



Luxembourg, November 2008

**Action against cancer: European platform
Brainstorming workshop organised by DG SANCO on the European Platform on
Cancer**

Luxembourg, 29 October 2008, room JMO M2

Minutes of the meeting

1. Welcome and Introduction

Participants were welcomed to the brainstorming workshop on **Action against cancer: European platform** by the chairman, Mr Nick Fahy, Head of Health Information Unit (SANCO - C2). A list of participants is enclosed (see Annex I). The aim of the meeting was an informal exchange of views about possible areas and directions to be considered within the framework of the European Commission's planned future initiative in the area of cancer. It was agreed at the beginning of the meeting that views expressed will be summarized in the minutes, but not attributed to individual speakers.

There were two main topics of discussion: how to structure the multi-stakeholder platform in the way to assure continuous action in the area of cancer prevention and control, and the immediate areas and actions to be addressed within the framework of the initiative.

The Commission identified four main areas of future actions that were broadly confirmed through the discussions:

1. Health information, collection and analysis of comparable data, and evidence to support learning and sharing of knowledge;
2. Primary prevention;
3. Identification and promotion of good practice in cancer-related healthcare;
4. Cancer Research.

As an introduction to the four main areas, colleagues from different Commission services gave the following presentations: DG SANCO – C6 Unit (tobacco legislation); DG EMPL – F4 Unit (occupational health and safety); DG ENTR – C1 Unit (general and sectoral accreditation); DG RTD - F2 Unit (cancer research in the EU Framework Programmes for RTD) and DG SANCO - C4 Unit (existing platforms on alcohol and on nutrition and physical activity from).

2. Discussion on the structure/process of the Cancer Platform, and on possible areas and actions

Structure/Process

The participants expressed their concerns about a cancer approach based on an EU “platform”, as is currently done in the areas of nutrition and alcohol. Those platforms bring voluntary commitment in areas where legislation is also possible. The general view was that a future structure/process in the cancer area should not be called a "platform" as there is a clear distinction between lifestyle related health determinants, such as nutrition and alcohol, and cancer as a disease. Participants felt that the foreseen cancer initiative should not be just a discussion forum for exchange of information, but it should rather lead to concrete actions that would bring a change and reduce the burden of cancer. As underlined by the participants, there already exists a solid basis for further action in cancer on a European level. The need for a concrete support structure/centre that would allow for continuity in action was expressed. It was agreed that the Commission should ensure a political leadership and coordinate the process.

The identification of relevant stakeholders to participate in the new structure was seen as a very important issue. The participation would not be open to everybody, and would have to be limited in number. Particular concerns were expressed about the participation of stakeholders who might not share the overall objective of reducing cancer, such as the tobacco industry. Similarly, the stakeholders participating in existing EU platforms should contribute to the area of cancer through the efforts undertaken by the platforms within primary prevention. Different views were expressed as regards the participation of pharmaceutical industry. It was felt important to include the representatives of employees and employers. It was also felt to be important to find the right approach as regards the participation of Member States and other stakeholders. Member States should have the opportunity to set their own priorities. Stakeholders should on the other hand also have a clear role and objectives in the foreseen cancer initiative.

The structure/process will have to work within the existing resources. For that reason, participants stressed the importance of seeking synergies and cooperation among different policy areas (different Directorates-General of the European Commission), where activities are already running and where resources are also available. It was also pointed out that for many valuable activities no additional resources will be required. For example, the exchange of best practices and cooperation of Member States does not necessarily mean new resources, but it can on the other hand bring added value to each Member State's effort in tackling cancer. Member States also have the possibility to use structural funds for infrastructure.

Areas and actions

Member States should be encouraged to prepare cancer plans and this should be the biggest role for the EU, according to some participants. Those plans could form a valuable basis to exchange best practice at EU level. Cooperation of Member States would be especially welcome in that area.

Participants also referred to the proposed recommendations for cancer plans that resulted from the cancer roundtable during the PT Presidency of the Council of the EU¹, Council

¹ http://www.acs.min-saude.pt/wp-content/uploads/2007/12/15h45robertozanettilisbonmeeting_new.pdf and Gouveia J. et al (2008) *Improving cancer control in the European Union: conclusions from the Lisbon roundtable under the Portuguese EU Presidency, 2007*. EJC (44), 1457-1462.

conclusions on reducing the burden of cancer, adopted on 10 June 2008² and European Parliament resolution of 10 April 2008 on combating cancer in the enlarged European Union³. Those could be seen as the overall aims that should be put in action so far as possible. According to some participants their implementation in Member States should also be monitored and supported.

1. Health information, collection and analysis of comparable data, and evidence to support learning and sharing of knowledge

There are five important indicators/elements for measuring the burden of cancer: incidence, prevalence, mortality, survival and cure. Those should be systematically collected in cancer registries across Europe. Health-related quality of life, quality of care and patients' satisfaction were also indicated by some participants as important indicators of outcome that should be considered; as well as information tailored to patients needs, so that they can make best informed decisions on treatment and lifestyle. Some participants stressed the need for statutory cancer registration. EU should do more to support registration on regional/national level, and at the EU level European networking of cancer registries is important. The issue of transposition of the Directive on data protection created some problems in cancer data collection in some of the Member States. Therefore the proposal was made to assess the transposition of the Directive in Member States in this area and to undertake a public survey that would reveal views of citizens on cancer data collection. Patients and patient groups also need information that would help them to influence national governments.

2. Primary prevention

A number of participants pointed out that cancer strategy for Europe is needed and the Commission should focus even more on prevention, including improving its evidence base, and screening (as part of secondary prevention). The European Code against Cancer should be adapted to the general public and revised according to emerging scientific knowledge. In this context also HPV vaccination should be looked at as well as more precise information on prostate and colorectal cancer. The information and messages that could be addressed especially to children and young people should be considered.

3. Identification and promotion of good practice in cancer-related healthcare

Inequalities are a problem that needs to be addressed as well as quality of care. Guidelines on treatment are needed to overcome inequalities. Health technology assessment and patient information were also mentioned as an area where cooperation and exchange of information among Member States is welcome. The issue of increased mobility of patients is relevant for certain types of cancers and as an option for some Member States. Integrated cancer care, including psychosocial care focused on the patient is another vital part that needs to be encouraged and examples of good practice looked at. Continuous work on implementation of organised screening programmes on breast, cervical and colorectal cancer is also very important. New developments should be followed in order to improve the available evidence base on screening. The development of voluntary European accreditation schemes for cancer screening is important, starting with a pilot accreditation scheme for breast cancer screening, and if positive outcome, followed by other forms of cancer that are part of the Council Recommendation of 2 December 2003 on cancer screening (2003/878/EC).

4. Cancer Research

As underlined by a number of participants, better coordination and collaboration (especially collaboration of cancer registries) is a key component to further enhance European cancer

² http://www.eu2008.si/en/News_and_Documents/Council_Conclusions/June/0609_EPSCO-cancer.pdf

³ <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P6-TA-2008-0121+0+DOC+XML+V0//EN>

research. There is also a need to focus more international attention on prevention research. Public health research should not be neglected.

3. Conclusion -main messages from the Workshop

The Commission should ensure the political leadership in the future European partnership against cancer, which should avoid being called “a platform”, to distinguish it from existing platforms in the area of health determinants. As part of the European action against cancer it is important to form a structure that will ensure sustainability in the concrete actions that are needed to tackle the European cancer burden. The participating stakeholders should be clearly defined as well as their role. Member States have to have a separate role.

The future action should focus on development and improvement of national cancer plans. Cancer registries are an important source of data on cancer, and in relation to that the implementation of EU legislation on data protection should be carefully looked at. The European Code against Cancer needs to be scientifically reviewed and its presentation needs to be clearer, in particular for children and young people. Voluntary European accreditation schemes for cancer screening should be developed. There is a cross-border dimension in the area of cancer treatment that should be looked at. In this context also centres of references and their networking across Europe are important. Integrated cancer care focused on the patient, including psychosocial care also deserves more attention. In the area of research, the research on prevention and better collaboration and cooperation was stressed. Public health research should not be neglected.

Annex I

Brainstorming workshop: Action against cancer – European platform 29 October 2008, Luxembourg

Name	Representing
Member States REPRESENTATIVE	
Jitka Abrahámová	Czech Republic
Eva Křemenová	Czech Republic
Karen Budewig	Germany
Luzia Travado	Portugal
Pedro Pimentel	Portugal
Samuel Ulfgard	Sweden
Mojca Gruntar Činč	Slovenia
EXPERTS/NGOs	
Michel Coleman	London School of Hygiene and Tropical Medicine
Alberto Costa	European School of Oncology (ESO)
Hildrun Sundseth	European Cancer Patients Coalition
Wendy Tse Yared	Association of European Cancer Leagues (ECL)
Ingrid M. Van den Neucker	ECCO - the European CanCer Organisation
INTERNATIONAL ORGANISATIONS	
Francois Decaillet	World Health Organization
Markus Pasterk	IARC - International Agency for Research on Cancer
Andreas Ullrich	World Health Organization

EUROPEAN COMMISSION	
Nick Fahy	DG SANCO C2
Maja Rupnik-Potokar	DG SANCO C2
Brita Kalterbrunner-Bernitz	DG SANCO C2
Karl Freese	DG SANCO C2
Philippe Roux	DG SANCO C4
Stefano Vettorazzi	DG SANCO C4
Terje Peetso	DG SANCO C6
Maria Vidal	DG RESEARCH
Alick Morris	DG EMPL
Annabel Brewka	DG ENTR
Stefan Schreck	EAHC
Angela Rincon	EAHC