

Social disparities of cancer in Europe: the hidden burden

*Kathi Apostolidis -ECPC-European Cancer Patient Coalition - Board Member (Dec. 2020 – todate)
President (June 2019 – Dec. 2020)*

Public Hearing

"Mind the gap: For equal access to cancer medicines and treatments"

Who we are?

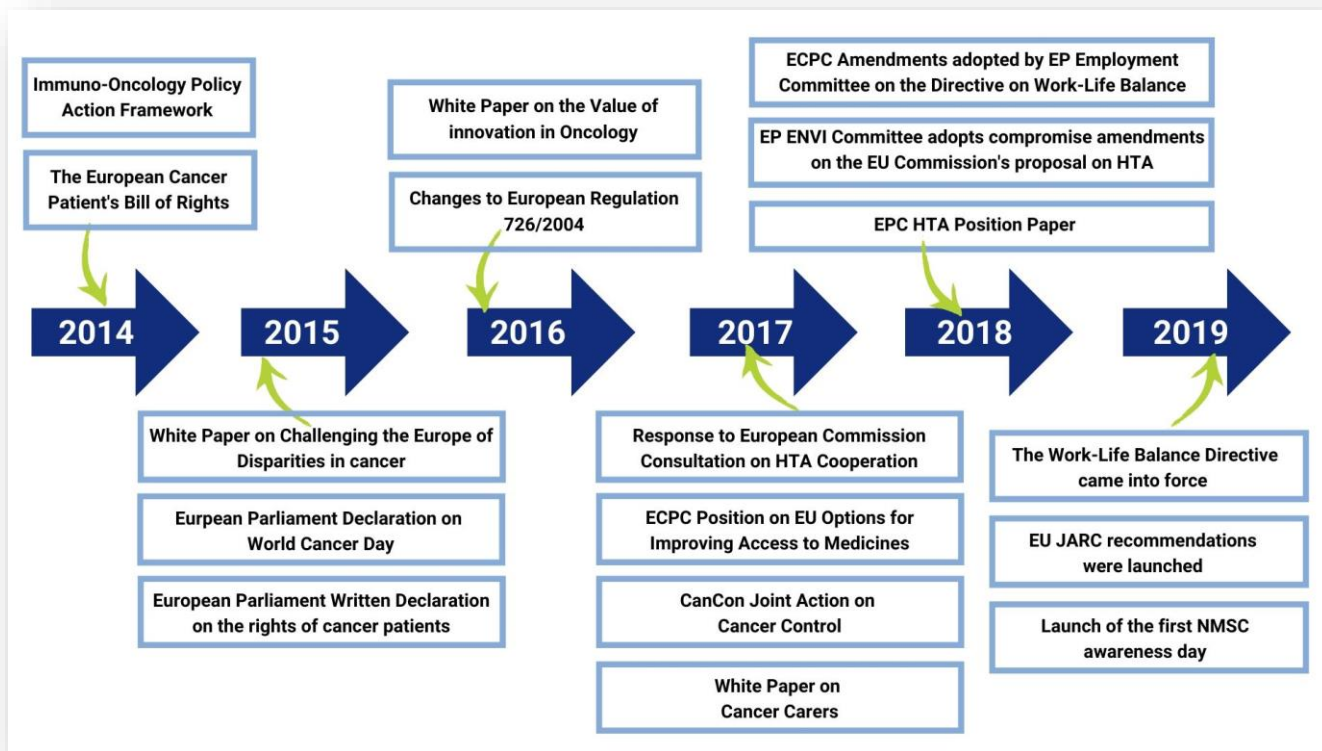
- **Largest** European cancer patients' umbrella organisation established in 2003
- **+450 member organizations** in 47 countries globally
- Advocate for patients to be acknowledged as **equal partners & co-creators of their own health**
- We work for a **Europe of equality**, where all Europeans with cancer have **timely & affordable access to the best treatment and care** available, throughout their life



Our top strategic goals

to make cancer a priority for action on the European health policy agenda and
to effect change in legislative or regulatory policies to help optimise cancer prevention, detection, treatment and care, rehabilitation and survivorship across Europe.

ECPC Advocacy Milestones 2013-2019



CHALLENGING THE EUROPE OF DISPARITIES IN CANCER

A FRAMEWORK FOR IMPROVED SURVIVAL AND BETTER QUALITY OF LIFE FOR

EUROPEAN CANCER PATIENTS

On Behalf of the Europe of Disparities in Cancer Working Group (Chair: Lawler M^{1,2}; Members: Apostolidis K¹, Banks F¹, Florindi F¹, Militaru M¹, Price R¹, Sullivan R¹, De Lorenzo F¹)

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Europe of Social Disparities

• In 2015, the European Cancer Patient Coalition published the Position Paper titled

“Challenging the Europe of Disparities In Cancer - A Framework for Improved Survival and Better Quality of Life for European Cancer Patients”

• In 2017 consultation with our members led to set the basis of a project presented at the **2018 AGM** for mapping the legal framework provisions for illness, pension & employment for cancer patients & their carers in all EU countries

• In 2019, the data collected were analysed to produce a **White Paper** on **“Challenging the Europe of Social Disparities in Cancer”**.

OBJECTIVES OF THE SOCIAL DISPARITIES MAPPING

- Need to get concrete information about social disparities in Europe based on legal documents
- Better understand the differences among Member States in social and employment conditions for cancer patients and carers
- Build evidenced arguments for advocacy at EU level and offer tools and empowerment to our members at national level

A Europe for cancer patients, survivors and carers



MANIFESTO FOR THE EUROPEAN ELECTIONS 2019



Every year, more than 3 million people are diagnosed with cancer.

An estimated 3.9 million people were faced with a diagnosis of cancer and 1.9 million have died from cancer in the European Union in 2018.

The right to health is a human right recognised in the international human rights treaties ratified by the Member States. For this right to be guaranteed, access to medicines, treatment and high-quality care must be ensured equally to all cancer patients in the EU. **The European Parliament and the Council of the European Union have the power and responsibility to adopt measures** setting high standards for accessibility, quality and safety of medicinal products, treatments and cancer care.

The European Cancer Patient Coalition (representing 448 cancer patient associations in all Member States) in partnership with Members of the European Parliament have achieved a number of accomplishments today, and we count on you to continue our collaboration.

We call on You

... to join our mission in the European Parliament to overcome inequalities in Europe, where all cancer patients have timely and affordable access to the best treatment and care available, throughout their life, by actioning the following.

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Reduce inequalities

for fast, safe and affordable access to surgery, radiotherapy and medicines

Embrace innovation

in cancer research and treatments

Enable cross-border collaboration

to ensure that cancer patients receive the most appropriate healthcare, regardless of where they reside

Promote survivorship programmes

as an essential part of cancer care at all levels, and formally support the role of cancer carers

A Europe for cancer patients, survivors and carers: MANIFESTO FOR THE EUROPEAN ELECTIONS 2019



European Cancer
Patient Coalition

Reduce inequalities for fast, safe and affordable access to surgery, radiotherapy and medicines

- 1 Establish benchmark standards for high-quality surgical care and provide information to patients about surgical practice in all cancer centres.
- 2 Make radiotherapy a central component of cancer care in policies, planning and budgets.
- 3 Adopt patient-centred strategic plans to ensure access to life-saving and essential cancer medicines.
- 4 Propose a new Transparency Directive on European Medicines Agency (EMA) to ensure effective controls and full transparency on pricing and reimbursement procedures of medicines in the Member States.
- 5 Observe and reinforce the EU competition legislation and its competencies on the pharmaceutical market in order to counter the abuse and promote fair prices for patients and the healthcare systems.
- 6 Review the EMA remit and to give consideration to enhancing its remit to coordinate pan-European activity to tackle medicines shortages in the Member States.

Embrace innovation in cancer research and treatments

- 1 Ensure timely approval of the EU HTA Regulation, to create a mandatory common framework for Health Technology Assessment (HTA) and ensure uptake of Joint Clinical Assessments (JCAs) by all Member States, guaranteeing meaningful patient involvement in all relevant areas, in order to assure real cost effective to the treatment.
- 2 Recommend measures to improve the rate of approval of novel therapies and the supply of these to patients and to reinforce the negotiation capacities of Member States.
- 3 Examine existing obstacles to driving innovation in medicines for children in the fields of oncology and promote advancement in research and access in this area.
- 4 Enhance the uptake of innovation and direct EU funds to invest in equipment and training on personalised medicines, surgery and radiotherapy to ensure equal capacity across the EU.

Enable cross-border collaboration to ensure that cancer patients receive the most appropriate healthcare, regardless of where they reside

- 1 Apply the recent European Parliament resolution on the Implementation of the Cross-border Healthcare Directive (CBHD), and continuously assess its implementation in the Member States.
- 2 Facilitate the development of reimbursement procedures in EU Member States, especially to support rare cancer patients, in full implementation of the CBHD.
- 3 Develop a plan for uptake of the Joint Action on Rare Cancers recommendations and their implementation in the European Reference Networks and Member States.
- 4 Drive consensus in the Council of the EU to put forward recommendations on the full implementation of the CBHD, to guarantee it allows patients to seek advice, treatment and care where it is available.

Promote survivorship programmes as an essential part of cancer care at all levels, and formally support the role of cancer carers

- 1 Support the Member States in the implementation of the European Joint Action on Cancer Control policy recommendations for quality improvement in cancer survivorship and rehabilitation in the Member States.
- 2 Allocate adequate funds for research on survivorship to generate data on late effects, as well as on the impact and cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial interventions.
- 3 Implement a pan-European strategy to prevent discrimination against workers with cancer and launch evidence-gathering initiatives to better understand the living conditions of cancer survivors who return to work.
- 4 Develop a common EU framework of social rights for cancer survivors, including financial incentives, non-discriminatory access to financial services such as loans, mortgages and insurance to facilitate reintegration into active life.
- 5 Ensure the effective implementation of the Work-Life Balance Directive and promote the development of tools and indicators to measure the implementation of the Directive and the actual access of carers to other social rights listed in the European Pillar of Social Rights.

A Europe for cancer patients, survivors and carers:

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Survey Profile

- ECPC's Legal Network for Cancer Patients developed survey
- Difficulties in collecting data as not all ECPC members have access to a social worker or legal professional
- Online survey to ECPC members in all EU countries
- Individual follow-up, verification of information
- Language difficulties

PICTURE OF SOCIAL DISPARITIES IN EUROPE

- Long waiting times for disability assessment in many countries. Effects of cancer and treatments not considered as an additional element
- Lack of palliative care and hospice care in many countries; patients and families pay out of pocket for these services
- Widely differing employment rights across Europe: variable access to paid sick leave, workplace adjustments, lack of protection from unfair dismissal. No incentives or support to facilitate cancer patients and survivors to return to work or find new work
- Self-employed workers have no or very limited financial support
- Only half of the participating countries foresee for pension contributions, missed as a result of illness.
- Access to health and life insurance, loans and mortgages often restricted or more expensive as a result of a cancer diagnosis

RECOMMENDATIONS

- Faster access to assessment for disability benefits and assessment criteria that recognise the specific challenges of patients with cancer and of those who care for them
- Improve harmonisation across Europe with respect to employment rights of patients and their carers, and effective enforcement of legislation protecting cancer patients from unfair dismissal
- Compensate for periods of ill-health resulting in gaps in pension contributions either due to illness or caring for a family member
- Regulatory changes to ensure that insurance, loan and mortgage providers do not unfairly discriminate against cancer survivors;
- Widespread cultural change concerning the rights and social rehabilitation of cancer patients and family carers

Covid-19 and cancer

The covid-19 pandemic added new challenges in social disparities in cancer:

- Patients who have a car can circulate more freely and avoid public transportation means
- Across Europe, many working patients, survivors and carers are jobless because business has been locked down
- Public servants, retirees have a guaranteed income in comparison to private sectors workers
- Good financial standing allows for having a cancer operation in a private hospital since many public hospitals have cancelled operations
- Health and digitally literate patients have been able to better cope with the limitations imposed by the pandemic

Thank you for your attention!



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