

A Bill of Rights for patients with cancer in Europe



In the next 20 years, substantial increases are predicted for cancer incidence, mortality, and morbidity—particularly in countries such as China, India, and Nigeria—precipitating a potential global epidemic of cancer. The trajectory of cancer in Europe is also increasing substantially, fuelled in part by changes in population structure that will lead to an unparalleled increase in the over-65 age group in the coming decades.¹ Despite the undoubted progress achieved in cancer care and research during the past 30 years, a substantial proportion of patients in many parts of the world will not benefit from these advances. However, this widening gap in cancer care is not limited to Africa and Asia; substantial differences in cancer incidences and mortalities are also seen within Europe,^{2,3} particularly evident in the recently published EURO CARE-5 study,³ suggesting inequalities in access to optimum cancer care between different national health-care systems.

We hope that the launch of the European Cancer Patient's Bill of Rights (which arose from meetings of the European Cancer Concord [ECC]; panel) on World Cancer Day (Feb 4, 2014) will serve as a catalyst for change—a charter to enable European citizens to receive an optimum standard of care across the cancer continuum. Three key principles underpin the Bill of Rights: the right of every European citizen to receive accurate information and be involved in their own care; the right of every European citizen to access specialised cancer care underpinned by research and innovation; and the right of every European citizen to cost-effective health systems that ensure optimum cancer outcomes. These principles are enshrined in the three articles of the Bill (appendix), which provide the framework to achieve an optimum standard of care for European citizens. Equality of purpose and shared leadership by health-care professionals and patients and their advocates provide a unique and powerful coalition to help to deliver effective change for Europe's citizens.

An overarching philosophy of ECC and the Bill of Rights is that any charter for change must be delivered with financial realism, in view of the economic situation within Europe. The 2008 Tallinn Charter,⁴ in which health ministers of the European Union pledged to invest in improvement of European health-care systems, is a distant memory. However, the justification

for this unprecedented commitment should not be forgotten; investment not only brings about better health, but is also a driver of economic growth through improved workforce participation, increased innovation, and improved productivity in a system that also reduces the pressure on future health and social welfare systems.⁵ ECC and the Bill of Rights also espouse this “health is wealth” philosophy, emphasising how appropriate resourcing of innovative approaches for prevention, treatment, and rehabilitation not only reduces the cancer burden, but can also contribute to the reinvigoration of European economies and societies.

Changing of cancer policies needs political will; policy makers should be presented with a strong evidence base for change and be reminded of the principles of the Tallinn Charter, which remain relevant despite the present economic downturn. Engagement and promotion is an essential part of the ECC's strategy, both at a European level and through national dialogue. These efforts include interaction with the European Cancer Organisation through its Patient Advocacy Committee, and with the European Cancer Patient Coalition and the European Cancer Leagues, two of the largest pan-European patient advocacy organisations. Engagement with national cancer societies and national departments of health (or their equivalents) is helping to embed the initiative at a Member State level. By launching the Bill of Rights at the European Parliament on World Cancer

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Panel: The European Cancer Concord

The European Cancer Concord is a collaboration between cancer health-care professionals, patients, and their representatives. The vision of the Concord is to build a patient-oriented environment for health preservation and health care focused on cancer, by promoting a shared understanding of the issues in cancer awareness, prevention, rapid access to appropriate specialised treatment, cancer-care delivery, quality of life, rehabilitation, patient survivorship, and end-of-life care, and by mobilising all stakeholders to implement improved innovation in cancer research and care across Europe. The collaboration includes oncology and patient advocacy leaders from 17 European countries; so far, 20 pan-European patient advocacy organisations for cancer, representing more than 750 national organisations and many millions of patients and survivors in Europe, have become active partners in this initiative (appendix).

See Online for appendix

Day, and translating it into different European languages to maximise engagement and national senses of ownership, it is hoped that this will focus attention on the unequal nature of cancer care in Europe, engage and influence political representatives, and most crucially empower every European citizen to use the Bill of Rights as a catalyst to achieve effective change in cancer-care delivery in their own country and region.

All ECC members have pledged to strive to improve outcomes for patients with cancer in Europe, by raising awareness and by shaping a favourable environment of mutual trust, transformational partnership, and cost-effective innovation at all stages of the cancer journey. Launching the Bill of Rights represents the important first step in a joint effort to nurture and accelerate a mentality of intent to change, fostering a dialogue that will challenge societies to deliver measurable benefits for patients with cancer. The principles of equity and partnership that characterise this initiative underpin a philosophy that is straightforward in its simplicity, but far reaching in its potential effect.

In 2012, three European citizens died every minute from cancer. The ageing of the European population means that this number will double in the next 20–25 years, resulting in a cancer death every 10 seconds. Europe needs to act now. The equal partnership between patients and health-care professionals, created and nurtured by the ECC, provides a platform for the change needed to deliver improved outcomes for European citizens and societies. This partnership will encourage and attract engagement from many stakeholders. Patients, patient advocacy organisations, and health-care professionals are the foundation of this initiative, but it also reaches out to families of those with cancer, patient carers, cancer registries, cancer charities, learned societies, industry, governmental agencies, politicians and policy

makers, the European Commission, health-care payers, agencies for health technology assessment, and other key stakeholders.

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