



EUROPEAN CANCER PATIENT COALITION'S RESPONSE TO: Commissioner Byrne's reflection process for a new EU Health Strategy "Enabling good Health for all"

Introduction

The European Cancer Patient Coalition (ECPC) was founded in September 2003 with the aim of giving European cancer patients a voice in shaping the European Union's policies that impact on cancer care. ECPC's goals are:

- Nothing About Us, Without Us!
- Promoting the fundamental rights of European cancer patients
- Increasing cancer patients' influence over European health policy
- Ensuring timely access to appropriate prevention advice, treatment and care
- Promoting the advancement of cancer research

Currently, ECPC has over 100 full members and 12 associate members from 9 EU Member States and represents patients with cancers of the commonest sites such as lung and colorectal cancer to the rarer cancers such as multiple myeloma and chronic myeloid leukaemia. At present, the Coalition is governed by a steering committee consisting of:

- Lynn Faulds Wood (UK), Lynn's Bowel Cancer Campaign
- Heide Preuss (Germany), Mamazone
- Ekke Büchler (Austria), Selbsthilfe Prostatakrebs
- Jan Geissler (Germany), Leukaemia Online
- Tom Hudson (Ireland), Europa Uomo – the European Prostate Cancer Coalition
- Claudia di Loreto (Italy), Assoc Italia Malati di Cancro (AIMaC)
- Patricia Huijbreghts (the Netherlands), the Dutch Federation of Cancer Patients' Organisation (NFK)
- Jesme Baird (UK), the Roy Castle Lung Cancer Foundation
- Kathy Redmond (Italy), the European School of Oncology

Four of these committee members are cancer survivors; the others represent cancer patient organisations and the organisation that is the Coalition's main source of funding – the European School of Oncology (Kathy Redmond). Further information about ECPC is available from www.ecpc-online.org

Background

Cancer is an important public health scourge and is set to increase dramatically due to our ageing populations. Every minute approximately 4 European Union citizens are diagnosed with the disease and at least 2 die from it. Despite the huge amounts of money that have been invested in the war against cancer, outcomes remain poor for many of the 200 different cancer types.

ECPC welcomes Commissioner Byrne's reflection process, together with the accompanying paper "**Partnerships for Health in Europe**", and the opportunity this provides for cancer patients to contribute to a new European health strategy. We very much appreciate the Commissioner's efforts to integrate health into all other EU policies. This is an important step as there is a great potential for influencing health outcomes through effective Internal Market legislation, social, economic and environmental policies. The important health challenges that our European societies are facing - and cancer as one of the biggest premature killers is foremost among them - can and should be addressed by sharing best practice across Europe. We fully support applying the open method of coordination in the health field.

As European cancer patients we are particularly anxious that the gaps in cancer prevention, treatment and care within and especially between the EU15 and the new Member States be eradicated. The Commission's paper and a recent Dutch presidency paper point out the variations in cancer mortality across the EU. In our view this difference is unacceptable. A recent article in the *Annals of Oncology* holds out hope that the application of available knowledge on cancer prevention, diagnosis and treatment may substantially reduce the disadvantage now registered in the cancer mortality of the new Member States.

Bridging the health gap

We whole-heartedly support the objective to make measurable progress in bridging the health gap between the Member States in the enlarged EU by

- Allocating a larger share of financing for projects under the annual work plans of the public health programme.
- Helping to mobilise a larger share of the structural funds for health related investment in the new Member States
- Helping to reduce health inequalities across the EU through a dedicated action plan that sets specific measurable targets for the reduction of cancer.

Partnerships for citizens' and patients health – enabling active participation in the health decision-making process

We are in full agreement with Commissioner Byrne that the important health challenges facing our societies in Europe are a shared responsibility and that this requires mobilizing the different sectors of society and governments. In our opinion the European Commission is well placed to act as the engine to create synergies between Member States to the benefit of patients and healthcare systems, encouraging cooperation, networks of centres of reference focusing on specialized treatment and use of spare capacity.

However, Europe's citizens - be they well or ill - can only make informed choices about their health and participate actively in the health policy decision-making if they have the necessary information and skills.

Cancer patient groups, patients and their advocates are particularly anxious to take part in this shared process and be given the tools to contribute. Europe's citizens and patients desire high-quality and accessible information relevant to their needs, what treatment options exist and how they can access them. At present the information needs of cancer patients are unmet. In a recent survey among our members one of the biggest problems faced by the patients they represent was access to timely and appropriate information about their disease, including prevention, screening, early intervention, best quality treatment and care.

- ECPC supports the setting up of an EU health portal to provide patients and citizens with more information and to make healthcare systems and their performance more transparent.
- ECPC puts great store in the European Medicines Agency and the new centralised procedure that applies to cancer drugs. Cancer patients hope that the Agency will provide them with the fastest access to new life-saving medicines. We are pleased that EMEA will include two patient groups on their Management Board and that EMEA have initiated a working group with patients. In order for patients to contribute effectively to discussion about medicines regulation, they need to develop an understanding of the processes and procedures involved. We therefore recommend that the EU public health programme gives support to a patient group training programme to equip patient representatives with the skills necessary to undertake their "expert" role in this new endeavour.
- The European Medicines Agency has an important role to play in ensuring European cancer patients get timely access to innovative cancer drugs and information about how to take these drugs in a safe and proper manner. Additional work needs to be undertaken to establish criteria at EU level for producing user-friendly publications and developing disease prevention and screening campaigns.
- A pilot project involving private-public partnerships could do much to support the vital and specific information needs of cancer patients. Such an initiative could make printed materials available and develop a realistic dissemination strategy in partnership with and include input from all stakeholder groups.

Conclusion

ECPC is most grateful to be able to contribute to health strategy consultation process and looks forward to the Commission's new policy document in early 2005. We hope that such a strategy will ensure that all cancer patients in the European Union have access to timely and appropriate information about prevention, screening, early intervention, best quality treatment and care and that health and treatment gaps will be eradicated across Europe.