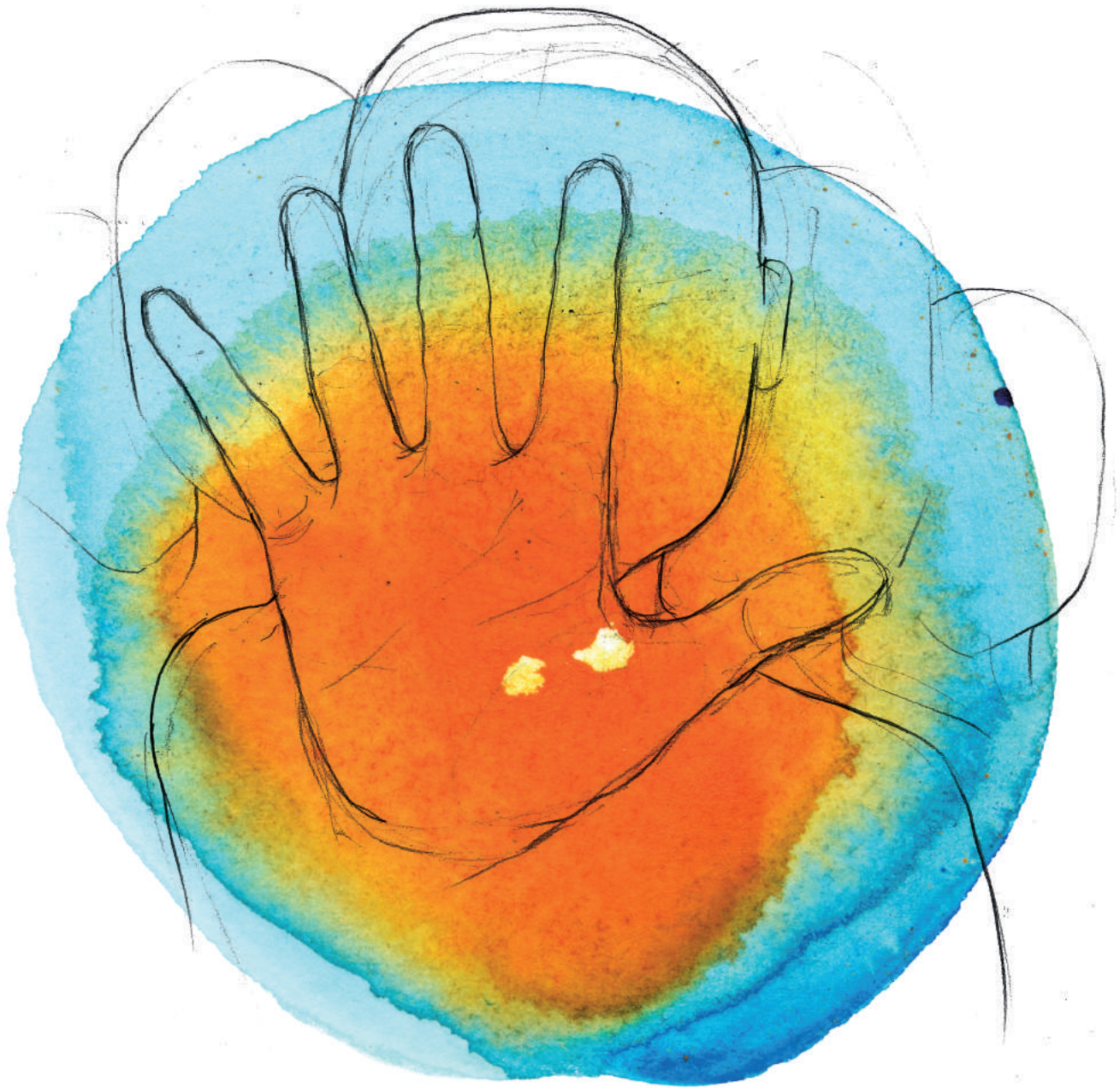


White Paper

on the needs of young people
living with cancer

YOUTH
CANCER
EUROPE



5 Calls
to action

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Young cancer patients and survivors face a myriad of difficulties when undergoing treatment and live with the results of their cancer treatment for the rest of their lives.

In the following white paper we focus on five specific domains that negatively affect cancer patients and survivors. The white paper will both highlight the problems and provide policy solutions in the following domains:

1 Ending discrimination against cancer survivors when accessing essential financial services such as mortgages and life insurances

2 Improving access to cross border healthcare for cancer patients

3 Increasing the availability of fertility preservation for cancer patients and fertility treatment for cancer survivors

4 Increasing the availability for dental and plastic reconstructive surgery services for cancer survivors

5 Increasing mental health support for cancer patients and survivors

These broad challenges need to be addressed on both a national and European policy level. Youth Cancer Europe (YCE) will play an instrumental role in enabling this policy change by hosting a series of meetings, mapping disparities across Europe, regularly publishing research papers and continuing an enabling dialogue with all concerned stakeholders. This white paper outlines five calls to action in five areas of cancer survivorship and lists the committed actions by Youth Cancer Europe to further advance the policy debate.

This document is the result of a collaborative effort of young cancer patients and survivors from across the continent within Youth Cancer Europe's network.

About Youth Cancer Europe

Youth Cancer Europe is made up of several thousand young cancer survivors, aged 18-39 from across Europe, to help shape European policy, collaborate in and promote research, fight for better access to care, for better treatments, better conditions and help fix disparities that exist across Europe for young people fighting cancer.

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Financial discrimination of cancer survivors



Financial discrimination of cancer survivors

A problem affecting 10 million cancer patients in Europe.

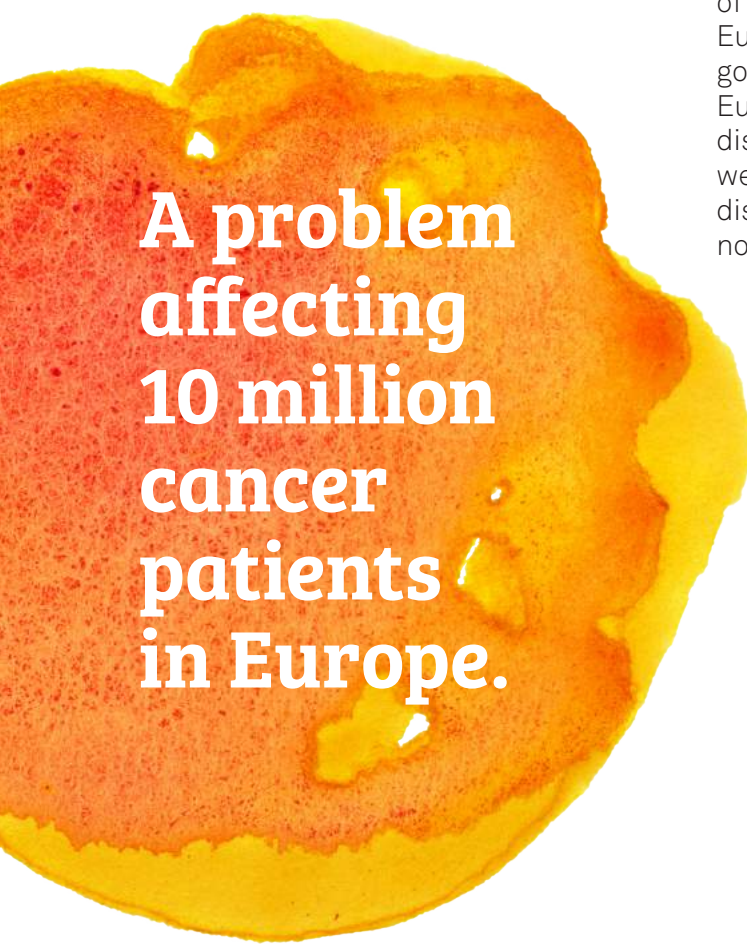
Medical advances in the diagnosis and treatment of cancer allows the majority of cancer patients to return to the life they enjoyed before hearing their cancer diagnosis. In Europe there are more than 10 million people living with cancer, while about 1.4 million people of working age are diagnosed with it each year. Although many cancer patients in remission can continue working and have comparable life expectancy to the healthy population, the average return to work rate is only 64 % after 18 months and those surviving cancer are 40% more likely to be unemployed and three times more likely to receive disability benefits.¹

Despite these barriers to return to normal life, cancer survivors face additional challenges when trying to obtain mortgage, life insurance, insurance for critical illness (which is not related to cancer) and even travel insurance. When applying for insurance, cancer survivors must disclose that they had a cancer diagnosis in the past. This results in the applicant being denied insurance or having to pay premium which is significantly higher than for a person with other chronic conditions. Research by national financial regulators have confirmed that most stakeholders accepted that it could be difficult for consumers who have or have had cancer, to find affordable insurances.²

This is further exacerbated by a lack of signposting services. Youth Cancer Europe therefore calls upon national governments, national regulators and European policymakers to end this discrimination. As cancer survivors, we are facing a life sentence of being discriminated by financial actors with no regulatory oversight.

¹How Can Cancer Survivors Best Be Supported to Return to Work? European Agency for Safety and Health at Work, 2018.

²Financial Conduct Authority (UK). Call for Input on Access to Insurance. Feedback Statement FS18/1, 2018.



**A problem
affecting
10 million
cancer
patients
in Europe.**

Status quo

Cancer survivors often face exclusion or pay significant extra premiums due to being diagnosed with cancer sometime during their lifetime. Insurers can also simply refuse to cover them. Making untrue statements about their treatment history however may lead to fines or even criminal prosecution against the customers and would also make any insurance contract void.

Cancer survivorship as handled by insurance and other financial providers to date is a life sentence for cancer patients. To put it in perspective: convicted persons in the European Union have their criminal record expired within several years (up to ten years for serious criminal offences) after serving the sentence. Cancer survivors on the other hand must declare their cancer history throughout their life and continue to suffer discrimination.

Recent examples

In 2016 France introduced the “Right to be forgotten” law, which provides legal rights for long-term cancer survivors not to disclose to insurers that they had been previously diagnosed with cancer (Figure 1). Patients will no longer have to inform insurers or loan agencies after a period of ten years after their treatment has ended, and five years for anyone who was under 18 when they underwent treatment for cancer.³ Belgium is taking a similar path and several western European countries are closely following these developments.

³Marie Mesnil, What do we mean by the right to be forgotten? An analysis of the French case study from a lawyer’s perspective, Journal of Cancer Policy, Volume 15, Part B, 2018, Pages 122-127, ISSN 2213-5383.

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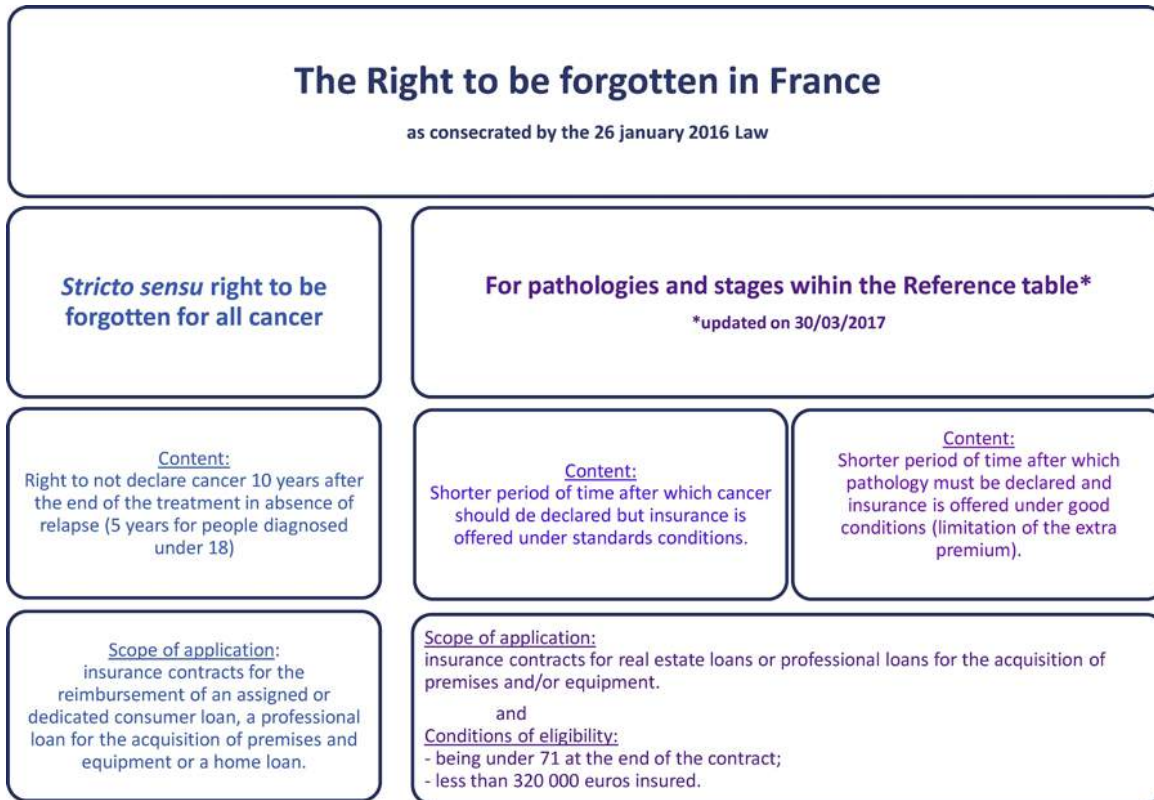


Figure 1: Content and scope of application of the right to be forgotten in France.

Youth Cancer Europe regards this as a positive change from the punitive exclusion of cancer survivors from many financial and insurance services. We advocate for the European application of the Right to be forgotten. Cancer survivorship should no longer be treated as a lifelong punishment.

The Financial Conduct Authority (FCA), the United Kingdom's financial regulator, published a paper in June 2018 where it challenged the financial and insurance industry to improve access to insurance for people with pre-existing medical conditions.⁴ For cancer survivors this means an obligation to disclose their cancer history indefinitely whenever they want to take out travel insurance.

Most insurance providers will not distinguish whether a person has been in remission and symptom free for 1 month or 10 years. While there are few insurance products that do not discriminate cancer survivors, with no regulatory oversight and lack of signposting, cancer survivors have no means to benchmark existing insurance products on the market.

⁴Financial Conduct Authority (UK). Call for Input on Access to Insurance. Feedback Statement FS18/1, 2018.

People with pre-existing medical conditions feel poorly served by travel insurance. There are specialist services out there, but often, people don't know where to find them.'

Christopher Woolard, Executive Director of Strategy and Competition at the UK Financial Conduct Authority said: "People with pre-existing medical conditions feel poorly served by travel insurance. There are specialist services out there, but, often, people don't know where to find them". There seems to be a disconnect between the insurance industry and consumers. The FCA report identified three common trends in the insurance industry:

1 A lack of quality information on alternative options available to consumers after they had received a high quote or had been refused cover, which can cause consumers to assume that they are uninsurable.

2 A lack of understanding amongst consumers and firms around insurance terms and the risk factors that are considered by providers when calculating the premium.

3 A lack of transparency around pricing, the risk factors which drive quotes and how premiums are calculated, which limits consumers' awareness about their options and can mean that they have difficulties in finding competitive insurance that is appropriate for their medical condition.

The way forward

From a regulatory perspective, it is also noteworthy that there seems to be general lack of understanding by both consumers and firms around insurance terminology and the risk factors that are considered by providers when calculating the premium. There is a lack of consumer awareness about their options and difficulties in finding competitive insurance that is appropriate for their medical condition.

Youth Cancer Europe acknowledges that for insurance companies cancer is a complex area and it is difficult to calculate the risk profile of their products taking into consideration the latest medical developments and novel anti-cancer therapies. As survivors we feel that there is inadequate transparency about how premiums are calculated and the way risk factors into the insurers' decision making. We would also like to highlight the inconsistency in insurers' assumptions around terms like "remission" and what it means to be "cancer free". These terms can mean something completely different to survivors and insurance companies.

This creates a lack of consistency for consumers, making it harder for them to compare quotes. Often there is no obvious single source of trusted information available about specialist providers or where to go to find them. Cancer survivors then face significant challenges navigating the market.

Youth Cancer Europe joins the ECCO initiative on Survivorship and Financial Discrimination, which demands that by 2025, in respect to accessing financial services, the right of cancer survivors not to declare their cancer 10 years after the end of the active treatment and 5 years if they had cancer under 18, should be codified across European countries.⁵ Youth Cancer Europe invites all respective stakeholders to join the dialogue by attending a series of meetings in the European Parliament as well as meetings with national cancer patient organisations. Youth Cancer Europe is committed to work with actuaries to understand their underlying risk assumptions and change the current lifelong discrimination towards cancer survivors.

⁵ Resolution: Survivorship (Financial Discrimination). European Cancer Organisation, 2018.

Youth Cancer Europe invites all respective stakeholders to join the dialogue by attending a series of meetings in the European Parliament as well as meetings with national cancer patient organisations.

Call to action

Youth Cancer Europe echoes the EORTC & ECCO initiative and calls for the following actions:

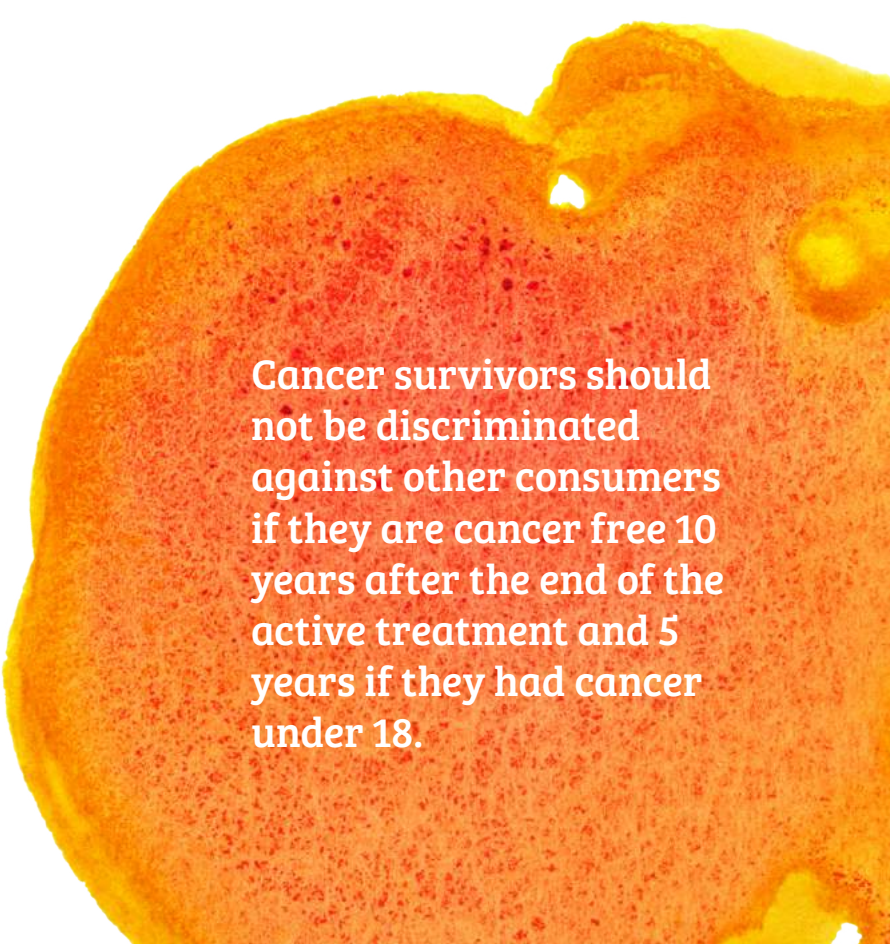
1 By the end of 2020 the European Insurance and Occupational Pensions Authority should issue guidance to insurers about the ethical principles that should apply in respect to cancer patients and cancer survivors insurance applications. This should include travel insurance, critical illness policies and definitions of cancer used by insurance companies.

2 By the end of 2021 EU authorities should conduct an EU level comparative study of EU Member States approaches towards ensuring the rights of cancer survivors to access financial services in a fair manner.

3 By the end of 2022 national governments should recognize the inequities and disparities that exist within the financial service landscape that apply to cancer survivors and having assessed their national legal frameworks should propose remediating measures, learning from the experience of France⁶ in this respect. This recognition could be expressed via a set of European Council conclusions.

4 By 2025 national governments and financial regulators should implement national legislations that ensure that cancer survivors should not be discriminated against other consumers if they are cancer free 10 years after the end of the active treatment and 5 years if they had cancer under 18.

⁶New Rules Benefit Cancer Survivors. The Connexion, 12 May 2015.



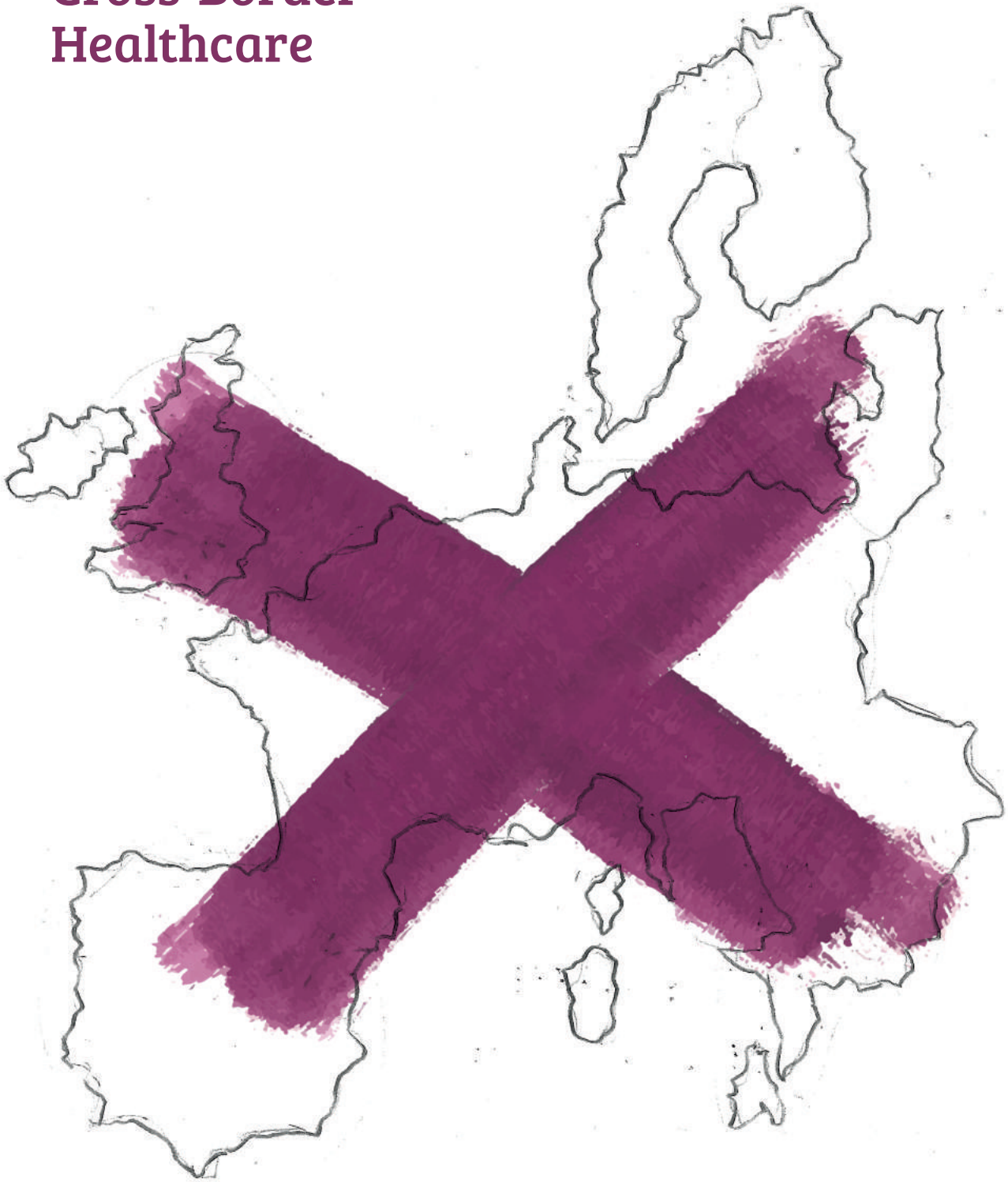
Cancer survivors should not be discriminated against other consumers if they are cancer free 10 years after the end of the active treatment and 5 years if they had cancer under 18.

Conclusions

Youth Cancer Europe invites civil society actors, patient organisations, healthcare professional and research associations and other stakeholder organisations to express a single consensus view on further measures to reduce the financial discrimination of those who had been diagnosed with cancer. In light of the French legislation on the Right to be forgotten Youth Cancer Europe believes that urgent change is needed. Currently, cancer survivors must declare their survivorship indefinitely, leading to denied insurance or paying exorbitant premiums compared to regular customers. Youth Cancer Europe is concerned that inequality exists and commits to take initiative to end the discrimination against cancer survivors.

**Cancer should not
be perceived as a life
sentence without parole!**

Cross-Border Healthcare



Cross-Border Healthcare

A directive that does not work

The Cross-border Healthcare Directive (CBHD)⁷ provides European citizens with the right to travel and receive treatment abroad, either in public or private healthcare institutions, anywhere in the European Union and to be reimbursed for those healthcare services up to the amount which would be paid if the healthcare services were received in the country they are permanently residing in. However, the promise of the CBHD to promote patient mobility is being wasted by the reluctance of national competent authorities to implement unbundling processes to apply for prior authorisation for in-patient services and to provide information about which treatments are available in other EU member states. Cross-border healthcare should be seen as a right of European citizens, not a last resort solution.

Youth Cancer Europe calls upon European policy makers to raise awareness about cross-border healthcare as after five years of CBDH existence the majority of cancer patients are not aware of their rights and lack signposting from the competent authorities.

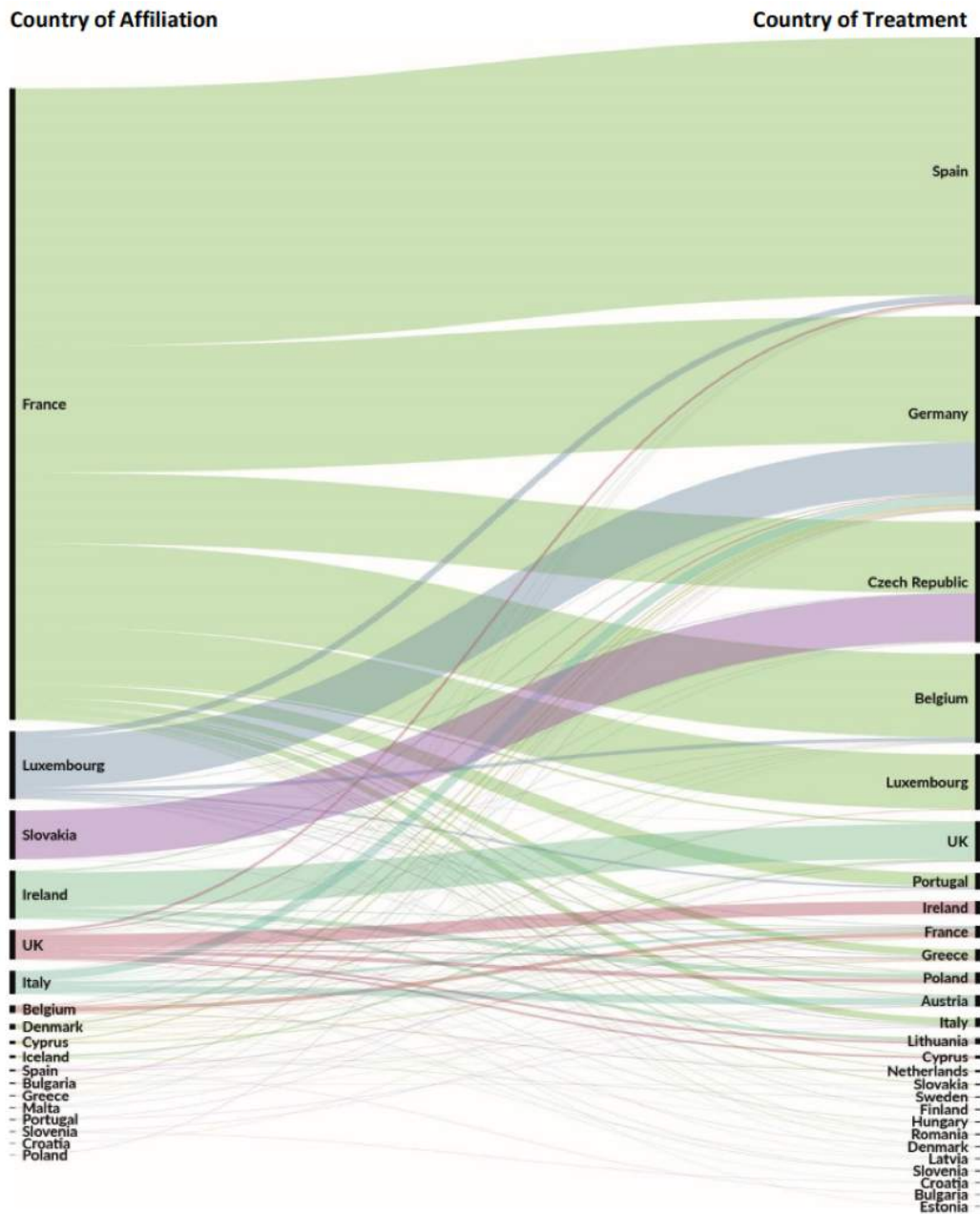
**A directive
that does
not work**

Status quo

The CBHD has been in force since 2013 and over 400,000 patients travel annually to another European Union Member State to receive treatment. In 2017, almost 40,000 requests for cross-border reimbursements were made within 20 countries that reported data. While many patients are accessing healthcare in a different country, there is still a divide between the EU15 Member States and the EU13 Member States (Central and Eastern Europe). As shown in Figure 2, the majority of patients from a country with a high GDP seek treatment in a country with a lower GDP and achieve cost savings. However, the reverse is not true. Going from lower income countries to higher income countries is often not feasible for most patients. This trend is further enforced by high out of pocket payment demands for the family of patients when travelling to a different country.

⁷ Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare OJ L 88, 4.4.2011, p. 45–65

**Cross-border
healthcare should be
seen as a right
of European citizens
not a last resort
solution.**



⁸ Member State Data on Cross-Border Patient Healthcare Following Directive 2011/24/EU. European Commission, 2016


Figure 2: Patient flows between countries (European Commission 2016⁸)

Cross-Border Healthcare often seems abstract to many. The following example illustrates a patient journey from Poland to Austria.

Peter, aged 5, was diagnosed with a paediatric malignant primary brain tumour (medulloblastoma) and underwent the standardized treatment protocol with chemotherapy, radiation and several surgeries in Warsaw. After 3 years of therapy Peter's symptoms worsened and he was only offered palliative therapy. Unfortunately, the local hospital proved hesitant in identifying alternative treatment solutions. Peter's parents reached out to other parents in a similar situation and contacted hospitals in other EU Member States. Eventually Peter was admitted to the hospital in Vienna, Austria. Peter qualified for a clinical trial with promising results. However, no clinic in Poland was ready to enrol patients in this specific trial and the family had to move outside of their country for the duration of the trial, which lasted for 2 years.

As Peter's health was rapidly deteriorating it was crucial for the parents to make the necessary down payment urgently so treatment could start. They raised the € 70,000 needed to co-pay for the € 400,000 treatment with the help of support groups and donations. In the meantime, Peter's parents also had to co-ordinate their relocation to another country and faced multiple hardships due to the lack of a support network in Austria and language barriers. They faced uncertainties from the competent Polish authority as well and they were not sure whether the treatment would eventually be reimbursed.

Peter's parents submitted the required documents to the Polish National Health Fund and received a positive reply from the Polish and Austrian medical institutions, which confirmed that the participation in the clinical trial is the best available option for the paediatric patient. To the parents dismay the competent Polish authority rejected their application after 3 months of administrative procedure, while at least two patients from Germany and Romania, who were enrolled in the same clinical trial, had their co-payments covered by their respective national competent authorities.



They raised the 70,000€ needed to co-pay for the 400,000€ treatment with the help of support groups and donations.

A study performed by the European Association for the Co-ordination of Consumer Representation in Standardisation (ANEC)⁹ found that cancer is within the top three reasons as to why people use Cross-border healthcare after dental services (e.g. teeth whitening, crowns) and obstetrician services (e.g. pregnancy, scans, giving birth).

Survey respondents stated: “Estonia and Romania told us that they receive many applications to travel abroad for the testing and treatment of serious illnesses, such as cancer, neurological diseases, bone and joint diseases, and cardiac and vascular diseases.”

Their study goes on to suggest that one of the key barriers to seeking planned treatment abroad is a lack of awareness about patients’ rights. When asked about their rights to cross-border healthcare, less than half (47%) knew that they could apply for reimbursement for certain in-patient therapies and to receive out-patient care in another EU member state.

When it comes to the practical availability of healthcare in another state, a clear picture evolves. The following heat map (Figure 3) outlines the scope of cross-border healthcare across European Union and the levels of reimbursements and travel (green = high number of reimbursements and travel, yellow = medium number of reimbursements and travel, red = low number of reimbursements

and travel). It should be noted that some countries (Czech Republic, Estonia, Finland, Germany, Lithuania, Netherlands, Sweden) did not provide data on authorised requests to receive treatment under CBHD.¹⁰ As the map below shows, the majority of competent authorities in European Union make it very difficult for their citizens to access healthcare in another member state. Only patients in France, Ireland, Luxembourg and Slovakia currently enjoy guarantees under CBHD without administrative pushbacks.

While the European Commission has initiated research into the utilisation of cross border healthcare services, there is still a gap in promoting the CBHD and the opportunities it offers for better treatment outcomes and lives saved.

Youth Cancer Europe welcomes the recent announcement of the European Court of Auditors to examine the European Commission’s monitoring and support for putting the EU legislation on cross-border healthcare access into effect.¹¹

⁹Cross-Border Healthcare Accessing Medical Treatment in Other EU Countries: Consumer Attitudes and Experiences. European Association for the Co-Ordination of Consumer Representation in Standardisation AISBL, 2018.

¹⁰Member State Data on Cross-Border Patient Healthcare Following Directive 2011/24/EU. European Commission, 2016

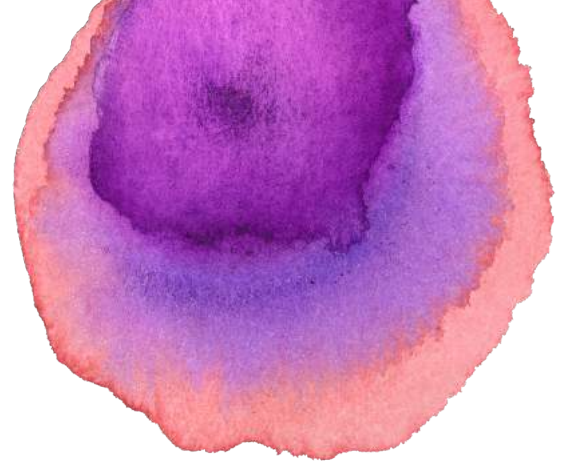
¹¹ EU Auditors to Examine Cross-Border Healthcare.” Press Release , European Court of Auditors, 201820 September 2018

The majority of competent authorities in the European Union make it very difficult for their citizens to access healthcare in another Member State.



¹² Member State Data On Cross-Border Patient Healthcare Following Directive 2011/24/Eu, https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2016_msdata_en.pdf, Accessed 20 September 2018

Figure 3: Does the CBHD work? Map based on Member State data on cross-border patient healthcare following Directive 2011/24/EU.



Call to action

1 By the end of 2019 national competent authorities should endeavour to apply similar prior-authorisation procedures and uniform application of reimbursement for cross-border healthcare services across EU Member States.

2 By 2021 the competent authorities on EU level should complete the coordinated and regular data collection and benchmarking of EU Member States for healthcare services that can be accessed under CBHD.

Conclusions

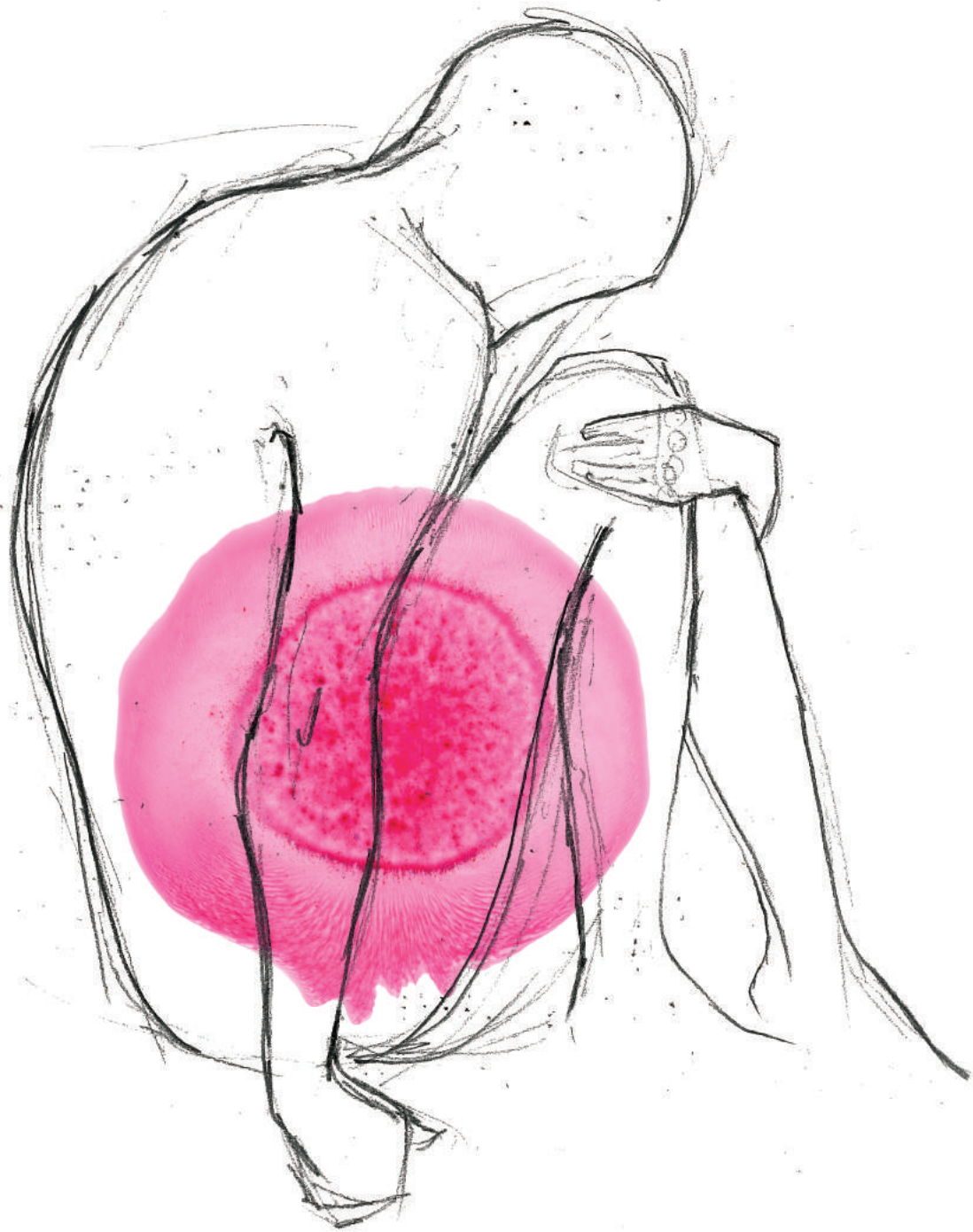
Youth Cancer Europe commits to coordinating activities with other patient and healthcare professional organisations to collect disease-specific data on prices and availability of treatment alternatives in different EU Member States.

Youth Cancer Europe supports the European Commission's determination to enforce patients' rights to Cross-border Healthcare by taking decisive action against national competent authorities that do not provide swift administrative guidance to the patients seeking healthcare in other EU Member States and encourages civil society actors – patient organisations, healthcare professional organisations and research organisations – to regularly monitor the implementation of CBHD in their respective countries.

Youth Cancer Europe will contribute to establishing a signposting process, helping patients compare available treatment options and their prices in different EU member states. As further research is needed to establish a database on prices in different countries, we will actively work with our partners and the European Association of Health Law (EAHL) to establish a database and benchmark how EU member states safeguard patients' rights that derive from European legal acts (including CBHD).

Health insurance bodies should fight for and not against their patients when they seek access to healthcare abroad!

Fertility Preservation



Fertility Preservation

The avoided topic that haunts cancer survivors for life

Fertility is an important issue for many young cancer survivors and perhaps the most life-altering late effect of cancer treatment, affecting the survivors' body image, sexuality, dating relationships, marriage patterns and sense of wellbeing.¹³ Studies suggest that between 40% and 80% of adult female cancer patients are at risk of becoming infertile and between one-third and three-quarters of male cancer patients may become sterile after treatment for cancer¹⁴.

Given the advances in fertility preservation, it is however disappointing that patients across Europe are not receiving appropriate counselling and having adequate access to fertility preservation solutions.

¹³Levine, Jennifer M., et al. "Fertility and Sexuality." Pediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management (2015).

¹⁴ Knapp, Caprice A., Gwendolyn P. Quinn, and Devin Murphy. "Assessing the reproductive concerns of children and adolescents with cancer: challenges and potential solutions." Journal of adolescent and young adult oncology 1.1 (2011): 31-35.

¹⁵Desandes, Emmanuel, and Daniel P. Stark. "Epidemiology of adolescents and young adults with cancer in Europe." Tumors in adolescents and young adults . Vol. 43. Karger Publishers, 2016. 1-15.



The avoided topic
that haunts cancer
survivors for life



Status Quo

While most cancer cases occur in later stages of life, around 66,000 young people (between 15-39 years) are diagnosed with cancer every year in Europe.¹⁵ Modern cancer treatments have led to significant reduction in mortality, but they also can have detrimental late effects such as reduced fertility. With increased survivorship, the preservation of fertility is an important topic and patients want to have the choice to potentially have families in the future.

Apart from worrying about the impact of cancer treatment on the body, fertility preservation can also have a financial impact on patients. Currently, in Europe there are huge disparities when it comes to the availability of fertility preservation services within national healthcare systems. Many young cancer patients are not offered a consultation as the age of consent for medical procedures varies widely across Europe. Scientific studies suggest that paediatric health professionals' knowledge and attitudes on fertility preservation shows deficits with regard to advanced fertility preservation techniques and limited interdisciplinary interchange, e.g. with infertility specialists.¹⁶ Over 60% of healthcare professionals reported difficulties regarding access to centres providing fertility preservation. Similarly, a qualitative study on oncologists of adult patients also revealed a lack of knowledge on fertility preservation resources as a major barrier to discussion.

It is recommended that cancer survivors who have not had access to fertility preservation before treatment should be able to access fertility treatment free of charge later in life.¹⁷

Every patient at risk should be made fully aware and have the opportunity to talk to a healthcare professional about their concerns via onco-fertility counselling. We also acknowledge that more research is needed to assess the impact medicinal products used during cancer treatment have on patient fertility.

Youth Cancer Europe seeks to establish a dialogue with European and national policymakers to acknowledge the scope of this problem. We further advocate for raising awareness for fertility preservation so patients can understand and explore the impact their treatment may have on their fertility with healthcare providers before beginning treatment.

International guidelines also recommend that treatment providers (e.g. nurses, physicians) discuss with all patients of reproductive age their risk of infertility before starting treatment.¹⁸ Healthcare providers should also provide additional information on the impact of a patient's cancer treatment and their ability to have children after cancer.¹⁹

All patients should be informed of existing options for fertility preservation and future reproduction prior to initiation of gonadotoxic cancer therapies, including surgery, chemotherapy, and radiotherapy by their treatment providers (e.g. nurses, physicians, psychologist). If fertility preservation is considered, it should always be covered by a patient's health insurance.

¹⁶Tschudin, Sibil, and Johannes Bitzer. "Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases." Human reproduction update 15.5 (2009): 587-597.

¹⁷Listen up! What Matters to Young Cancer Patients. All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer Inquiry into Patient Experience, July 2018.

¹⁸Loren, Alison W., et al. "Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update." Journal of Clinical Oncology 31.19 (2013): 2500.

¹⁹Lambertini M, Del Mastro L, Pescio MC, et al. Cancer and fertility preservation: international recommendations from an expert meeting. BMC Medicine. 2016; 14:1.

Call to action

1 By the end of 2021 Youth Cancer Europe commits to map the availability of fertility preservation services within national healthcare systems across Europe.

2 By 2022 healthcare professional organisations working in the field of oncology should develop guidelines defining a unified age when underage patients should be provided with a choice to have their sperm or eggs preserved.

3 By the end of 2024 national health insurance authorities should include services related to fertility counselling and subsequent fertility preservation procedures as an essential requirement of cancer care delivery.



Conclusions

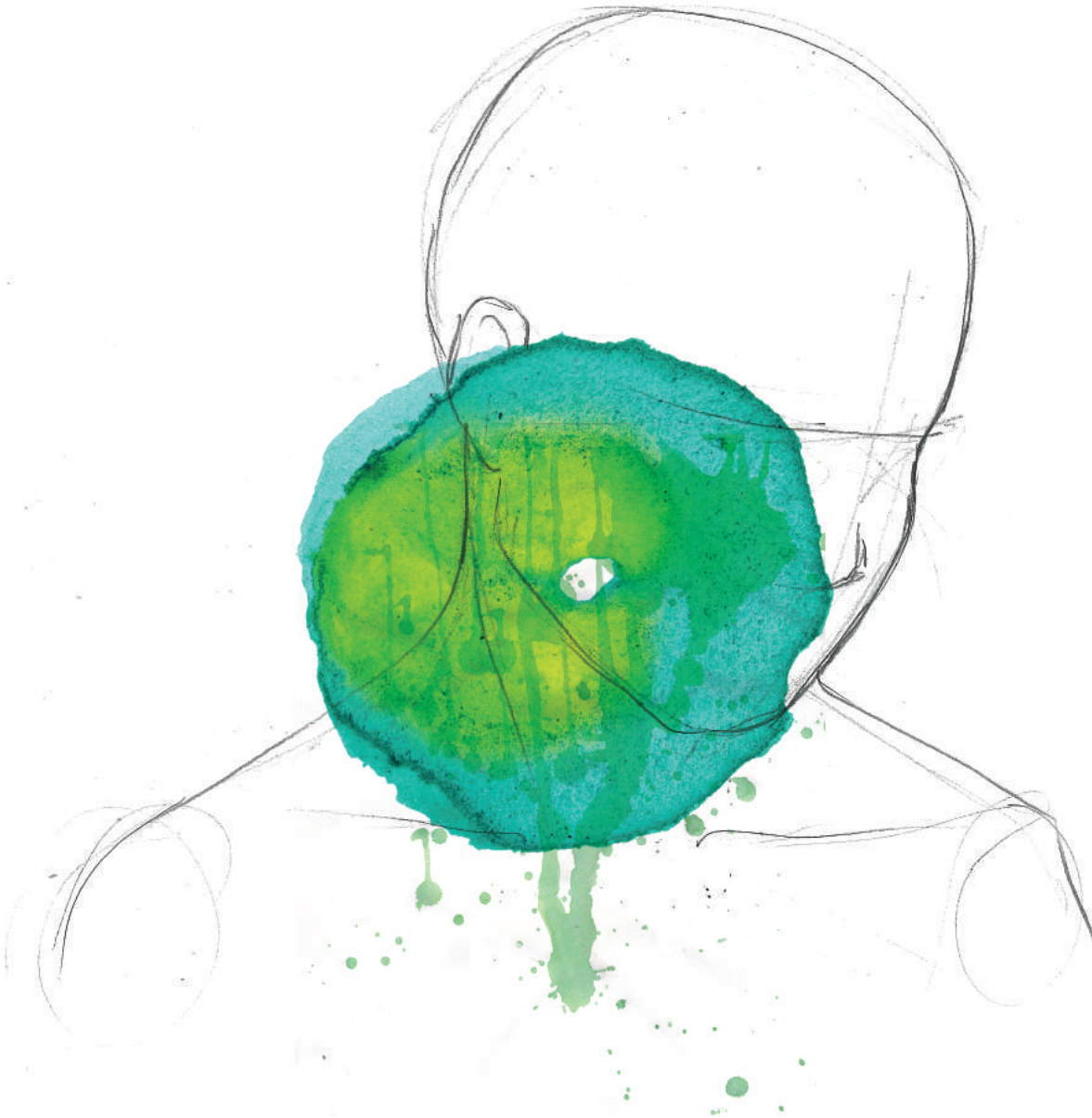
Youth Cancer Europe invites health policymakers at the European and national level to acknowledge that the time has come to address the issues related to fertility preservation in regular discussions about quality of cancer care. Youth Cancer Europe seeks dialogue with healthcare professional organisations on educating patients to understand the impact cancer treatment may have on their fertility before initiation of the therapy.

Together with our partners, Youth Cancer Europe commits to map the availability of fertility preservation services within national healthcare systems across Europe by the end of 2021. This study will help to further advance the policy discussion around fertility preservation.

The preservation of patient sperm and eggs (or other fertility preservation approaches) before starting therapy should always be covered by a patient's health insurance. Youth Cancer Europe will continue this dialogue through a series of meetings with national governments, European policy makers and healthcare professional organisations.

**Fertility preservation should
always be an option for patients,
irrespective of their age
or financial means!**

Dental care and reconstructive surgery



Dental care and reconstructive surgery

Where the dignity of patients is at stake

Treatment for cancer can result in multiple early and late side effects that can impact general wellbeing and the quality of life of cancer patients and survivors. These often have life-long impact on their ability to eat, drink, speak, swallow, smell, breathe, have social interaction and the ability to work. Dental care and reconstructive surgery can therefore play an important role in the rehabilitation of cancer patients and survivors.

Status Quo

Patients undergoing radiotherapy can experience several unwanted oral side effects, which have both short-term and long-term implications.²⁰ For example, radiation-induced caries can start within three months of the completion of radiation. High rates of body image concerns have also been documented for cancer patients and survivors. Up to 75% of patients with head and neck cancer have been found to express concerns or embarrassment about bodily changes following cancer diagnosis. The surgical removal of certain cancers, such as head and neck tumours, can leave patients and survivors with scars and physical deformities for life.²¹ The availability of reconstructive surgery and proper dental care for cancer patients and survivors varies widely across Europe and is not properly understood nor researched.

²⁰ Jawad, H., Nicholas Anthony Hodson, and P. J. Nixon. "A review of dental treatment of head and neck cancer patients, before, during and after radiotherapy: part 1." *British dental journal* 218.2 (2015): 65.

²¹ Nouraei, S. A. R., et al. "Role of reconstructive surgery in the management of head and neck cancer: a national outcomes analysis of 11,841 reconstructions." *Journal of Plastic, Reconstructive & Aesthetic Surgery* 68.4 (2015): 469-478

Where the
dignity of
patients is
at stake

Dental Care

Many head and neck cancer patients and survivors experience problems with swallowing as a result of surgery or radiotherapy. This can result in difficulties or an inability to eat solids and can lead to a diet consisting of only fluids, pureed or mashed foods. Alteration of taste often occurs as a result of the direct effect of radiation on taste buds and due to changes in the saliva. This ranges from the inability to taste, decreased ability to taste or distorted taste. While most patients have their taste restored after completing radiation some patients and survivors might experience changes to their tastes for life.

Another problem is related to cost. For example in the United Kingdom, restorative dental treatment done in the hospital system is free of charge but where this isn't available, patients have to register with a local dentist where National Health System (NHS) dental charges apply. If they cannot get access to an NHS dentist, they may be forced to go private and pay all the cost themselves.²² As costs can reach several thousand Euros, for many, this is simply not an option.

We call for more research to map the free availability of these treatments and raise awareness for the problems cancer patients and survivors face.

Reconstructive Surgery

Head and neck cancers pose considerable problems due to the vital nature of the organs treated (oesophagus, trachea), their essential functions (speech, swallowing, chewing) and the major aesthetic after-effects of surgery.²³ Apart from the physical impact of cancer treatment, it often leaves patients with a distorted body image. Studies have shown that over 90% of cancer survivors and patients report concerns about their changes in appearances.

How often do you think about your appearance?



Figure 4: Body image concerns in percentages reported by cancer patients and survivors²⁴

Unfortunately, research suggests that physicians are not adept or comfortable with evaluating or managing patient distress.²⁴ Lack of time is the most frequently reported barrier for medical professionals in being able to identify and manage patient stress and anxiety.

It is not uncommon for cancer patients and survivors to worry about being 'vain' and experience shame and embarrassment about having body image concerns. For those reasons, it is critical to raise awareness about these issues and engage in a broad dialogue with policymakers and health professionals alike. More research is needed to map the availability of existing therapy options and to raise awareness for the problems cancer patients and survivors face.

²² Forde, Emma. The Hidden Cost of Mouth Cancer. BBC News, 11 May 2013.

²³ Reconstructive Surgery and Cancer. Institut Curie, 21 Apr. 2017.

²⁴ Fingeret, Michelle Cororve, et al. "Body image screening for cancer patients undergoing reconstructive surgery." *Psycho Oncology* 23.8 (2014): 898-905.

Call to action

1 Youth Cancer Europe calls upon national policymakers and healthcare professional organisations to routinely recommend dental and reconstructive surgery for cancer patients and survivors and to ensure that patients are properly consulted on dental care and reconstructive surgery elements before, during and after their cancer therapy.

2 Youth Cancer Europe commits to provide meaningful overview of the availability of dental care and reconstructive surgery for cancer patients within their respective national health systems and to map barriers to access of these services across Europe by the end of 2023.

3 Until the end of 2025 Youth Cancer Europe commits to organising meetings with national governments to improve access to dental and reconstructive surgery services for cancer patients.

Conclusions

It is imperative that cancer patients have a pre-therapy dental assessment to help maximise the patient's quality of life during and following oncological treatment. There should also be awareness among policymakers that the current treatment guidelines do not allow for many cancer patients and survivors to access these vital treatment and recovery options.

Additionally, the medical complexities of these patients and survivors affects dental treatment planning, prioritisation and timing of dental care. They require significant support from multidisciplinary (dental) teams before, during and after radiotherapy. Maintaining and restoring oral health as well as reconstructive surgery can help to ultimately improve quality of life for cancer patients and survivors.

Reconstructive surgery and dental care are not lifestyle interventions but cost-effective remedies for cancer survivors to ensure their dignity and good quality of life!

Reconstructive surgery and dental care are not lifestyle interventions but cost-effective remedies for cancer survivors to ensure their dignity and good quality of life!

Mental Health



Mental Health

The unseen burden of cancer survivorship

Significant number of cancer therapies, including certain kinds of chemotherapy and radiotherapy can cause short-term and long-term mental health problems. These psychological effects are often not recognised by the healthcare professionals and are therefore not treated adequately. Youth Cancer Europe is reiterating that psychological care is needed during all stages of cancer treatment and after its aftermath. Highlighting the European Union's commitment towards the sustainable development goals established by the United Nations to "ensure healthy lives and promote wellbeing for all at all ages in non-communicable diseases and mental health"²⁵, Youth Cancer Europe hopes to witness considerable progress in the area before 2030. Special psychological care is also needed for cancer patients' caregivers and close relatives. Youth Cancer Europe commits to engaging in dialogue with cancer specialists and psychologists to improve their wider understanding of these issues.

Status Quo

It is unreasonable to assume that someone could be unaffected psychologically by the strain of a cancer diagnosis. Cancer diagnosis and treatment may be accompanied by profound physical, emotional, social, occupational, and financial stressors, as well as associated increases in anxiety and depressive symptoms. Population-based data suggest that cancer survivors are more than twice as likely to have disabling mental health problems compared with adults without cancer²⁶. In the UK a survey by Channel 4 and the Teenage Cancer Trust reported that eight out of ten young people found the mental health impact of cancer as hard to deal with as the physical aspects²⁷. A paper published by CLIC Sargent found that half of all teenagers with cancer do not receive psychological support.²⁸

²⁵ Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions next Steps for a Sustainable European Future European Action for Sustainability. European Commission, Nov. 2016.

²⁶ Naughton, Michelle J., and Kathryn E. Weaver. "Physical and mental health among cancer survivors considerations for long-term care and quality of life." *North Carolina medical journal* 75.4 (2014): 283-286.

²⁷ Channel 4 News and Teenage Cancer Trust Special Report on Mental Health among Teens and Young People with Cancer. Teenage Cancer Trust, 30 May 2018.

²⁸ The Mental Health Impact of a Cancer Diagnosis on Young People. CLIC Sargent, 2017.



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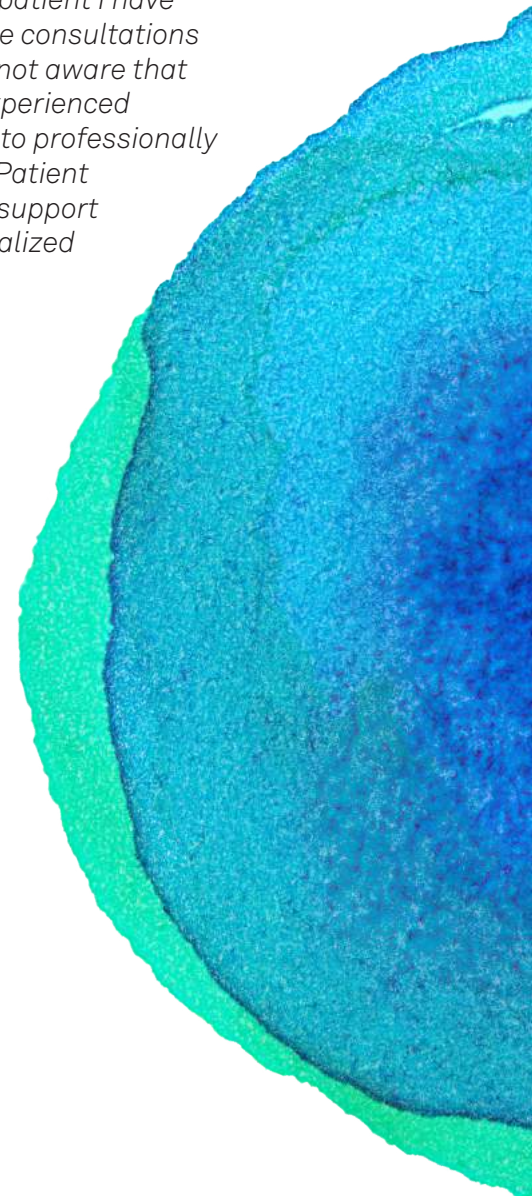
The extent of the problem is illustrated by the following personal stories of Youth Cancer Europe members:

**Seren, 22
United Kingdom**

“After living with cancer for several years I am now suffering from post-traumatic stress disorder (PTSD) and extreme anxiety, which has gotten worse since my cancer diagnosis. I was not feeling anxious before and I believe that the time I have spent in the intensive care unit had this negative impact on my mental state. I was offered support at a time which might seem logical to health care professionals, but it didn’t work for me. A few years later, I have now accessed this team due to my issues with PTSD and anxiety from the ward. I remember this process as being extremely slow and laborious. I was sat in a room with 3 other specialists to discuss my problems, yet I had never met them before and it was overwhelming for someone with anxiety. After several months of consultations, I was promised an opportunity to see my medical notes to understand what happened to me while I was hospitalised, but I’m still waiting to see them, and this further contributes to my anxiety. I think the oncology services for young cancer patients in the UK are focused on long-term physical effects but are not examining the mental effects. The services are sporadic, hard to find, and not responsive enough for someone who has suffered from psychological trauma. Partly because my general physician did not acknowledge my situation and proved uncooperative, I had to be admitted to emergency care unit several weeks ago due to my panic attacks and horrendously anxious thoughts heightened by my current medication.”

**Emmi, 30
Finland**

“Just after hearing my cancer diagnosis I was offered to see a psychiatric nurse and talk with her. While I had the opportunity to have mental health support, I felt like they didn’t have the experience to help cancer patients. In the end I didn’t get the help that I wished for. As a cancer patient I have an opportunity to receive consultations at my hospital but I am not aware that hospitals would have experienced personnel who are able to professionally assist cancer patients. Patient organisations and peer support groups offer more specialized help for us.”



The specific needs of cancer patients and survivors are currently not readily acknowledged. Many patients and their carers do not receive psychological support. It is often not available during treatment. Medical personnel are often unaware of the unique challenges cancer patients are facing and cannot respond adequately to the unique needs of cancer patients. In addition, there are long waiting lists to see qualified psycho-oncologist, which is an additional barrier to accessing psychological treatments tailored to cancer patients and survivors.

It is important to reduce the stigma of mental health treatment of cancer patients. Raising awareness of national health policy makers and healthcare professional organisations on the benefits of personalised mental health services for cancer patients during and beyond treatment is crucial. Youth Cancer Europe recognises the lack of specialists in this area. The field of psychosocial oncology is still underdeveloped and according to the International Psycho-Oncology Society there were only 2 psycho-oncology master programmes (in Germany and Spain) in Europe in 2017 . In 2018 the first generation of qualified psycho-oncologists graduated their master program from the Lithuanian University for Health Sciences.

Call to action

1 Youth Cancer Europe calls upon universities in Europe to implement master programs for training psycho-oncology specialists, who would be equipped to work with cancer patients and their relatives as members of the multidisciplinary teams in cancer centres of excellence.

2 By the end of 2021 Youth Cancer Europe commits to organise a series of expert level discussions with healthcare professional organisations and psychologist societies to create an action plan on providing specialised mental health care services for cancer patients and their relatives.

3 By 2025 national healthcare insurance bodies should include the cost of providing mental health support for cancer patients and their caregivers as routine service. Additionally, the costs of long-term mental health issues and psychological support, including psychotherapy and psychiatric care must be covered within health insurers' programs managing late effects of cancer therapy.

²⁹ Kadan Lottick, Nina S., et al. "Psychiatric disorders and mental health service use in patients with advanced cancer: a report from the coping with cancer study." *Cancer: Interdisciplinary International Journal of the American Cancer Society* 104.12 (2005): 2872-2881.

³⁰ Faller, Hermann, et al. "Utilization of professional psychological care in a large German sample of cancer patients." *Psycho-oncology* 26.4 (2017): 537-543.

³¹ "Information on Various Continuing Education and Graduate Level Training Courses" *Continuing Education, International Psycho-Oncology Society, 2017*

Conclusions

Youth Cancer Europe is committed to share stories and insights of cancer survivors with professional mental health professionals and their respective associations to enrich discussions around adequate mental healthcare for cancer patients. Currently, the mental health burden as late-effect of cancer therapy is under-researched and underestimated, however, it impacts 10 million cancer survivors in Europe. Taking into consideration that healthcare is within the competence of EU Member States, Youth Cancer Europe urges national health policy makers to see the benefits of mental health services and the impact it has on cancer survivors.

Neglecting the emotional and psychological wellbeing of people is like only treating half a person instead of the whole patient.

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