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Next Level EU Cancer Survivorship and Quality-of-Life Policy

A Reflection on Progress and Gaps: Are We Doing Enough?

POLICY REPORT

Contents

Acknowledgements

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Background

Are we doing enough to ensure that every person affected by cancer in Europe can live well during and after treatment?

Cancer survivorship and quality-of-life together represent one of the greatest tests of Europe's health systems and social resilience. Medical innovation has transformed cancer from a fatal disease into a condition that many now live with or overcome. Yet this success brings a new responsibility: to make sure that cancer patients and survivors live better, physically, mentally, socially, and economically.

This paper explores how far Europe has progressed in converting political commitments into practical outcomes since the initiation of Europe's Beating Cancer Plan in 2021 alongside the EU Cancer Mission. It reviews the advances made across policies, research, and care delivery, while exposing the persistent gaps that prevent equitable support for all people affected by cancer. Drawing on evidence, expert reflection, and the collective insight of the European Cancer Organisation's member societies, Focused Topic Networks, and patient communities, the paper serves as both a reflection on progress and a call to action.

Decisive action cannot be delayed: survivorship and quality-of-life focused initiatives are now visible in policy, but they remain unevenly implemented and undervalued in practice. While frameworks exist, they are inconsistently applied. While resources have been mobilised, inequities endure. Too many patients, survivors, and carers continue to face fragmented care and unmet needs. This paper therefore examines what has been achieved, what remains undone, and how Europe can deliver lasting, measurable improvement.

The recommendations presented here will form the foundation of a **European Cancer Survivorship and Quality-of-Life Charter**, to be launched in 2026. This Charter will outline a shared vision for embedding quality-of-life and survivorship as essential pillars of cancer policy and care. It will unite European and national actors, policymakers, clinicians, researchers, and advocates around one common goal: ensuring that every person affected by cancer - wherever they live- can benefit from equitable, and sustainable care.

Executive Summary of Recommendations

To ensure that people affected by cancer receive the sustained support they need, it is recommended that EU institutions and Member States take long-term action to embed survivorship and quality-of-life at the heart of cancer policies. The following recommendations, detailed in the final chapter of this document, will be subject to consultation and will form the basis of the Survivorship and Quality-of-Life Charter, to be publicly launched in 2026.

Key Recommendations for EU Institutions:

1. Ensure continuity and legacy of the EU's cancer policy framework post-2027;
2. Embed cancer survivorship and quality-of-life investment in the next EU Multi-annual Financial Framework for 2028-2034;
3. Establish a coordinating mechanism for EU cancer research action, such as in the form of a European Cancer Institute;
4. Develop and adopt EU Council recommendations on quality-of-life in cancer systems;
5. Maintain and strengthen binding legislative momentum at national and EU level to protect cancer survivors from unfair financial discrimination and implement a Right to Be Forgotten;
6. Conduct studies on the economic impact of sub-optimal support for quality-of-life in cancer systems, mobilising existing quality-of-life measurement tools to inform policy and investment decisions;
7. Increase activities to heighten employer awareness across Europe of good practices and legal obligations to support the Return-to-Work needs of cancer survivors;
8. Maintain and further develop established cancer survivorship tools and initiatives - such as the Cancer Survivor Smartcard App ('SmartCARE'), the EUonQoL measurement tool, and the INTERACT-EUROPE 100 inter-specialty training programme.

Key Recommendations for EU Member States:

1. Guarantee that all people living with and beyond cancer receive personalised long-term survivorship follow-up care plans and quality-of-life assessments;
2. Promote collection of Patient-Reported Outcome Measures as well as measurement of quality-of-life across cancer care services;
3. Ensure all National Cancer Control Plans include a survivorship and quality-of-life pillar, mirroring Europe's Beating Cancer Plan;
4. Mandate inter-specialty cancer training that fosters collaboration across healthcare teams.

Foreword: Dr. Luzia Travado

A Foreword from ECO's Survivorship and Quality-of-life Network chair Dr. Luzia Travado

Europe's Beating Cancer Plan has reignited hope by placing quality-of-life and survivorship at the forefront of cancer policy and research. But hope must be matched by action. Clinical guidelines and policy recommendations remain largely absent from routine practice in many regions. We must ask ourselves: **are we truly doing enough?**

This paper offers a timely and necessary reflection on the current state of cancer survivorship and quality-of-life across Europe. It challenges us to confront the gap between policy and practice, and to reimagine health as the World Health Organization defined it in 1948: not merely the absence of disease, but a state of complete physical, mental, and social well-being.

As we look to the future, this is not just a matter of policy - it is a matter of humanity. Cancer touches all of us. And when it does, we want the best care, the best support, and the best chance at life beyond cancer. That future depends on the choices we make today.

Let this paper be a catalyst for renewed commitment, deeper collaboration, and bold action. Because survivorship is not the end of the story - **it is the beginning of a new chapter**. And every survivor deserves to write it with dignity, strength, and hope.

Foreword: Billy Kelleher MEP

A Foreword from MEP Billy Kelleher, member of the European Parliament's Committee on Economic and Monetary Affairs, Substitute Member of the Committee on Public Health and Committee on Women's Rights and Gender Equality.

"Is fearr an tsláinte ná na táinte." An old Irish saying that translates as 'Health is better than wealth'. This proverb was much in mind as I was invited by the European Cancer Organisation to review and support this important new landmark policy action paper.

A wide variety of quality-of-life matters are covered by the report, many of which paint an all too familiar pattern. The full spectrum of health and wellbeing needs of cancer patients and survivors are simply not being given the attention they deserve by our health, welfare and even financial services sectors:

- Long-time survivors left unable to access mortgages and loans
- Informal carers and families taken for granted, unsupported and unaccounted for in welfare and pensions arrangements
- Patients and survivors facing a wide variety of financial consequences from their diagnosis and too often unable to return to work due to inflexible employment arrangements

Many other case studies and scenarios are presented within the report and should give serious pause for thought to any elected representative or decision-maker about the steps that can be taken to care for the 20 million people in Europe beyond cancer with the dignity we should all expect that they be afforded.

Recommendations I especially support include:

1. Sustaining and evolving Europe's Beating Cancer Plan and the EU Research Mission on Cancer into the future, to enable a long-term EU agenda on cancer survivorship to be achieved.
2. Binding legislation at European and national level to enshrine a 'Right to Be Forgotten' for cancer survivors when it comes to accessing financial services
3. Achieving synergies between Europe's Beating Cancer Plan and the forthcoming European Cardiovascular Health Plan by encouraging in tandem projects to address problems of co-morbidity and cardiovascular complications of cancer treatment

I commend this report without hesitation to my Parliamentary colleagues and look forward to working with all partners in the European cancer community in advancing together the practical, workable and achievable proposals contained within.

Introduction: Beating the Odds – Living Well With and Beyond Cancer in Europe

KEY DATA ON CANCER

- In Europe in 2020, an estimated **23.7 million people** (5.0 % of the population) were alive after a cancer diagnosis (1)
- Within the EU alone, there were **22.3 million people** living with cases in 2020 (2)
- Between 2010 and 2020, this number of prevalent cancer cases increased by 41%, **3.5% per year on average** (2)
- In 2021, cancer was the **second leading cause of death** in the EU, causing 1.1 million deaths (21.6 % of all deaths) (2)
- By 2040, cancer diagnoses will increase by 21% compared to 2020 (3)
- Cancer leads to an additional 85 000 cases of depression annually in the EU, with up to 80% of patients under active treatment reporting (4)

In Europe 5.0 % of the population were alive after a cancer diagnosis

In 2021, cancer was the second leading cause of death in the EU (21.6 % of all deaths)

Quality-of-life needs

Disease burden

- Long-term and late effects (fatigue, pain, insomnia, cognitive dysfunction, sexual dysfunction, other treatment sequelae) (5)
- Co-morbid chronic conditions or multimorbidity requiring ongoing surveillance (6)

Psychological & emotional well-being

- 42% of people diagnosed with cancer report anxiety symptoms (7)
- 29.5% report depression symptoms (7)
- Suicide rates are 85% higher in cancer patients compared to the general population (8)
- Under-diagnosis and under-treatment of mental health needs (9)

Healthcare experience, follow-up & support

- Need for survivorship care plans, coordination, communication among specialists and primary care (6,10)
- Gaps in supportive care, psychosocial support, rehabilitation services (11)
- Variation in access, equity, and quality of post-treatment follow-up (11)

Socioeconomic & daily life challenges

- Employment, workplace discrimination, reintegration, productivity loss (11)
- Financial toxicity, insurance & credit discrimination, “Right to Be Forgotten” issues (12)
- Body image and fertility issues, especially in young adults and women (13), (14)

'Our Plan aims to ensure that cancer patients not only survive but then live long, rich and fulfilling lives, free from unnecessary obstacles.' **Stella Kyriakides**, Commissioner for Health and Food Security 2019-2024, Opening Remark of the High-Level Conference on Ending Financial Discrimination Against Cancer Survivors

According to the WHO's 1946 definition, *'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'* (15).

Cancer incidence continues to rise in the European Union (EU), with new cases increasing by 2.3% since 2020, reaching 2.74 million in 2022 (16). Progress in modern medicine has transformed cancer from a fatal diagnosis into a condition that many now survive, live with over the long term, or manage as advanced disease.

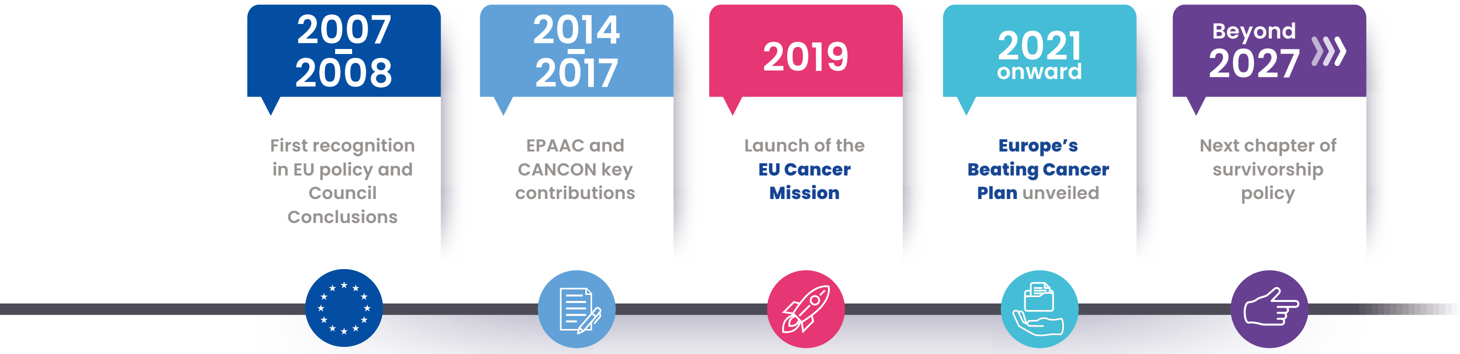
As cancer outcomes improve, survivorship is also rising (6). According to the CONCORD-3 study, the 5-year net survival rates for most cancers in most countries of the European Union have gradually increased from 2000–2004 to 2010–2014 (17). Advances in early detection, innovative therapies, and supportive care have led to a growing population of individuals living beyond a cancer diagnosis and treatment, now **surpassing 20 million across Europe** (18). While this progress reflects significant strides in cancer treatment, it also highlights a critical need to address the distinct and multifaceted challenges faced by the population and community affected by cancer. Life with and after treatment often involves **managing physical side effects, coping with emotional and psychological distress, navigating social and financial challenges**. The risk factors, causes, and symptoms of the disease, along with the condition itself, the potential short and long-term side effects of treatment, and the impact on quality-of-life, **also often contribute to stigmatisation**. These issues can persist long after the conclusion of active treatment - necessitating robust and sustainable policies - yet are also crucial for people living with advanced/metastatic cancers who need continuous treatment and support. Caregiving also plays a crucial role in this phase, as family members and informal carers often shoulder significant emotional, physical, and financial burdens that require greater recognition and structured support within survivorship policies. Cancer can pose significant challenges and opportunities for healthcare systems and policymakers, particularly in terms of quality-of-life and survivorship care services.

Issues concerning **cancer survivorship and quality-of-life were first formally acknowledged within the European Union policy framework in 2007** and subsequently endorsed through the Council Conclusions adopted in 2008. These early efforts laid the groundwork for further developments, including key contributions from initiatives such as the European Partnership for Action Against Cancer (EPAAC) and the Cancer Control Joint Action (CANCON). However, it wasn't until 2019 that survivorship and quality-of-life were granted central and sustained attention, more than a decade after having been introduced.

In 2019, the EU Cancer Mission - one of five Horizon Europe missions- was launched, with the aim to improve the lives of cancer patients and survivors through better prevention, diagnosis, treatment, and care. It provides a strategic framework for collaborative cancer research and innovation across the EU. A core pillar of the mission is ensuring that **more people live longer and better after a cancer diagnosis**. Ensuring that more people live well beyond cancer has become a cornerstone of the mission, **driving a timely focus on survivorship- and quality-of-life in research agendas**. Recognising that survival alone is not enough, the mission also pushes for a more holistic approach to post-treatment care.

As a strategic response to the growing impact of cancer, and in line with the Cancer Mission, the European Commission unveiled Europe's Beating Cancer Plan (EBCP) in 2021. This ambitious initiative in the EU's efforts to combat cancer comprehensively **sought to address every stage of the cancer continuum**, through its four pillars: prevention, early detection, treatment, and survivorship. The Plan also inspired and paved the way for concrete action such as the European Code of Cancer Practice (19), a patient-centred tool that sets out 10 key rights to ensure high-quality cancer care across Europe, empowering patients and guiding professionals in delivering care aligned with patients' needs and expectations. **The issues of survivorship and quality-of-life became a dedicated focus of the Plan**, reflecting a political will to be integrated in mainstream cancer treatment and care. The sixth section of Europe's Beating Cancer Plan 'Improving the quality-of-life for cancer patients, survivors, and carers' is dedicated to survivorship and quality-of-life, with other actions also connected to it throughout the Plan.

The question remains: have these promises been supported by the necessary policies and resources? And looking ahead, what directions must be pursued to ensure concrete and lasting improvements for people affected by cancer?



Despite limited resources and literature dedicated to the evolution of survivorship and quality-of-life policies, some point out that *'cancer survivorship care remains an afterthought in care organisation […] with an underlying glaring inequity between survivorship and other cancer care continuum domains.'* (18) (20) (21)

Europe prides itself on its leadership in cancer care, yet its patients and survivors are too often left navigating fragmented support, leaving gaps at clinical and political level that demand urgent political attention.

The essential frameworks and guidelines are already in place or being implemented. However, limited resources and inadequate training on patient needs continue to hinder progress and reinforce inequalities. Even in well-resourced settings, the uptake and practical application of existing guidance and evidence remain weak. **It is worth asking: do systemic barriers - such as lack of long-term funding, lack of data and PROMs** (22) **- and flawed incentives stand in the way of implementing established and essential policies on survivorship and quality-of-life?**

In the first section, this paper analyses the political ambition, by exploring **the progress made since the launch of Europe's Beating Cancer Plan and of the EU Cancer Mission in addressing the challenges of survivorship and improving the quality-of-life for Europeans living with and beyond cancer.** It critically measures the quality of actions launched, evaluates key initiatives' advancements, identifies persistent gaps and barriers, and reflects how to advance such issues beyond 2027, to ensure cancer survivorship needs and care remain a priority.

The second section of this paper evaluates the implementation, by reviewing national-level initiatives and strategies relating to overall quality-of-life. **The organisation of healthcare and health systems, while supported at EU level, indeed remain national competences.** Significant disparities exist across Member States in access to survivorship care and support services. – some such as France, the Netherlands, Denmark & Ireland have for dedicated budget shares to survivorship care. The necessity of establishing structured, patient-centred, and multidisciplinary survivorship care plans -underpinned by robust monitoring- is critically assessed. Without national commitment, EU-level ambitions risk being frustrated. Individuals living with and beyond cancer often face fragmented care due to lack of coordination between oncology and primary care. **Investing in quality-of-life should not be seen as a moral obligation but rather as a strategic and cost-effective one as well, reducing recurrence as well as improving social and work reintegration, productivity as well as well-being.**

The third section of this paper **delves into what should be the next chapter of cancer survivorship and quality-of-life policy, as well as on how to address unmet needs, with the underlying question: How can we further recognise survivorship and quality-of-life as a political and clinical priority?**

Recognising Survivorship and Quality-of-Life Needs: The EU's Pioneering Commitment Since 2019

I. Advancing Survivorship and Quality-of-Life: Europe's Beating Cancer Plan in Action

Progresses in cancer screening, early diagnosis, treatment and care have substantially improved quality-of-life and survival rates across Europe, albeit differently for each cancer type and unequal between and within countries. Nevertheless, individuals living with and beyond cancer may face a range of lasting medical impacts which may include chronic fatigue, pain, insomnia, anxiety, depression, maladjustment behaviours, cognitive impairment, infertility and cardiovascular complications amongst many others, which interfere with returning to 'normal life'. Mental health, an essential component of survivorship, remains under-resourced in many European contexts, limiting access to timely psychological and psychiatric support. They might also encounter various forms of discrimination, including workplace bias, limited career advancement opportunities, difficulties in accessing financial and social protection services and obtaining adequate healthcare coverage, as well as social stigma and misconceptions regarding their capabilities. **These challenges can differ significantly by age and gender, with younger survivors and women for instance often experiencing distinct psychosocial and functional burdens**. This overall hinders societal reintegration and perpetuates inequities. Cancer often changes life in ways that make 'normal' life difficult to reclaim. These challenge also are particularly true for those living with advanced/metastatic, largely incurable, cancer.

Three out of the 42 Flagships of Europe's Beating Cancer Plan directly target survivorship and quality-of-life, and are all featured in Chapter 6 (20). These measures reflect the EU's dedication to improving both the length and quality-of-life for those affected by cancer.

Nonetheless, they are still pending completion and deployment. Although significant delays in the Plan's implementation can be attributed to the COVID-19 pandemic, structural and political challenges persist. The financial implications of these measures at national level, coupled with a general lack of political will to prioritise survivorship and quality-of-life, have contributed to slow progress. Survivorship and quality-of-life remain a largely invisible and undervalued area, often overlooked by administrators, policymakers, and even medical professionals, despite its clear long-term societal and economic benefits. The United Nations' 3rd Sustainable Development Goal, "Good Health and Well-Being," aims to ensure healthy lives and promote well-being for all at all ages. Yet this global objective remains far from universally implemented. Likewise, the World Health Organization's definition of health, encompassing physical, mental, and social well-being, remains far from universally implemented, despite having been articulated more than 75 years ago.

This first section delves into each flagship, analysing its real impact on cancer survivorship and quality-of-life across the European Union.

Figure 1: Overview of Europe's Beating Cancer Plan's Chapter 6 Flagships

Improving the Quality of Life for Cancer Patients, Survivors and Carers (6)		
34	**Flagship: 'Better life for cancer patients'** initiative: 1. Create a tailor made **'Cancer Survivor Smart-Card';** 2. Create the **'European Cancer Patient Digital Centre'** supporting the exchange of patients' data and monitoring of survivors' health condition.	2021 - 2023
35	Address fair access for cancer survivors to financial services via development of a **Code of Conduct** and a reflection process on long-term solutions.	2021 - 2023
36	1. Launch a study addressing issues related to the return to work; 2. Address in the **Strategy on the Rights of Persons with Disabilities 2021- 2030** the rights of cancer patients and survivors considered as persons with a disability; 3. Ensure full implementation of the **Directive on work-life balance for parents and carers**.	2021 - 2022

I. 1. A Chapter Dedicated to Survivorship and Quality-of-Life

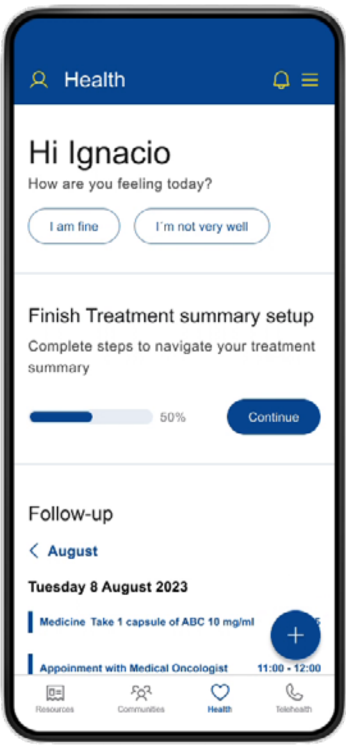
I. 1. 1. Creating a Tailor Made 'Cancer Survivor Smartcard'

'The smartCARE project has the power to transform cancer care delivery and improve patient outcomes like never before. By leveraging digital technologies and innovation, we can create a patient-centred, integrated, and sustainable survivorship ecosystem that meets the needs of European patients and their families.' **Csaba Dégi**, President of the European Cancer Organisation and Co-Chair of the smartCARE Steering Committee

Cancer survivors face ongoing needs after treatment, from late effects and side effects to psychological challenges and comorbidities. Addressing these requires innovative, patient-centred solutions, as recognised in Europe's Beating Cancer Plan.

One response is the smartCARE project, which developed the Cancer Survivor Smartcard, a digital tool designed to empower survivors and support long-term well-being. The first prototype was completed and tested successfully, and it was presented to a broad audience in November 2024, marking a significant milestone in its development.

However, to achieve impact, **smartCARE requires dedicated funding to move from prototype to roll-out**. With full roll-out, SmartCARE has the capacity to transform survivorship care in Europe and set a global standard.



Hi Ignacio

How are you feeling today?

Finish Treatment summary setup

Complete steps to navigate your treatment summary

Follow-up

Tuesday 8 August 2023

Medicine Take 1 capsule of ABC 10 mg/ml

Appointment with Medical Oncologist 11:00 - 12:00

Furthermore, with such strong presence of cardiovascular comorbidities in cancer care, as well as cardiovascular complications of treatment, the opportunity is open to ensure synergy between Europe's Beating Cancer Plan and the new European Cardiovascular Health Plan through smartCARE.

Next level EU cancer survivorship and quality-of-life policy recommends that the new European Cardiovascular Health Plan support the full roll-out of smartCARE to help address survivorship and quality of life needs of both cancer and cardiovascular patients..

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. A second phase of the SmartCARE project to take the Smartcard concept, developed through the Europe's Beating Cancer Plan from idea and prototype stage to real life application- also extending to patients with advances/metastatic cancers;
2. That Europe's upcoming Cardiovascular Plan takes inspiration and builds from the SmartCARE project to help ensure oncology patients and survivors with cardiovascular co-morbidities and complications can receive special assistance from this pre-created European platform;
3. That the SmartCARE concept is fully integrated in European Health Data Space.

I. 1. 2. Addressing Fair Access for Cancer Survivors to Financial Services

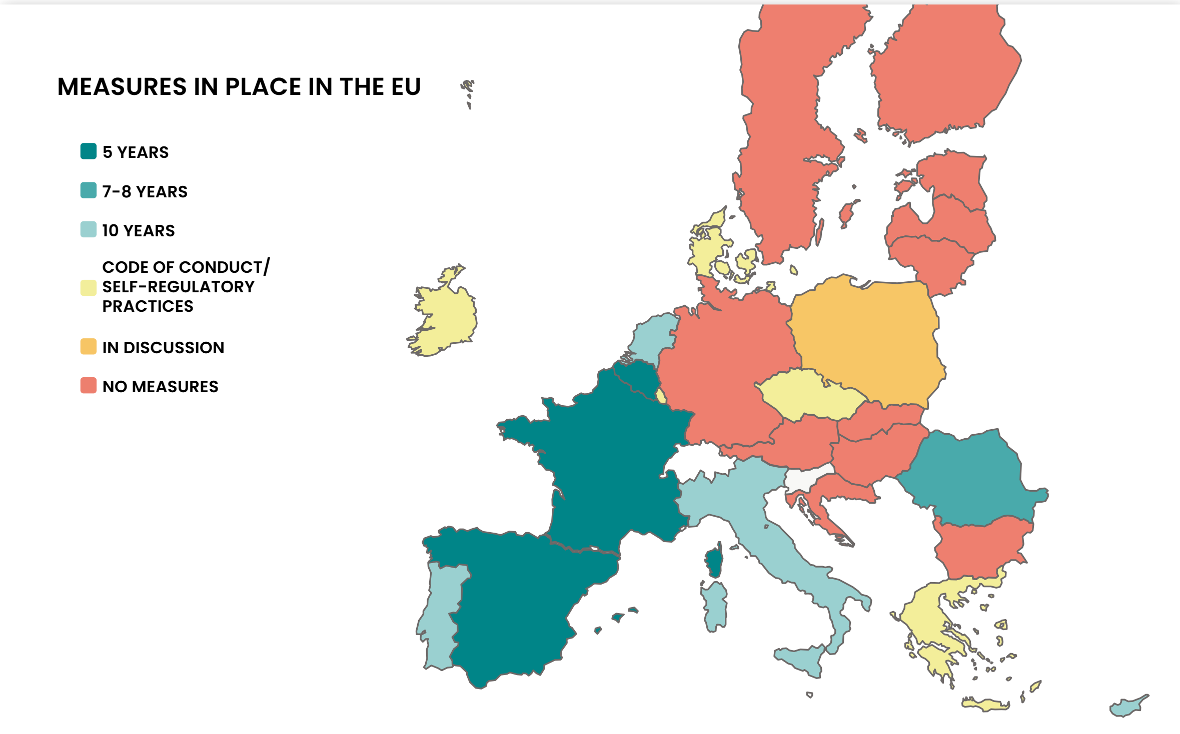
'Facing a diagnosis of cancer and undergoing treatment is an ordeal. Once declared cancer free, and without relapsing after 5 years, cancer survivors should not have to pay twice to access financial services. It is not a question of compassion, but a matter of justice and human rights.' **Prof. Dr Françoise Meunier**, Founder of the Ending Discrimination Against Cancer Survivors Initiative.

Many survivors, despite being fully cured, face significant challenges in their financial journey following end of active treatment (23). This can, too often, be due to unfair and discriminatory consideration of their past cancer history by financial service providers, resulting in having to pay higher premiums, restriction of access, or outright denial of services. A survivor seeking loans, mortgages, or insurance policies is often refused access due to a past cancer diagnosis, no matter how long ago that diagnosis was received and regardless of achieving a complete remission since a set number of years. Some studies **have suggested up to 25% of those living beyond their cancer may be having more difficulty accessing appropriate financial services and face discrimination**(24) (25).

The "Right to Be Forgotten" is a legal provision addressing this issue and designed to protect cancer survivors. It refers to the **rights of cancer survivors to resume a "normal" lifestyle without encountering discrimination based on their past cancer diagnosis, after they have been declared cured** (26). By ensuring that a history of cancer does not lead to lifelong penalties or unequal treatment, this initiative promotes fairness and supports the reintegration of survivors into society and the workforce. Ultimately, ending discrimination against cancer survivors is a cornerstone of improving their quality-of-life, upholding their dignity, and fostering a more inclusive and equitable Europe.

To date, nine EU Member States (France, Spain, Belgium, Cyprus, Portugal, the Netherlands, Italy, Romania, Slovenia) have established a binding legal framework to guarantee a Right to Be Forgotten, ensuring that cancer survivors are not subject to ongoing discrimination in access to financial services. Notably, France, Belgium, and Spain have adopted a five-year timeline for protection as well as implemented reference grids that allow for shorter timelines for cancers with very good prognoses, which should both serve as a model for other Member States. Several other countries have introduced non-binding measures. While these provide some guidance and recognition, **they fall short of offering full legal protection or enforceable rights**. Despite these advances, twelve Member States currently have no measures in place, leaving survivors exposed to persistent inequities across the European Union (see map below).

Figure 2: 'Overview of legislation at European level' (Ending Discrimination Against Cancer Survivors) (27)



Recently, following a number of presentations in the Irish parliament, the Minister of Finance in Ireland Pascal Donohoe committed to introducing the Right to Be Forgotten into Irish Law. **Prof. Mark Lawler**, Professor of Digital Health at Queen's University Belfast said: *'When a cancer professional says that you are cured and international benchmarking agrees, then why do the financial institutions say that you are not? Cancer patients should not be punished for one of the worst things that has ever happened to them, because of financial institutions' ability to hold someone's history over their head.'*

The topic of discrimination in accessing financial services has been tackled in Europe's Beating Cancer Plan. **Flagship 35 was introduced to** develop a voluntary Code of Conduct to improve access to financial products for cancer survivors and was initially planned for 2021 to 2023. From August 2023 to May 2024, representatives of the cancer community and of the insurers' community of the have been involved in the numerous roundtable negotiations for the development of a Code of Conduct on Fair Access of Cancer Survivor to Financial Services (HADEA/2022/OP/0019), chaired by DG SANTE and DG FISMA. **Agreement between partners on such a Code was never achieved**. Contractors published a Final Study Report in September 2024, highlighting that 'at the time of drafting this report, discussions on a Code of Conduct between some of the involved stakeholders are still ongoing.'(28)

The inability to secure agreement on the Code represents a clear shortcoming to date, underscoring the need for the fight against financial discrimination of cancer survivors to be actively advanced at Member State level. Nevertheless, the medical evidence, exchanges, relationships and advances made during these nine months should not be lost and **should inspire fresh binding initiatives at European and national level under the new Commission period for 2024-2029**. The inclusion of a Right to Be Forgotten in EU legislation establishes an important legal precedent, reinforcing the principle that a history of illness should not permanently disadvantage individuals seeking to rebuild their lives.

The European Union has already taken strides, through the revised Consumer Credit Directive (Directive (EU) 2023/2225), adopted in October 2023. Notably, the Directive includes a reference to the "Right to Be Forgotten" in the context of creditworthiness assessments: stating that *'personal data, such as personal data found on social media platforms or health data, including cancer data, should not be used when conducting a creditworthiness assessment'*. This was further strengthened by the provisional agreement, calling for the maximum amount of years to be capped at 15 years after end of active treatment.

The adopted timeframe nevertheless falls significantly short of the European cancer community's call for a five-year cap (12), already established in countries such as France, Spain and Belgium (25). The potential revision of the EU Mortgage Credit Directive during the 2024-2029 mandate would present a critical opportunity to establish a new legal framework for the Right to Be Forgotten for cancer survivors.

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. No let-up in momentum for **binding national and European legislation** to protect cancer survivors from unfair discrimination;
2. That the established French and Belgian **5 years after end of active treatment** be taken as a gold standard for future legislation;
3. That any future **revision of relevant EU consumer legislation** embraces the opportunity to establish the Right to Be Forgotten as an EU right.

I. 1. 3. Addressing Work and Work Rehabilitation

> *'Work is a cornerstone of identity and recovery for people living with and beyond cancer. Yet too many face stigma, inflexible practices, and inadequate support. We must move from ad hoc initiatives to systemic implementation, embedding the right to work, reasonable adjustments and sustained employer education into all national cancer and employment policies. Empowering people to work well with and after cancer is essential to Europe's vision of living better, not just longer.'* **Veronica Foote**, Head of Policy and Consulting, Working with Cancer.

Managing cancer is not only a matter of treatment, but also a question of 'how well' cancer patients and survivors live (29). Addressing work and work rehabilitation for cancer patients is a crucial issue, given the growing number of cancers diagnosed in people of working age. The disease often leaves behind visible and invisible disabilities, such as memory loss, reduced concentration, brain fog, difficulties standing up, bowel dysfunction and mental fatigue, making work reintegration particularly difficult. Flagships 36(1), 36(2) and 36(3) of Europe's Beating Cancer Plan, analysed below, are dedicated to working conditions and work rehabilitation, altogether aimed at improving the quality-of-life after a cancer treatment and promoting a more holistic consideration of survivorship.

Flagship 36(1) Launching a study addressing issues relating to the return to work

As part of the implementation of Europe's Beating Cancer Plan, the European Commission published a *Study on Job Retention and Return to Work of Cancer Patients and Survivors* (30) in October 2024. The study provides a detailed analysis of the multifaceted barriers encountered by cancer patients and survivors, reviews existing national measures, and puts forward a set of policy recommendations aimed at strengthening action primarily at the Member State level. National legislative frameworks remain **inconsistent and insufficient**. In response, the European Commission urges coordinated policy action in the study, including promotion of **flexible and adaptive working arrangements** - such as teleworking and graduated return-to-work pathways- targeted **financial incentives** for employers, **tackling stigma and discrimination, reinforcement of national legal and policy frameworks** and more.

As emphasised by former Commissioner for Health and Food Safety, Stella Kyriakides, this initiative must be seen not as an endpoint, but as a catalyst for sustained policy engagement: *"This is the beginning of the conversation [...] we must now turn today's challenges into tomorrow's opportunities."* (31).

To reach this end, a decisive shift is needed, one that recognises the return to work not merely as a labour market objective, but as a fundamental component of survivorship. Both political will and policy implementation are required to translate asks into concrete legislation.

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Promoting EU-level policy frameworks that support **graduated return-to-work schemes** for cancer survivors as a key measure to improve quality-of-life and long-term reintegration;
2. Integrating **work retention and return-to-work support as a standard element of survivorship care and national cancer plan**s;
3. Including **guidance and training for employers** in EU and national cancer strategies to support staff affected by cancer, covering flexible work options, stigma reduction, and workplace adjustments;
4. Ensuring EU and national legislation **provides adequate recovery periods for cancer survivors before returning to work**, supporting sustainable reintegration;
5. Incorporating return-to-work and job retention indicators into the **European Cancer Inequalities Registry (ECIR)** and other EU monitoring frameworks.

Flagship 36(2): Addressing the rights of cancer patients considered as persons with a disability in the Strategy on the Rights of Persons with disabilities 2021-2030

The EU Strategy for the Rights of Persons with Disabilities 2021–2030(32) outlines priority areas to combat poverty, discrimination, and social exclusion affecting persons with disabilities. Although it does not explicitly mention cancer patients, relevant initiatives, including those fostering inclusive labour markets and accessible workplaces, could benefit this population, where eligibility criteria are met. Of note for cancer patients and survivors is the enhancement of the **European Disability Card and Disability Parking Card** (33), designed to strengthen and harmonise cross-border rights, including in areas such as parking entitlements and access to services.

However, numerous barriers persist across and within Member States:

1. The 2024 implementation European Parliament IPOL report for the EU Strategy for the Rights of Persons with Disabilities 2021-2030 notes substantial disparities in national transposition, underlining the need for stronger enforcement and greater ambition.

2. Cancer patients face procedural and legal hurdles in acquiring formal disability status. This highlights a pressing need to formally recognise cancer as a potential disability within EU and national frameworks, notably for those with advanced or metastatic cancers, or survivors with confirmed long-term consequences of the disease. Addressing this will require both political will and legislative clarity. This could include formal legal guidance to ensure that Art. 5 of Council Directive 2000/78/EC, which requires employers to provide reasonable accommodations for disabled persons, also applies to cancer patients and survivors.

3. A significant legislative gap persists concerning recovery time for cancer survivors before returning to work. Currently, no legal framework guarantees patients a dedicated recovery period, resulting in fragmented and inconsistent practices. Survivorship should be recognised as a legitimate phase of recovery, with flexible provisions allowing 3 to 6 months remunerated off work depending on the type and intensity of treatment, as well as the possibility to work part time (34).

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. EU institutions and member states to ensure clear, consistent guidance on how advanced/metastatic cancer patients and survivors with long-term complications can access the benefits of disability initiatives, specifying both **eligibility criteria and practical pathways to support**;
2. EU and national legislation should **guarantee a recovery period** for cancer survivors before they return to work, ensuring adequate time to recuperate and support a sustainable reintegration.

Flagship 36(3): Ensuring full implementation of the Directive on work-life balance for parents and carers

Directive 2019/1158 on work-life balance aims to promote gender equality in caregiving but remains narrowly focused on parental responsibilities. While it introduces carers' leave and flexible working rights, its scope **largely excludes the needs of those caring for cancer patients**. The minimum entitlement of **five unpaid days per year** is insufficient for managing the prolonged and intensive care cancer often requires. The lack of income protection further limits its accessibility, especially for lower-wage workers.

By failing to address long-term or episodic caregiving, including for adults with serious illnesses, the directive **falls short of today's care realities**. A broader, better-funded framework is needed to reflect the full spectrum of informal care and ensure equal protection across life stages and care settings.

The latest implementation report (35) published in 2024 **also states important gaps in the transposition of the directive**, one year after the transposition period deadline. Overall, the conclusions are quite simply summarised by the subtitle given to the report: *"Considerable work still to be done"*.

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. **Extending existing paid and flexible carers' leave** to explicitly include adult care responsibilities, such as supporting individuals during cancer treatment, recovery, and long-term survivorship.
2. Establishing mechanisms to **monitor the implementation** and impact of carers' leave legislation across Member States, ensuring that legal entitlements are effectively applied.

I. 2. Other Initiatives of Europe's Beating Cancer Plan Aiming at Improving Survivorship and Quality-of-Life

The terms 'survivors' and 'survivorship' appear throughout Europe's Beating Cancer Plan, notably in Chapter 7 dedicated to reducing cancer inequalities across the EU, yet also in Chapters 5.1 (delivering higher-quality care), 5.2 (Ensuring a high-quality workforce), and 8 (Putting childhood cancer under the spotlight) (20). On the other hand, 'quality-of-life' is only mentioned in Chapter 7 and 8, yet not in dedicated flagships.

A recent study published in the Archives of Public Health (20) has tabled all flagships related to survivorship and quality-of-life, now a total of twelve (20), and the below subsection analyses which concrete actions have been implemented since their announcement in 2021.

Table 1: based on the work of Mbengi R.K., Schittecatte, G. & Theys, S. Policy Brief – Survivorship is cancer survivorship the poor cousin of cancer control within the EBCP?. Arch Public Health 82 (Suppl 1), 143 (2024). https://doi.org/10.1186/s13690-024-01371-9

Action	The flagship, initiative or action	Possible impact on survivorship care	Planned or ongoing projects including survivorship
1	'Knowledge Centre on Cancer'	Indicators to monitor the QoL of survivors, the quality of survivorship care, access to rehabilitation, return-to-work	Currently one indicator on Right to Be Forgotten featured in the quality-of-life category of ECIR.

Action	The flagship, initiative or action	Possible impact on survivorship care	Planned or ongoing projects including survivorship
13	Occupational Safety and Health Strategic Framework 2021–2027.	Inclusion of binding legal basis for the protection of workers with cancer and job maintenance	The EU strategic framework on health and safety at work 2021-2027
23.1	Creation of an EU Network of Comprehensive Cancer Centre(s) – EunetCCC	Inclusion of prerogatives for CCCs in cancer survivorship care and rehabilitation	The first CraNE Joint Action has been concluded, the second one (EUnetCCC) is ongoing, including an aim to develop and implement personalized cancer survivorship programs in all CCCs across Europe
23.2	New cancer Networks of Expertise	These new Reference Networks will look at specific, challenging cancer conditions, which will benefit from cross-border cooperation and EU expertise. These conditions include metastatic diseases, comorbidities in cancer care, complex cancers with poor prognosis, paediatric cancers and specific conditions related to genomics in cancer care, **palliative care and survivorship**	New joint action JANE-2 following the conclusion of JANE-1 (Joint Action on Networks of Expertise) which includes ongoing work to develop a European Network of Expertise on survivorship and one on palliative care
26	Inter-specialty training programs	Ensure the training of professionals in survivorship care and rehabilitation and facilitate expertise and knowledge sharing	Survivorship – One course dedicated to health advocacy and survivorship (in development) QoL – Unit on quality-of-life in cancer care, key quality indicators to monitor within a course[1]
41	EU Network of Youth Cancer Survivors	Improve transnational cooperation and efforts to improve QoL of Children, Adolescents and Young Adults (CAYAs)	Launch of the Youth Cancer Network (YARN) project in 2025, Building on the legacy of EU-CAYAS-NET and OACCUs. Designed to empower young people affected by cancer through peer support, digital innovation, and inclusive care.

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1. This section has been added by the European Cancer Organisation and does not feature in the original table

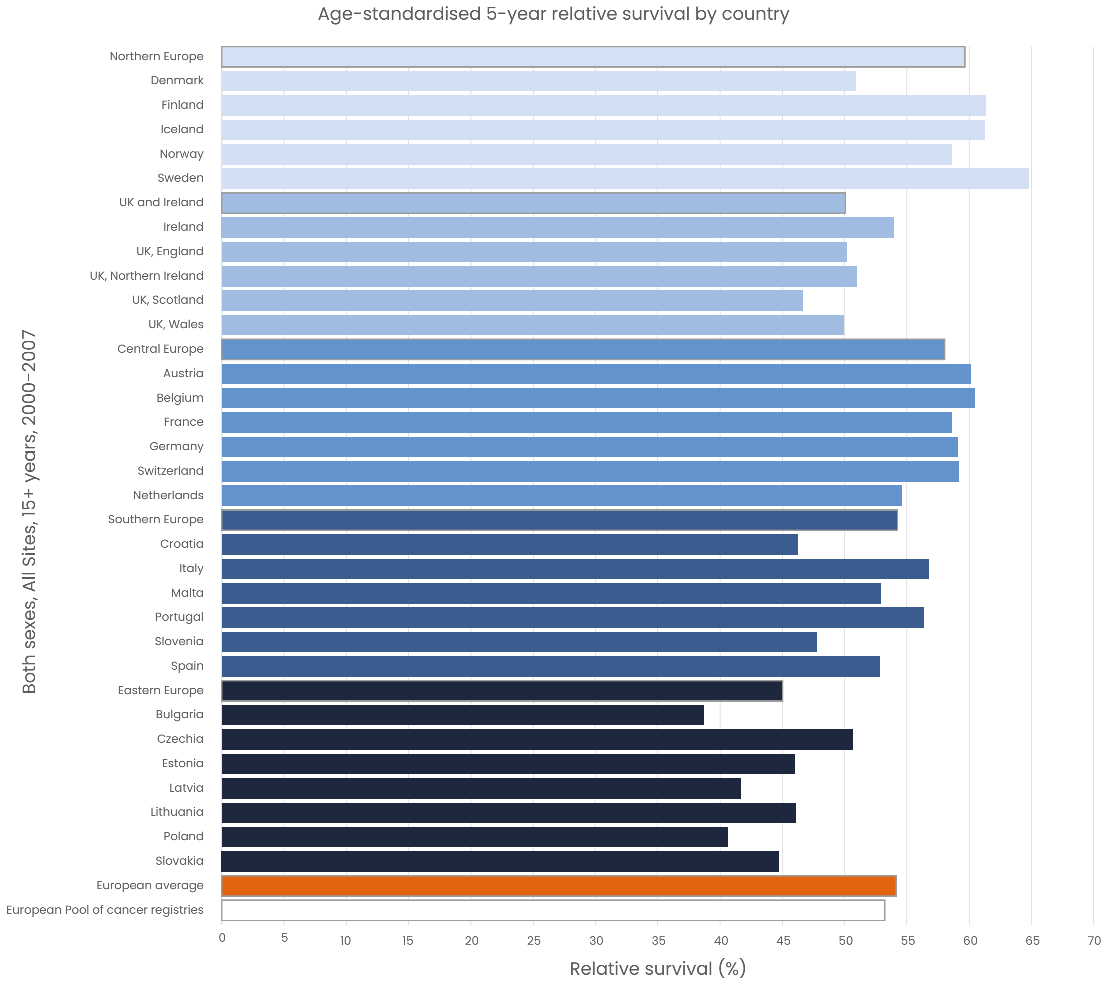
I. 2. 1. Knowledge Centre on Cancer (Flagship 1)

The Knowledge Centre on Cancer, operated by the European Commission's Joint Research Centre (JRC), is a scientific and evidence-base data tool aiming to support the Europe's Beating Cancer Plan and the Cancer Mission(36). It builds on five core pillars:

1. **European Cancer Information System (ECIS)**, providing cancer burden indicators (incidence, mortality, survival data);
2. **European Cancer Inequalities Registry (ECIR)**, aiming to identify disparities and inequalities in cancer care
3. **Health Promotion and Disease Prevention**, focusing on cancer prevention – The ECIR was a flagship initiative of the Europe's Beating Cancer Plan;
4. Cancer screening, diagnosis and care, providing **European guidelines and quality assurance schemes** for breast, colorectal and cervical cancers;
5. **EU Platform on Rare Disease Registration (EU RD Platform)**, tackling interoperability of data on rare cancers.

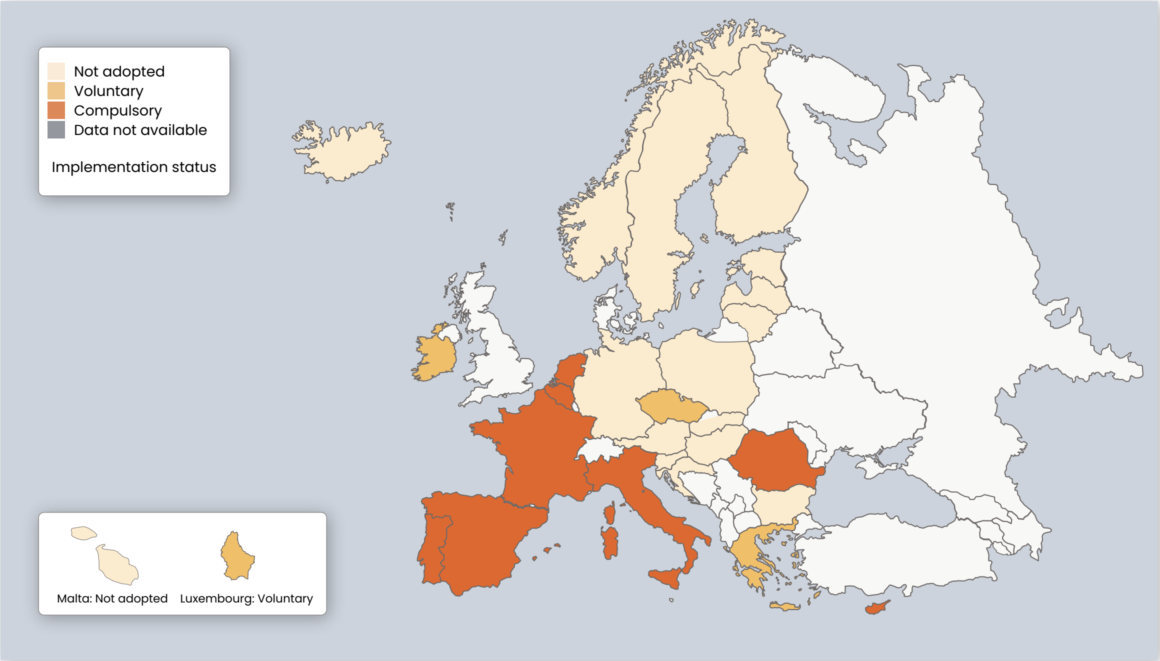
The Knowledge Centre on Cancer, through instruments such as the ECIS and ECIR, furnishes essential data on five-year and age-specific cancer survival rates across Europe (see below).

Figure 3: 5-year relative survival by country 2000-2007 (both sexes, all cancer sites, 15+ years) - ECIS data explorer (37)



However, to date, the European Cancer Inequalities Registry (ECIR) **only includes one indicator related to survivorship and quality-of-life of cancer patients: the implementation of a Right to Be Forgotten initiative for Cancer Patients by country in 2024**.

Figure 4: Implementation of a Right to Be Forgotten initiative (2024) by country - ECIR data tool (38)



Other indicators on the quality of survivorship care, or the quality and implementation of return-to-work legal provisions (for example based on the findings of the Study on Job Retention and Return to Work of Cancer Patients and Survivors) would be valuable to monitor the quality-of-life of cancer patients and survivors across Europe.

These datasets predominantly concentrate on survival metrics and **frequently overlook broader dimensions of quality-of-life and the enduring challenges encountered by cancer survivors**. Despite increased policy attention, considerable gaps remain, particularly in the systematic collection of comprehensive quality-of-life data and in guaranteeing equitable support and care for all cancer survivors throughout Europe. To close existing gaps, the JRC/KCC should coordinate with Member States' health ministries to systematically gather and evaluate quality-of-life data for all cancer survivors in Europe.

I. 2. 2. Occupational Safety and Health Strategic Framework 2021–2027 (Flagship 13)

Europe's Beating Cancer Plan made the following promise: *"In the upcoming Occupational Safety and Health Strategic Framework, the Commission will look into psycho-social risks and disadvantaged groups, including cancer survivors* (29)."

The **Occupational Safety and Health Strategic Framework 2021–2027** (39) falls short on a key promise: the European Commission's only textual commitment is a call for Member States to "actively support reintegration, non-discrimination and the adaptation of working conditions of workers who are cancer patients or cancer survivors."

The **Survivorship & Quality-of-life Network Paper** argues that Europe's Beating Cancer Plan has yet to fully deliver on this commitment.

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. For **EU-OSHA** to be mandated and adequately resourced to produce EU-level guidance for employers on supporting cancer patients and survivors in the workplace;
2. Stakeholders, including cancer patient advocacy organisations and employer representatives, to be **actively engaged in shaping this guidance**, ensuring that reintegration, non-discrimination, and workplace adaptation move from rhetoric to reality.

I. 2. 3. Creating an EU Network of Comprehensive Cancer Centres (Flagship 23.1)

The Joint Action "European Network of Comprehensive Cancer Centres" (EUnetCCC) was launched in October 2024 and will run until 2028.

The EU Network of Comprehensive Cancer' core ambition is to **ensure that 90% of eligible cancer patients have access to high-quality, multidisciplinary care in accredited Comprehensive Cancer Centres (CCCs) by 2030**. These centres are not just designed as hubs for advanced treatment, but also for cutting-edge research, education, and patient-centred innovation.

Theoretically, the successful creation of this network would have profound implications for survivorship and quality-of-life. CCCs are uniquely positioned to offer integrated, long-term follow-up and survivorship care plans, which address not only medical needs but also psychosocial support, rehabilitation, fertility preservation, and the management of late effects (Work Package 8).

Despite being a well-recognised pillar of quality care, psychosocial and psycho-oncological services remain **severely under-resourced and inconsistently implemented across Member States**. This gap undermines patients' ability to cope with high levels of distress profound shifts in personal and professional identity. Clinical psycho-oncology care is not an optional extra: it is a core element of improving self-efficacy, emotional well-being, clinical outcomes and long-term quality-of-life. **Without concrete action and full implementation of these resources, the EU risks failing to deliver on its promise of person-centred survivorship**.

The European Cancer Organisation (ECO), through the **Essential Requirements for Quality Cancer Care (ERQCC)**, already calls for the full integration of psycho-oncology within Multidisciplinary Teams (MDTs) as a standard component of quality cancer care. This requirement must now be systematically embedded in Quality Assurance Schemes at both EU Comprehensive Cancer Centre level and national levels.

I. 2. 4. Joint Action on European Networks of Expertise (Flagship 23.2)

The **JANE (Joint Action on European Networks of Expertise)** project is a strategic EU-funded initiative designed to support the implementation of high-quality, equitable cancer care across Europe. Anchored in the objectives of Europe's Beating Cancer Plan, JANE (2022-2024) and the currently undergoing JANE-2 aim to strengthen the development and operationalisation of **European Networks of Expertise** in cancer. JANE-2 represents a key building block in Europe's mission to reduce cancer inequalities and ensure that **high-quality expertise and support is available to every patient, regardless of where they live**.

JANE plays a vital role in advancing cancer **survivorship** by embedding survivorship care as a core component within future European Networks of Expertise. One of the key agreements reached during the launch meeting was the proposal of a "working definition" for cancer survivor, which will serve as the basis for establishing and promoting an integrative care model for cancer survivors in Europe.

This Joint Action aims to create seven Networks of Expertise (NoE), two of which are on survivorship (WP7) and palliative care (WP6). Each WP corresponds to the creation of an NoE.

Work Package 7 is for example directly dedicated to the creation of a Network of Expertise on survivorship, with the aim to ensure that survivorship is not treated as an afterthought, but as a fundamental phase of the cancer care continuum, delivered with the same level of expertise and coordination as diagnosis and treatment. The interim report points out that survivorship Networks of Expertise should provide:

- Guidelines for recurrences and second primary cancers;
- Guidelines for effects of primary cancer and chronic medical conditions;
- Guidelines for psychological effects of cancer;
- Guidelines for social, work, and financial effects of cancer;
- Guidelines for cancer prevention and overall health and well-being promotion.

Further information on this topic can be found in Deliverable 7.1 of the Joint Action on Networks of Expertise (40).

I. 2. 5. Establishing an Inter-Specialty Cancer Training Programme (Flagship 26)

INTERACT-EUROPE 100 is a flagship three-year initiative, co-funded by the European Union, with a crystal-clear ambition: to revolutionise how cancer care is delivered across Europe, by promoting interprofessional collaboration. Building on the foundations laid in its first phase, this second wave of the **INTERACT-EUROPE** project is designed to bring the **Inter-Specialty Cancer Training Programme** to life in over 100 cancer centres across Europe.

The Inter-Specialty Cancer Training Programme comprises five innovative courses across 31 units, equipping participants with cross-disciplinary knowledge and practical tools in:

- Clinical excellence across oncology specialties;
- Communication and collaboration in multidisciplinary teams;
- Professional practice and continuous learning;
- Leadership in healthcare systems;
- Health advocacy and survivorship.

Course 5: Health Advocacy and Survivorship, developed in close partnership with patient advocates to ensure real-world relevance and impact, tackles critical topics of interest to this paper , including:

INTERACT-EUROPE 100 Train-the-Trainer course in Bucharest 25 to 27 September 2025

1. The evolving concept of survivorship;
2. Defining roles in survivorship care;
3. Designing and delivering personalised survivorship care plans;
4. Using Patient-Reported Outcome Measures (PROMs), Experience Measures (PREMs) and Importance Measures (PRIMs) to centre care on what truly matters;
5. Understanding the broader impact of cancer: financial, social, functional, and occupational.

NTERACT Europe 100 - has modules ECO has a big role and we are moving forward, baby steps but into the right direction of better addressing patients' needs. However we need 'care plans' not only treatment plans, and as well SCPs!

Whereas survivorship is well taken into consideration in the programme quality-of-life considerations appear to be less sizable. In the 'Health Advocacy and Survivorship', only unit.

Training multiprofessional teams in delivering coordinated, person-focused care which includes psycho-oncology, survivorship planning, and social support is a prerequisite for high-quality cancer services. Only by embedding this paradigm shift into professional education can the EU meaningfully address the complexity of modern cancer care and ensure equitable quality across Member States.

The 'Next level EU cancer survivorship and quality-of-life' policy paper contends that the INTERACT-EUROPE programme is proving an efficient and effective means to share and inculcate key principles of quality survivorship related care in cancer centres across the EU and beyond. It notably recommends that:

1. The now developed platform could be further enhanced in future **with additional specialist modules and close connections to allied EU level initiatives such as the standard setting work of the EU Network of Comprehensive Cancer Centres**.

I. 2. 6. Creating a New Network of Youth Cancer Survivors (Flagship 41)

'European and national cancer policies must be built with, not just for, young survivors. Their lived experience is the key to designing inclusive, equitable, and forward-looking cancer strategies that extend beyond treatment, placing lifelong care and quality-of-life at the centre.' **Childhood Cancer International-Europe**

'Just as Yarn is made of individual threads woven together, the European Youth Cancer Network (YARN) connects the voices, stories and strengths of young people across Europe affected by cancer.'
Youth Cancer Europe

In Europe, there are around 500,000 survivors of childhood, adolescent, and young adult cancer. While survival rates have improved over the years, many young survivors continue to face significant long-term challenges (41).

To address such challenges, two complementary projects were funded between 2022 and 2025 Under the EU4H-2021-PJ call: **EU-CAYAS-NET** and **OACCUs**. Together, they strengthened support for young people living with and beyond cancer by building youth-led structures for peer support and empowerment, advancing tools for long-term follow-up and quality-of-life, promoting mental health and social reintegration, and raising youth participation in European cancer policy in line with Europe's Beating Cancer Plan.

The EU-CAYAS-NET project, led by CCI Europe, first united 9 core partners and 28 associated organisations across 18 countries, creating a cross-border alliance of patients, survivors, researchers, healthcare professionals, and policymakers. It achieved numerous milestones, such as the creation of an EU-CAYAS-NET Ambassadors Group and the publication of Policy Recommendations for Equitable, Diverse and Inclusive Cancer Care (42) as well as a White

Paper on optimising quality-of-life after Youth Cancer (43).

With both projects now concluded, the YARN – European Youth Cancer Network, launched in 2025 and lead by Youth Cancer Europe, will run until 2028 to carry this legacy forward and scale it up. Spanning 25 EU Member States and 3 eligible neighbouring countries, it seeks to continue improving the quality-of-life for children, adolescents and young adults affected by cancer.

Taking stock of the EU-CAYAS-NET Ambassadors, YARN introduced the Youth Cancer Council, a pan-European advisory group of 100 young people with lived experience of cancer who contribute to decision-making, consultation and design across the project. YARN will drive progress on EDI certification across healthcare and patient organisations, equip systems with personalised tools for long-term and end-of-life care, and establish evidence-based standards for mental health and shared decision-making. It will empower youth advocates and healthcare professionals through targeted training and raise public awareness to foster lasting change. Its Digital Knowledge Centre is available at **beatcancer.eu**.

To ensure that the unique challenges faced by the AYA population living with and beyond cancer are effectively addressed in the years ahead, the 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Integrating EU-CAYAS-NET, OACCUs, and YARN outcomes into national Cancer Mission and Beating Cancer Plan implementation through projects such asJANE2, ECHoS & EU-NET-CCC to **foster multistakeholder collaboration and strengthen survivor and youth engagement**;
2. Expanding **dissemination of resources** to reach all relevant stakeholders;
3. **Strengthening engagement** of people with lived experience through advocacy, training, and peer support;
4. Prioritising the **development of more targeted metrics** to assess impact on quality-of-life, the core focus of this paper;
5. **Fostering collaboration** with parent, survivor, and community organisations involved in paediatric, AYA, and family support;
6. Prioritising national-level network-building to ensure long-term sustainability and impact.

Other EU legislation impacting survivorship & quality-of-life

- Pharmaceutical Package (2023/0131 & 2023/0132)
    - Although centred on unmet medical needs through reducing morbidity and mortality, the current criteria risk overlooking key survivorship aspects such as long-term quality-of-life, late effects, and functional well-being. Broadening definitions to include these is vital to truly support survivors.
- Health Technology Assessment Regulation 2021/2282
    - This regulation harmonises treatment assessments, yet must better reflect how side effects, toxicity, and safety improvements affect survivors' day-to-day lives, ensuring new therapies enhance both survival and quality-of-life.
- European Health Data Space (2025/327)
    - By enabling comprehensive, cross-border sharing of health data, this initiative has the potential to transform survivorship care through improved monitoring of long-term outcomes and patient-centred quality-of-life measures, if survivor-relevant data is given priority.

Europe's Beating Cancer Plan marked a breakthrough by explicitly addressing survivorship and quality-of-life, areas long neglected in health policy. Yet progress is fragile. The reallocation of EU4Health funding has jeopardised projects such as smartCARE, while efforts to deliver a voluntary code of conduct on fair financial access collapsed, leaving survivors across half of Member States without legal protection. Return-to-work remains inconsistent, with cancer rarely recognised as a disability and carers' rights narrowly defined. At the same time, quality-of-life data remain almost absent from the Cancer Inequalities Registry, meaning that policymakers cannot properly measure or compare outcomes across Europe.

The result is that cancer quality-of-life and survivorship still occupies a marginal space in European policy, acknowledged in principle but undermined in practice. Significant gaps also in the attention to survivorship and quality-of-life within national health systems, with many lacking structured pathways, resources, or monitoring mechanisms.

Important foundations have been laid, yet the gap between ambition and implementation remains wide.

II. 'Mission Possible': EU's Advances in Survivorship and Quality-of-Life Research

Under the Horizon Europe programme, **the European Commission launched five flagship Research and Innovation Missions**, dedicated to climate change, cancer, oceans, cities and food , designed to tackle pressing societal challenges through collaborative, innovative solutions.

The EU Cancer Mission has set the goal to *"improve the lives of more than 3 million people by 2030, through prevention, cure and for those affected by cancer including their families, to live longer and better"* through 5 intervention areas, understanding, prevention, diagnosis and treatment, quality-of-life and equitable access. It notably seeks to reduce stigma, monitor programmes for survivors of cancer, provide a better understanding, as well as provision for solutions to a range of physical and mental side effects and comorbidities.

Figure 5: Overview of EU Mission on Cancer resources (44)

The EU Mission on Cancer benefits from support through a range of sources:

€255 MILLION

The Horizon Europe 2021- 2022 workplan has assigned €255 million across the four Cancer Mission objectives;

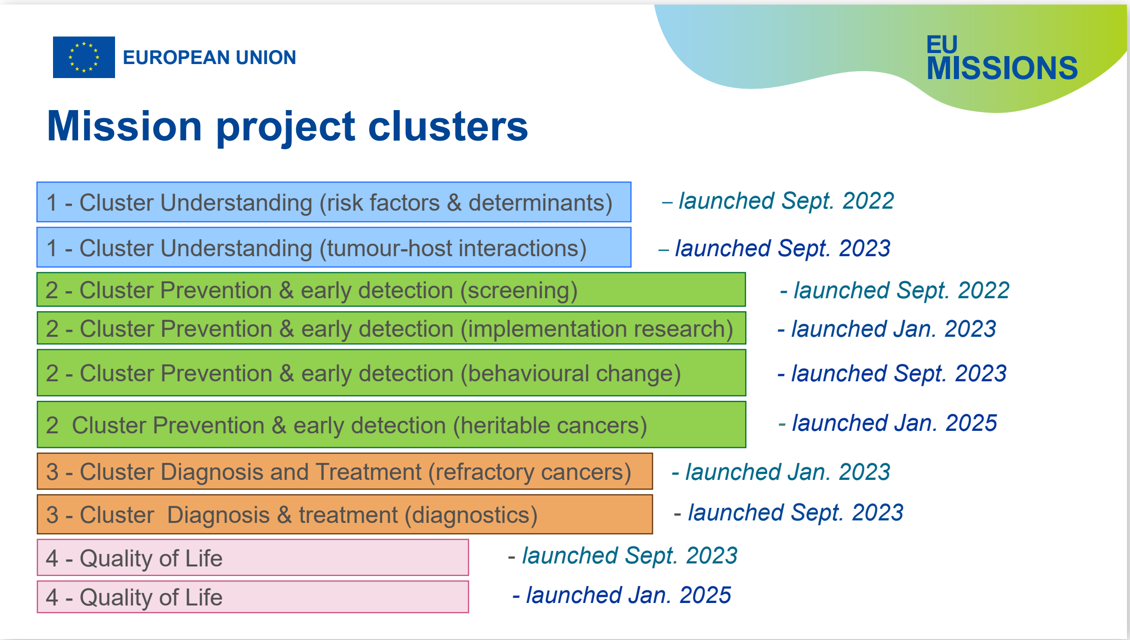
TOTALLING €1.25 BILLION

Funding to Europe's Beating Cancer Plan: the EU4Health programme, totalling €1.25 billion; the Digital Europe Programme, which will provide up to €250 million to cancer-related projects and other digital health investments; the Erasmus+ programme; the Marie Skłodowska-Curie actions, which will provide up to €500 million for projects in education, training and research on cancer; and national funds and private investments.

II. 1. The EU Cancer Mission’s Commitment to Advance Quality-of-Life

To build the cancer mission portfolios, **project clusters** have been set up, bringing together projects funded under each call topic (45). The fourth cluster is currently dedicated to quality-of-life.

Figure 6: EU Mission Cancer - Mission Project Clusters, European Commission.



EUROPEAN UNION

EU MISSIONS

Mission project clusters

1 - Cluster Understanding (risk factors & determinants)	– launched Sept. 2022
1 - Cluster Understanding (tumour-host interactions)	– launched Sept. 2023
2 - Cluster Prevention & early detection (screening)	- launched Sept. 2022
2 - Cluster Prevention & early detection (implementation research)	- launched Jan. 2023
2 - Cluster Prevention & early detection (behavioural change)	- launched Sept. 2023
2 Cluster Prevention & early detection (heritable cancers)	- launched Jan. 2025
3 - Cluster Diagnosis and Treatment (refractory cancers)	- launched Jan. 2023
3 - Cluster Diagnosis & treatment (diagnostics)	- launched Sept. 2023
4 - Quality of Life	- launched Sept. 2023
4 - Quality of Life	- launched Jan. 2025

II. 1. 1. By Funding EU Cancer Mission Research Projects Advancing Cancer Survivorship and Quality-of-Life

Name of the project	Goal	Commentary
EUonQoL	The EU-funded **EUonQoL** project is developing, piloting and validating the **European Oncology Quality-of-life Toolkit (EUonQoL-Kit)**, a co-designed, digital instrument for measuring health-related quality-of-life among cancer patients and survivors. The EUonQoL-Kit stands out as it is co-designed with patients, to ensure it captures what truly matters to individuals who have experienced cancer It is available in multiple languages, enabling consistent, comparable data across diverse European settings. **EuonQoL aims to directly address longstanding gaps in standardised, patient-centred outcome measurement**. By delivering an accessible tool, the EUonQoL-Kit can inform healthcare policy, and drive equitable improvements across the EU’s cancer care systems.	While extraordinarily promising, EUonQoL’s success hinges on effective integration into routine care and policy frameworks as well as implementation. Digital inequities, variable digital literacy, and the capacity of national systems to adopt and fund PROMs **will determine whether the EUonQoL-Kit transitions from a research asset to a policy instrument**. Moreover, meaningful patient involvement beyond design, in deployment, interpretation and governance, is essential to avoid the tool becoming technocratic rather than transformative.

Name of the project	Goal	Commentary
E-QuoL	E-QuoL (Health tools to promote Equity in Quality-of-life) is centred on children, adolescents, and young adults who have survived cancer, as well as their families. In a pioneering move, it co-designs digital e-health tools with patients, caregivers, and other stakeholders to address unique survivorship challenges. This notably includes puberty, sexuality, and emotional well-being, often under-recognised in paediatric oncology follow-up care. The project's ultimate aim is to foster equality in quality-of-life across Europe, while promoting personalised, accessible, and multilingual health management tools.	
TRANSCEND-XR	TRANSCEND-XR was launched in 2025 and aims at co-creation and implementation of an intervention to improve the understanding of TesticulaR cANcer late effects and unmet Supportive CarENeeDs of AYA survivors using eXtended Reality.	
MAYA	MAYA aims to empower Adolescents and Young Adults (AYA) cancer survivors to manage their cardiovascular (CV) health through digital tools that address cardiotoxic-related late effects of cancer treatment. The project envisions using the iCARE health hub, which integrates a smart mirror and an AI-powered conversational agent, to deliver personalised care and continuous monitoring. SHINE will lead the multi-stakeholder engagement activities ensuring that the implementation of the MAYA solution addresses the needs, preferences, and barriers of all key actors. Ensuring that the voices of the AYA survivors are at the heart of MAYA, SHINE will coordinate the co-research and patient community activities. Additionally, SHINE will lead the ethics and gender management of MAYA and the liaison and Cancer mission cluster activities, building on its extensive network.	
LATE-AYA	LATE-AYA, launched in 2025, addresses critical gaps in survivorship care for adolescents and young adults (AYAs) by deploying AI-driven digital phenotyping to monitor and manage late effects (LE) of cancer treatment. Using smartphones and wearables, the project applies a holistic, non-invasive approach to track physical, psychological, and social well-being. It promotes preventive health behaviours, psychological support, and social reintegration, delivering personalised digital interventions to improve long-term quality-of-life and enable early LE detection.	
PredictAYA	PredictAYA, launched in 2025, is a multidisciplinary research project to better understand the late effects of cancer treatments on AYAs aged 15-39. A key goal of PredictAYA is to identify and validate genetic biomarkers that explain individual variability in treatment-related organ toxicity, especially reproductive toxicity.	
PanCare4AYA	PanCare4AYA, launched in 2025 is a pioneering project dedicated to improving long-term care for adolescent and young adult (AYA) cancer survivors across Europe. These survivors face increased risk of long-term complications from both their cancer and its treatments, which can severely affect their quality-of-life (QoL), mental health, and socio-economic stability. The project addresses these challenges by developing a new international guideline for screening and follow-up, implemented through the AYA Cancer Survivor Screen: a novel, person-centred screening programme.	

Source: https://research-and-innovation.ec.europa.eu/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/eu-missions-horizon-europe/eu-mission-cancer/implementation-page/cancer-mission-objectives_en#quality-of-life-for-patients-survivors-and--their-families (45)

II. 1. 2. By Funding Key Flagships

The Mission is not only funding EU project but also supporting key flagships, **such as the creation of a European Cancer Patient Digital Centre (ECPDC)**, where patients and survivors will be able to access their own clinical data, to deposit clinical and patient reported health data in a standardised, ethical and interoperable manner, and share their data with healthcare professionals and researchers in a secure way. This would also facilitate the tracking of patients across EU countries and strengthen cancer registry efforts, including the establishment of a much needed registry of relapses to determine the number of patients living with metastatic disease, which remains currently unknown.

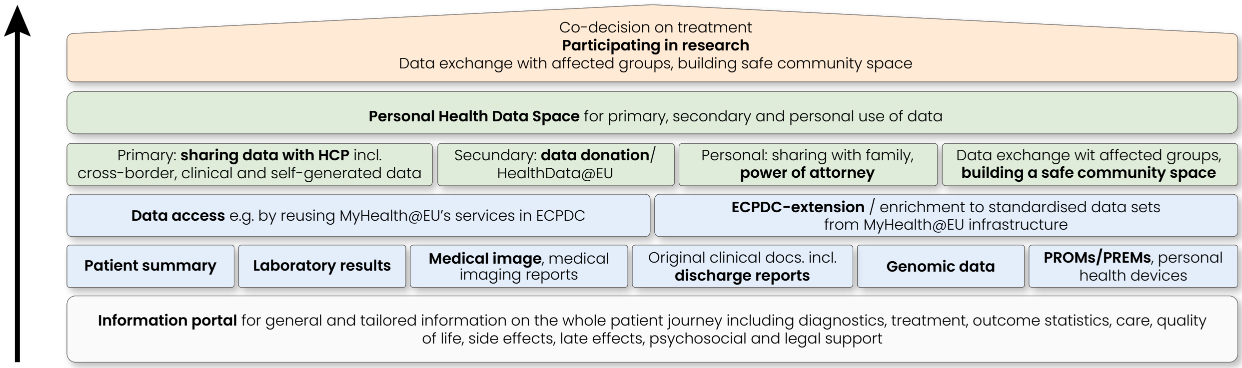
The European Cancer Patient Digital Centre

The 2021 Implementation Plan of the EU Cancer Mission set out an ambitious vision for the creation of a federated European Cancer Patient Digital Centre (ECPDC), designed to strengthen patient empowerment, improve survivorship support and foster research participation, in the form of a portal.

In May 2022, a first Horizon Europe call for tenders was issued to create the ECPCD, yet was unsuccessful, with no suitable candidacy.

The same year, the European Commission awarded contract RTD/2022/MVP/0012 to the Berlin Institute of Health at Charité for delivering a study on an operational concept for a European Cancer Patient Digital Centre (46). In its 2024 publication 'An operational concept for a European Cancer Patient Digital Centre',(47) it delivered a study on feasibility, utility and sustainability of the ECPDC, and a blueprint (see Project ECPDC) (48).

Figure 7: New Architecture of ECPDC (48)



A call for project was launched in 2024, with a new project EU-CIP (European Cancer Information Portal) having started in 2025.It will develop the information portal, the first building block of the EPCDC.

While EU-level initiatives derived from Europe's Beating Cancer Plan and the EU Cancer Mission provide an important framework for advancing cancer survivorship and quality-of-life, their implementation is still ongoing and has faced delays. Continued EU political and financial support is evidently required to secure the successful delivery of the EU's survivorship and quality-of-life ambitions in cancer policy. In this respect, a particular focus should be placed on ensuring the long-term sustainability of these initiatives, providing mechanisms to guarantee their long-term impact beyond project lifetimes.

Member States play a critical role in translating these frameworks into practice, shaping national infrastructures and care pathways. By examining national contexts, we can better understand the diversity of implementation approaches, identify areas where EU support is still needed, and highlight opportunities for shared learning across Europe.

Advancing Survivorship and Quality-of-Life: The Role of National Policies

*Advancing survivorship and quality-of-life (QoL) in cancer care requires a holistic **patient-centred care** approach that addresses not only medical outcomes but also the broader social, psychological, and structural dimensions of living with and beyond cancer. As survival rates continue to rise across Europe and as patients with advanced/metastatic cancers live longer, the challenge for health systems is to ensure that both all those affected by cancer can lead fulfilling lives, free from unnecessary burdens or discrimination.*

In this respect, this section focuses on the status of:

- ***National policy frameworks**, examining whether survivorship and QoL are explicitly embedded in National Cancer Control Plans and how the Right to Be Forgotten is implemented to protect survivors' rights beyond the health system;*
- ***Health and care delivery infrastructures and practices**, including the availability of psycho-oncological services, responses to the mental health burden such as depression, the integration of PROMs and PREMs as tools to evaluate and improve patient-centred care and **palliative care provision** as a cornerstone of QoL.*

I. National Cancer Policy Frameworks: Unequal Attention to Survivorship and Quality-of-Life

The following elements may readily be examined when it comes to the integration of survivorship and quality-of-life considerations in national cancer policy frameworks:

- The embedment of quality-of-life as a **section of the countries' national cancer control plans** (NCCPs), as mapped by the OECD series of EU Country Cancer Profiles 2025 (4);
- The **quality of national cancer control plans when it comes to the organisation of palliative and supportive care provision**, as established by the International Cancer Control Partnership (49);
- The existence of the **Right to Be Forgotten** legislation, which protects survivors from discrimination in accessing financial services such as insurance and loans, as identified by the Ending Discrimination Against Cancer Survivors initiative (27).

Table 2: National Cancer Survivorship and Quality-of-Life Frameworks: A High-Level Comparison

Country	QoL policy embedded as a section of the NCCP	NCCP Index on supportive and palliative care	Right to Be Forgotten legislation
Austria	🟨	78%	✗
Belgium	N/A[1]	N/A[2]	✓
Bulgaria	✓	N/A[2]	✗
Croatia	✓	78%	✗
Cyprus	🟨	56%	✓
Czechia	✓	78%	🟨[3]

Country	QoL policy embedded as a section of the NCCP	NCCP Index on supportive and palliative care	Right to Be Forgotten legislation
Denmark	✓	78%	🟨[3]
Estonia	✓	89%	✗
Finland	✓	33%	✗
France	✓	78%	✓
Germany	✓	N/A[2]	✗
Greece	N/A[1]	N/A[2]	🟨[3]
Hungary	✓	N/A[2]	✗
Iceland	✓	89%	✗
Ireland	✓	89%	🟨[3]
Italy	✓	N/A[2]	✓
Latvia	✓	67%	✗
Lithuania	✓	67%	✗
Luxembourg	🟨	56%	✓
Malta	✓	N/A[2]	✗
Netherlands	✓	N/A[2]	✓
Norway	✓	89%	✗
Poland	✓	78%	✗
Portugal	✓	78%	✓
Romania	✓	22%	✓
Slovakia	🟨	67%	✗
Slovenia	✓	56%	✓
Spain	✓	56%	✓
Sweden	✓	N/A[2]	✗

✓ - implemented; ✗ - not implemented; 🟨 - incomplete implementation; N/A - Not applicable; [1] - NCCP currently under development; [2] - NCCP not presently reviewed by the International Cancer Control Partnership; [3] - Code of conduct (self-regulated, not legally binding)

With regard to **survivorship and quality-of-life policies**, there is considerable variation in how these are integrated within national plans. Some countries embed survivorship and QoL as dedicated sections, while others only address them in a limited manner or not at all.

Furthermore, there are wide disparities in the quality of such integration, with some countries (Estonia, Iceland, Ireland, Norway) demonstrating comprehensive addressing of supportive and palliative care, whilst others (Romania, Finland) only provide partial consideration.

The adoption of the **Right to Be Forgotten** for cancer survivors is progressing but remains uneven. Only nine EU Member States (France, Spain, Belgium, Cyprus, Portugal, the Netherlands, Italy, Romania, Slovenia) have established a binding legal framework. Other European countries have yet to introduce this protection, creating significant disparities across the region.

This assessment clearly shows the need for progress and alignment of national cancer policy frameworks when it comes to survivorship and quality-of-life, in order to deliver on the European vision of equal access to patient-centred care and support for all those affected by cancer across Europe. Sustained EU-level political momentum and collaborative initiatives will be crucial in this respect. Importantly, national cancer policy landscapes are however highly dynamic, with a number of national cancer control plans being currently under development or revision (e.g. Finland, Belgium, Sweden, Greece), offering the promise of increasing alignment with Europe's Beating Cancer Plan in the field of survivorship and quality-of-life.

II. Building Capacity: Enhancing Infrastructure and Workforce Development

The successful delivery of survivorship and quality-of-life patient-centred cancer care involves the collaboration of a range of clinical and non-clinical specialties and disciplines, including supportive care, pain management, psycho-oncology, nutrition, sexual health and social support, as well as the seamless integration with primary and community-level care settings and the adequate management of potential comorbidities and complications.

In this respect, a set of requirements may be identified from national health systems:

- Access to relevant **health system infrastructure and specialised services**;
- Availability of **adequately trained workforce** and associated professional recognition;
- **Organisation of survivorship and quality-of-life care** through the development and effective implementation of adequate multidisciplinary guidelines and care frameworks, such as long-term follow-up care plans;
- Relevant **data collection and analysis systems**, with a focus on patient-reported outcome measures (PROMs) and patient-reported experience measure (PREMs) enabling measurement of overall quality-of-life and specific quality-of-life issues.

In spite of past EU-level collaborative efforts and guidelines in the field, national implementation and effective deployment of these requirements remains unequal and no comprehensive mapping of the current status is available in most cases.
In this context and based on readily available information, this section will explore the status of European countries in respect to:

- The use of PROMs and PREMs in cancer care;
- Interventions, infrastructures and initiatives in psycho-oncology across Europe;
- The distribution of palliative care services, as well as the availability of related medicines, and the related education and training frameworks.

II. 1. Experiences, Outcomes and the Supportive Infrastructure

One of the most practical ways to assess the quality-of-life status of people living with and beyond cancer is through the collection of PROMs and PREMs. On the clinical side, these measures allow to place the patient voice at the centre of care, tracking whether health and care interventions are truly effective in optimising their quality-of-life, and what adjustments in the care plan may be required. On the policy side, they provide health systems with the evidence required to improve services, identifying where infrastructure is underdeveloped, guiding the design of better care pathways, and pointing to workforce and training gaps. In this way, measurement becomes more than a monitoring exercise: it is a tool for driving change, strengthening survivorship care across Europe, and ultimately improving all those affected by cancer.

On this basis, the table below maps the adoption and usage of PROMs and PREMs in cancer care across EU Member States, Iceland, and Norway, based on data from OECD Country Profiles 2025 (4). It highlights national practices for assessing patients' quality-of-life and care experiences, providing insight into how countries integrate patient perspectives into policy and service delivery.

Table 3: Use of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) in Cancer Care across Europe

Country	PROMs and PREMs usage
Austria	• Piloting electronic PRO collection in cancer care, including recall systems for follow-up. • Participates in EU eSMART Project evaluating benefits of electronic PRO systems.
Belgium	• Belgian Cancer Registry collects patient-reported indicators alongside epidemiological and clinical data.
Bulgaria	• Some private hospitals collect patient satisfaction data influencing management decisions. • Rarely done in public hospitals and not mandatory.
Croatia	• Uses PROs in European Health Survey to monitor quality-of-life of cancer patients in primary care.
Cyprus	• Facilities collect self-completed PROM/PREM questionnaires, but systematic national approach lacking.
Czechia	• National Oncology Registry does not include PROMs or PREMs.
Denmark	• National and regional PROM/PREM collection, plus cancer-specific databases with annual reports. • Biannual Barometer Survey measures patient-reported care quality.
Estonia	• Legal requirement for patient experience surveys; several PROMs pilots for breast and lung cancer. • No centralised national PROM/PREM system yet; Cancer Control Plan 2021–30 aims to address this.
Finland	• PROMs collected electronically at Helsinki University Hospital Comprehensive Cancer Centre. • Cancer Registry includes quality-of-life indicators.
France	• Multidisciplinary care approach includes systematic needs assessments.
Germany	• Federal Joint Committee developing patient surveys; existing initiatives for specific cancers (e.g., breast surgery).
Greece	• PROM/PREM data collection not systematic; mostly ad hoc academic or clinical projects.
Hungary	• PROM/PREM collection for cancer care remains underdeveloped.
Iceland	• PREMs collected in 2020–21; plans for systematic PROM/PREM collection in Cancer Registry.
Ireland	• Annual National Inpatient Experience Survey includes cancer patients. • Developing specific Cancer Patient Experience Survey tool (2024).
Italy	• National Cancer Plan 2022–27 aims to expand PROM/PREM use; local initiatives in Tuscany for breast cancer interventions.

Country	PROMs and PREMs usage
Latvia	• Surveys patient experiences (e.g., Green Corridor pathway); limited PROM use and monitoring.
Lithuania	• PROM/PREM pilots integrated into national e-Health system.
Luxembourg	• Cancer Programme 2023 assessing PROMs; mandatory PROM collection for breast cancer piloted in all hospitals. • Colive Cancer study uses online patient feedback and QoL monitoring.
Malta	• Cancer Registry lacks PROM/PREM data; intention to integrate such data but limited research capacity.
Netherlands	• Strong PROM use in cancer networks; breast cancer PROM project produced tools, training, and aftercare protocols.
Norway	• 12 national cancer quality registries include genomic, clinical, PROM, and PREM data for multiple cancer types.
Poland	• National Cancer Registry collects quality of care data (extent unspecified).
Portugal	• Advocates PROM/PREM use for screening; national breast cancer PROM initiative launched in 2020 using OECD PaRIS protocol.
Romania	• Cancer outcome data limited in quality, coverage, and use; PROM/PREM reporting rare.
Slovakia	• Participates in EUonQoL Project to develop standardised cancer quality-of-life questionnaire.
Slovenia	• PREMs monitored nationally via e-Health portal; PROM digitalisation underway for clinical use. • Planning national PROM implementation in oncology under Value-Based Healthcare initiative.
Spain	• No national PROM/PREM use; regional breast cancer initiatives collect PROMs on satisfaction, emotional and social functioning.
Sweden	• National cancer registries and over 30 clinical registries include PROM/PREM data. • Standardised national PROM forms available for cancer care follow-up.

There is wide variation in the collection and use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) across Europe:

- A small group of countries, such as Denmark, Sweden, Norway, the Netherlands, and Luxembourg, have **integrated PROMs and PREMs into national cancer registries or quality programmes**, often with electronic collection and feedback systems.

- Several others, including Austria, Finland, Portugal, Slovenia, and Italy, have established promising regional or disease-specific initiatives and are **moving towards broader implementation**.

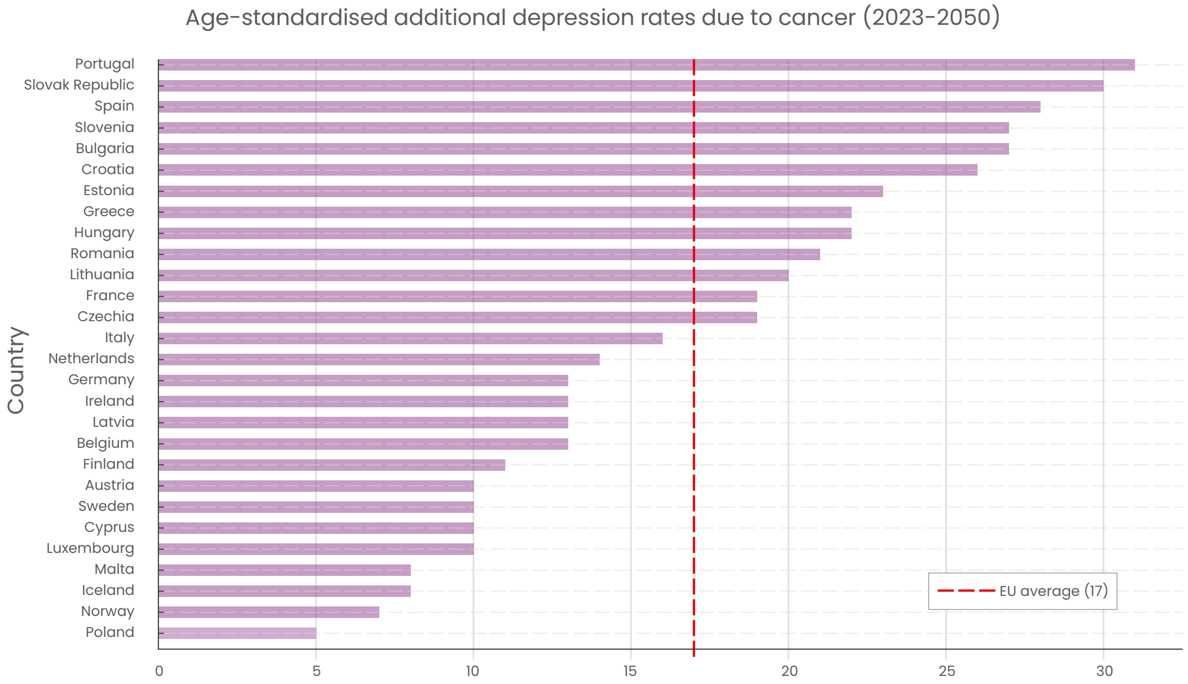
- In contrast, **many countries, particularly in Eastern and Southern Europe, collect patient-reported data only sporadically or in pilot projects, with limited national coordination, infrastructure, or use of the data for quality improvement**.

This patchwork approach risks widening disparities in patient-centred cancer care, as robust PROM/PREM systems are closely linked to quality monitoring, service improvement, and value-based healthcare. Leveraging ongoing flagship EU-level initiatives in the field, such as the EUonQoL project, will be important to address these gaps and utilise the full potential for PROMs and PREMs for the reorientation of health systems towards quality-of-life for all.

II. 2. Interventions, Infrastructures and Initiatives in Psycho-oncology Across Europe

Psycho-oncology, as a specialised healthcare intervention investigating and treating the psychological and social effects of cancer on patients and their families, is a crucial component of patient-centred quality-of-life cancer care. Mental health impacts of the cancer journey are indeed large-ranging, with on average an additional 17 cases per 100,000 people per year across Europe. Interestingly, this burden varies significantly across countries, from roughly 5 per 100,000 people per year in Poland to 31 per 100,000 people in Portugal (see Figure 8 below).

Figure 8: Additional depression rates due to cancer 2023-2050 (OECD SPheP modelling) (4)



In assessing psycho-oncological interventions and infrastructures across Europe, it becomes clear that countries differ not only in levels of need, but also in their ability to measure and respond to that need. **Countries with robust data collection systems and active use of PROMs and PREMs, such as the Netherlands, Germany, and the Nordic countries, are better positioned to design care pathways and allocate resources effectively**. These health systems have invested in dedicated psycho-oncology services and training programmes, making psychological care an expected component of oncology rather than an afterthought. **France, the Netherlands, Denmark, Norway and Ireland** stand out in the race to the top.

- **France** has arguably the most codified model. Supportive oncology care has been part of the standard pathway since 2017 and was strengthened by the 2021–2030 Cancer Strategy. Every authorised provider must assess needs systematically and offer a nine-service supportive package (core: pain, dietetics, psychology, social/professional support; plus physical activity, fertility, sexual health, lifestyle advice, and support for relatives). Post-cancer assessments and reimbursed consultations create financial levers that many countries lack. France's depression burden (19) sits slightly above the EU average, but the policy architecture is mature and comprehensive.

- **The Netherlands** combines strong services with data infrastructure. IKNL's PROMs systems track quality-of-life at scale, and there is a national AYA network with person-centred care pathways. The burden (14) is below EU average, suggesting reasonable alignment between need and capacity.

- **Denmark** operationalises access simply: up to 12 psychologist sessions (with partial copayment) via GP referral, plus a well-resourced cancer society offering counselling and drop-in centres nationwide. That mix of statutory and civil-society provision is pragmatic and scalable.

Other relevant models can be highlighted: **Iceland** (integrated, multilingual counselling and structured peer support; low burden at 8) and **Cyprus** (holistic centre staffing and survivorship education; burden 10).

A second group of countries has developed important initiatives or regional programmes, but without the same consistency or national-level integration: **Austria, Germany, Finland, Sweden, Luxembourg, Latvia and Poland**. Here, services may depend on individual institutions, project-based funding, or local champions. Patients may benefit from good access in some regions, but face significant gaps in others, and the workforce often lacks the scale or specialised training required to meet growing demand.

Finally, a number of countries face a dual challenge: high psychosocial burden, as reflected in elevated depression rates among people with cancer, combined with limited or fragmented psycho-oncological infrastructure. In these settings, the absence of systematic monitoring means that unmet needs remain largely invisible in health policy, and the workforce is often too small or insufficiently trained to provide comprehensive support. **These countries (Portugal, Slovak Republic, Spain, Slovenia, Bulgaria, Greece, Hungary, Estonia, Romania, Lithuania) represent the areas where urgent investment and capacity-building are most needed**.

Altogether, this landscape underscores the ongoing underinvestment in psychosocial and mental health services in many countries. Many health systems remain predominantly biomedical, falling short of the biopsychosocial approach and the expectation from all those with lived cancer experience for adequate support on their mental health needs. Moving forward, opportunities for best practice sharing between European countries should be leveraged in order to advance the equitable provision of psycho-oncology across Europe.

II. 3. Palliative Care Services

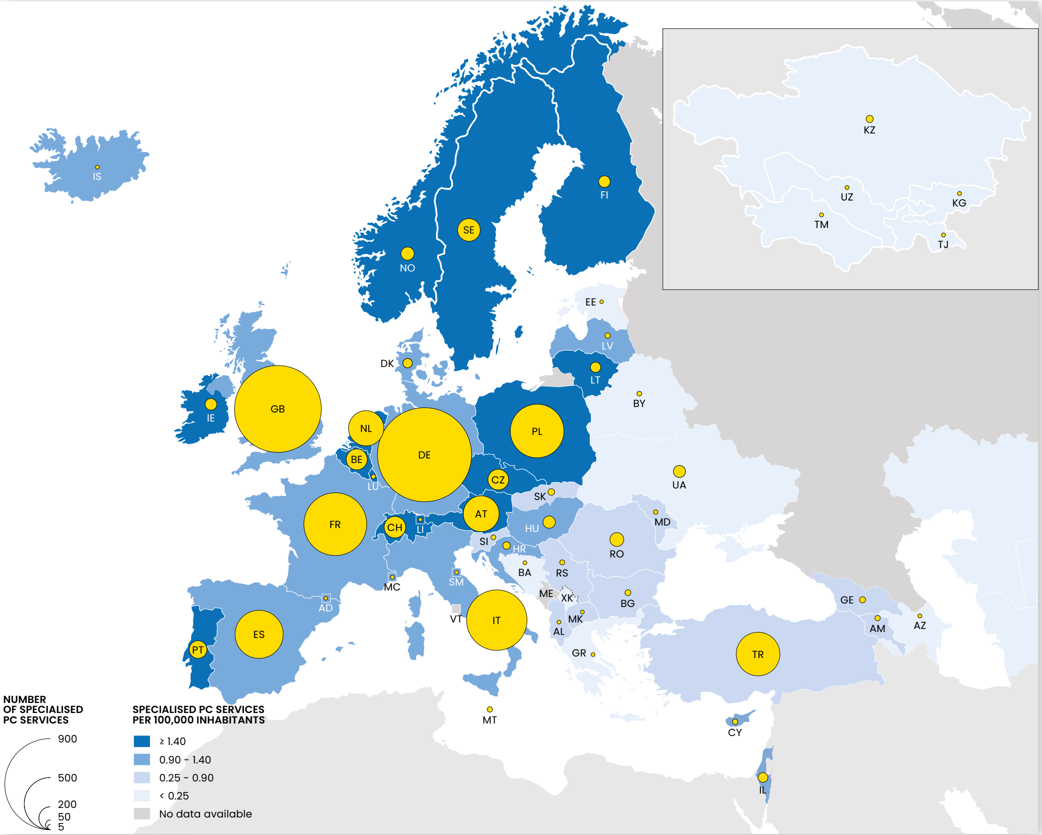
Palliative care (PC) is a vital part of **universal health coverage (UHC)**, aiming to ease suffering and improve quality-of-life. An estimated **4,279,278 people annually in Europe**, including 66,114 children, require palliative care. With cancer being among the most predominant life-threatening illnesses, the application of PC in the oncology field is a critical component of patient-centred cancer care.

Its status across European countries may be assessed through:

- The density of specialised palliative care services, as established by the 2025 Atlas of Palliative Care (Figure 9) (50);

- The overall infrastructure for palliative care, across the dimensions of relevant health policies, availability of essential medicines, education and research and specialised services, as defined by the WHO (51).

Figure 9: Specialised palliative care services across Europe (50)



Countries exceeding or nearing the 2010 EAPC standard of 2 specialised services per 100,000 inhabitants include Austria (3.68), Lithuania (2.51), Sweden (1.89), the Netherlands (1.85), Norway (1.82), Czech Republic (1.68), Ireland (1.63), Belgium (1.54), Finland (1.52), and Luxembourg (1.50).

- Austria stands out for its integrated provision of specialised PC for both adults (296 services) and children (38 services), with a total of 336 services.
- Nations recognized for advanced and systematically provided paediatric palliative care services include Denmark, France, Germany, Ireland, Latvia, the Netherlands, Norway, Poland, and Slovakia.
- High opioid consumption indicates good access in countries like Austria (19,773), Germany (15,252), and the Netherlands (15,074).

Several countries show minimal or very low provision of specialised palliative care services per 100,000 inhabitants. These include Greece (0.04), Estonia (0.22), Bulgaria (0.39), Slovenia (0.47), Romania (0.56), Slovakia (0.64), and Malta (0.72).

Health Policies

In the **EU Member States, Iceland and Norway**, palliative care is recognized in the list of health services provided at the primary care level, either through the General Health Law or government decree/law. However, only **10** of these countries have a well-defined and structured national coordinating authority for PC (scientific and technical) within their Ministry of Health: **Austria, France, Germany, Italy, Luxembourg, Netherlands, Poland, Portugal, Slovakia, and Switzerland**.

Essential Medicines

Based on data for the EU27+2 region, **23 countries reported very good availability** (in over 70% of primary healthcare centres) of **Immediate Release Oral Morphine (IR OM)**.

However, availability is lower in several EU27+2 nations, including **Bulgaria, Cyprus, Latvia, Romania, Slovenia, Italy, and Malta**. For example, in **Bulgaria**, only parenteral forms of morphine are reported as generally available.

Education and Research

Palliative care education is reported as mandatory for all medical students in 5 of the EU27+2 countries (**Estonia, Finland, Ireland, Lithuania, and Luxembourg**).

Palliative medicine is recognized as a specialty or subspecialty (or equivalent denomination) by competent national authorities in 15 EU27+2 countries: **Austria, Czech Republic, France, Germany, Hungary, Ireland, Italy, Latvia, Malta, Poland, Portugal, Romania, Slovakia, Sweden, and Switzerland**.

Specific national research calls dedicated to PC exist in four EU27+2 nations: **Germany, Ireland, Netherlands, Portugal, and Switzerland**.

Specialised Services

Only **13 countries reported an integrated system** of specialised palliative care services provided systematically nationwide: **Austria, Belgium, Denmark, France, Germany, Ireland, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, and Sweden**. For paediatric palliative care, advanced integration (systematically provided services) was reported by merely **nine nations**.

However, the integration and accessibility of PC within European healthcare systems are **inconsistent**. Despite a 2014 World Health Assembly resolution advocating for better access, many individuals, especially in lower-income European countries, still lack adequate care. The provision of PC to the roughly 750 million people in the WHO European Region shows **considerable diversity** in access, quality, and integration into national health systems, with limitations in service, essential medicine access, and education persisting, often correlating with countries' income levels and geographic distribution. These discrepancies are therefore significantly **contributing to inequalities in cancer control** across Europe, and specifically in respect to quality-of-life.

These significant regional and sub-regional variations highlight the ongoing need for targeted strategies to achieve equitable and comprehensive palliative care across Europe, emphasizing health policies, service provision, medicine access, research, education, and community empowerment.

The preceding sections examined both the political ambition underpinning survivorship and quality-of-life policies, and the realities of their implementation at Member State level. The scientific evidence and guidelines are available, and many tools and resources are accessible. The gap currently lies in consistent application, as they are often overlooked in daily practice, content rarely translating into systematic action. What emerges is the need for a systemic response, one that provides the means to deliver a genuine paradigm shift.

Recognising survivorship and quality-of-life as a political and clinical priority is now an imperative.

Securing the Future: Prioritising and Investing in Survivorship and Quality of Life Beyond 2027

Europe's Beating Cancer Plan (EBCP) and Europe's Cancer Mission represent a concrete momentum in cancer prevention, detection, and treatment. However, as analysed in the previous section, its ambitions in survivorship and quality-of-life remain incomplete as the EU looks toward the next Multiannual Financial Framework (MFF) cycle (2028–2034). As the population of cancer survivors grows, exceeding 20 million - so does the urgency to fill the current policy and implementation gaps.

Europeans living with and beyond cancer require structured and organised prehabilitation where needed, follow-up programmes, nutritional support, psychological care and social assistance, not occasional and reactive advice. Validated tools such as distress thermometers, late effects checklists and functional assessments should be routinely deployed. Survivorship assessments and follow up must be integrated into clinical pathways, scheduled and reimbursed as standard practice.

I. Shaping Tomorrow's Survivorship and Quality-of-Life Priorities

Certain critical themes explored below have not been sufficiently addressed within the current policy framework, despite clear evidence and urgent need.

These unaddressed or under-addressed dimensions – discussed below - reveal deeper inequities in access, patient experience, and long-term outcomes across Member States. The need for sustained policy prioritisation, dedicated funding in the next MFF is clear: without it, EU cancer policy risks losing touch with the everyday realities of people affected by cancer.

I. 1. Beyond Treatment: Advocating for Better Patient-Centred Care

I. 1. 1. Primary Care

Primary care is a cornerstone for maintaining and improving quality-of-life for people affected by cancer, particularly after the active treatment phase. **General practitioners (GPs) – or equivalent - are often the healthcare professionals closest to patients and their communities**, placing them in a unique position to monitor for recurrence, manage long-term side effects, and address comorbidities.

Beyond medical surveillance, primary care also plays a crucial role in health promotion. GPs can bridge the gap between specialised cancer services and broader social or psychological support, coordinating care across multiple providers and ensuring that survivors' holistic needs are addressed. Nursing personnel can also serve as "navigators" throughout the patient journey, coordinating care, facilitating communication, and helping survivors access psychosocial and community resources to address their holistic needs.

Despite this potential, **integration of primary care into cancer survivorship pathways remains limited in many settings**. Communication between oncology specialists and GPs is often fragmented, **and primary care teams may lack the resources, training, or structured pathways needed to fully support survivors**. Strengthening the role of primary care, therefore, is essential for enhancing quality-of-life, reducing gaps in post-treatment support, and promoting more equitable and patient-centred survivorship care.

I. 1. 2. Supportive Care

> *'The integration of supportive care within European cancer policy is not optional, it is fundamental to delivering value-based, sustainable cancer care. As the leading international society advancing supportive care in cancer, the Multinational Association of Supportive Care in Cancer (MASCC) calls for supportive care to be recognised as a pillar of comprehensive cancer control. Embedding it in European policy frameworks will mitigate and alleviate the negative effects of cancer and its treatment, reduce disparities, strengthen system resilience, and ensure that every person with cancer receives care that addresses both survival and wellbeing* (52).*'* **Multinational Association of Supportive Care in Cancer (MASCC)**

MASCC™ MULTINATIONAL ASSOCIATION OF SUPPORTIVE CARE IN CANCER

Supportive care in cancer, as defined by the Multinational Association of Supportive Care in Cancer (MASCC), encompasses the prevention and management of the adverse effects of cancer and its treatment, extending across the continuum of care - from diagnosis to survivorship and end-of-life -. Complementary to curative treatment, it for instance includes the management of physical and psychological symptoms, side effects, and toxicities, as well as interventions to maintain optimal function, dignity, and quality-of-life for patients and their families .

Supportive care remains a missing pillar in EU cancer policy (53). While treatment and screening dominate current frameworks, the absence of systematic investment in supportive care undermines equity and health system efficiency across Member States.

At present, national approaches to supportive care are fragmented, with services ranging from psycho-oncology and nutrition to rehabilitation and survivorship care depending on local capacity, rather than shared EU standards. This patchwork model entrenches inequalities, disproportionately affecting patients in lower-resourced regions. Without EU-level leadership, short-term and long-term supportive care will remain peripheral, despite clear evidence of its impact on reducing hospitalisations, improving adherence to treatment, and enabling return to work.

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends to:

1. **Embed supportive care as a formal priority** in Europe's next cancer agenda, with specific funding streams under the EU4Health Programme and Horizon Europe;
2. **Mandate integration of supportive care services in all Comprehensive Cancer Centres**, ensuring minimum quality standards and cross-border comparability;
3. **Develop EU-wide indicators and patient-reported outcome measures** to benchmark supportive care delivery and hold systems accountable for quality-of-life;
4. **Invest in workforce development** by supporting EU-level curricula and accreditation in supportive care disciplines, aligned with initiatives such as INTERACT-EUROPE 100;
5. **Leverage a smart use of digital tools to meet preferences, needs and abilities**, supported by EU data infrastructure, to ensure continuous, accessible supportive care irrespective of geography.

Failure to implement such breakthroughs risks embedding a two-tier cancer care system, where survival is possible, but recovery, dignity, and equity remain out of reach.

I. 1. 3. Palliative Care

> *'Palliative care is not a luxury 'add-on' - it is a fundamental part of cancer care. Across Europe, too many people are still denied the right to live well with serious illness because of inequities in access. Our aim is clear: to ensure that every person diagnosed with cancer has timely access to quality palliative care. By embedding palliative care into cancer strategies, we can close the equity gaps, reduce unnecessary suffering, and enable people to live – and die – with dignity.'*
> **European Association of Palliative Care – EAPC**

The World Health Organisation defines palliative care *'as an approach that improves the quality-of-life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual'*(54).

Access to palliative care for adults with **cancer must be better positioned as a vital pillar within cancer funding and European health policy**. The 2004 National Institute for Clinical Excellence (NICE) guidance established a holistic template, calling for the integration of supportive and palliative services from the moment of diagnosis, irrespective of social status. The objective is to ensure patients and their families receive the information, care, and psychosocial support they require.

The European Association of Palliative Care (EAPC)'s guidelines further underscore that **high-quality palliative care is a matter of equality, dignity, human rights, demanding availability across all settings, delivered by trained multidisciplinary teams** (55). Early integration of palliative care for instance alleviates suffering and pain, addresses both physical and psychosocial needs, and supports patient autonomy, ultimately enhancing quality-of-life. Robust evidence shows that the early use of specialist palliative care results in improved symptom control, psychological well-being, and satisfaction with care, while simultaneously reducing inefficiencies and costs within hospitals and health systems (56).

As analysed in the above section on national implementation (II.2), palliative care is highly fragmented in the European Union. Nonetheless, there are ways to improve end-of-life care - The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Ensuring systematic **early referral to palliative care**;
2. Guaranteeing **access to palliative care** regardless of diagnosis, setting, or socioeconomic status;
3. Implementing **the routine use of patient-reported outcomes**;
4. Encouraging **community-based and home-care palliative services to be adequately resourced**, recognising that most patients wish to remain at home where possible.

Integrating these asks into European cancer policy will ensure that palliative care is not an afterthought but a core element of person-centred, sustainable, and just cancer care for all.

I. 2. Addressing the Long-Term Impact and Symptoms of Cancer

I. 2. 1. At the Physical Level

Nutrition and Clinical Nutrition

> *'The landscape of cancer is rapidly shifting to that of a chronic and disabling disease. In this context, preserving and restoring physical function is key to protect patients' autonomy and therefore their quality-of-life. Nutrition, i.e., the science studying the impact of nutrients on protecting or facilitating recovery of nutritional status, body's integrity and functionality, is key in developing approaches aiming at enhancing quality-of-life, as well as reducing the risk of reoccurrence and development of other chronic diseases, particularly in adolescent and young adults.'* **The European Society for Clinical Nutrition & Metabolism - ESPEN**

ESPEN
The European Society for Clinical Nutrition and Metabolism

Cancer-related malnutrition is one of the most pressing **but persistently undervalued facets of cancer survivorship policy in Europe**. Up to 70% of cancer patients experience malnutrition, but fewer than one in three receive the nutritional support they need(45). This reality prompted the 2022 European Parliament's Special Committee for Beating Cancer (BECA) to draft a resolution **explicitly urging EU Member States to incorporate clinical nutrition into all facets of cancer care**. WHO Europe has also issued a call for urgent policy change to tackle this underrecognized issue. Yet, despite compelling scientific evidence, the EU's approach to survivorship within Europe's Beating Cancer Plan has, so far, has not fully integrated nutrition as a core element of long-term recovery and quality-of-life.

For cancer survivors, proper nutrition is not a matter of lifestyle, but a medical necessity. The physical and psychological toll of cancer and its treatments can result in involuntary weight loss, diminished muscle strength, and compromised immune function. These consequences exacerbate fatigue, delay healing, and may limit a patient's ability to complete recommended treatments or return to daily life. Systematic identification and management of nutritional risk can only lead to better outcomes: such as better treatment tolerance, shorter hospital stays, and overall enhanced quality-of-life.

Solutions exist but are underutilised. Nutritional care, that includes medical nutrition, is proven to support patient outcomes. Patients have more strength and energy, feel better, and equipped to fight diseases and the physically demanding treatment. Research also demonstrates that addressing malnutrition with medical nutrition can substantially contribute to cost savings within our healthcare systems (58). Yet, most still lack systematic training or mandates to screen for malnutrition, and many patients never receive even basic nutritional advice.

However, these proven benefits are not matched by policy or funding, falling short of meeting the needs of millions of cancer patients and survivors across EU Member States. Access to professional dietetic counselling is fragmented: it too often depends on geographic luck, cancer centres' resources, and financial capacity to handle out-of-pocket expenses. This leads to deep health inequalities: **the socioeconomically vulnerable, or those with complex co-morbidities face the steepest barriers to accessing the nutritional interventions vital to their health and dignity**.

Moreover, **most healthcare teams still lack systematic training or mandates to screen for malnutrition**. Every patient should receive regular and structured nutritional assessments from the point of diagnosis. Despite this, a significant share of patients does not receive even basic advice, and transitions between oncology and primary care often leave nutrition entirely unaddressed.

Few Member States support scalable, digital, or blended models to make professional support universal. By investing in digital platforms and remote monitoring, this approach could yield savings by decreasing complications. For instance, nutrition formed an integral part of the smartCARE project, co-funded by the European Union (see I.1.1), paving the way for future digital innovation – only accessible through dedicated EU funding.

To address these gaps, and in line with the Parliament's BECA report and the WHO Europe call, the 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Systematically **screening and monitoring** cancer patients for malnutrition to provide timely nutritional care;
2. **Implementing existing clinical nutrition guidelines** for patients with cancer;
3. Providing **equal access to and reimbursement** of medical nutrition;
4. Ensuring multidisciplinary oncology teams **include dietitians or registered nutritionists**;
5. **Educating healthcare professionals and patient advocates** on the importance of nutritional care, and inform patients about the role of nutrition in cancer care.

Pain and Pain Management

> *'Cancer-related pain is the most common symptom at diagnosis and persists as a major burden throughout treatment and survivorship. It is time the EU treats pain management as an essential, integrated element of quality cancer care.'* **European Pain Federation – EFIC**

Pain is one of the most pervasive and debilitating consequences of cancer and its treatments. Nonetheless, its place within Europe's Beating Cancer Plan is strikingly marginal – in spite of its profound impact on quality-of-life.

Despite advances elsewhere in oncology, cancer-related pain remains both underrecognized and undertreated, with up to 40% of cancer survivors, and at least 66% of adults with progressive or advanced cancer, experiencing significant pain (59). For many, this pain can become a chronic, life-limiting burden, resulting in sleep disturbance, fatigue, loss of independence, depression, and decreased social participation. Pain is not only a side effect; it can fundamentally limit or halt the benefits of cancer therapies. Poorly managed pain is associated with reduced adherence to treatment, longer hospital stays, increased emergency care, and greater financial toxicity for both families and health systems.

When pain is poorly controlled, survivors' ability to return to work or family life, maintain physical function, or even retain hope for recovery is fundamentally undermined. **Access to pain management still depends heavily on where one lives in the European Union**. In some Member States, specialist pain services are scarce, drugs access is restricted or misunderstood, psychosocial services are lacking, and clinical staff may not have the knowledge, skills or time to address complex pain syndromes. **In others, access to strong opioids us restricted due to regulatory barriers, leading to undertreatment.**

The complexity of cancer pain demands a coordinated, holistic approach across the care continuum. This is precisely the standard set out by the European Pain Federation (EFIC), which have called for a multi-modal, multidisciplinary, and biopsychosocial framework for cancer pain management. Yet, policy translation lags far behind these recommendations. Too often, cancer pain is addressed as an isolated symptom, **with pathway gaps between oncology, primary care, palliative care, rehabilitation, and psychological support**.

Europe's Beating Cancer Plan made initial advances in recognising the wide burden of survivorship, but pain management still occupies a peripheral role, despite recurrent appeals from patients, professionals, and advocacy groups. As the EU prepares for the next Multiannual Financial Framework, decisive action is needed to embed pain management at the centre of survivorship strategy. This means explicit EU guidance on the integration of pain assessment and control into cancer care at all stages, strong funding for workforce training such as within the Interact program and incentives for cross-sector collaboration (including primary care, oncology, palliative and psycho-oncology services)(60).

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. The EU and Member States should allocate **dedicated and sustainable funding** for research into pain and other causes of distress in cancer and palliative care.
2. Member States should ensure that **systematic pain assessment and management** are integrated into all cancer services and patient pathways as part of **standard reimbursed services**.
3. Healthcare professionals at all levels should receive **comprehensive education and training** in pain assessment, management, and palliative care principles.

(Source: SIP position on the importance of addressing cancer-related pain management in Europe's Beating Cancer Plan and beyond, 2020)

Rehabilitation and Physiotherapy

> *'Rehabilitation services should be integrated at the point of cancer diagnosis through to cancer survivorship. Physiotherapeutic interventions offer a solution for many of the impairments experienced by patients living with and beyond cancer, such as declines in physical function and complex cancer-related side effects such as pelvic health dysfunction and lymphoedema.*
> *Physiotherapists also play a central role in providing exercise guidance and programming, an essential component of cancer care.'*
> Cancer Working Group, Europe Region of World Physiotherapy

World Physiotherapy
Europe region

Cancer and its treatments may affect how one feels, is able to move and to think. Cancer rehabilitation encompasses a wide spectrum such as **physiotherapy, occupational therapy, speech therapy and other supportive interventions**, all designed to improve quality-of-life. Evidence shows that comprehensive rehabilitation improves functional outcomes, reduces fatigue, lowers the risk of secondary complications, and facilitates return to work and social participation. It is a direct enabler of resilience and recovery.

The European Code of Cancer Practice states the right of every cancer patient in Europe to "Receive and discuss with your care team a clear, managed and achievable plan for your survivorship and rehabilitation (19). It is notably designed to help relief physical pain and improve overall physical capacities - care plans which include rehabilitation can help to organise care, monitor patient outcomes, facilitate communication within teams and promote adherence to best clinical evidence in order to optimise patients' quality-of-life (61).

Cancer physiotherapy aims to address the physical challenges and impairments that may arise as a result of cancer and its treatment. It is a critical yet under-recognised component of comprehensive cancer management that must be embedded systematically into cancer care pathways. Exercise lowers risk for at least seven major cancers and reduces recurrence risk by 20-40% (62) **Prehabilitation** exercise programmes, implemented after diagnosis and prior to treatments such as surgery, optimise patients' physical and psychological reserves to reduce postoperative complications, shorten hospital stays, and enhance recovery and quality-of-life.

It is also essential to incorporate exercise into patients care during and after treatment to **prevent and manage cancer related impairments** such as fatigue and pain. Many people do not return to baseline levels of physical activity following cancer treatment. It is important all people living with and beyond cancer, including specialist populations such as paediatric patients and those with advanced cancer, can access exercise counselling to maximise treatment tolerance and efficacy as well as patient outcomes.

All national cancer plans should include components to address Return to Work and rehabilitation needs, including the strengthening of primary care, and further actions to better coordinate primary and secondary care.

To maximise cancer survivorship and quality-of-life across Europe, physiotherapy must be recognised and resourced as a standard component of cancer care. The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Immediate **functional assessment and rehabilitation planning** by physiotherapists to accompany cancer diagnosis, shaping personalised care pathways;
2. Integrating physiotherapists as **core members of oncology care teams**, working alongside medical and radiation oncology, nutrition, and psycho-oncology to deliver coordinated, evidence-based interventions.;
3. Cancer rehabilitation services, including physiotherapy, to be **universally accessible** at all treatment and survivorship stages,;
4. Increasing **investment in specialised oncology physiotherapy education** and workforce capacity to meet growing demand;
5. Fostering European-wide research on novel physiotherapy interventions, implementation science, and long-term survivorship outcomes.

Comorbidities and Complications

Many cancer patients live with **pre-existing chronic conditions, such as cardiovascular disease, diabetes, or respiratory illness, which may be exacerbated by cancer symptoms & treatment**. For example, certain chemotherapies and radiotherapies increase the risk of cardiac dysfunction, metabolic disorders, and secondary malignancies. 30-50% or more of cancer survivors also live with one or more chronic conditions beyond cancer, with prevalence depending heavily on cancer type, age, and comorbidity definitions (63).

Moreover, many survivors develop new chronic conditions as they age, often linked to treatment side effects, reduced physical activity, or long-term physiological changes following cancer. These comorbidities can be harder to cope with and present additional challenges for treatment and overall quality-of-life.

Neuropathy, chronic pain, fatigue, and "chemo brain" are among the most frequently reported complications that persist long after active treatment ends. These can limit capacity to return to work, participate in social life, and maintain independence, **thereby reducing overall quality-of-life**. Psychological comorbidities, including anxiety, depression, and post-traumatic stress, further compound the burden, often remaining underdiagnosed and undertreated.

The coexistence of cancer-related complications and other chronic diseases places individuals living with & beyond cancer at high risk of fragmented care and unmet needs. Without integrated, multidisciplinary approaches that include oncology, primary care, and supportive services, these overlapping health challenges risk being managed in isolation.

Addressing comorbidities and complications is therefore central to improving survivorship and quality-of-life, as exemplified earlier in the sub-section dedicated to Smart CARE. It requires systematic follow-up ensuring patients and survivors are not treated solely though the cancer lense, but as individuals with complex, evolving health needs.

ECO identifies opportunities for addressing co-morbidities and complications within the forthcoming EU Cardiovascular Health Plan. The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Fully rolling-out the **smartCARE** project, **integrating the needs of cancer and cardiovascular co-morbidity and cardiovascular complications** of cancer treatment;
2. Including further add-on modules on cardio-oncology related matters within the unique multidisciplinary learning platform created by the **INTERACT-EUROPE 100** project.

I. 2. 2. At the Psycho-Social Level

Sexual Health and Sexual Life

'It is time that the management of sexual problems and side effects caused by cancer treatments, both physical and psychological, becomes an accepted and natural part of quality-of-life considerations. This intimate and still highly stigmatised area deserves equal recognition and appropriate care yet major obstacles remain, including gaps in communication, limited psychological support, lack of long-term follow-up and the inadequate involvement of partners. Now more than ever, there is an urgent need to establish sexual rehabilitation as an integral part of comprehensive cancer care'. **Icó Tóth**, European Society of Gynaecological Oncology (ESGO) - European Network of Gynaecological Cancer Advocacy Groups (ENGAGe), past co-chair, QoL Series project leader, Sexual Health specialists for gynaecological cancers.

ESGO
European Society of Gynaecological Oncology

Research highlights that cancer survivors report markedly poorer sexual health outcomes than the general population (64). Cancer treatments, including surgery, chemotherapy, radiotherapy, and endocrine therapies can trigger anatomical, hormonal, and neurological changes that impair sexual desire, function, and comfort. For women, especially those with gynaecological or breast cancers, common effects include early menopause, vaginal dryness, pain, and changes in body image. Men frequently face erectile dysfunction, particularly after prostate or testicular cancer. These physical changes often combine with psychological distress, anxiety, depression, and altered self-perception, further affecting quality-of-life. These outcomes are preventable and treatable with appropriate interventions.

However, sexual health and sexual life remain systematically overlooked in European cancer survivorship and quality-of-life policies, despite their fundamental role in the well-being and quality-of-life of millions of patients and survivors. The European Cancer Organisation's report *Women and Cancer: More Than 12 Million Reasons for Action* underscores that sexual dysfunction is a prevalent and persistent late effect of cancer treatments, affecting people across all tumour types, genders, and ages. Both the European Society for Sexual Medicine (ESSM) and the European Society of Gynaecological Oncology (ESGO) have consistently emphasised that such issues, ranging from loss of libido and difficulty with arousal, to painful intercourse and diminished sexual confidence, **profoundly affect relationships, body image, and overall quality-of-life**.

Sexual health for instance also remains one of the most overlooked aspects of living with and beyond bladder cancer. The World Bladder Cancer Patient Coalition *Global Bladder Cancer Patient & Carer Survey Report* (65) for instance highlights that nearly half of respondents (45%) reported receiving no counselling before the surgery to remove their bladder about potential sexual side effects, with women being notably less supported than men.

'Bladder cancer care, and indeed care for all cancer patients, must look beyond treatment to the person behind the diagnosis. People must be supported to understand how treatment may affect their sexual health and wellbeing, and be guided through intentional shared decision-making, comprehensive counselling, and ongoing supportive care before, during, and after the active phase of treatment'. **Alex Filicevas**, Executive Director, World Bladder Cancer Patient Coalition.

World Bladder Cancer Patient COALITION

Open communication about sexual health within oncology remains rare, because of limited healthcare professional training, and structural neglect within survivorship care pathways. Sexual health should no longer be seen as an optional or secondary concern (66). **Routine sexual health assessments, transparent information provision for patients and partners, multidisciplinary referral networks, and the integration of specialist sexual counselling and rehabilitative services** throughout the cancer trajectory should also be better funded and integrated. Failure to embed these standards perpetuates inequalities, leaving many survivors without the support they need. There is also pressing need for systematic training of healthcare professionals, inclusion of sexual health metrics in survivorship monitoring, and guaranteed equitable access to sexual medicine and counselling services.

The ‘Next level EU cancer survivorship and quality-of-life’ policy paper recommends:

1. **Developing EU-wide guidelines and quality standards** for the integration of sexual health into oncology and survivorship pathways;
2. **Supporting capacity-building and training programs** for healthcare professionals through cross-border education, Erasmus+ health modules, and EU-funded training curricula;
3. **Mandating the inclusion of sexual health indicators** in EU survivorship monitoring frameworks, ensuring consistent data collection and benchmarking across Member States;
4. **Facilitating best-practice exchange** through European Reference Networks and cancer mission platforms, supporting innovation in sexual health counselling, supportive devices, and partner-inclusive care;
5. **Ensuring equitable access to services** by addressing disparities between and within Member States, particularly in underserved regions.

Distress, Anxiety and Depression

The psychological impact of cancer often persists long after treatment ends, driven by the trauma of diagnosis, side effects, fear of recurrence, social or financial strain. Distress, anxiety, and depression affect a significant number of cancer survivors, **yet cancer policies have not fully incorporated the evidence-based guidelines needed to address these challenges effectively**.

‘Distress during Cancer Care’ and ‘Distress Management’ (2024 Guidelines from the National Comprehensive Cancer Network (NCCN) highlight the importance of continuous psychosocial assessment and interventions tailored to survivors evolving needs. Central to these recommendations is the role of healthcare professionals, as the first line of psychosocial support, which requires sustained training and development.

Many cancer care professionals remain undertrained in psychosocial care, and routine distress screening such as with the Distress Thermometer (67) is uncommon. This gap disproportionately affects vulnerable groups, deepening inequalities and leaving many survivors without critical psychological support. Untreated psychological distress also negatively influences treatment adherence and recovery, potentially increasing caregivers’ burden at home.

As survivorship numbers grow, addressing psychological disorders, anxiety and distress must become a core and thoroughly funded part of cancer care. This can take the shape of mandatory training in communication and distress management for healthcare workers, and the implementation of systematic psychosocial screening following existing guidelines.

Equally important in new frameworks would be the recognition of the value of patient-to-patient support, which helps patients and carers navigate daily challenges, from managing well-being and nutrition to coping with non-clinical aspects of survivorship by sharing experiences, practical tips, and emotional support (65).

Policies and framework along with the crucial role of psycho-oncologists and psychologists should also recognise the role of social workers and community health workers in survivorship care. Their involvement brings support closer to patients’ daily lives, ensures psycho-social needs are met outside hospitals, and helps reduce inequalities in access to care.

The 'Next level EU cancer survivorship and quality-of-life' policy paper recommends:

1. Mandating **routine screening for distress and psychosocial needs**, by recognising distress as the sixth vital sign in cancer care and implement standardised tools such as the Distress Thermometer at diagnosis, during treatment, and follow-up;
2. Implementing **mandatory training for oncology professionals**, ensuring all cancer care providers receive regular training in communication and psychosocial aspects of care to embed emotional and social support into clinical practice;
3. **Integrating psychosocial specialists into multidisciplinary teams**;
4. to provide coordinated, holistic support across hospital and community settings;
5. **Incorporating international standards** (e.g. NCCN Guidelines) on distress management and survivorship care into national cancer plans, ensuring measurable outcomes and accountability;
6. **Guaranteeing access to psychosocial support for all cancer patients**, with targeted investment in underserved populations and innovative delivery models such as telehealth and community-based care.

As we enter the next budgetary cycle, the EU has an opportunity and a responsibility to set a new agenda for survivorship and quality-of-life: one that secures nutritional care as a right; delivers real pain and distress management; integrates robust psychosocial and palliative support; and meaningfully levels up access to supportive and palliative services. Effective policy must not only celebrate more survivors and new treatment options but guarantee that citizens living with and beyond cancer are guaranteed dignity and inclusion.

Towards a European Cancer Survivorship and Quality-of-Life Charter

For Europe's Beating Cancer Plan and the Cancer Mission to achieve lasting impact, commitments must translate into action. The success of cancer screening should serve as a model, showing how Council recommendations, supported by monitoring and collaboration, can drive tangible improvements. Adopting a comparable approach is now imperative to advance survivorship and quality-of-life across Europe.

In this context, the European Cancer Organisation aims to launch a **European Cancer Survivorship & Quality-of-life Charter** in 2026, on **National Cancer Survivor Day**, with the ambition of providing a unifying framework to guide action and enhance accountability across Europe.

I. A commentary on System Incentives

The preceding sections of this paper have amply demonstrated the welcome, **yet still nascent, EU level response to cancer survivorship and quality-of-life needs**. While expert led, evidence-based tools now exist to address key needs in the field, including quality-of-life assessment, return to work guidance, and psychosocial support, their full potential remains underutilised in practice.

So why are these tools not being widely taken up in every national country?

The Survivorship and Quality-of-life Network Paper argues that this inertia is largely driven by **misaligned system incentives and insufficient accountability mechanisms**. Too often national systems are responsive to dominant performance metrics such as survival rates, while being unresponsive to long-term outcomes and quality-of-life, which represent far more than survival rates alone. In other words, the political accolade is available for the duration that a cancer patient survives but not how the patient survives or how well the patient experiences treatment and care. Routine data collection and publication fail to adequately convey a picture to the public and politicians on the national response to survivorship and quality-of-life needs. All too often, it is not possible to assess such matters as:

- Number of cancer patients unable to return to work;
- Labour productivity loss and labour force participation rate;
- Level of disability induced as a result of cancer diagnosis and treatment;
- Reported discrimination experienced by cancer patients and survivors;
- Levels of pain, nutritional status, distress and anxiety – that could be routinely screened;
- Broader psychosocial impacts, including trauma, fear of recurrence or progression, depression, anxiety, cognitive impairments, and disruptions to family or social life, emphasising the need for systematic assessment and access to psychological support;
- Unmet reproductive and sexual health needs induced by cancer diagnosis and treatment;
- Adverse events and reactions suffered by patients as a result of cancer diagnosis and treatment and in the long-term aftermath of cancer treatment.

Without more open accountability for these metrics, it is too likely that national health systems will remain unresponsive to these growing needs of the rising numbers of cancer survivors.

Kaplan and Norton, creators of the Balanced Scorecard approach to system management, advised *"If you can't measure it, you can't manage it. If you can't manage it, you can't improve it."*

The Survivorship & Quality-of-life Network Paper highlights that meeting Europe's cancer survivorship and quality-of-life **needs requires a fundamental shift in how health, social care and other related systems recognise and respond to these often-overlooked - but measurable issues**.

With the advance of patient reported outcome measures, the building of a new European Health Data Space, and even the promotion of and EU Competitiveness Agenda, the means and motivation can be summoned.

We call for "a Balanced Scorecard approach" to the quality of cancer care delivered in Europe, in which metrics on survivorship and quality-of-life feature just as prominently as other metrics such as cancer incidence and cancer survival rates.

II. Policy Recommendations

To address the survivorship and quality-of-life needs of people living with and beyond cancer and their carers and families, it is recommended that EU institutions:

1. **Ensure continuity and legacy of the EU's cancer policy framework post-2027;**

2. Embed cancer survivorship and quality-of-life investment in the next EU Multi-annual Financial Framework for 2028-2034;

3. Establish a coordinating mechanism for EU cancer research action, such as in the form of a **European Cancer Institute**, with a broad mandate including addressing gaps in survivorship research and related implementation research, while also pursuing other missions, to ensure cancer survivorship and quality-of-life remain a sustained European priority;

4. Develop and adopt **EU Council recommendations on quality-of-life in cancer systems**, with a focus on practical, measurable goals:

    - *Encouraging Member States to include screening for distress and quality-of-life assessments for people affected by cancer - patients, survivors, caregivers, and bereaved individuals - in national health surveys.*

    - *Promoting survivorship assessment and care planning in line with clinical guidelines and quality cancer care recommendations*

    - *Setting up regular EU reporting, tracking progress and supporting implementation*

    - *Commissioning JRC guidelines on quality-of-life services for those living with and beyond cancer, aligned with Council recommendations*

    - *Embedding quality-of-life in national cancer care quality assurance frameworks*

    - *Promoting further development of quality-of-life measurement and collection of patient reported outcomes measurements;*

5. Maintain and strengthen **binding legislative momentum at national and EU level** to protect cancer survivors from unfair financial discrimination and implement a Right to Be Forgotten, ensuring that existing and future laws are fully implemented and enforced across Member States;

6. **Conduct studies on the economic impact of sub-optimal support for quality-of-life** in cancer systems, mobilising existing quality-of-life measurement tools to inform policy and investment decisions;

7. Increase activities to **heighten employer awareness across Europe of good practices and legal obligations to support the Return-to-Work needs of cancer survivors**, and utilise any future updates to EU employment directives to support progress in this policy area;

8. Maintain and further develop established cancer survivorship tools and initiatives - such as **the Cancer Survivor Smartcard App ('SmartCARE'), the EUonQoL measurement tool, and the INTERACT-EUROPE 100 inter-specialty training programme**. Such initiatives could also provide an important template of response to other disease areas such as cardiovascular disease.

To address the needs of people with and beyond cancer, is recommended that EU Member States:

9. Guarantee that all people living with and beyond cancer receive **personalised long-term survivorship follow-up care plans and quality-of-life assessments**, supported by trained professionals and monitored for access and impact;
10. Promote **collection of Patient-Reported Outcome Measures as well as measurement of quality-of-life** across cancer care services, using standardised tools such as the EUonQoL questionnaires;
11. **Ensure all National Cancer Control Plans include a survivorship and quality-of-life pillar**, mirroring Europe's Beating Cancer Plan;
12. **Mandate inter-specialty cancer training** that fosters collaboration across healthcare teams, highlighting the essential roles of supportive forms of care such as palliative care, psycho-oncology, pain medicine, sexual medicine, and nutritional care in safeguarding patients' quality-of-life.

Europe possesses the knowledge, tools, and resources necessary to ensure that people living with and beyond cancer enjoy the highest possible quality-of-life. The challenge lies not in understanding what is needed, but in fostering political will, accountability, and organised delivery across healthcare systems and at the policy level. Building on Europe's Beating Cancer Plan, the European Cancer Organisation urges all stakeholders to strengthen their collaboration to ensure improved survivorship care and enhance the quality-of-life for all people affected by cancer. In response, the European Cancer Organisation will publicly launch Paper on Quality-of-Life Measurement in Q1 2026, as well as a **European Cancer Survivorship & Quality-of-life Charter in 2026**, timed to coincide with the symbolic National Cancer Survivor Day. This Charter will establish a framework for structured action, promote consistent implementation across Member States, and lay the groundwork for the development of a **Survivorship and Quality-of-life Index**, serving as a tool to monitor progress, strengthen accountability, and drive improvements in survivorship care across Europe.

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As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

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