analysis should be considered by specialised epidemiologists from the CRs working within the ENCR. Issues like projections for capacity of equipment and professionals should be included.

# Cancer Care: Population Based Versus Clinical Approach, Possible Integration, The Roles of the Clinical Cancer Registry

Ulrik Ringborg, Karolinska Institute

The translational cancer research continuum covers all the steps from basic/preclinical research to clinical research (early translational research) and further implementation and evaluation of clinical effectiveness and health economy in the health care system before adoption (late translational research). EurocanPlatform, a EU-funded consortium of 28 European cancer research centres and organisations, is building a platform for a comprehensive translational cancer research. One of the important infrastructures to be established is a clinical cancer registry.

Today no centre has a clinical cancer registry containing detailed patient and tumour information as well as data regarding both primary treatment and treatment of recurrent disease. Establishment of comprehensive clinical cancer registries has a high priority. Registries will be harmonized to allow compilation of patients from different centres. Interventions and outcomes of specific treatment will be registered. Such a structure will contribute to innovation in several ways: late translational cancer research will be possible; evaluation of clinical effectiveness of specific treatments; complete outcomes research support development of evidence based cancer medicine; health economy will cover cost-effectiveness assays; long-term follow-up of patients for identification of late side-effects; involvement of quality of life indicators; linkage clinical information to the biobanks will support development of treatment predictive biomarker discovery and biological studies of resistant tumours; compiled data from clinical cancer registries will be useful for clinical epidemiology research; effects of multidisciplinarity and comprehensiveness can be demonstrated.

An important problem is the selection of patients in many cancer centres. In some centres, however, there are already population based clinical registries covering primary treatment. There is a goal to expand those registries to cover also recurrent disease. It will be important to collaborate and integrate clinical cancer registries with the population based registries to be able to identify effects of innovations and organisation of the cancer activities on unselected patient populations

## **Inequalities Across Europe and the Needs of Cancer Survivors**

Francesco de Lorenzo, European Cancer Patient Coalition

The EU's population is changing: Europeans are living longer, and this pattern is expected to continue. Disparities within the EU have also increased and recent figures show that, while in some countries (mainly eastern European countries) life expectancy is about 70 years of age, in other EU countries, it is reaching or surpassing 80 years. A similar pattern has emerged with respect to cancer survival rates. Indeed, there has been a dramatic improvement in the 5-year survival rate for those who have been diagnosed with cancer. The survival rate (all cancers combined) 5 years after a cancer diagnosis is now about 50%, but there are still notable differences within regions or even countries: the 5-year cancer survival rate ranges from about 40% to almost 60% across European countries. This situation has a major effect on the future of Europe public policy and the sustainability of the health and care system. To deal with these challenges, it is imperative for Europe to continue to collect cancer statistics where this vital activity is already promoted, but it is also necessary to expand and integrate population based data collection everywhere across the European countries. Available information should now be able to describe cancer patients' experiences after diagnosis in order to quantify cancer rehabilitation needs. Historically, cancer registries have been the primary source of major cancer burden indicators (i.e. incidence, survival, prevalence and mortality), but probably patients surveys are today necessary to integrate the cancer data, in the direction to support evidence based lines for the management of cancer survivors.

In the EU, cancer has become so prominent in terms of social and economic implications that it has to be considered an important element of the European societies and of political contrast to the health disparities. European health and care systems urgently require restructuring to match the demands of ageing societies and in this instance, the need of cancer survivors. The EU Council's conclusions on "reducing the burden of cancer" adopted in 2008, the European Innovation Partnership on Healthy and Active Ageing established in 2010 and the European Partnership for Action Against Cancer established in 2009, now producing its results, are important platforms that patient organisations have called on their national and EU politicians to create. Such partnerships reflect the fact that healthcare is becoming ever-more patient-centred, with the patient increasingly going to be an active participant in the management of his or her health. These Partnerships help to identify models so that cancer treatment and care should be multidisciplinary, involving the cooperation of oncologic surgery, medical oncology, radiation oncology, psycho-social support and, importantly, rehabilitation and palliative care - a model that internationally is often called cancer control, when it is able to involve all the cancer stakeholders. By these initiatives, patients' organizations can provide a contribution also to research per se because they are actors of these processes. In order to meet cancer survivorship-related needs, the ongoing productive Partnerships should be the bases to promote an EU Survivorship Care Plan, with the intention to provide a reference benchmarking for care of cancer survivors. It has to include as key priorities: timing and content of follow-up, rehabilitation, raising awareness of short and long- term treatment-related effects, control of comorbidities and risk factors potentially worsening prognosis, information on legal protections and psycho-social support services. A major goal for the survivorship care plan is to establish a comprehensive care summary and follow up (to be discussed with patients) for patients completing primary treatment; and collaborations with medical organisations such as the European Society of Medical Oncology (ESMO) in order to formulate recommendations providing information on longterm cancer-related and treatment-related effects, and tertiary prevention.

The health authorities at a country level should be invited to take into account the psycho-social needs of cancer patients and improve their quality of life through support and palliative care, and also through rehabilitation measures aimed at facilitating early return to work. Welfare and job protection benefits will need to play a key role within cancer rehabilitation programs. For example, in the fields of welfare and healthcare, public and private employment, equal treatment for all cancer patients, and communication/awareness campaigns are mandatory tasks. Specific programs have to be performed at European national and local level with interventions into existing legislation for workers or economic and social support if work is not sustainable due to worsening health status. Any effort in supporting patients in early return to the life preceding the disease and any action to avoid disparities between EU citizens with and without the disease should be considered a goal against the health inequalities; resources devoted to these objectives should be taken by the European societies not as costs but as investments in enabling to maintain active and productive those who have had the disease.

The central challenge is to find better innovative models to deliver quality healthcare to patients and cancer survivors, while keeping down costs and maintaining the efficiency and sustainability of health systems, and, importantly, offering the same services to all the European citizens. Strong patient organisation involvement and interaction can contribute to improving quality and efficiency and the European Cancer Patients Coalition - ECPC - is willing to support this multi-stakeholder approach. ECPC is committed to documenting, at the European level, the results obtained by EU collaborative efforts and specifically by the European Partnership for Action Against Cancer: the cancer patients do hope that this ongoing project will be an important vehicle to improve the life for those who have met the disease.

## **European Cancer Information System**

Riccardo Capocaccia, Instituto Superiore di Sanita

Population based information on cancer is fundamental for cancer control activities as well as for health care research and, thanks to the existence of registries and to a long tradition of epidemiological research, is much more available than for most other diseases. In addition, a very wide and high level research activity related to cancer information and data is ongoing in Europe. These considerable amounts of experience and resources are not yet fully deployed to produce a proportionally great advance of knowledge in the field of cancer epidemiology. The EPAAC WP 9 is developing proposals for the best use of all these resources, overcoming the present fragmentation and duplication of efforts.

To this aim, the need is recognized to start developing the future European Cancer Information System (ECIS), intended to function as the sum of all institutions, persons, procedures, and resources dealing with cancer information and data, and coordinated to provide the knowledge necessary to optimize cancer control activities. ECIS should unify the coordination of the entire process of data centralization, quality control, management, analysis, and diffusion. It should allow a public access to the data, and also pursue a regulated but open access at individual level data by the scientific community and other stakeholders. In order to work as efficiently as possible, the ECIS activities should be implemented by putting together existing resources and experiences from European institutions that are already involved in cancer information and data diffusion, most of which have already developed knowledge, skill and instruments able, if well coordinated, to carry out the main tasks required.

The Joint Research Centre, the European Commission in-house science service, should most appropriately take on the task of hosting and managing the central data repository. The European Network of Cancer Registries could play a crucial role in maintaining a strict connection between the ECIS activities and those of the participating cancer registries. The International Agency for Research of Cancer (IARC) should continue to exercise the function of accreditation of cancer registries, training, and provision of comparable cancer information at the global level. A network of European scientific institutions (such as those involved in EUROCARE or EUROCOURSE) is the most appropriate organizational structure able to carry out in an efficient way the activities of data quality control, analysis, diffusion and dissemination.

Assuring a permanent source of funds is also necessary to evolve from the present variety of independent and fragmented initiatives to a sustained information system. If based on the concept of networking the already existing technical and scientific capacity, the development and maintenance costs of the cancer information system would be relatively low and sustainable.

## Role and Tasks of JRC in the Future ECIS, Relationship with Registries

Ciarán Nicholl, Joint Research Centre

Many EU projects and activities related to Cancer Information are coming to a head. The European Network of Cancer Registries (founded in 1989) no longer has the means to continue its work, the EUROCOURSE project will come to end in 2012, as will the means to physically maintain the European database of cancer registries which is located at the IARC in Lyon. With EPAAC destined to end in early 2014, the future of cancer information in Europe looks far from promising.

The JRC is the European Commission's in-house science service and although it's a new player in this domain, it will outline first steps towards providing a sustainable and long-term solution for harmonising, improving and using population-based cancer information in Europe.

### The ENCR Contribution to ECIS

Stefano Rosso, Centro di Prevenzione Oncologica, Turin

The European Network of Cancer Registries (ENCR), since its establishment in 1989, has among its aims providing regular information on the burden of cancer in Europe, and promoting the use of cancer registries in cancer control, health-care planning and research. The first realisation was Eurocim in the nineties, a stand-alone program where analysis tools were delivered together with data. Eurocim was not a public domain product, it was distributed to the collaborating registries and it was intended for research purposes. The Eurocim database has been recently revamped, thanks to the EUROCOURSE project, and updated with new data from more registries. Since 2002 estimates of incidence in all European countries were also available. Since then, statistics and indicators of cancer burden were published in the web, and the European Observatory of Cancer, presented earlier in this Open Forum, is our last effort in disseminating our results.

With these products already available, one can think that the contribution of ENCR to the ECIS was already fulfilled, but in reality, the very, although obscure, work of ENCR goes elsewhere: in constantly improving quality and comparability of our data. Without the perennial exchange of experience within the Cancer Registries, the issuing of recommendation and standards for collecting cases, and finally the development of tools for controlling final quality, we would not be able to draw the correct inference from our analysis and statistics. This is the essential function of the ENCR that needs to be fully and constantly supported for achieving unbiased results.

However, the next challenges, in the direction of empowering the role of what ENCR has built until now and that we can consider the very core of the future ECIS, are essentially two:

- 1. Facilitating the use of available data for research purposes: the potential for research cannot be fully exploited centrally, therefore our data should be made available for the interested researchers through a controlled mechanism where quality of research protocols is transparently evaluated and registries can maintain control over their data.
- Empowering the information of ECIS including other sources of data, such
  as clinical data and repository or biobanks data: although partial, this
  information is highly valuable and the experience of standardization of ENCR
  can be exploited for improving their use and comparability.

## **Posters**





# A European Network on cervical cancer surveillance and control in the new Member States

Wit publication erice from the project 74,81087 which has received funding from the European Union in the promoney of the fluids the property.

# Description of the project

screening - (2003/978/EC) and according to the European galdelines for quality essurance in AURORA is developed according to the Council Recommendation on cancer Cervical Cancer Screening- 2nd edition

and collaboration among experts and stateholders, Furthermore, AURORA consortium believes that advocacy is essential to stimulate governmental surboitties to implement servical cancer presention and therefore the peoplet mission includes ter cervical cancer in the new EU-states through exchanging know-how and expertise, training of healthcare prefessionals Bacommendation ALRORA movin is to promote the implementation of high quality population based prevention vities can significantly reduce the incidence of cervical cancer in Burage. Based on this concept and on the European 14 partners around Eurobe are cooperating in AUROR A project, sharing the same concept that prevention acts the training of advocacy leaders.

AURGIA project to particularly dedicated to the Hard to reach papalation (HTRF), considered as those sections of the community that are difficult to involve in public participation. The term can be used to refer to minority group such as others group, semetimes to hidden populations such as illegal immigrants, comotimes to unserved aroups On service and little for these arounds or service "resistants" (people fulling to access the services that are

Key words: Cervical cancer prevention, Hard to reach populations, Training, Advocacy. Pilot Action

Activities

AURORA activities are organised in 8 WPs (work packages) during 36 month.

The main results of AURORA will be:

Analysis of the local contexts and needs of the participating countries, useful to stakeholders to organize more tive training and prevention activities.

dificultion of common strategies in the fight against Carvical Cancer and promotion

with stakeholders and to influence public policies on Cervical Cancer

surses to all Interested key actors.

care Centres to offer quality services

BALDA

Occupation instituted collisies della falura della free businessimina ella sociali sulla sulla sociali sulla sulla













The project started in 14 Jan 2011, so far as nowestays the following activities have been completed:

Analysis of the local context available on the AURORA project website:

Concer epidemiology, Screening and vaccination programmer, and on hard to reach population groups; these groups It has been corried out in all the project participating countries with the aim to cafect information about Cervical http://www.auccie-project.eu/sphadideherables/AtBORA Analysis of the local context D3.pdf Now been Abertified to each confind and their perforator need is now been asserted as part of the enelysts.

Report about the good practices available on the AURORA project website

Good practices are collected from partner countries (covering most flew EU Member States) as well as "gold standfast" countries. http://www.non-project.eu/uplood/deliverables/D4 Report about the Good Practices.pdf

E-learning platform is online on the AURIORA project website http://www.auriori-project.cu/en/wgt/c-learning-34 3 modules (scientific background, communication out arbocary) solome/ser healthcare professorals and an

Training for health one prefessionals and advocacy loaders is planned for October, 24-34 2012 in Millan.

The network of pilot centers will be completed within the end of the project.





#### Addressing Cancer Disparities in Central and Eastern Europe (Czech Republic, Hungary, Poland, Romania, and Russia)

Focus on Nursing In the Community: Training, Capacity Building and Community Partnerships to Improve Health Outcomes in Populations Disproportionately Affected by Cancer



The Bristol-Myers Squibb Foundation is a U.S-based independent charity that is committed to helping to reduce health disparities around the world. It does so by focusing on improving community-based health care and supportive services and on engaging potentials and communities in the Eight against serious diseases.

Since 2007, the Foundation's Bridging Cancer Care initiative has directed grant making and partnership development to cancer disparities in Central and Battern Europe with programs focused on a wriety of needs, including psychosocial support, disease information, pallative care care coordination, assessment of cancer services, and building remaining capacity.

Through these programs, the Foundation and its pareners seek to develop, pilot and evaluate innovations and sustainable improvements in community-based care provided to populations disproportionately affected by cancer, including the poor, ethnic minorities, and people living in rural communities with limited access to cancer services.



In some instances, the innovation is a new model of care; in other instances, the innovation is a new means of scaling up care or expanding to hard so reach populations. To date, the Foundation has made grants for projects in Ceech Republic, Hungary, Foland, Romania, and Russia.

#### The following projects are currently being funded by the Bristol-Myers Squibb Foundation's Bridging Cancer Care initiative:

Prevention and early detection (including tobacco-control) Engaging nurses in projects that promote health education, disease awareness, healthy lifestyles, and the importance of screening and early detection, and in shapelling mytha and misconceptions about cancer.

#### Tobacco control

International Society of Nuruss in Cascor Care (ISNCC); (Cooch Republic)
Two-year grant to support a collaborative project that includes a series of capacity-building Tobacco Cestation Leaderthip Workshops to educate nuruse on advances in robustop control, cancer prevention, treatment and care

#### Screening and early detection

- Project Hope Poland (Poland) Two-year grant to help improve early detection of cancer in children by training community nurses and printary healthcare teams.
- Romanian Cancer Society: (Romania) Two-year grant to train nurses on how to dissentinate information on presention, early diagnosis, treatment guidelines and follow-up for stormad, codon and melanone cancers to their communicies. 
  National Center of Narring and Other Health Professions: (Ceech Republic) Two-year grant to support a project to educate community nurses.
  - in cancer prevention, and to actively engage rurses in the education and promotion of healthy lifestyle for cancer patients

#### Evidence to practice - successes and gips

University of Washington (Russia) Two-year grant to partner with Bashkir State Medical University to train nurses in evidence-based oncology nursing practices

#### Dispelling myths and misconceptions about carcer

 Hungarian Hospice Foundation: (Hungary) Two-year grant to engage general practice nurses in efforts to encourage Roma people to participate in cervical, breast and prostate cancer screenings, and to seek cancer care services when needed.

#### Cancer care and survivorship

Nurse training and education on contemporary models of cancer care, innovations in service delivery and improving the quality of life for cancer patients and survivors.

#### Innovations in service delivery

National School of Public Health, Management and Professional Development:
 (Romania) Two-year grant to adapt and implement the U.S. model of the
 Oncology Name Navigator

#### Quality of life in cascer care

Partners in Progress (Romania) Two-year grant to support a project to increase health steracy and improve the quality of life for cancer patients by educating community nurses and forming partnerships between nurses. Etraries and patients

#### Palliative care

Establishing nurse training programs in pallative care

#### Estdence-based training 999999 Beckman Research Institute of the City of Hope: (Casch Republic, Hungary, Poland, Romania and Russ Technologies to transferred the Confession

(Casch Republic, Hungery, Poland, Romania and Russia) Two-year great to implement the End-of-Life Maning Enhances Cascathian, a rational education initiative to improve palliative care

#### apacity building

Projects that aim to train and build capacity of oncology and general practice nursing for delivering cancer care in the community. Empowering nurses as mornbers of the cancer worldorce

- Polish Amazons Social Movement. (Poland) Two-year grant to train community nurses on career presention, epidemiology, treatment and patient care, and to establish regional information centers that community nurses can contact with questions
- World Sentem of La Crosse, Inc.; (Russia) New-year grant to develop and implement training to enhance cancer nursing skills and to enhance health system capacity for provertion, screening sed contemporary care models, and a wed-year grant to improve nursing skills and expand the ecope of nursing practice in primary care claims.









## INEQUALITIES IN PARTICIPATION AND/OR ADHERENCE TO COLORECTAL CANCER SCREENING PROGRAMMES



Molina-Barceló A (1), Salas D (1,2), Peiró-Pérez R (1,2), Giner F (1), Vanaclocha M (1), Moreno J (1), Talavera M (3), Vallés G (3), Miranda J (1,2), Castán S (1,2), Alcaraz N (1,2).

(1) CSISP. (2) DGISP. (3) Universidad de Valencia.

#### **Objective**

Inequalities in cancer are the result of policies that structure in complex socio-cultural factors that shape axes of inequality (ethnicity, culture, age, gender, educational and socioeconomic level), generating inequalities in exposure to risks, participation in screening programs and access to treatments. The objective is to review the literature on factors associated with inequalities in participation and/or adherence to colorectal cancer (CCR) screening programmes.

#### Methodology

DESIGN: Bibliographic review in an electronic databases (Pubmed and Embase).

SEARCH STRATEGY: It has combined Mesh and EMTREE terms with the Boolean terms AND & OR.

ELIGIBILITY CRITERIA: 1. Have been published in peer review journals; 2. Language: English or a European language other than English; 3. Type of study: observational (cross-sectional, cohorts, cases and controls); 4. Developed countries; 5. CCR screening programmes; 6. Factors of influence in participation and/or adherence, from the perspective of social inequalities in health, taking into account sex/gender variables, age, cultural/ethnic minorities and socioeconomic/educational level.

DATA ANALYSIS: The analysis period was December 2011 to January 2012. It has analysed the titles and abstracts, by 2 persons independently (concordance analysis of 5% of the articles: 85% of agreement).

Descriptive analysis by R, using the chi-square statistic and assuming a significance level of 5%.

#### Results

It has been identified **701 documents** (665 at Pubmed and 36 at Embase). From these documents **239 were classified as "valid"** regarding the "Eligibility criteria". The characteristics of the valid articles are presented in **Graphs from 1 to 6**.

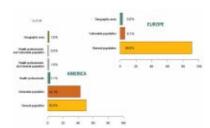
Graph 1. Continent of the studies



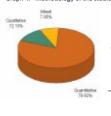
Graph 2. Country of the studies

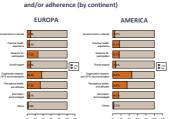


Graph 3. Population/Scope of study of the studies (by continent)



Graph 4. Methodology of the studies





Graph 5. Factors analysed connected with participation and/or adherence (by continent)

Graph 6. Axes of inequality analysed



#### **Conclusions**

- 1. There are few studies on inequalities in Europe.
- 2.In the U.S.A. there is a greater presence of studies focussing on the vulnerable population, and analysing the ethnic-cultural group as inequality axis. In Europe, on the other hand, most of the studies focus on the general population, analyse the socioeconomic/education level and sex/gender as an inequality axis.
- 3.Territorial inequalities are scanty analysed.
- 4.Few qualitative studies are performed.

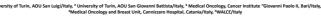
#### Recommendations

It would be necessary to include the perspective of inequalities as a basis for developing public policies to improve equity in access to screening programmes for colorectal cancer, and therefore the equity in cancer.



## WALCE (Women Against Lung Cancer in Europe) and information booklets about Lung Cancer

S. Novello<sup>1</sup>, C. Mantovani<sup>2</sup>, Domenico Galetta<sup>3</sup>, Giuseppe Banna<sup>4</sup>, E. Capelletto<sup>1</sup>, S.G. Rapetti<sup>1</sup>, M. Giaj Levra<sup>1</sup>, M. Longo<sup>1</sup>, T. Vavalà<sup>1</sup>, B. Crida<sup>1</sup>, S. Vallone<sup>5</sup>





#### Rackground

The correct information is fundamental for patients and relatives and the need of receiving the accurate one is particularly relevant among cancer patients and their families. When people have just been diagnosed with cancer it is almost certain that they will have many questions about.

#### Correct and controlled information is crucial to patients and caregivers.

Considerable material is now available through the internet, but although it is an important information tool, because it offers widespread access to health information and the advantages of interactivity and anonymity, it can not ensure equal access for patients and the validity and quality of information are variable and sometimes can reflect the view of individuals or interest of groups, rather than current evidence or best practice.

#### This may add to rather than reduce patients' confusion.

Lack of information, or inconsistent and contradictory one can make patients uncertain and can have a negative impact on them and their families increasing the sense of **anxiety**.

#### There is a serious problem for patients in the effective and autonomous use of the information.

Moreover, in the patient communication, the correct understanding of words used by health care professionals is sometimes complicated by the use of a scientific-technical language, which can increase the sense of helplessness of the patient because it does not facilitate the understanding of the situation and can discourage him to ask questions.

Poor understanding and poor retention of verbal inomration, in addition with the quantity and quality of it, about disease and treatments, can limit the effectiveness

## The requests of cancer patients are: To satisfy their need of knowledge To facilitate the doctor-patient relationship





#### Conclusions

#### Providing patients with adequate information is an important component of care.

Cancer patients require the improvement of information at every stage of the disease and wish to take an active part in understanding and managing the current situation. Indeed, healthcare system require patients to be better informed and empowered in order to become

In summary, information booklets is a popular method of providing health-related information to patients and it can be an *important source for patients diagnosed with cancer* to empower them in the process of participation in decision making.

However, the efficacy of this resource may be dependent on such factors as **readability**, determinant of patient understanding and **recall** of important information about their illness and treatment.

### Although other media, including video and internet have been explored, written material is the simplest e more common one.

However, developing acceptable and effective informational material is not easy, even for the apparently simple tool as booklets or leaflets.



more responsible users.



#### Method

Currently patients are getting active partners in their own health care and for that they need and want to receive accurate, practical information and advice. The aim of our project is to help patients in recalling information and facilitating the understanding, improving the readability and user-friendliness of patient educational booklets and providing understandable, up-to-date, high-quality and non-promotional information, even if scientifically valuable.

During these years, the WALCE Scientific Committee was involved in producing a series of educational booklets in the thoracic oncology field for patients, their families and carers to educate them about the disease (symptoms, diagnosis, staging, treatment options) and other issues such as:

- Side effect management
- Supportive therapies

The draft text is normally evaluated by specialists in order to be reviewed by patients or relatives. This booklet collection is realised in Italian and English and spread it out among patients trough <u>International Potient Advocacies</u> and a well-established <u>health professional network</u> at national and international level.



#### Special thanks to:

Dr. M. Aieta, Dr. S. Binato, Dr. F. Cecere, Dr. D. Cortinovis, Dr. A. Follador, Dr. O. Martelli, Dr. G.M. Numico, Dr. C. Putzu, Dr. M. Tiseo.

#### Reference

- Phyllis Butow, Elizabeth Brindle, David McConnell, Robert Boakes, Martin Tattersall: Information booklets about cancer: factors influencing patient satisfaction and utilization. Elsevier - Patient Education and Counseling, Vol. 33, Issue 2, 1 February 1998, Pages 129-141
- Kinta Beaver, Karen Luker. Readability of patient information booklets for women with breast cancer. Patient Education and Counseling, Vol. 31, Issue 2, 1 June 1997, Pages 95–102
- G. Ionomou, A. Viha, A. Koutras, I. Koukourikou, V. Mega, T. Makatsoris, A. Onyenadum, K. Assimakopoulos, A. G. Vagenakis and H. P. Kalofonos Impact of providing booklets about chemotherapy to newly presenting patients with cancer: a randomized controlled trial. Oxford Journals, Annals of Oncology, Vol. 17, Issue 3–Pp. 515–520.
- R. J. W. Cline and K. M. Haynes. Consumer health information seeking on the Internet: the state of the art. Oxford Journals. Health Educ. Res. (2001) 16 (6): 671-692.



## WALCE (Women Against Lung Cancer in Europe) and the primary prevention – educational kit for children



S. Novello¹, Domenico Galetta², Giuseppe Banna³, S. Vallone⁴,E. Capelletto¹, S.G. Rapetti¹, M. Giaj Levra¹, M.V. Pacchiana¹, M. Longo¹, T. Vavalà¹, B. Crida¹, R. Ronchetta²

1 University of Turin, AOU San Luigilitaly, 2 Medical Oncology, Cancer Institute "Giovanni Paolo II, Barilitaly, 3 Medical Oncology and Breast Unit, Cannizzaro Hospital, Catania/Italy, 4WALCE/Italy

#### Background

Lung cancer is the leading cause of cancer-related mortality worldwide and several studies reveal that smoking is the most important risk factor of preventable diseases and deaths and there is a clear association between smoking, including passive smoking, and the onset of the lung cancer. Some provided that the control of the control

There are currently no established methods to support screening for lung cancer, so the most effective measure to prevent this and most chronic diseases, is the *smoking avoidance or the smoking cessation*.

#### 70-85.000 deaths/years in Italy

1/3 Cardiovascular disease 1/3 Respiratory disease 1/3 Oncology disease

It is important to convince people not to smoke or to quit this habit, but it is even more important to conduct an effective and persuasive anti-smoking campaign among kids in the schools.

The data Doxa-Iss Ossfad presented in May 2011 on the occasion of World No Tobacco Day highlighted:

#### In Italy children aged 11 smoke their first cigarette

who started so early, at age 13 consume an average of 14 cigarettes per day between age 15 and 24, smokers represent the 21.8% among girls and 15.9% among boys in some EU countries girls outnumber boys 15.7% took up smoking before age 15 71.3% took up smoking between age 15 and 20

To confirm these data, an ISTAT study declares that out of 100 Italian smokers and ex-smokers, between age 14 and 80, more than six people reported that they started before age 14.







#### Method

- It is possible to prevent the consumption and the spread of tobacco and the severe consequences through:
- · the awareness of the problem
- the adoption of strategies involving the institutions and the individual.

The consumption of tobacco represents a social health problem impressive for death and disability rates so that WHO defined smoking as the leading cause of preventable death in the world. Scientific researches confirm that an effective tobacco control policy should start in the childhood when learning is faster and more immediate and when attitudes and approaches tighten up and persist into adulthood. Through appropriate prevention programs, kids may understand that taking care of themselves will affect their adult well-being. Children spend their first years of life and live their first experiences in the school, which plays a key role in the formation of their health-consclousness and in the promotion of the most suitable healthy lifestyles.



#### The Project

In consideration of these facts, WALEE Onliss in collaboration with Carthusia designed "Questa non me la fumo", an educational kit for kids who may develop a specific attitude towards the prevention of smoking with the aid of teachers. This is an information and woreness campaign on damages of smoking and on healthy lifestyles, to support educational activities targeted for 10-11 year-old pupils with the aim of providing schools with skills, working tools and support to pursue an holistic approach to promote health, in a complete synergy with the teachers.

#### The kit contains:

- 1. a big book for the class
- a tool that helps teachers to capture children's attention

  2. 24 notebooks
  - one per student with a dossier for parents
    3. an instruction guide for the teacher
  - 4. the box-aame for the class
- the game represents a moment for children to express spontaneously themselves learning and growing up.



#### Conclusions

In 2005 in Italy a legislation was introduced to regulate smoking in all indoor public places, including the workplaces. This smoking ban (Sirchia law) had positive effects, but there are warning signs confirming the increasing number of smokers, especially among young people and girls. This requires that institutions and organizations operating in this field continue their efforts to maintain and improve the results achieved through more structured strategies and interventions at various levels. In our country the problem of smoking is a real emergency, therefore, the strengthening of educational interventions in the schools should start from the primary school, involving parents and families.

It is essential that the <u>information is positive</u>, that does <u>not emphasize only negative concepts</u> related, but <u>highlights the positive actions</u> that parents and teachers can make for their children.









➤ In the *immediate future*, the initiative's success will be the **adherence** of a large number of classes and the **positive feedback** from children.

In the short-run a survey will be made among children who participated to the project and, after few years WALCE will supervise through a questionnaire the classes (for example, the last year of the secondary school on early high school) in order to evaluate the health-consciousness of children who received the anti-smoking campaign.

> In the *long run* (smoking damages unfortunately have a very long latency period) a regional survey could conducted on the incidence of lung diseases in the areas involved in the campaign.



Smoking reported to carried

Smoking représents a critical hazard for women et all ages, especially in their reproductive years and during psegnancy. Tobacco industry has been systematically fragefing women of all ages and file circumstances. Marketing strategies tink cigarette use to typical female values. It is generally thought that the cessation rate for female smokers is lower than for mole smokers. It is not the designant rate for handle smokes a lower than for more smokes. It is not known, whether this is because women are less likely to remain abstraint when they do guit or because they are less likely to attempt to guit smoking. (Reichert VC, 2004). The World Health Organization (WHO) estimates that the number of women smoking will almost fligle over the next generation (Deland K, 2000).

Carcinogens in tobacco smoke In tobacco smoke In tobacco smoke Iffere are many potentially noxious chemicals (Kumar V. 2001), in fact, Islabocco cardiotin services (2004), and 4000 substances, more than 400 at which have been identified as carcinogens (1000).

lar	Carcinoperesis
Nitrosomine	Carcinopenesis
Polycyclic aramatic hydrocarbons	Carcinogenesis
Serzopyrene	Carcinogenesis
Nicotne	Tumor promotion
Phenoi	Turner prometion
Formoldehyde	Toxicity to cella

Carton monoxide impaired aware tonsport and utilization

finale 1. Some tobacco substances and their effects

## Cançers associated with tobac

Smoking in Women

Active smoking may play a role in breast cancer effology and seems to be an indirective for preinvalve and invasive cervical concer. Other cancers that are cannot tobacce inventing in women one lung and branchial cancer, bladder and xannot of oropharyax, esophageal and pancreatic cancer.

Breast cancer
Smoking may play a role in breast concer etiology. More than Smoking mary play a role in breast concer effoliagy. More than 100 000 women with no previous breast concer diagnosis participated in a large study (Colifornia Teaches Study), 2006 of the women weets newly diagnosted with invasive breast concer (Reynolds P. 2004). The incidence of breast concer (Reynolds P. 2004). The incidence of breast concer was higher aroung current smokers than among these who never smoked (Hazard Rots = 1.52, 9% confidence Internal (C) = 1.20 to 1.3 matches to all never smokers than 4.00 of 1.3 matches to a role of 1.20 to 1.3 matches to 1.20 to 1.20 to 1.3 matches to 1.20 to 1.

Cervical cancer
Tobacco smoking seems to be an independent risk factor for preinvasive and invasive cervical cancer (Coker AL. 2009). A brewinste data interfere de into a moderni de la factoria del la factoria de la factoria del la factoria de la factoria del la fact a lower rate of screening for the deese. The outhors conclude that efforts to increase prevalence of screening hists compliance should target current smakers

Lung cancer

A recent french population based case-control study
confirmed that cigarelle smoking is by far the most important
cause at the current epidamic of lung cancer among french
women. Smoking cigarettes at some firm was associated with
a 8-fold increase in lung cancer (Papadapoulos A, 2011).

The data indicate that fobacco-related diseases have become a women's health issue of epidemic proportions. Concers that are connected with tobacco smoking in wome are serviced and breast concer, lung and bronchid concer, bladder and kidney cancer, cancer of oropharyax, esophagy and poncreatic cancer, fobacco industry continues systematically targeting women of all ages. It is possible that lung concer rates emong women may exceed that in men away the man and the service of the ser The data indicate that tobacco-related diseases compliance among current smakers.

## onclusion

Smoking represents a critical hazard for women of all ages, Tobacco smoke contains more than 60 carcinogens. Among tobacco related diseases, there are different types of concers, including lung. cervical and breast concer. The number of women smoking will almost triple over the next generation according to the estimations of the WHO. There is the urgent need to educate women, elevate the cessation rate for female smokers and revene these

Decord C. Lewis S. Toylor A., Developing o public colicus

## **Annexes - How Europe Went into Public Health in 1987**

History of a Beginning: Europe Against Cancer Michel Richonnier



## Annex 1: European Code Against Cancer (1987 and 2003)

#### **European Code Against Cancer (1987)**

Source : Text written in 1986-1987 by the Committee of Cancer Experts.

"If these 10 commandments were respected, a significant reduction in death by cancer will occur that could already reach some 15% by 2000", the Committee of Cancer Experts of the "Europe Against Cancer" programme.

#### **CERTAIN CANCERS MAY BE AVOIDED:**

- Do not smoke. Smokers, stop as quickly as possible and do not smoke in the presence of others.
  - 2. Moderate your consumption of alcoholic drinks, beer, wine or spirits.
    - 3. Avoid excessive exposure to the sun.
- Follow health and safety instructions, especially in the working environment concerning production, handling or use of any substance that may cause cancer.

Your general health will benefit from following two commandments which may also reduce the risks of some cancers:

5. Eat frequently fresh fruit, and vegetables and cereals with high fiber content.

#### **European Code Against Cancer (2003)**

Source: European Code Against Cancer and scientific justification (2003)", P. Boyle & al, Annals of Oncology 14: 973–1005, 2003

NB: According to § 1.3 of the European Commission communication COM (2009) 291 of 24.06.2009, the objective is to reduce by cancer incidence in Europe by 15% by 2020.

#### Many aspects of general health can be improved and many cancer deaths prevented, if we adopt healthier lifestyles:

- 1. Do not smoke; if you smoke, stop doing so. If you fail to stop, do not smoke in the presence of non-smokers.
- 2. Avoid Obesity.
- 3. Undertake some brisk, physical activity every day.
- 4. Increase your daily intake and variety of vegetables and fruits: eat at least five servings daily. Limit your intake of foods containing fats from animal sources.
- 5. If you drink alcohol, whether beer, wine or spirits, moderate your consumption to two drinks per day if you are a man or one drink per day if you are a woman.

6. Avoid becoming overweight and limit your intake of fatty foods.

## MORE CANCERS WILL BE CURED IF DETECTED EARLY

- Sea a doctor if you notice a lump or observe a change in a mole or abnormal bleeding
- 8: See a doctor if you have persistent problems, such as a persistent cough, a persistent hoarseness, a change in bowel habit or an unexplained weight loss

#### For women:

9. Have a cervical smear regularly

 Check your breasts regularly and, if possible, undergo a mammography at regular interval above the age of 50.

Comments: The 1987 version is very cautious with respect to nutrition and screening. Thanks to studies funded by Europe Against Cancer, the 2003 Code is more precise:

- maximum two drinks per day if you are a man or one drink per day if you are a woman;
- eat at least five servings of fruit and vegetable daily;
  - some brisk, physical activity every day;
     from 50 years of age participate in colorectal screening;
- participate in vaccination programmes against hepatitis B

- 6. Care must be taken to avoid excessive sun exposure. It is specifically important to protect children and adolescents. For individuals who have a tendency to burn in the sun, active protective measures must be taken throughout life.
- 7. Apply strictly regulations aimed at preventing any exposure to known cancer-causing substances. Follow all health and safety instructions on substances which may cause cancer. Follow advice of national radiation protection offices.

There are Public Health programmes which could prevent cancers developing or increase the probability that a cancer may be cured:

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

## Annex 2: Overview of European Laws on Tobacco Control

## Ban of smoking in places open to the public (Resolution):

Resolution of the Council and the Ministers for Health meeting within the Council on 18/07/1989 (OJ C 189 of 27.07.89)

Maximum tar yield of cigarettes (Directive 90/239/EEC)

- 15 mg as from 31.12.1992 - 12 mg as from 31.12.1997.

Temporary derogation for Greece:
- 20 mg as from 31.12.1992, 18 mg as from 31.12.1998, 15 mg as from 31.12.2000, -12 mg
as from 31.12.2006.

Comments: (1) No reference to CO yield since it is highly correlated to tar (R= 0, 95 for a sample of 40 different cigarette packets). (2) No application lodged at the European Court of Justice (ECJ) for the annulment of this directive.

Labeling of tobacco products (Directive 89/622/EEC)

1) General warning: Tobacco seriously damages health (4 words)

Alternating warnings for cigarette packets
 A. Warnings which must be included on national lists:

This non binding European Resolution has been implemented in several countries through a binding national law..

The two directives of 1989 and 1990 were replaced by the **Tobacco products directive 2001/37/EC.** Main characteristics:

## Maximum tar, nicotine and CO yields of cigarettes

From January 1st 2004:

10 mg for tar, 1 mg for nicotine, 10 mg for carbon monoxide.

Temporary derogation for Greece: 01.01.2007 for the tar yield.

#### II. Labeling

- a) General warnings:
- 1) Smoking seriously harms you and others around you

(NB: Twice as long as in 1989)

2) Smoking kills, or Smoking can kill (as in 1989)

These general warnings shall be rotated in such a way as to guarantee their regular appearance. b) Alternating warnings taken from the following list:

- 1. Smoking causes cancer (3 words)
- 2. Smoking causes heart disease (4 words)
- B. Warnings among which Member States may choose
  - Smoking causes fatal diseases (4 words)
     Smoking kills (2 words)
    - 3. Smoking can kill (3 words)
- 4. Smoking when pregnant harms your baby (6 words)
  - 5. Protect children : Don't make them breathe your smoke (8 words)
    - 6. Smoking damages the health of those around you (8 words)
- 7. Stopping smoking reduces the risk of serious disease (8 words)
  - 8. Smoking causes cancer, chronic bronchitis and other chest diseases (9 words)
  - More than (...) people die each year in ... (country name) from lung cancer (12 words!)
     Every year (...) people are killed in road accident in (country name)-... time more dies from their addiction to smoking (20 words!)
  - 11. Every year, addiction to smoking claims more victims than road accidents (11 words!)
  - 12. Smokers die younger (3 words)
    13. Don't smoke if you want to stay healthy (8
    words)
    - 14. Save money: stop smoking (4 words)

Comments: (1) This directive will be slightly amended in 1992 (92/41/EEC) and will prohibit the sale of certain tobacco for oral use.

(2) No application lodged at the European Court of Justice (ECJ) for the annulment of this directive

- 1. Smokers die younger (as in 1989)
- 2. Smoking clogs the arteries and causes heart attacks and strokes (similar)
- 3. Smoking causes fatal lung cancer (similar)
- 4. Smoking when pregnant harms your baby (as in 1989)
- 5. Protect children: don't make them breathe your smoke (as in 1989)
- 6. Your doctor or your pharmacist can help you stop smoking (new)
- 7. Smoking is highly addictive, don't start(new)
- 8. Stopping smoking reduces the risk of fatal heart and lung diseases (similar)
- 9. Smoking can cause a slow and painful death (similar)
- 10. Get help to stop smoking: (telephone/postal address/internet address/consult your doctor/pharmacist) (new)
- 11. Smoking may reduce the blood flow and causes impotence (new)
- 12. Smoking causes ageing of the skin (new)
- 13. Smoking can damage the sperm and decreases fertility (new)
- 14. Smoke contains benzene, nitrosamines, formaldehyde and hydrogen cyanide (new)

**Comments:** (1) Two warnings of 1989 disappeared for no obvious reason: Smoking causes cancer and Smoking causes heart disease.

- (2) The Commission decision 2003/641/EC provides for a set of color photographs or other illustrations as health warnings on tobacco package http://ec.europa.eu/health/tobacco/law/pictorial/index en.htm
- (3) The tobacco industry lodged at the ECJ an application for the annulment of this directive without success.

# Ban of advertising and sponsorship of tobacco products (98/43/CE) (Overturned by ECJ on 05.10.2000)

On April 1989, the European Commission presented a directive proposal for controlling advertising in the press and by means of bills and posters (cf. COM (89)163 final, OJ 89/C 124 p.5). In March 1990, during the cooperation procedure, the European Parliament voted in favor of a total ban of advertising and sponsorship of tobacco products.

In May 1991, the European Commission modified its initial proposal along these lines.

After 7 years of lengthy discussions, this directive was finally adopted on 06.07.1998, despite the strong opposition of Germany and Austria.

Germany lodged at the ECJ an application for the annulment of this directive. The ECJ indeed overturned it in 2000, emphasizing that certain type of advertisement were not related to the Internal Market, such as advertisement on posters, ashtrays or in movie theaters.

# Directive 2003/33/EC relating to the advertising and sponsorship of tobacco products

After this decision of the ECJ, all three institutions resumed working on a new text leading to directive 2003/33/EC which bans, as of July 31 2005, advertisement in the press (except those intended exclusively for professionals in the tobacco trade), or via radio-broadcasting or internet.

Moreover, sponsorship of events or activities involving or taking place in several Member States or otherwise having cross-border effects is prohibited.

Comments: (1) Germany lodged at the ECJ a new application for the annulment of this new directive. This time, the directive was carefully written and Germany was defeated.
(2) Advertisement for tobacco products on TV were already banned by Article 13 of directive 89/522/EEC on television broadcasting activities ("TV without frontiers").

## References - How Europe Went into Public Health in 1987 History of a Beginning: Europe Against Cancer

- Former European Commission official, in charge of "Europe Against Cancer" from 1986 to 1990. This contribution is based on my own archives, on recent documents transmitted by Dr Karl Freese, a veteran of Europe Against Cancer, and on an extensive search on the Web. Comments and opinions expressed in this article do not commit the European Commission.
- <sup>®</sup> All three European institutions (Parliament, Commission and Council of Ministers) agreed to select the European flag and anthem that were already adopted by the Council of Europe in the 1950s.
- The Euratom Treaty did contain articles covering both public health (protection of population against ionizing radiations) and occupational health (protection of workers).
- <sup>iv</sup> The EEC Treaty (art 100, unanimity) allowed to protect consumer health against certain dangerous substances as early as 1976 (directive 76/769/EEC of 27.07.1976) or to protect workers against asbestos (directive 83/477/EEC of 19.09.1983).
- <sup>v</sup> In October 1996, this Committee became, by Commission Decision, the Consultative Committee for Cancer Prevention and it was chaired by Professor Veronesi who replaced Professor Tubiana. This Committee did not meet after January 2001.
- <sup>vi</sup>The tobacco lobby was well informed about the composition of this internal task-force and its working calendar! See for instance: http://legacy.library.ucsf.edu/tid/nut32e00/pdf;jsessionid=D4C 0EE76FC12A2C954383A20676F8429.tobacco03. William Hunter, my right hand in the task-force, would be appointed in 1993 as the first director of Public Health in the European Commission. Fernand Sauer, another member of the task-force, would replace him in 2001.
- vii Cf. OJ C 50 of 26.02.1987 or the special issue of Social Europe on Europe against cancer, 1991-I. OPOCE, Luxembourg.
- vii This led to a Council decision (OJ L 160 of 28/06.1988) with more than ECU 10 million for this exceptional information campaign.
- ix Cf. the special issue of Social Europe on Europe against cancer
- \*Cf. « Mémoires », Jacques Delors, (p.215), Plon 2003

- xi A 3rd directive proposal was announced in the first action plan to control advertising for tobacco products. The initial proposal, adopted by the European Commission in April 1989, was modified in 1991 and, after a saga of 14 years, the Council and European Parliament finally adopted Directive 2003/33/EC relating to the advertising and sponsorship of tobacco products. (see Annex 2).
- xiii Cf. Michel Richonnier « How the European Community went into Public Health », Chapter 14 in "Winning in the New Europe: Taking advantage of the Single Market", Liam Fahey Editor, Prentice Hall, New Jersey, 1992.
- \*\*\* These two directives were combined and updated in 2001 http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2001:194:0026:0034:EN: (cf. Annex 2 for a comparative overview or "Tobacco or Health in the EU», OPOCE, Luxembourg, 2004).
- xv OJ C 189 of 26.7.1989
- xvi Cf. COM (90) 185 final of 08.05.1990. Available at http://aei.pitt.edu/4702/1/4702.pdf.
- xvii These European studies and actions allowed not only to improve the European Code Against Cancer in 2003 (cf. Annex 1), but also to identify optimal screening policies thus allowing the Council to adopt, in 2003, a Recommendation on screening (OJ L327 of 16.12.2003) based on the scientific opinion of the Consultative Committee for Cancer Prevention (January 2001).

  xviii Decision 90/238 OJ L 137 of 30.05.1990
- xix "Measuring progress against cancer in Europe" P. Boyle & al; Annals of Oncology, 2003 pp1312-1325 http://annonc.oxfordjournals.org/content/14/8/1312.full
- xx Of course, these 850.000 people died or will die from natural ageing or from another illness.
- <sup>xxi</sup> On 16.05.2000, the European Commission adopted a proposal for an integrated programme in Public Health (Cf. COM (2000) 285 final, http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM :2000:0285:FIN:FR:PDF), replacing the eight existing programmes: six targeted ones (fight against cancer, communicable diseases and AIDS, drug dependence, etc.) and two horizontal ones (health promotion, health monitoring). It was finally adopted more than two years later on 23.09.2002 (Decision No 1786/2002/EC).
- xxii Cf. Robert Coleman, former Director General for Public Health and Consumer Protection in the European Commission until 2003, «EU policies and programmes concerning health: a short history», Queen's University Belfast Briefing Paper Gov/BP/2004/2 http://www.saglik.gov.tr/extras/dokuman/EU%20Policies%20and%20Programmes.pdf.

- <sup>xxiii</sup> In the 1980s, Europe Against Cancer had two strategic axes: (i) Promotion of European legislation; (ii) Financial support to European partnerships. In the 1990s, after the adoption of all the legislations mentioned in the first action plan, the second strategic axis was granted the name Europe Against Cancer. Obviously, however, European legislations had a key role to play for reaching (partially) the 2000 objective of the programme.
- xxiv Cf. "The Construction of Healthier Europe: Lessons from the Fight Against Cancer", Louise Trubek, Mark Nance, Tamara Hervey, Wisconsin International Law Journal, Paper No. 1062 July 2008 http://ssrn.com/abstract=1169363
- xxv Cf. the Commission information note of 29.09.2009 (IP/ 09/1380) on the re-launching of Europe Against Cancer http://europa.eu/rapid/pressReleasesAction.do?reference=IP/09/1380&format=HT ML&aged=0&language=FR&guiLanguage=en
- xxvi Some countries like France have already done so (at least for "Smoking causes cancer").

## **Save the Date for the next Open Forum:**

**OPEN FORUM III, Spotlight on National Cancer Plans & Screening** 

Brdo pri Kranju, Slovenia - November 2013 Hosted by the National Institute of Public Health, Slovenia



### Contact us:

For further information on the European Partnership for Action Against Cancer Joint Action:

Write us: partnership.cancer(at)ivz-rs.si

Visit us: www.epaac.eu & https://webgate.ec.europa.eu/sanco/heidi/index.php/Cancer\_partnership

Like us on: Facebook at www.facebook.com/epaac Follow us on Twitter: http://twitter.com/EPAAC JA

Watch us on Youtube: www.youtube.com/EPAACJointAction