



Editorial

Transforming Breast Cancer Together: European elections manifesto 2019 seizing the opportunities for breast cancer patients



A B S T R A C T

With the European Parliament elections having taken place in May 2019 and a new European Commission (EC) taking office in November 2019, this year is critical for European policymakers, as goals and priorities of the European Union (EU) for the next five years will be discussed and agreed upon. This Manifesto issued by the Transforming Breast Cancer Together initiative calls upon policymakers to improve services for patients in an area still of high unmet need and reduce the societal impact of breast cancer by elevating it as a health policy priority to improve breast cancer prevention, diagnosis and care across Europe.

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1. Introduction

Breast cancer is the most common type of cancer in Europe and has a profound impact on the European society [1]. In 2015, it caused 94,300 deaths among European women and accounted for 16% of all female cancer deaths [2].

Breast cancer incidence varies across the EU with vast discrepancies between various regions. Incidence rates are higher in Northern, Southern and Western Europe – where they are amongst the highest in the world [3] - than in Eastern Europe [4]. However, while we find the highest rates of new cases of breast cancer in Northern and Western Europe, it is in Eastern Europe where we find the highest mortality rates from breast cancer. This concerning situation illustrates the large health inequities that currently exist across and within the EU Member States [5]. Indeed, while survival rates of patients with breast cancer have increased in most countries across the EU they still remain lower in Estonia, Poland, the Czech Republic, the UK and Ireland [6].

2. EU cancer policy overview

The EU has a mandate and obligation in the policy domain of public health, despite healthcare governance within the EU being predominantly a competence of the individual Member States. In this respect, EU institutions play a key role in promoting policies to ensure cancer care and resources' prioritization across Europe.

With the adoption, in 2009, of the “Communication on Action Against Cancer: European Partnership” [7], the European Commission reinforced its long-term commitment to the fight against cancer by launching the European Partnership for Action Against Cancer (2009–2013) [8]. This partnership aimed to ensure that integrated cancer plans are in place in all EU countries (resulting in an

increase from 17 plans to 25); reduce the incidence of cancer in the EU by 15% by 2020; and carry out 500 million screening examinations for breast, cervical and colorectal cancer between 2010 and 2020.

The EU Joint Action on Cancer Control [9] (CANCON - 2014–2017), an EU-financed collaboration among European public health institutes and stakeholders to foster a quality-based screening program and better integration of care, was an important milestone in the development of EU cancer policies. It delivered a European Guide on Quality Improvement in Cancer Control [10], with evidence-based recommendations to reduce inequalities in cancer care, including recommendations for breast cancer care.

The European Commission Initiative on Breast Cancer (ECIBC) was launched in 2012 [11] with a goal to establish a European quality assurance scheme for all breast cancer services from screening to palliative care. In June 2017, it published the European Guidelines for Breast Cancer Screening and Diagnosis [12]. This work on Guidelines development is planned to be completed in 2019 with a total of 80 recommendations to be issued and to be publicly accessible for healthcare professionals, patients/individuals and policymakers.

In 2015 the European Parliament adopted a Written Declaration on Breast Cancer, led by Europa Donna, the European Breast Cancer Coalition [13]. It called for the implementation of nationwide mammography screening and multidisciplinary specialist breast units (SBUs). The declaration stated that women diagnosed with metastatic breast cancer should have access to, and be treated in, an SBU, and their ongoing needs for care and psychosocial services should be coordinated and supported by the SBU as per the European guidelines.

This Declaration followed from the European Parliament 2010 Written Declaration on the fight against breast cancer in the EU

[14] and the more detailed European Parliament Resolutions on Breast Cancer of 2003 [15] and 2006 [16], which outlined many of the demands still being made today.

3. Transforming Breast Cancer Together

The ‘Transforming Breast Cancer Together’ initiative was established in November 2017, by Lieve Wierinck and Elena Gentile, former Members of the European Parliament (MEPs) with a goal to improve services for patients in an area of still high unmet need. It also aims to reduce the societal impact of breast cancer by elevating it as a health policy priority to improve its prevention, diagnosis and care, across Europe.

The initiative has been working under the leadership of former MEPs Lieve Wierinck from the Alliance of Liberals and Democrats for Europe and Elena Gentile from Progressive Alliance of Socialists and Democrats, and MEP Cristian Silviu Buşoi, from the European People’s Party, alongside patient organisations, breast-cancer-related organisations and industry representatives.

Throughout 2018, the group executed several awareness raising activities under the concept of a ‘String of Pearls’, where each activity aimed at raising awareness of pressing issues concerning breast cancer represents a new ‘pearl’ on the string.

Through these pearls, the initiative has identified priority areas where the EU needs to take concrete action and urges the incoming policy makers to place breast cancer high on the political agenda.

4. Issuing a call to action

In light of the above, this Manifesto comes at a crucial time for the EU, with European Parliament elections having taken place in May 2019 and a new European Commission taking office in November 2019. The coming months will be critical for European policymakers, as goals and priorities of the European Union for the next five years will be discussed and agreed upon.

The ‘Transforming Breast Cancer Together’ initiative therefore calls on the incoming Members of the European Parliament and the European Commission as a whole, to ensure that breast cancer prevention, screening and care is a priority during their mandate and ranks highly on both the EU and Member States agendas.

The group driving the initiative has identified four priority areas where the EU needs to take concrete action on breast cancer.

4.1. Ensure breast cancer is screened, diagnosed and treated at an early stage

As of 2016, 25 countries in the EU were planning, piloting, or rolling out population-based breast cancer screening programmes [17]. The coverage of these screening programs varies across Member States with the highest participation rate for women ages 50–69 in Denmark (83.5%) and the lowest in the Wallonia region of Belgium (6%) [1]. Large inequities in screening exist within many EU countries, with a key challenge remaining of how to reach out to socio-economically disadvantaged women [18].

The overall risk of dying from breast cancer is decreasing, in line with improvements in screening, diagnosis and treatment; however, variation in the rate of reduction exists according to stage of disease and country [1]. The CONCORD study demonstrated that five-year relative survival for breast cancer in Europe ranged from 57.9% to 62.9% in Slovakia and Poland, respectively, to 75.5%, 79.8%, and 82% in Germany, France, and Sweden with regional variations evident [19]. Factors implicated include late diagnosis associated with advanced stage at presentation as well as variation in treatment [20].

These inequalities demand that European and national decision-

makers assign the highest priority to initiate the much-needed measures necessary to see a consistent and continued improvement in survival rates. The EU needs to invest in both primary and secondary prevention to highlight risk factors and ensure breast cancer is screened, diagnosed and treated at an early stage, when there is the greatest opportunity to ensure the best long-term survival.

Transforming Breast Cancer Together recommendations:

- **Revise the 2003 Council recommendations on cancer screening.**
- **Ensure implementation of nationwide breast cancer screening programs** conducted in accordance with the New European Guidelines being developed by the European Commission Initiative on Breast Cancer, across Europe.
- **Ensure that every patient diagnosed with breast cancer has access to the highest standard of treatment in a specialist breast-unit** (centre) with dedicated breast specialists working in a multidisciplinary approach, including patients with advanced/metastatic breast cancer [21]. Ongoing needs for care and psychosocial services for all women with breast cancer should be co-ordinated by the specialist breast unit.
- Ensure that **surgical treatment** is undertaken by trained breast surgeons in a way that reduces morbidity and maintains body image.
- Foster a favourable environment for and dedicate sufficient funding to programmes designed to **equip providers with the knowledge and skills that address patients’ needs beyond the physical and to embrace the need for psychological care** as an integral part of a comprehensive treatment plan.
- **Ensure that patients have access to life altering technologies and treatments**, including genetic testing, essential biomarker analysis and critical therapeutics, and **ensure that women have access to fertility preservation.**

4.2. Ensure return to work programmes for breast cancer patients and survivors

Breast cancer and advanced breast cancer diagnosis has devastating repercussions on all the aspects of patients’ life, from their physical state to their mental health, social life and professional career. Often, when diagnosed with cancer, patients suffer unfair treatment and dismissals at their workplace because of their illness.

At EU-level there is no legislation to protect ill and terminally ill employees. The EU Employment Equality Directive (EED), which protects all workers from discrimination, provides a framework to protect workers living with a disability, however, as there is no EU-wide agreed definition of disability, it is unclear whether ‘sickness’ can be considered as such. Therefore, it is still difficult to assess whether cancer represents a form of disability and is under the remit of the EED. No distinctive policy has been adopted on the matter so far.

Regardless of the absence of a European legislative framework surrounding the rights of cancer patients and survivors to work, the difficulty of remaining in or finding work is still a significant issue. Indeed, numerous hurdles ranging from diagnosis and long periods of sick leave to several functional restrictions making it more difficult for patients and survivors to remain in or re-enter the job market [22]. This issue is set only to increase due to parallel rises in cancer incidence and survival [23], a scenario which results in a growing number of people living – and needing to work – with the disease or with the long-term side effects.

At a national level, there has been some progress in this regard, with several countries, such as the Netherlands, Ireland and the United Kingdom, giving cancer patients the same rights as those

with disabilities and laws in Italy giving workers with cancer the right to move to part-time employment and return to full-time work after treatment [24]. However, in many European countries a relevant legislative framework is still not in place or remains ambiguous [25].

Transforming Breast Cancer Together recommendations:

- Ensure the **development and implementation of programmes that support breast cancer survivors to flexibly return to work**, look after their families and contribute to society before, during and after treatment.
- **Develop and implement information, guidelines and toolkits designed specifically for** employees with cancer, employers, co-workers, carers, family members, and health professionals in all EU Member States.
- Use tools such as the **European Social Pillar to strengthen and reinforce the principles and guidelines for equal opportunities and workplace inclusion** of breast cancer survivors.

4.3. Maintain a favourable environment for the collection of breast cancer data and the development of innovative health technologies

Building on the findings from recent research, the potential for further significant scientific advances in the prevention, detection, treatment and management of breast cancer is high.

Population-based cancer registries can provide data that enables better monitoring of cancer prevalence and incidence in defined populations. Naturally, the reliability and utility of the information provided by cancer registries depends on the completeness and the validity of the data collected. Therefore, the roll-out of quality cancer registries with higher than 80% national coverage across the EU and the aligned standards for data collection is necessary, as it could facilitate the development of the European cancer registry. Additionally, the data on relapses and not just incidence and mortality, should be collected systematically to estimate the number of patients living with metastatic disease in Europe (which currently is not the case) [26,27].

While new research on cancer provides hope for the development of new treatments, it also adds a layer of complexity. For instance, historically, “breast cancer” was understood to be a single disease until Perou et al. (2000) classified it into 4 distinct subtypes [28]. Today further research – yet to be validated – suggests that there could be at least ten distinct molecular subtypes of breast cancer that could each require a different treatment approach [29].

Moreover, further scientific advance will require increased funding of research, increased cross-disciplinary collaboration, improved clinical trial methodologies and the communication of and translation of research findings into clinical practice.

If we do not ensure that policymakers maintain a favourable environment for breast cancer research, from increased investment to facilitating the gathering and use of key data, we will not be able to address the gaps in diagnosis, treatment and care which subsist across Europe. To do this will require increased dedication to addressing the current challenges and creating a favourable environment to foster research and innovation in breast cancer cure and care.

Transforming Breast Cancer Together recommendations:

- **Put breast cancer research at the top of the EU research agenda and increase the investment in breast cancer research** through a dedicated research ‘mission’ in the upcoming Horizon Europe framework programme.
- **Deepen cooperation on breast cancer research in Europe** and increase cross disciplinary collaboration.

- **Develop a harmonized breast cancer registry process** in Europe to collect breast cancer data, both for early breast cancer and metastatic breast cancer.
- **Collect patient reported outcomes and re-evaluate treatments in the post-marketing authorisation phase**, for a better understanding of the value of the treatment.
- **Encourage data collection on the quality of life of patients**, as well as **data collection on support and palliation for advanced breast cancer**.

5. Conclusion

Breast cancer is the most common cancer in women bringing high physical, psychological and social burden to patients and survivors. There are significant discrepancies in the incidence, patterns and quality of treatment, and outcomes (i.e survival rates) of breast cancer. Therefore, ‘Transforming Breast Cancer Together’ initiative calls on the incoming Members of the European Parliament and the European Commission as a whole, to ensure that breast cancer prevention, screening and care is a priority during their mandate and ranks highly on both the EU and Member States agendas.

Conflict of interest

Fatima Cardoso: *Consultancy role for:* Amgen, Astellas/Medivation, AstraZeneca, Celgene, Daiichi-Sankyo, Eisai, GE Oncology, Genentech, GlaxoSmithKline, MacroGenics, Medscape, Merck Sharp, Merus BV, Mylan, Mundipharma, Novartis, Pfizer, Pierre-Fabre, prIME Oncology, Roche, Sanofi, Seattle Genetics, Teva.

Cristian-Silviu Buşoi: http://www.europarl.europa.eu/pdf/meps/appropriateBehaviourDeclarations/9/38420_BUSOI.PDF.

Ivana Cattaneo: being by Novartis as my employer, and have stock options in Novartis.

Antonella Cardone: No conflict of interest.

Donatella Decise: being by Novartis as my employer, and have stock options in Novartis.

Alex Filicevas: No conflict of interest.

Elena Gentile: http://www.europarl.europa.eu/mepdif/124847_DFI_LEG8_rev2_IT.pdf.

Susan Knox: Regarding receipt of grants: EUROPA DONNA – The European Breast Cancer Coalition, the organization of which I am the CEO, has a sponsorship policy which safeguards the totally independent and autonomous voice of EUROPA DONNA on breast cancer issues. Link to sponsorship policy: <https://www.europadonna.org/about/policies/>

To see a complete list of EUROPA DONNA funders and sponsors, please go to the ED website www.europadonna.org where annual reports and financial statements can be found.

Regarding receipt of honoraria or consultation fees: I do not accept honoraria or fees for services, neither paid to the institution nor paid directly to myself.

Regarding investments: All personal investments are made at the discretion of a financial advisor under written financial advisory agreement.

Silvia Sebastiani: I’m an employee at Helsinn Healthcare SA.

Carole Terrasanta: I’m an employee at Helsinn Healthcare SA.

Sonia Ujupan: I am an employee of Eli Lilly and Company.

Roberta Ventura: No conflict of interest.

Lieve Wierinck: http://www.europarl.europa.eu/mepdif/183022_DFI_LEG8_rev1_NL.pdf.

Barbara Wilson: my company has undertaken paid work for Novartis, providing training and consultancy as part of a global project to support Novartis’s employees affected by cancer. They also pay my company for my contribution to the TBCT project.

Isabel T. Rubio: Honoraria from Roche.

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