

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.

Enrico Rossi
D. Sauer *D. ...* *Peter Conte*
Peter ...
João Paulo ECCO
Michèle Bugnot
Christa ...
Christof Zillich
Gerh. ...
Sonst ...







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* , 4th February 2014;

² Lawler et al *The Oncologist* , 4th February 2014

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Lawler M, Le Chevalier T, Murphy MJ, Banks I, Conte PF, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Armand JP, Barbacid M, Barzach M, Bergh J, Bode G, Cameron D, de Braud F, de Gramont A, Diehl V, Diler S, Erdem S, Fitzpatrick JM, Geissler J, Hollywood D, Højgaard L, Horgan D, Jassem J, Johnson PW, Kapitein P, Kelly J, Kloezen S, La Vecchia C, Löwenberg B, Oliver K, Sullivan R, Taberero J, Van de Velde CJ, Wilking N, Wilson R, Zielinski C, zur Hausen H, Johnston PG

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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



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- **A Catalyst for Change!**



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 - **A Mandate for Improved Cancer Care In Europe**



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- **A Catalyst for Change!**
 - **A Mandate for Improved Cancer Care In Europe**
 - **Empowering the European Citizen**



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***Observer**



ECC Partners ¹

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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)

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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)

Italian Association of Cancer Patients (AIMaC)

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