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The European Cancer Patient's Bill of Rights, update and implementation 2016

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ABSTRACT

In this implementation phase of the European Cancer Patient's Bill of Rights (BoR), we confirm the following three patient-centred principles that underpin this initiative:

1. The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.
2. The right of every European citizen to optimal and timely access to a diagnosis and to appropriate specialised care, underpinned by research and innovation.
3. The right of every European citizen to receive care in health systems that ensure the best possible cancer prevention, the earliest possible diagnosis of their cancer, improved outcomes, patient rehabilitation, best quality of life and affordable health care.

The key aspects of working towards implementing the BoR are:

- Agree our high-level goal. The vision of 70% long-term survival for patients with cancer in 2035, promoting cancer prevention and cancer control and the associated progress in ensuring good patient experience and quality of life.
- Establish the major mechanisms to underpin its delivery. (1) The systematic and rigorous sharing of best practice between and across European cancer healthcare systems and (2) the active promotion of Research and Innovation focused on improving outcomes; (3) Improving access to new and established cancer care by sharing best practice in the development, approval, procurement and reimbursement of cancer diagnostic tests and treatments.
- Work with other organisations to bring into being a Europe based centre that will (1) systematically identify,

evaluate and validate and disseminate best practice in cancer management for the different countries and regions and (2) promote Research and Innovation and its translation to maximise its impact to improve outcomes.

INTRODUCTION

Our growing knowledge of the fundamental biology of cancer and its treatment has resulted in radical improvements in outcomes for patients with cancer and an enhanced patient experience. Over half of all patients with cancer can expect long-term survival beyond 10 years after their diagnosis, and for most of these people the outcome is a cure. Good quality of life is now achievable for many patients on active therapy and for long-term survivors. However, patients with cancer, their carers and cancer professionals must work hard together to ensure that these benefits are shared by all and that the pace of progress is maintained and outcomes and patients' experience continue to improve.

Despite the advances outlined above, cancer and the provision of cancer care still places a significant burden on Europe's patients, citizens and economies. As the population ages and if lifestyle-associated cancer risks such as smoking and obesity are not adequately addressed, then in many European countries more than half of the population will develop a cancer at some time in their lives.

Europe provides some of the best cancer care in the world and conducts high-quality,

Box 1 The three patient-centred principles of the European Cancer Patient's Bill of Rights

1. The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.
2. The right of every European citizen to optimal and timely access to a diagnosis and to appropriate specialised care, underpinned by research and innovation.
3. The right of every European citizen to receive care in health systems that ensure the best possible cancer prevention, the earliest possible diagnosis of their cancer, improved outcomes, patient rehabilitation, best quality of life and affordable healthcare.

globally recognized cancer research. However, there are still significant disparities between European nations and regions in a number of key areas including: public information about cancer, accessing cancer care, delivering optimal treatment, supporting cancer survivorship and integrating cancer research and innovation across European countries. There are major disparities in the quality of cancer management and in the degree of expenditure. This results in unacceptable inequalities in cancer outcomes for European patients with cancer. In addition, costs of current treatments and long-term follow-up are placing significant economic burdens on European healthcare systems. Improvements in quality of care, translation of research discoveries and promotion of innovation will have to be achieved within affordable healthcare models.

The European Cancer Concord (ECC®), an equal partnership of Europe's patients, patient advocates and

leading cancer professionals, was formed to address these challenges.

The ECC seeks to catalyse change by working in an innovative, supportive and collaborative way with the many organisations which strive to improve cancer outcomes at the European and national level. To provide tangible benefits for European patients with cancer, the ECC created a 'European Cancer Patient's Bill of Rights', a patient charter that underpins equitable access to optimal cancer control, cancer care and research for Europe's citizens.¹⁻³ This was launched at the European Parliament and endorsed by the European Union Health Commissioner on World Cancer Day (4 February 2014). Three patient-centred principles underpin the European Cancer Patient's Bill of Rights (box 1):

The means of reducing cancer incidence are clearly available through increased public awareness and lifestyle changes. Optimal organisation of the diagnostic approaches to identify cancer and precancerous conditions as soon as possible will also improve outcomes and save lives. Timely access to specialised multidisciplinary treatment can result in long-term survival, greater than 10 years, for a majority of patients; most of these patients are cured of their disease. In countries with the best diagnostic and clinical practice and excellent organisation of their cancer care, this long-term survival rate now approaches 60% of patients. The skills that are essential to effectively monitor and support cancer survivors are being developed in many countries. A significant number of these advances have been mediated through the implementation of National Cancer Control Plans. Research and innovation for cancer has delivered improved diagnostic

Box 2 The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care

National Cancer Control Programmes (NCCPs) should develop cancer services which are patient centred, reflecting the views and needs of patients and their families. Access to reliable and comprehensive information about their disease, its treatment and the cancer care services available will empower patients to seek high-quality answers and choices for their care, which will in itself help to drive up the quality of services and the engagement of healthcare professionals and systems. Individuals may have different perceptions of their needs as compared with healthcare professionals. Good communication between healthcare professionals and patients will greatly improve care and enhance patient satisfaction. Shared decision making, involving a two-way transparent process between the healthcare providers and the European citizen, must be the overarching theme of this first principle.

European citizens should be managed through NCCPs, which seek to ensure:

- ▶ The right to access, if they so choose, all information regarding their state of health and to proactively participate in decision making regarding their treatment.
- ▶ Patient-focused information strategies that clearly state in a form and language that they can understand, their right to an optimal standard of care at all stages of their cancer journey.
- ▶ Information that their cancer unit or centre satisfies agreed optimal quality thresholds in relation to an appropriate degree of specialisation of cancer care.
- ▶ Transparency in access to all national anonymised data on treatments and clinical outcomes from healthcare institutions, cancer registries and independent audit programs, prior to the start of their treatment.
- ▶ A clear and transparent personalised care plan for their disease prior to the start of any treatment, with the right to a second opinion.
- ▶ Their privacy respected, with the level of confidentiality of their own data to be decided by the patient.
- ▶ Information on the research and innovation activities relevant to their cancer that are available locally, nationally and across Europe.
- ▶ Information on cancer survivorship and support services for post-treatment issues and a personalised survivorship care plan.
- ▶ Representation and support through patients' advocacy organisations that empower patients to be an equal partner in all areas that affect their health and well-being.
- ▶ The presence of a nominated member of the treatment team who can answer patient concerns and who can coordinate care on a patient's behalf when necessary.

Box 3 The right of every European citizen to optimal and timely access to a diagnosis and to appropriate specialised care, underpinned by research and innovation

Access to essential diagnostic and therapeutic cancer services must be the right of every European citizen, regardless of socioeconomic status, gender, age or nationality. Clear pathways of access to clinical innovation and associated research activities must inform all stages of the patient's cancer journey. This second principle depends on equitable and transparent access to optimal cancer care.

European patients must be cared for in a system that ensures:

- ▶ Timely and well-organised access to validated diagnostics regardless of tumour type, with specialist second opinions in cases of doubt, to ensure accurate and earliest possible diagnosis of their cancer.
- ▶ Their diagnosis provided to them in an accurate and compassionate manner, by a specialist/experienced clinician.
- ▶ Timely access to an optimal quality of appropriately multidisciplinary specialised care, including relevant clinical research and innovation, to ensure best possible outcomes.
- ▶ Access to state-of-the-art care for each of the modalities of cancer treatment which underpin best practice including surgery, radiotherapy, chemotherapy and targeted therapy, immunotherapy and interventional radiology.
- ▶ All patients can benefit from the increasing precision in cancer diagnosis and treatment, which maximises the chance of benefits and reduces the risk of toxicity.
- ▶ Care delivered locally wherever possible and centralised where recommended by nationally or internationally approved guidelines and expert treatment recommendations.
- ▶ Access to appropriate psychological support at all stages of their cancer journey to deal with the impact of screening, diagnosis, treatment, quality of life and survivorship.
- ▶ The right to choice of location for diagnosis and treatment, even across national borders, moving their medical information as required to achieve this goal.
- ▶ Rapid access to the latest innovations in diagnosis and treatment for the individual patient with cancer following relevant regulatory approval.
- ▶ The right to access good quality care based on their need and not on their ability to pay for it.
- ▶ The right to expect research to be conducted on their particular cancer type and to be offered access to clinical studies where available and relevant to their condition.
- ▶ In the case of children and teenagers with cancer, the right to be treated in a specialised unit with an optimal standard of care, underpinned by research.

and treatment approaches and has doubled the long-term survival of patients with cancer over the last three decades. Major improvements in the concepts and technologies of cancer discovery science in the last 10 years promise further diagnostic and therapeutic advances in the next two decades.

On World Cancer Day 2016, the ECC presented an updated version of the Bill of Rights (BoR) in Brussels and Strasbourg, recording progress and revealing a BoR Implementation Strategy. Successfully implementing the BoR will result in reduced cancer incidence and radically improved outcomes which will be demonstrated and measured in many ways. However, to demonstrate the scale of our ambitions, the ECC selected a specific goal.

- ▶ *Improve the length and quality of patients' survival. Our aim is to reach 70% survival beyond 10 years for all European citizens by 2035.*

This 70:35 Vision will be addressed by three main mechanisms:

1. *Identifying, evaluating, validating, sharing and implementing best practice in cancer diagnosis and care at national and regional levels in Europe.* An actively managed, systematic approach to identifying and sharing best practice in cancer control and cancer care across European countries and regions is needed. We envisage that this will raise 10-year survival from an average of about 50% to around 60%, which is already being achieved in some countries.

2. *More intense research and innovation in discovery, translational, clinical and health-related cancer sciences.* Sustaining and increasing the intensity of research and innovation and rapid translation of cancer research into practice is essential. Based on ongoing research, largely informed by existing concepts and technologies, this may provide a further increment in long-term survival towards or beyond 70% and improve both quality of life and the patient experience.
3. *Improving access to new and established cancer care by sharing best practice in the development, approval, procurement and reimbursement of cancer diagnostic tests and treatments.* There are many ways in which the experience of different countries may be shared to improve approaches to bringing new diagnostic tests and all treatment modalities (including chemotherapy, immunological therapy, radiotherapy and specialist surgery) into practice as quickly as possible and in an affordable and sustainable way.

This high-level selected goal of the 70:35 Vision has helped to focus discussions and served to communicate our scale of ambition to improve cancer outcomes. However, it addresses only one aspect of the challenge we all face. Redoubling our efforts to prevent cancer through lifestyle changes and the application of our increasing scientific knowledge of the environmental and molecular causes of cancer, is critically important to

Box 4 The right of every European citizen to receive care in health systems that ensure the best possible cancer prevention, the earliest possible diagnosis of their cancer, improved outcomes, patient rehabilitation, best quality of life and affordable health care

Cancer prevention and care at a national level must be organised in healthcare systems according to an integrated, efficiently budgeted National Cancer Control Programme (NCCP) that conforms to European guidelines and good international practice. The NCCP should develop a cancer centre/cancer network/multidisciplinary team model that captures all aspects of cancer care, research and innovation, from diagnosis through treatment and rehabilitation, including patient survivorship and end-of-life care. A comprehensive and holistic approach, encompassing the entire cancer care continuum, must inform this third principle. Healthcare systems should recognise the socioeconomic inequality in cancer outcome and seek to minimise this at all points along the patient pathway.

European citizens and patients must be cared for in a system that ensures:

- ▶ Evidence-based public health interventions which can prevent cancer are a cornerstone of cancer control and include some of the most effective and affordable anticancer approaches.
- ▶ High-quality screening and diagnostic services delivered in a timely way must be accredited to ensure an optimal standard.
- ▶ NCCPs should be organised according to national guidance and regularly reviewed by external experts, including patient representatives and informed by pan-European guidance.
- ▶ As part of the NCCP, results should be audited to ensure optimal progress and benefit for the patients with cancer and the results of regular audits of outcomes should be used to inform service improvements.
- ▶ Cost-effective care should be provided at all stages of the cancer journey, from early diagnosis through treatment and supportive care. Appropriate use of health economic analyses can drive the improvement of effective and affordable care.
- ▶ The key issues of long-term follow-up and patient survivorship must be addressed to ensure best quality of life and personal fulfilment with active reintegration and participation in society and the work place. European citizens should have good access to comprehensive and continuous treatment for comorbidities, across the whole socioeconomic spectrum.
- ▶ Optimal pain and symptom management strategies must be in place for patients with cancer throughout their cancer journey.
- ▶ Sufficient expertise and experience in treating particular cancers in the patient's healthcare institution is essential, including education and training for all healthcare and allied professionals involved in patient care.
- ▶ Patient advocacy organisations must be recognised as equal partners in all aspects of cancer control, cancer service developments, research and innovation.
- ▶ Specialised multidisciplinary teams must conform to national requirements, driven by recognised pan-European guidelines.
- ▶ Timely and transparent referral and follow-up between community healthcare/primary care professionals and cancer units or centres is essential, ensuring necessary treatment within an optimal and predetermined period of time.
- ▶ Cancer professionals must ensure that the patient is protected from harm caused by potentially poor-functioning health services, medical malpractice or errors.

reduce cancer incidence and mortality. Early diagnosis and prompt therapy are vitally important and depend on active engagement of primary and community healthcare services in improving cancer outcomes. Patients' quality of life and the quality of the patient experience must be improved in parallel with improving survival, and this depends on effective, patient centred and integrated care provided by all the oncology professions, primary care, palliative care and the many other healthcare disciplines and professionals who diagnose and manage cancer patients in Europe.

The three key cancer patients' rights

The three patient-centred principles which underpin the European Cancer Patient's Bill of Rights are described in [boxes 2–4](#).

THE WAY FORWARD

The ECC will interact closely with Europe's many excellent cancer organisations to catalyse the implementation of the BoR and improve cancer outcomes in Europe. All of these organisations have major contributions to make to the development of shared strategic plans and their implementation. The ECC will:

- ▶ Work with other organisations to advocate a formal sustained strategic Europe-wide approach to

improve cancer control and outcomes, based on identifying, evaluating and sharing good practice between countries and regions;

- ▶ Collaborate with and support other organisations at European and national levels to advance cancer control and research;
- ▶ Deliver evidence-based papers to inform improvements in cancer care;
- ▶ Initiate specific workstreams, in collaboration with other cancer organisations, to identify, disseminate and support the implementation of new approaches to improve patient outcomes.

The key aspects in the next 2 years, of our work towards implementing the BoR are ([box 5](#)):

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Box 5 The next steps for the Bill of Rights

- ▶ *Agree our high level goal.* The 70:35 vision: Achieving 70% long-term survival for patients with cancer by 2035, promoting cancer prevention and cancer control and the associated progress in ensuring good patient experience and quality of life.
- ▶ *Establish the major mechanisms to underpin delivery of the 70:35 vision.* (1) The systematic and rigorous sharing of best practice between and across European cancer healthcare systems; (2) the active promotion of Research and Innovation focused on improving outcomes; (3) improving access to new and established cancer care by sharing best practice in the development, approval, procurement and reimbursement of cancer diagnostic tests and treatments.
- ▶ *Work with other organisations to bring into being a Europe-based centre,* which will (1) systematically identify, evaluate and validate and disseminate best practice in cancer management for the different countries and regions and (2) promote Research and Innovation and its translation to maximise its impact to improve outcomes.

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