

14 MILLION REASONS TO DISCUSS

LIFE AFTER CANCER:

IMPLEMENTING THE RIGHT TO BE

FORGOTTEN ACROSS EUROPE



1. Introduction

On 19 February 2021, the European Cancer Patient Coalition (ECPC) supported Professor Françoise Meunier in the organisation of an online event titled [“14 million reasons to discuss life after cancer: Implementing the Right to be Forgotten Across Europe”](#).

The event was co-hosted by Members of the European Parliament, MEP **Manuel Pizarro** (S&D, Portugal), MEP **Tilly Metz** (Greens, Luxembourg), MEP **Tomislav Sokol** (EPP, Croatia), and MEP **Véronique Trillet-Lenoir** (RE, France) and saw keynote contributions given by the EU Commissioner for Public Health and Food Safety, Ms. **Stella Kyriakides**, and the Portuguese Minister of Science, Technology and Higher Education, Mr. **Manuel Heitor**. Throughout the event, the co-hosts showed their commitment to addressing this long-standing issue and agreed to act within their institutions with the aim of tackling financial discrimination of cancer survivors at European level.

The event took place during the Portuguese Presidency of the European Union and followed the publication of Europe's Beating Cancer Plan and the launch of Horizon Europe's Cancer Mission to discuss the practical implementation of the Right to be Forgotten across Europe. For a number of years, Prof. Meunier has argued that the implementation of this right at the European level would help ensure that former cancer patients no longer suffer from financial discrimination following the end of their treatment which sees them blocked from being able to secure the loans and mortgages they need to pursue their lives. The proposal for the creation of a European Cancer Survivors' Day, seen as the possibility of launching a more formal and consistent celebration of survivorship in Europe, was also discussed during the event.

Over 200 participants joined the event which saw a wide range of European policymakers, representatives of the European Commission attending the session alongside representatives from EU Member States. The high number of institutional participants was a clear signal that Europe's policymakers see it as their duty to ensure that cancer patients never again have to pay twice for their disease and that there is widespread willingness to eliminate this form of financial discrimination across Europe.

2. Welcome Address

MEP Manuel Pizarro opened the event by welcoming attendees and underlining the importance of the Right to be Forgotten which he approaches, not only from the perspective of a politician, but also as a doctor. He stated that policies addressing cancer care and prevention should be complemented by strategies aiming at ensuring that cancer survivors are equally treated and can pursue their lives. He expressed his interest in supporting a cross-European solution and highlighted that the European Parliament will certainly have a major role to play in overcoming this form of discrimination and inequality among EU citizens. He called for the European Parliament's MEPs to promote a cross-party solution to this topic.

MEP Tilly Metz likewise welcomed the audience and underlined that she considers it essential to support campaigns aiming to improve the quality of life of European cancer survivors. She highlighted that her home country of Luxembourg has introduced policies on the Right to be Forgotten and underlined that, despite the principle of subsidiarity in health-related matters, the European Parliament can also positively contribute to tackling this issue. She said that the inclusion of the Right to be Forgotten in the EU's Beating Cancer Plan was a positive step which allows policymakers to push for the harmonisation of the EU's legal framework and restated her commitment to fight for the issue through her roles in both the Committee on the Environment, Public Health and Food Safety (ENVI) Committee and the MEPs Against Cancer (MAC) Group

3. Setting the scene

Prof. Dr. Françoise Meunier of the Federation of European Academies of Medicine (FEAM) and European Academy of Cancer Sciences (EACS) has, for the last five years, been one of the main actors responsible for raising awareness of the Right to be Forgotten at the European level. She reviewed how the cancer landscape had evolved during her professional career. No longer a death sentence thanks to the tremendous progress of medicine and research, she explained that the implementation of the Right to be Forgotten has never been more important given the growing number of cancer survivors across Europe. She asked participants why it was that cancer survivors had to pay twice for their illness; once because the disease and a second time because of financial discrimination.

This is because, without any medical justification, cancer survivors are turned away or are imposed excessive premiums by insurance providers when they seek financial services. She highlighted that this issue primarily affected consumers' rights and access to financial services which meant that the EU is competent to address it. She called for the development of a legal framework which follows the example set by France and Benelux; countries who have already implemented legislation on this matter. In fact, she underlined that the existing legislation in these four Member States, despite their national specificities, all have a common ground in allowing cancer survivors to contract life insurances or other financial instruments such as mortgages and loans and are in general united in allowing them to get back their lives.

Prof. Dr. Françoise Meunier expressed her delight with current progress at the European level, especially in light of the publication of the Interim Report of the Cancer Mission and the Beating Cancer Plan, and how these initiatives incorporated considerations for cancer survivorship. She nonetheless called on European policymakers to make a more ambitious proposal on the Right to be Forgotten and encouraged EU decision makers to take stock of what has been achieved in France and the Benelux and create a taskforce including experts from these four nations who could best propose a solution which may be applicable across Europe.

4. The life of cancer survivors: unmet needs, discrimination, and rehabilitation

This session saw representatives from two patient organisations, **Ms. Judith Taylor**, Thyroid Cancer Alliance and **Ms. Katie Rizvi**, Youth Cancer Europe, took to the floor. Ms. Judith Taylor spoke of her own experiences as a cancer survivor, discussed financial discrimination, as well as workplace discrimination and its impact on cancer survivors. She noted that high premium rates imposed by banks were a major issue for cancer survivor applying for mortgages and deplored that this discrimination would happen even decades after a patient is cured. In the Netherlands, a survey demonstrated that 60% of applicants were either refused insurance or charged higher premiums. However, she explained that cancer survivors had seen their situation improve with the recent entry into force of legislation on the Right to be Forgotten in the Netherlands and the development of a roadmap with guidelines dedicated to helping newly diagnosed cancer patients and their employers.

Ms. Katie Rizvi spoke of the priorities of Youth Cancer Europe and the various challenges young people who have been diagnosed with cancer encounter in their daily lives. She discussed how widespread financial difficulties for cancer patients and survivors are across the world and specifically referred to an American study showing that young citizens with cancer are spending more of their monthly income when compared to their non-cancer peers and called for a similar study to take place in Europe. She also stressed that young cancer patients are also spending significant amounts on mental health support and called for in-depth investigation regarding issues surrounding fertility and adoption policies for cancer survivors. She concluded her presentation with a point regarding the need to implement policies at the EU level on issues such as adoption and stated that the European Commission should likewise look to develop a code of conduct addressing this issue in parallel to its efforts on discrimination in other financial services regarding the Right to be Forgotten.

5. There is life after cancer: the crucial role of cancer survivorship research

The event continued with a presentation by **Prof. Christine Chomienne**, Vice-Chair of the Cancer Mission and Professor of Cellular Biology at the Université de Paris, France, who talked about the cancer mission, one of Horizon Europe's five missions. She stated that the Mission's goal is to involve citizens and stakeholders more closely in setting research priorities, reviewed the functioning of the cancer mission board works, and underlined the collaborative approach it seeks to promote across stakeholder groups.

During her presentation, Prof. Chomienne highlighted four recommendations from the cancer mission which had been developed for the benefit of cancer survivors. She discussed how these recommendations would look to promote health equity in the EU across the disease continuum, improve return-to-work policies and ensure mental health and social care for patients, survivors, and their families. She added that the Right to be Forgotten had been considered within these recommendations. She discussed the implications these recommendations could have for the development of an EU-wide research program devoted to improving the quality of life of cancer patients and survivors. Her final statements were focused on the creation of a European Cancer Patient Digital Centre through which cancer patients and survivors could deposit and share their data for personalised care.

6. The empowerment of cancer patients: advocating for the Right to be Forgotten

During the next section, **Ms. Antonella Cardone** and **Dr. Grazia Scocca** of the European Cancer Patient Coalition provided their input on the ECPC's position on the Right to be Forgotten and the vehicles for its implementation. Ms. Cardone mentioned that obstacles affecting cancer survivors, such as the Right to be Forgotten, can be lifelong struggles as almost all European countries lack adequate policies to ensure rehabilitation and do not currently provide for the smooth reintegration of cancer survivors into society. She called on all stakeholders participating in the event and the representatives of key initiatives on cancer in Europe, to support the formalisation of a European Cancer Survivors Day and proceed with the organisation of an annual event dedicated to cancer survivorship.

Dr. Scocca's presentation focused on the presentation of commonalities and national differences when it came to the national legislation adopted on the Right to be Forgotten in France, Belgium, Luxembourg and the Netherlands. Current fragmentation in the practices of banks and insurances across Europe and a general lack of awareness regarding this form of financial discrimination were identified as major obstacles for cancer survivors seeking financial support. She stated that the Right to be Forgotten has to be perceived as an Internal Market issue which concerns consumer rights and access to financial services. She therefore proposed to either amend the 2014 Directive on Credit Agreements for Consumers or introduce a new legislation based on several articles from the Treaty on the Functioning of the European Union (TFEU), the EU treaty and the charter on fundamental rights devoted to overcoming this issue. She specified that more work would be needed when it came to the European Commission's proposal for a Code of Conduct as suggested in the EU Beating Cancer Plan. She said there were risks of duplicating existing legislation and not ensure an effective or harmonised measure covering all operators in the EU. She concluded by calling for an EU policy strategy on cancer survivorship based on a holistic approach of patients' rights promoting the highest level of health, quality of life, respect of fundamental rights, equality, and social inclusiveness.

7. Keynote speech: The Right to be Forgotten as part of the EU Beating Cancer Plan

The EU Commissioner for Public Health and Food Safety, Ms. Stella Kyriakides, addressed the audience in a keynote speech during which she focused on the publication of Europe's Beating Cancer Plan and the sections focused on the Right to be Forgotten. She stressed that the burden of cancer could be challenged if employers, health, and social care systems worked closely together and underlined that our perspective on cancer survivorship needed to progress from the amount of time people lived after cancer to one which incorporates considerations for their quality of life.

She referred to initiatives focused on the quality of life of cancer survivors which are included in Europe's Beating Cancer Plan such as the cancer survivorship Smart Card and the European Cancer Patient Digital Centre which will allow the exchange of patient data and the monitoring of survivors' health conditions. Following on Ms. Rizvi and Ms. Taylor's contributions, she highlighted that the Commission will be looking at challenges' patients face when returning to work, on the situation of carers, the work-life balance of parents, as well as those occasions where cancer has caused disabilities and discrimination.

Regarding the Right to be Forgotten, she underlined that the European Commission would need to work with bankers and insurers as they tend to take over precautionary measures due to someone's medical history and cannot easily assess the risks associated with cancer and possible relapses. Finally, she warmly welcomed the development of the Right to be Forgotten and concluded by stating that the Commission's plan will enable a discussion on how to best develop science-based legislation that accounts for medical progress, social equality and allows all cancer survivors in the EU to enjoy equal access to financial services.

8. Implementing the Right to be Forgotten across Europe

The Portuguese Minister of Science, Technology and Higher Education, **Manuel Heitor**, spoke on behalf of the Portuguese presidency of the Council of the European Union. He focused his speech on the research sector and stated that the idea to have a comprehensive transnational cancer research approach focused on personalised medicine and covering the entire cancer research care will be critical for Europe. He stated that Portugal's hopes to achieve long-time survival of at least 10 years for three out of four cancer patients by 2030 and that it is critical to involve patient organisations in this process.

He recalled the lessons learned from the development of a European Network of Comprehensive Cancer Centres and our growing understanding of clinical and preclinical research, clinical testing, and outcome research. He promoted the idea of a continuum across research infrastructures as a particularly important one for the Portuguese presidency. He concluded that rehabilitation and survivorship are key issues that need to be included within the research continuum and that the creation of synergies across European initiatives, such as the Cancer Mission, would help ensure their success.

MEP **Tomislav Sokol** (EPP, Croatia) focused his contribution on the legal argumentation for the implementation of the Right to be Forgotten which he believes has to be achieved through the internal market perspective. He underlined that the adoption of a European code of conduct represents a good approach when it comes to insurance companies and stakeholders, but that it is only the first step. He mentioned that it would be necessary to follow on this initiative by harmonising legislation, on the basis of Article 114 of the TFEU regarding the regulation of the internal market. Mr. Sokol argued that a harmonised approach to the Right to be Forgotten implemented across European countries will help prevent further inequalities between EU Member States and committed himself to tackling this issue in the months to come.

MEP **Véronique Trillet-Lenoir** (RE, France) underlined the challenges that cancer survivors face and suggested that, following the publication of Europe's Beating Cancer Plan, the European Parliament will centre their activities around four key actions. First, to issue guidance to insurances about the ethical principles that should apply in respect to cancer patients and cancer survivors. Second, to conduct an EU-level comparative study of EU member states' approaches towards ensuring the Rights of cancer survivors. Third, to call on national governments to recognise the inequities and disparities that apply to cancer survivors and propose remediating measures and finally, the fourth action, to implement national legislation that ensures that cancer survivors should not be discriminated against other consumers if they are cancer-free 10 years after the end of treatment and 5 years if they had cancer before 18.

Finally, the event also welcomed a member of the Council of Europe, **Ms. Béatrice Fresko-Rolfo**, who talked about the activities of the Council when it came to the development of a resolution targeting discrimination against people with chronic diseases which likewise incorporates consideration for the Right to be Forgotten. Through her contribution, she demonstrated that the scope of the Right to be Forgotten goes beyond the European Union and that other institutions will also closely follow the matter. She concluded by suggesting that, on the basis of the day's discussion, she will be reporting to her colleagues with some proposals for the file.

9. Concluding Remarks

The conclusion saw the president of ECPC, **Mr. Ken Mastris**, thank all participants for their contributions and highlighted the role of ECPC as a platform to elevate the concerns of cancer patients and survivors. He noted that the formalisation of a European Cancer Survivors' Day would represent a fantastic outcome of the event.

Prof. Dr. Françoise Meunier likewise supported the call for the launch of an EU Cancer Survivor's Day, as a more formal and consistent celebration of survivorship in Europe. She underlined that an annual event dedicated to cancer survivorship topics would help ensure that, in addition to the Right to be Forgotten, other topics would be provided a platform for discussion.

MEP Manuel Pizarro thanked all speakers for their contribution which showed that the introduction of European legislation to erase financial discrimination against cancer survivors across all European countries is of major importance. He highlighted that the event was the first step in a long-term process that will seek to ensure the implementation of the Right to be Forgotten and expressed his willingness to support the introduction of a legislative framework in the coming months.

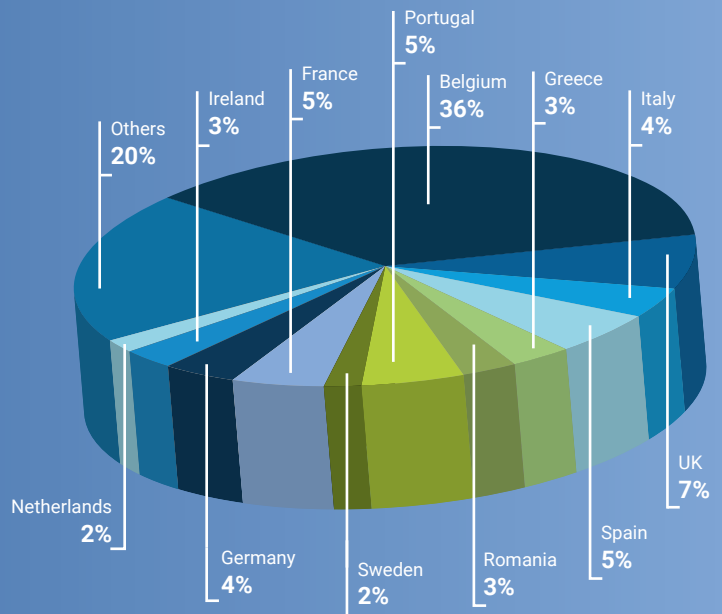
Outcomes



- Policymakers from a wide range of European institutions, in addition to the Council of Europe, expressed their willingness to promote and support initiatives regarding the Right to be Forgotten that go beyond the Code of Conduct proposed in the Beating Cancer Plan.
- The creation of a taskforce incorporating experts from the four countries where policies regarding the Right to be Forgotten are already in place and supported by policymakers.
- Representatives of patient organisations expressed their will to collaborate with the EU Parliament and the commission to develop a code of conduct or any legal framework addressing the issue of adoption policies including the Right to be Forgotten for cancer survivors.
- The call for the creation of a European Cancer Survivors' Day as a more formal and consistent celebration of survivorship in Europe was likewise supported by the many attendees on the call.

With 273 people registering for the event, the Right to be Forgotten has now attracted the attention of numerous stakeholders across the world. The majority of attendees joined from EU Member States and the United Kingdom, but the event also saw participants join from North America, North Africa, and Asia.

NATIONAL BACKGROUND



PROFESSIONAL BACKGROUND

