

The European Cancer Patient's Bill of Rights: Action Steps for Success

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Health care delivery systems across the globe share a common goal: to provide efficient and high-quality cancer care equitably to all patients. As they strive to deliver such care, health care systems struggle with increased detection capabilities, diagnostic and treatment innovations, substantial growth in the number of cancer survivors, and shortages of some health care personnel [1]. Inadequate cancer control poses societal and economic harms, such as increased public and private health care spending, decreased worker productivity, and increased job loss [2]. Without an organizing framework to prioritize goals for delivering cancer care that is coupled with concrete action steps, nations will face significant challenges to meet the needs of people with cancer and their families.

In this issue of *The Oncologist*, a new policy statement by the European Cancer Concord (ECC) is a welcome first step to improve outcomes for European patients with cancer and their families [3]. With a population of more than 500 million, the European Union (EU) has a large and growing cancer burden [4]. Cancer is the second leading cause of death in the EU, and EU citizens are aging faster than other populations [5]. The ECC partnered with patients, caregivers, clinicians, and advocates to construct three articles that form a Patient's Bill of Rights. These include the rights to shared information and decision making; timely access to appropriate specialty care supported by research and innovation; and receipt of high-quality, affordable care to achieve improved outcomes. These three rights and their specific supporting tenets provide a foundation for pursuing legislative, regulatory, and programmatic changes that will be needed in EU countries to decrease the societal burden of cancer.

A major strength of the ECC initiative is its broad engagement with patients, clinicians, and other stakeholders across EU countries to articulate a patient-centered vision for improved

cancer care. As a key component, the ECC developed its principles within the context of widespread economic austerity measures and rising costs of cancer care that require just and cost-effective pricing of services to ensure effective access. Importantly, the recommendations span the continuum of cancer care, from cancer prevention through survivorship and end-of-life care. These strengths can serve as a catalyst for sustained improvements in cancer care.

Amid these strengths, the Patient's Bill of Rights would be fortified by concrete action steps to assure these rights are achieved. These action steps should be considered within the distinctive structural and cultural context in which EU policy making occurs across national boundaries. Moreover, transparent timelines should be developed, and key stakeholders should be identified to lead these action steps. In addition, we propose four key action steps that will advance the agenda of the ECC. These include (a) robust cancer registries, (b) monitoring the quality of care, (c) broader stakeholder engagement, and (d) dissemination of best practices.

INVEST IN AND SUSTAIN ROBUST CANCER REGISTRIES TO PRIORITIZE PROBLEMS AND EVALUATE PROGRAMMATIC CHANGES

Substantial improvements in the cancer registries of EU nations will enable their health care systems to monitor progress toward cancer control priorities. Valid and reliable data are necessary to understand the size and scope of cancer burden within and across EU nations. Population-based registries that capture incidence, diagnosis, treatment, surveillance, and survival data are instrumental to formulate evidence-based cancer control plans [4, 6]. With reliable and valid data on cancer incidence, treatment, and outcomes, these plans can mitigate the societal burden of cancer. Variations

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in care can be tracked to identify the presence or absence of equitable treatment across important subgroups, including immigrants who may be at risk for suboptimal care. Countries across the EU vary in the quality of cancer registry reporting [4]. Countries that have more experienced registries with higher-quality data can share their expertise with countries that are new to collecting these data. Over time these registries can be linked with broader health system data on the use and costs of health care services for cancer patients, as has been done in the U.S. through the SEER-Medicare database [7].

MONITOR THE QUALITY OF CANCER CARE

Efforts to monitor and improve the quality of cancer care are a global priority [8]. Detailed recommendations to improve cancer care in the U.S. were issued by the Institute of Medicine in 1999 [9]. More recently the Institute of Medicine has highlighted the need to monitor and improve the care of cancer survivors [10]. A core finding of these reports was the need for evidence-based performance measures to monitor the quality of cancer care. Quality of cancer care can be assessed by measuring structure, process, and outcome components. In addition to clinical outcome measures, data sources for cancer care quality should incorporate the perspectives of patients and providers. Although progress has been made toward this goal over the past decade, many challenges remain [11]. For the Patient's Bill of Rights set forth by the ECC, these mixed experiences with efforts to improve cancer care systems in the U.S. underscore that achieving these rights will be a daunting task.

ENGAGE A BROADER GROUP OF STAKEHOLDERS THAT INCLUDES OTHER HEALTH CARE PROFESSIONS, LEGISLATORS, AND GOVERNMENT MINISTRIES

The ECC's early work has established a working group of stakeholder groups that span disciplines and countries. To realize the goals of the efforts, deeper stakeholder engagement is needed across three key areas. First, professional societies in nursing, pharmacy, and general medical practice should be engaged in implementing the Patient's Bill of Rights. These clinicians deliver substantial amounts of care to patients with cancer. Their engagement will increase the likelihood of programmatic success. For example, general practitioners in Belgium, Italy, The Netherlands, and Spain have formed collaborative networks to monitor end-of-life care, and up to one-half of patients in these networks are dying of cancer [12].

Second, increased connection to local, national, and EU policy makers will assure policy development is harmonized and congruent with the stated Bill of Rights. With well-established national health systems in European countries, the policy makers who allocate resources to cancer care must be

fully engaged in efforts to achieve the best value in patient-centered outcomes from these investments.

Third, participation by European countries with fewer financial and clinical resources must be explicitly supported. Depending on the basic elements of a cancer care plan, the costs of full access to drugs, surgery, and irradiation (such as proton therapy) may be prohibitive; it may be equally important to emphasize early detection and prevention as major initiatives in such a plan, particularly for low- and middle-income countries. Overall economic health across the European Union countries varies considerably, as does total health care spending and government-funded health care spending [13]. These wide variations threaten equity in cancer treatment across EU countries. The needs and challenges of countries with fewer financial resources warrant increased attention and support by EU and national policy makers.

DISSEMINATE BEST PRACTICES

Remarkable advances have been made in the prevention of colorectal cancer and cervical cancer and in the early detection, treatment, and supportive care for breast, colorectal, and cervical cancer. Yet it is unclear whether these advances have been disseminated broadly across care delivery systems. Existing expertise is available to disseminate these efforts and consult with less experienced delivery systems. Thus, the ECC may wish to partner with existing networks for knowledge translation and dissemination to accelerate the delivery of evidence-based cancer care. One promising model is Entente, a European project to increase knowledge transfer activities related to health research [14].

The EU motto, "United in Diversity," summarizes both the challenges and opportunities for the European Cancer Patient's Bill of Rights. It is important to recognize that the proposed Bill of Rights resonates across many countries, despite noteworthy differences in health care financing. Despite differences in economic resources, both developed and developing countries can use the proposed framework as a way to prioritize cancer policy efforts and monitor progress. Equitable distribution of available resources should be the guiding principle.

To realize the desired change, investments must be made to support the data infrastructure to inform policy development. These enhanced data systems can measure the quality of care delivered to EU patients. Broader engagement among the clinicians, policy makers, and countries affected by this effort is required. Finally, participants should disseminate existing best practices in care delivery for rapid translation across EU care delivery systems. These tangible actions will promote patient-centered, high-quality cancer care for all EU residents.

DISCLOSURES

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EDITOR'S NOTE: See the related article, "A Catalyst for Change: The European Cancer Patient's Bill of Rights," on pages 217–224 of this issue.