A CATALYST FOR CHANGE: THE EUROPEAN CANCER PATIENT’S BILL OF RIGHTS

ARTICLE 1:
THE RIGHT OF EVERY EUROPEAN CITIZEN TO RECEIVE THE MOST ACCURATE INFORMATION AND TO BE PROACTIVELY INVOLVED IN HIS/HER CARE.
The European Cancer Patient’s Bill of Rights

- A charter to challenge the current inequalities that cancer patients in Europe are experiencing on a daily basis\(^1,2\)

- A catalyst for change and empowerment for cancer patients

Lawler et al *Lancet Oncology*, 4\(^{th}\) February 2014;
\(^2\) Lawler et al *The Oncologist*, 4\(^{th}\) February 2014
The European Cancer Patient’s Bill of Rights

The European Cancer Patient’s Bill of Rights

Article 1: The right of every European Citizen to receive the most accurate information and to be proactively involved in his/her care
The European Cancer Patient’s Bill of Rights

Article 2: The right of every European citizen to equal and timely access to appropriate specialised care, underpinned by research.
The European Cancer Patient’s Bill of Rights

Article 3: The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable health care
The European Cancer Patient’s Bill of Rights

Article 1: The right of every European Citizen to receive the most accurate information and to be proactively involved in his/her care
Article 1: Overarching Principles

- **Patient-centered cancer services**, reflecting the views of patients and families
- The **right** to the most **up-to-date** information
- **Good communication and collaboration**
- **Shared transparent decision making** between the healthcare provider and the European citizen
European Citizens should have

- Evidence based public health interventions
- High quality screening and diagnostic services
- Right to information on their state of health
- Patient Focussed information strategies
- Transparency in access to treatment and outcome data
- Information that their centre satisfies optimal treatment and specialisation thresholds
European Citizens should have

- Clear transparent personalised care plan
- Privacy with degree of confidentiality decided by patient
- Information on research and innovation activities
- Information on cancer survivorship/support services
- Representation and support through Patient Advocate Organisations (PAOs)
The European Cancer Patient’s Bill of Rights

Article 2: The right of every European citizen to equal and timely access to appropriate specialised care, underpinned by research.
Article 2: Overarching Principles

• Equitable and transparent access to optimal cancer care must be the right of the European Citizen

• Clear pathways of access to clinical innovation, (diagnostics, surgery, radiotherapy, medicines) informed by research activities
European Patients should have

• Timely access to validated diagnostic platforms and optimal specialised care underpinned by research
• Care delivered locally where possible or nationally when recommended by approved guidelines
• Right to mobility for diagnosis and treatment
• Timely access to innovations in diagnosis and treatment
European Patients should have

- Treatment freely accessible
- The right for research to be performed on their condition
- Access to appropriate psychological support at all stages of cancer journey
The European Cancer Patient’s Bill of Rights

Article 3: The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable health care
Article 3: Overarching Principles

- Essential cancer care at National level must be organized according to an integrated National Cancer Control Plan (NCCP)
- Cost effective cancer care
- Cancer survivorship: active re-integration and participation in society
- Patient Advocates as equal partners
Patients should receive care in systems that

• Provide care at all stages of cancer journey
• Address survivorship, ensuring active reintegration and participation in society
• Recognise Patient Advocates as equal partners
• Are underpinned by National Cancer Control plans that are subject to regular external review
• Provide timely and transparent referral and follow up
Patients should receive care in systems that

- Respect the patient, ensuring timely treatment
- Ensure the patient is protected from harm
- Recognise and promote high quality research
- Involve patients and their advocates in all aspects of clinical trial design and research
- Encourage and maintain expertise and training
- Ensure optimal pain and management strategies
- Implement / maintain integrated palliative care strategy
• A Catalyst for Change!
• A Catalyst for Change!
• A Mandate for Improved Cancer Care In Europe
A Catalyst for Change!
A Mandate for Improved Cancer Care In Europe
Empowering the European Citizen
Acknowledgements

Jean-Pierre Armand (FR)
Ian Banks (UK)
Mariano Barbacid (ESP)
Michèle Barzach (FR)
Jonas Bergh (SWE)
Gerlind Bode (ICCCPO)
Ruth Boyd (NICRCF)
Jonas Bergh (SWE)

Volker Diehl (GER)
Sarper Diler (MPE)
Sema Erdem (ED)
John Fitzpatrick (IRL)
Jan Geissler (EUPATI)
Jola Gore Booth (EC)
Maggie Grayson (NICRCF)
Donal Hollywood (IRL)
Denis Horgan (EAPM)
Lou Iovino (SAATCHI)
Jacek Jassem (POL)
Patrick Johnston (UK)

Peter Kapiten (I2L)
Joan Kelly (ECL)
Sandra Kloezen (DBCA)
Carlo La Vecchia (IT)
Mark Lawler (UK)
Thierry LeChevalier (FR)
Bob Löwenberg (NL)

Ann Murphy (STO)
Martin J. Murphy (STO)
Françoise Meunier (BEL)
Mihaela Militaru (ROM)
Anastassia Negrouk (EORTC)

Kathy Oliver (IBTA)
Bob Pinedo (NL)
Peter Selby (UK)
Josep Tabernero (ESP)
Kyriaki Tzozani (EMA) *
Veronica van Nederveen (NL)
Cornelis van de Velde (NL)
Nils Wilking (SWE)
Roger Wilson (SPE)
Wendy Yared (ECL)
Christoph Zielinski (AUS)
Harald zur Hausen (GER)

*Observer
ECC Partners

Cancer Research UK (CRUK)
Centro Nacional de Investigaciones Oncólogicas (CNIO), Madrid, Spain.
Chronic Myeloid Leukaemia Advocates Network
Dutch Breast Cancer Organisation (BVN)
Erasmus University Medical Center, Rotterdam, The Netherlands
Europa Donna
EuropaColon
European Alliance for Personalised Medicine (EAPM)
European Cancer Leagues (ECL)
European Cancer Patient Coalition (ECPC)
European Men’s Health Forum (EMHF)

European Organisation for the Research and Treatment of Cancer (EORTC)
European Patient’s Academy of Therapeutic Innovation (EUPATI)
Hôpital Saint-Antoine, Paris, France.
Inspire 2 Live (I2L)
Istituto Oncologico Veneto, Padova, Italy
Istituto di Ricerche Farmacologiche "Mario Negri" Milan, Italy
International Brain Tumour Alliance (IBTA)
International Confederation of Childhood Cancer Parent Organisations (ICCCPO)
Irish Cancer Society (ICS)

¹ ECC is actively engaging with potential partners
## ECC Partners (continued)

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<thead>
<tr>
<th>Organization</th>
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<tbody>
<tr>
<td>Italian Association of Cancer Patients (AIMaC)</td>
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<td>Italian Federation of Volunteer-based Cancer Organizations (F.A.V.O.)</td>
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<td>Kings Health Partners Integrated Cancer Centre, London UK</td>
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<td>Leiden University Medical Center, Leiden, The Netherlands (LUMC)</td>
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<td>Leukaemia Patient Advocates Foundation (LPAF)</td>
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<td>Medical University of Gdansk, Gdansk, Poland.</td>
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<td>Medical University Vienna Austria</td>
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<td>National Cancer Institute, Milan, Italy</td>
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<td>Northern Ireland Cancer Research Consumers Forum (NICRCF)</td>
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