Ending discrimination against cancer survivors

21 OCTOBER 2026

Ending Discrimination Against Cancer Survivors

The Right to be Forgotten as a Human Right

THIS EVENT IS RECOGNISED AS AN ASSOCIATED EVENT OF THE IRISH PRESIDENCY OF THE COUNCIL OF THE EUROPEAN UNION 2026



ÉIRE2026.EU
IRELAND2026.EU
Imeacht Gaolmhar | Associated Event

In collaboration with
Irish Cancer Society

10:00 - 10:10

Introductory Remarks

Setting the Ambition for the Day

Ending discrimination against cancer survivors

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Irish Cancer Society





MASTER OF CEREMONY: LUTZ DOMMEL, CEO RPP GROUP, PARTNER PARITEE

Prof. Françoise Meunier

Founder, Ending Discrimination Against Cancer Survivors

Prof. Mark Lawler

Professor, digital health, Queen's University Belfast and immediate Past Chair, International Cancer Benchmarking Partnership, **IE**

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Ending discrimination against cancer survivors

In collaboration with Irish Cancer Society

Opening Remarks

Prof. Mark Lawler

Professor of Digital Health, Queen's University Belfast, UK,
Co-Lead, All Island Cancer Research Institute
Immediate Past Chair, International Cancer Benchmarking Partnership
Co Chair, Lancet Oncology 'Omics and Precision Oncology Commission
Vice Chair Cancer Focus Northern Ireland

Ireland



Evidence Not Compassion

- This is **not about compassion**; this is **about evidence** and acting on that evidence justly.
- When a cancer professional states that **you are cured after 5 years** and international benchmarking concurs (**International Cancer Benchmarking Partnership – Lawler Immediate Past Chair**), **why do financial institutions claim that you are not?**
- Those who are living beyond their disease **should not be penalized for a previous cancer diagnosis**

5

YEARS

the benchmark for cure — the point at which cancer professionals and ICBP say you are cured

Lawler M, Meunier F. Don't make cancer patients pay twice, the right to be forgotten should be the law everywhere. BMJ 2022
Lawler M, Scocca G, Meunier F. Ending Financial Discrimination for Cancer Survivors: embedding the Right To Be Forgotten in legislation across Europe. Lancet Oncology (2024)
Meunier F, Scocca G, Tulkens F. Towards promoting a legal framework for ending discrimination against cancer survivors. A human rights-centered approach. Journal of Cancer Policy, Volume 43, 2025

Ending discrimination against cancer survivors

Irish Cancer Society

THE LANCET Oncology

Cancer Focus NORTHERN IRELAND

NECRET North East Cancer Research & Education Trust

ICBI International Cancer Benchmarking Partnersh

QUEEN'S UNIVERSITY BELFAST

A Step Forward and a Victory for Cancer Survivors… BUT

PUBLISHED 15TH JANUARY 2025



PAGE 20

- "**Legislate** for a 'Right to be Forgotten' for cancer survivors, **requiring insurers to disregard a cancer diagnosis** where treatment ended more than **7 years** prior to application (or more than 5 years if the applicant was under 18 at the time of diagnosis), taking account of EU requirements."

- **If it's 7 years we are still discriminating against Irish cancer survivors, as by our criteria they are already "cured"**

- **NEEDS TO BE 5 YEARS! Cancer doesn't wait, cancer survivors cannot wait any longer, for what should be due to them BY RIGHT**

Ending discrimination against cancer survivors
Irish Cancer Society
THE LANCET Oncology
Cancer Focus NORTHERN IRELAND
NECRET North East Cancer Research & Education Trust
ICBI International Cancer Benchmarking Partnersh
QUEEN'S UNIVERSITY BELFAST

Never Be Satisfied Until You Get What You Want!

So I presented our data from the **International Cancer Benchmark Partnership (ICBP)** to the Minister and his team, highlighting that **5 not 7 years is our benchmark for cure**



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And Guess What?



The Minister Agreed!

- And announced at this year's **All-Island Cancer Summit** that the Bill would go through the Dáil (Lower House) and Seanad (Upper House) so as to **come into law** before the Parliamentary summer recess
- Ireland only the **second country in Europe** to go straight to the 5 years eligibility

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RTBF Law Came into Force in Ireland

Fast Forward to 6 Days Ago (15th October 2026)

And **on the very first day**, cancer survivors availed of the new legislation. Thanks to our great colleague **Tom Grant, OneLife Insure**:

€451 → €75

PER MONTH

New mortgage protection premium for a client with a significant cancer-related loading — a saving of €376 per month, or > €4,500 per year

~€270 → €35

PER MONTH

Non-Hodgkin lymphoma six years ago — without the five-year window she would have had to wait another year, needlessly

>85%

PREMIUM DROP

For both cancer survivors — just two of many who will benefit from this new law

After 5 years of persistent campaigning, the first cancer survivors are finally getting what is rightfully theirs: JUSTICE

Ending discrimination against cancer survivors

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THE LANCET Oncology

Cancer Focus NORTHERN IRELAND

NECRET North East Cancer Research & Education Trust

ICBI International Cancer Benchmarking Partnersh

QUEEN'S UNIVERSITY BELFAST

10:10 - 11:10

Session I

Living Beyond Cancer: Survivor Experiences and the Reality of Financial Discrimination

Ending discrimination against cancer survivors

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Irish Cancer Society



Jacqueline Daly
Ireland

Magali Mertens de Wilmars
Belgium

Dr. Stefan Schmidt
Germany

Miriam Vogt
Germany

Izabela Chełkowska-Klasa
Poland

Antonella Cardone
CEO, Cancer Patients Europe

Ending discrimination against cancer survivors

11:10 - 11:30

Ending Discrimination Against Cancer Survivors

The Right to be Forgotten as a Human Right

COFFEE BREAK



ÉIRE2026.EU
IRELAND2026.EU
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11:30 - 12:30

Ending discrimination against cancer survivors

Session II

From Commitment to Advancing the Right to be Forgotten Across Europe - National Perspective

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Hugo Soares
AICIB, Co-Coordinator of ECHoS project and the Portuguese National Cancer Hub, **PT**



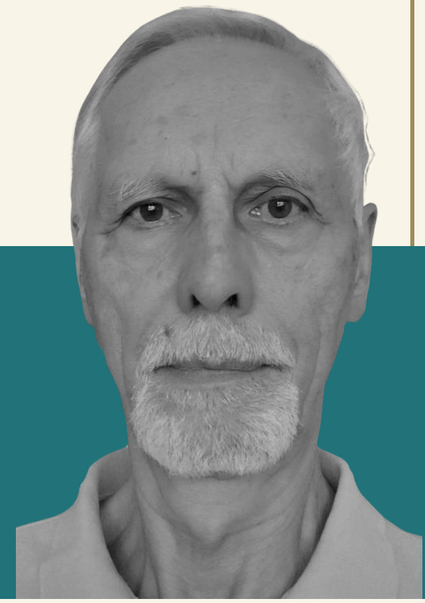
Emma Harte
Policy and Campaigns Manager, Irish Cancer Society, **IE**



Prof. Dr. Inken Hilgendorf
Deputy Director, Clinic of Internal Medicine II, Jena University Hospital, **DE**



Dr. Gabriele Calaminus
Lead Long term follow-up and Quality of Life research Unit, University Bonn, **DE**



Pavel Trcka
Patient Advocate, HOP (Cancer Patients Voice), **CZ**

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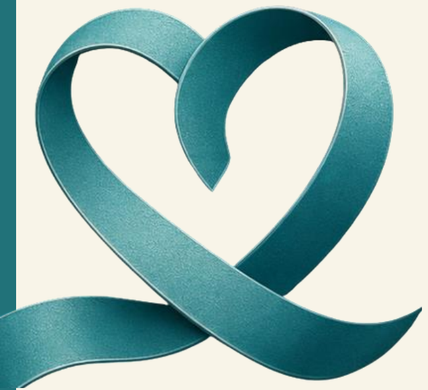
From Commitment to Advancing the Right to be Forgotten Across Europe

Hugo Soares

AICIB, Co-Coordinator of ECHoS project and the Portuguese National Cancer Hub

Portugal



AICIB

AGÊNCIA DE INVESTIGAÇÃO CLÍNICA E INOVAÇÃO BIOMÉDICA

Presentation Outline

- Agency for Clinical Research and Biomedical Innovation (AICIB)
- Building the legal right – the Journey
- Current situation
- ECHoS project and theNational Cancer Mission Hubs

Agency for Clinical Research and Biomedical Innovation

Resolution of the Council of Ministers N. 27/2018

AICIB
AGÊNCIA DE INVESTIGAÇÃO CLÍNICA E INOVAÇÃO BIOMÉDICA

FOUNDING MEMBERS

Health Cluster Portugal

Infarmed
Autoridade Nacional do Medicamento e Produtos de Saúde, I.P.

apifarma
ASSOCIAÇÃO PORTUGUESA DA INDÚSTRIA FARMACÊUTICA

MISSION

To promote, coordinate and support activities in the areas of clinical and translational research and biomedical innovation, **contributing to the optimisation of Portugal's clinical, scientific and technological potential.**

FROM ADVOCACY TO LAW

Building the legal right

The journey from survivor advocacy to a statutory right in credit and associated insurance.

Pre-2021
Public advocacy
Discrimination placed on the policy agenda

ACREDITAR

18 Nov 2021

Law 75/2021
Right established and discrimination prohibited

2022
Entry into force
Protection becomes legally applicable

2022–2023

Implementation gap
Parliament calls for operational measures

Legal refinement
Framework amended while regulation remains pending

OUTCOME **Historical health data cannot be requested after statutory waiting periods**

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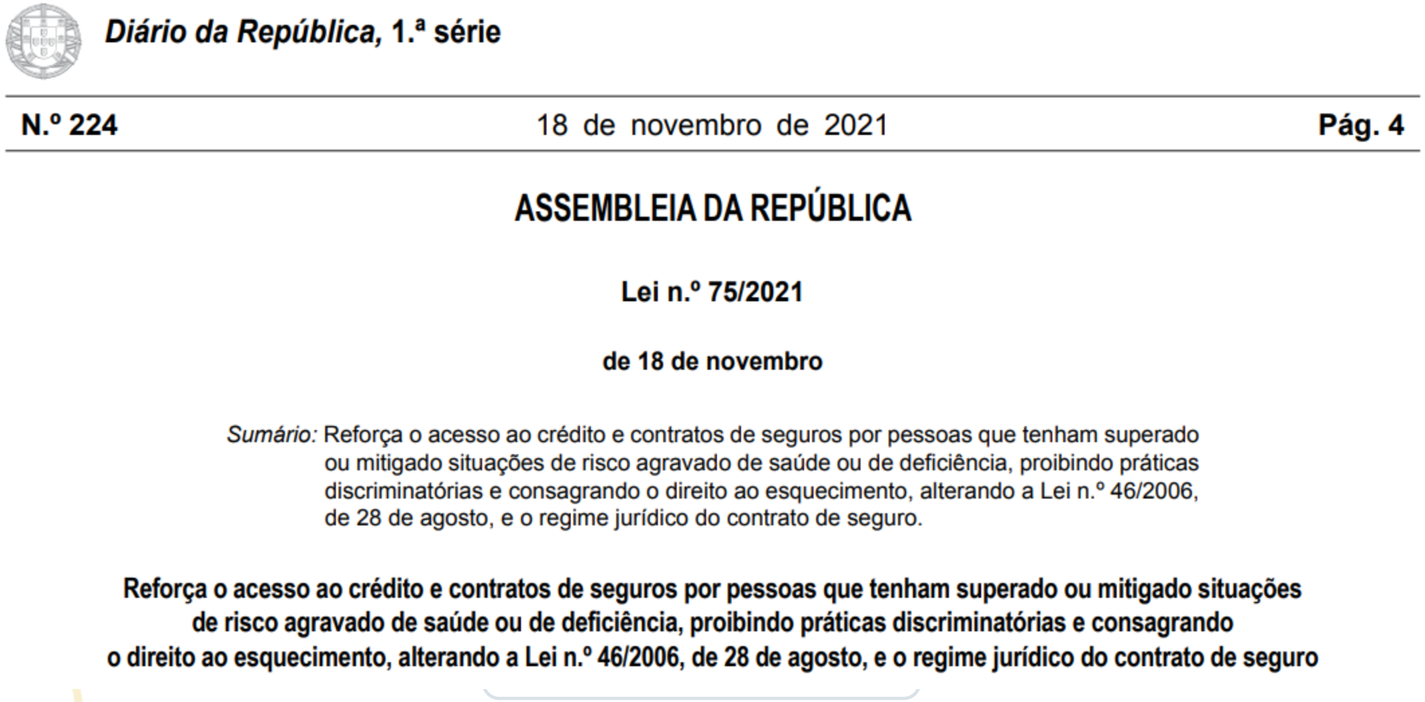

Diário da República, 1.ª série

N.º 224 — 18 de novembro de 2021 — Pág. 4

ASSEMBLEIA DA REPÚBLICA

Lei n.º 75/2021

de 18 de novembro

Sumário: Reforça o acesso ao crédito e contratos de seguros por pessoas que tenham superado ou mitigado situações de risco agravado de saúde ou de deficiência, proibindo práticas discriminatórias e consagrando o direito ao esquecimento, alterando a Lei n.º 46/2006, de 28 de agosto, e o regime jurídico do contrato de seguro.

Reforça o acesso ao crédito e contratos de seguros por pessoas que tenham superado ou mitigado situações de risco agravado de saúde ou de deficiência, proibindo práticas discriminatórias e consagrando o direito ao esquecimento, alterando a Lei n.º 46/2006, de 28 de agosto, e o regime jurídico do contrato de seguro

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OUTCOME **Historical health data cannot be requested after statutory waiting periods**

FROM RULES TO OPERATION

Making the right usable

Regulatory clarification, consumer information and full operationalisation.

Sep 2024

Public consultation

ASF Consultation 10/2024 opens

Formal Complain in court

17 Dec 2024

Insurance rules

ASF Regulation 12/2024-R approved

2025

Consumer channel

Guidance and FAQs made available at ASF website

17 Mar 2026

Full regulation

Reference grid and redress mechanisms introduced

Updated framework

Guidance and legislation consolidated

PARLIAMENT	GOVERNMENT	ASF + BANK OF PORTUGAL	Directorate General for Health Portuguese Medical Councilc
Creates and amends the legal right	Regulates the statutory framework	Supervise information and sector duties	Support scientific reference updates

FROM RULES TO OPERATION

Making the right usable

Regulatory clarification, consumer information and full operationalisation.

Sep 2024

Formal Complain in court

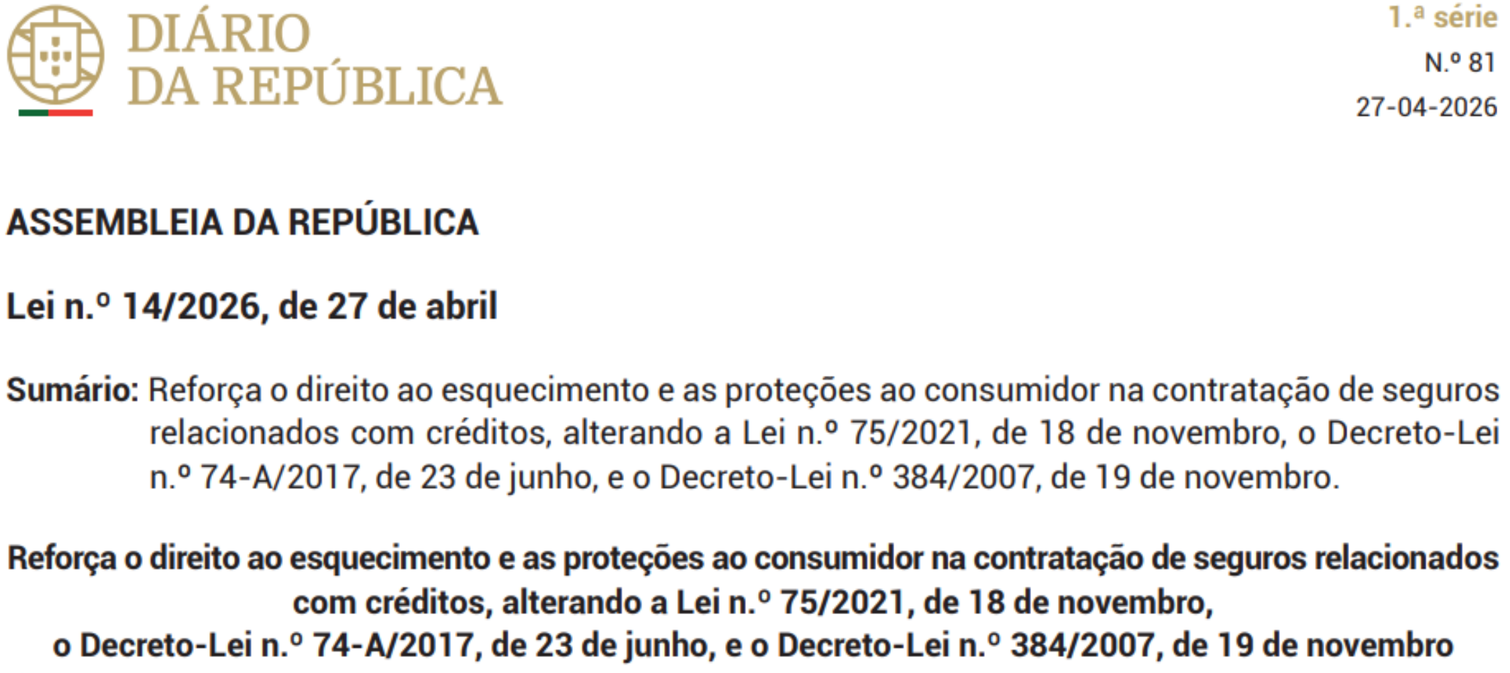
ACREDITAR

DECO SEMPRE CONSIGO

LIGA PORTUGUESA

GAT GRUPO DE ATIVISTAS EM TRATAMENTOS

ser+ Associação Portuguesa para a Prevenção e Desafio à Sida



DIÁRIO DA REPÚBLICA

1.ª série
N.º 81
27-04-2026

ASSEMBLEIA DA REPÚBLICA

Lei n.º 14/2026, de 27 de abril

Sumário: Reforça o direito ao esquecimento e as proteções ao consumidor na contratação de seguros relacionados com créditos, alterando a Lei n.º 75/2021, de 18 de novembro, o Decreto-Lei n.º 74-A/2017, de 23 de junho, e o Decreto-Lei n.º 384/2007, de 19 de novembro.

Reforça o direito ao esquecimento e as proteções ao consumidor na contratação de seguros relacionados com créditos, alterando a Lei n.º 75/2021, de 18 de novembro, o Decreto-Lei n.º 74-A/2017, de 23 de junho, e o Decreto-Lei n.º 384/2007, de 19 de novembro

Updated framework

Guidance and legislation consolidated

PARLIAMENT

Creates and amends the legal right

GOVERNMENT

Regulates the statutory framework

ASF + BANK OF PORTUGAL

Supervise information and sector duties

Directorate General for Health
Portuguese Medical Councilc

Support scientific reference updates

High-Level Conference 2026: The Right To Be Forgotten as a Human Right

21 Oct 2026

Implementing Survivorship and quality-of-life survey

The role of the Portuguese NCMH

National Cancer Hub PT

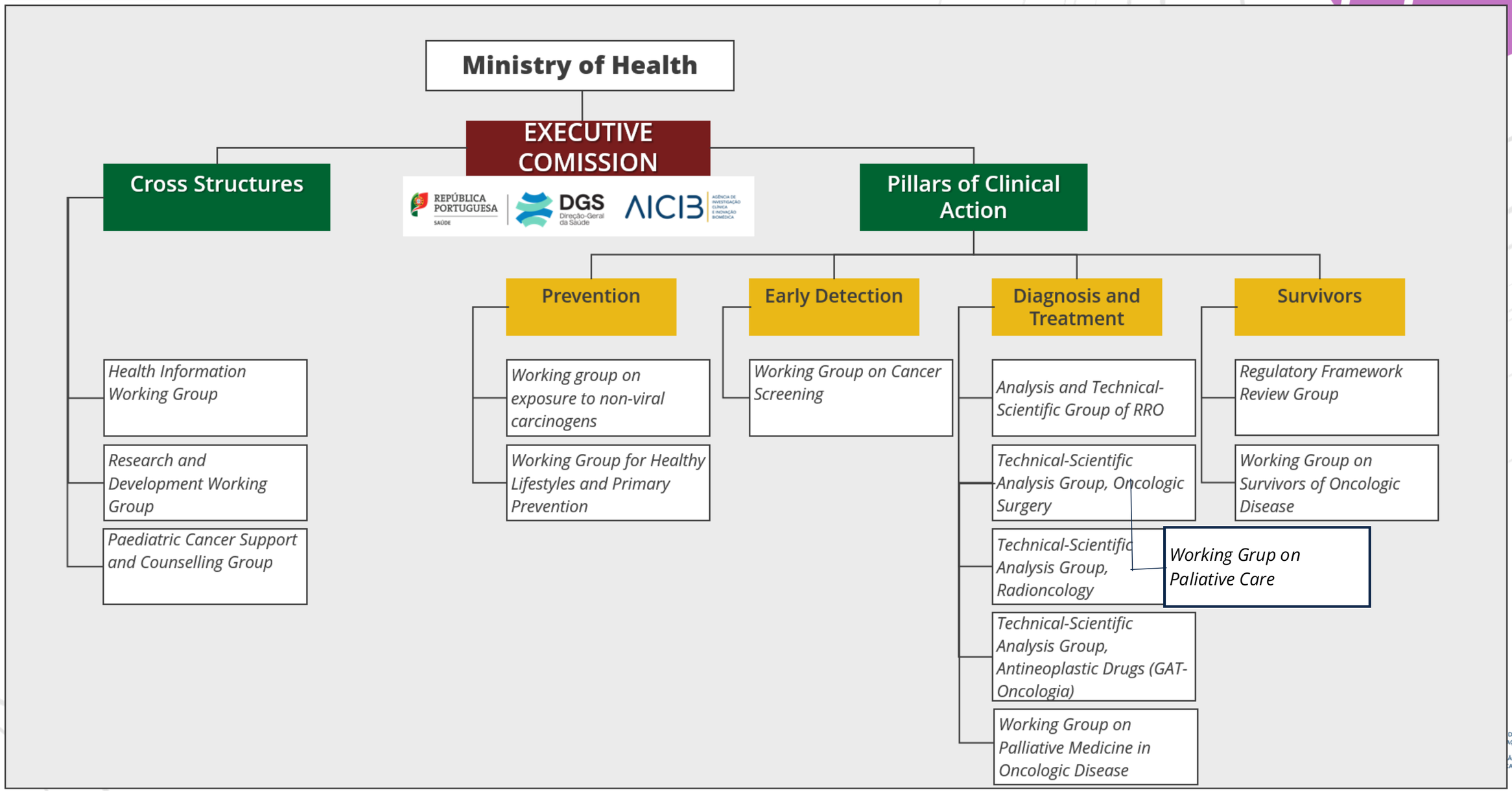
NCH PT

REPÚBLICA PORTUGUESA
SAÚDE

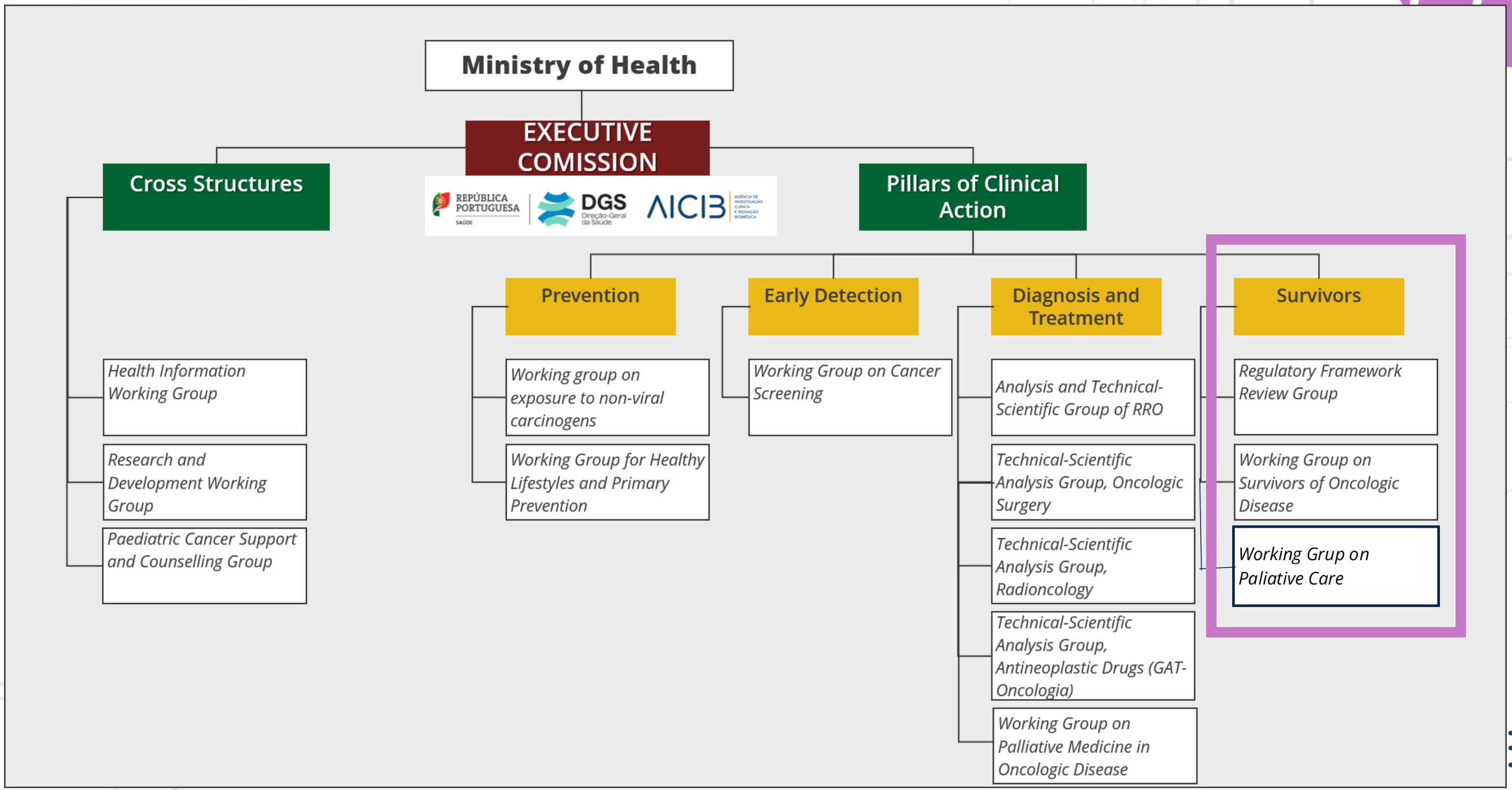
DGS
Direção-Geral da Saúde

AICIB
AGÊNCIA DE INVESTIGAÇÃO CLÍNICA E INOVAÇÃO BIOMÉDICA

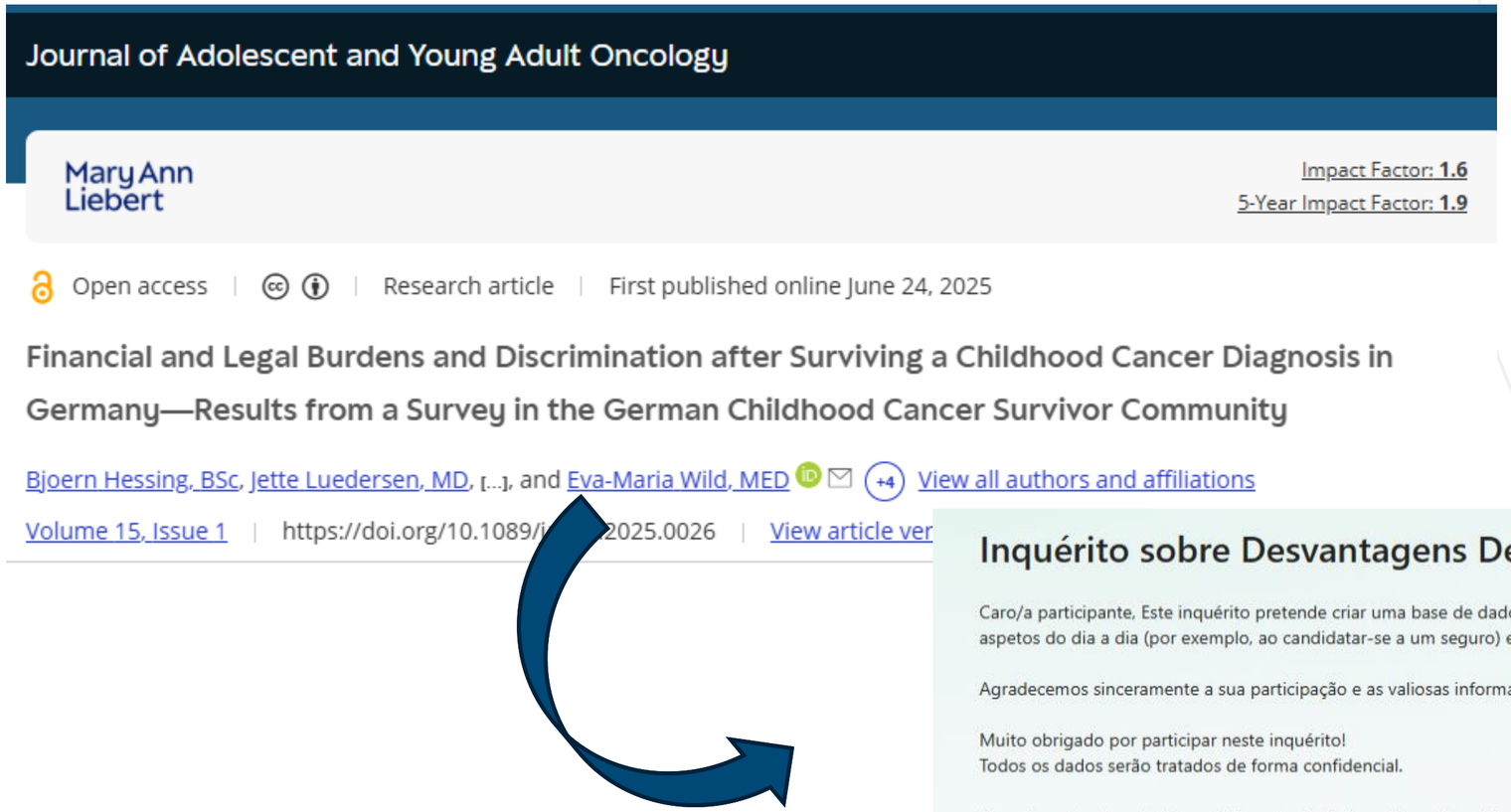
National Cancer Control Strategy, Horizon 2030



National Cancer Control Strategy, Horizon 2030



National Cancer Hub support



Journal of Adolescent and Young Adult Oncology

Mary Ann Liebert

Impact Factor: 1.6
5-Year Impact Factor: 1.9

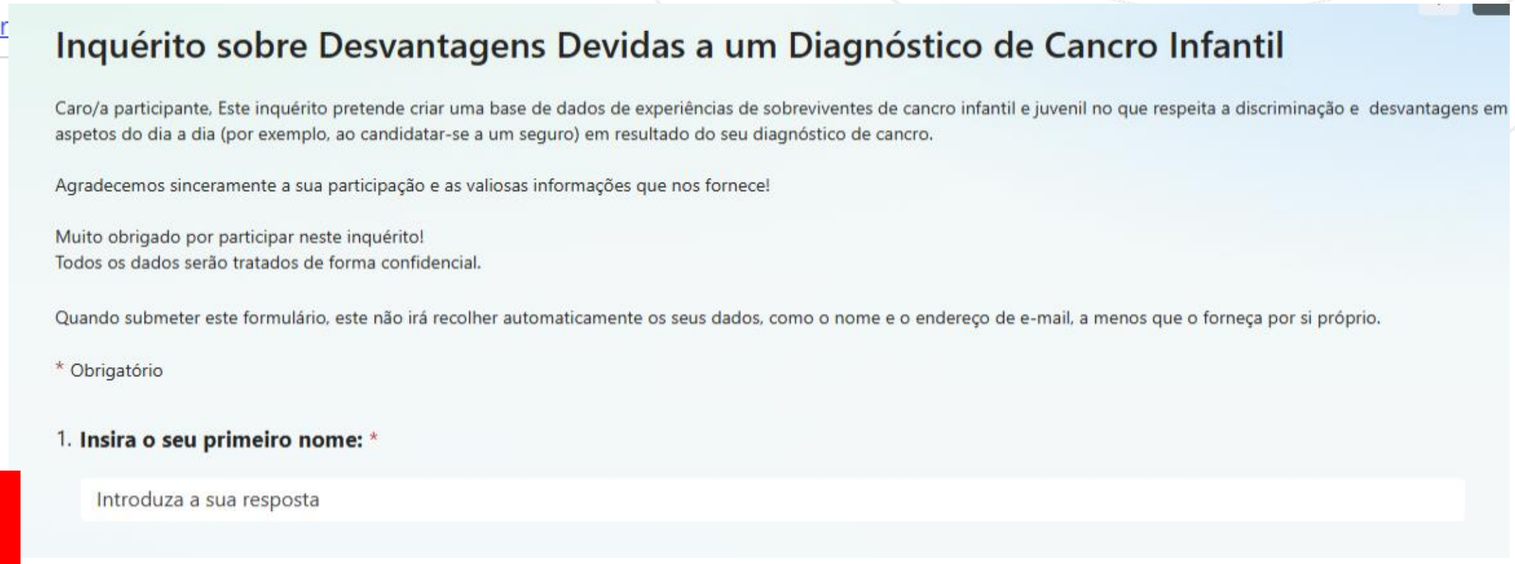
Open access | Research article | First published online June 24, 2025

Financial and Legal Burdens and Discrimination after Surviving a Childhood Cancer Diagnosis in Germany—Results from a Survey in the German Childhood Cancer Survivor Community

Bjoern Hessing, BSc, Jette Luedersen, MD, [...], and Eva-Maria Wild, MED +4 View all authors and affiliations

Volume 15, Issue 1 | https://doi.org/10.1089/j 2025.0026 | View article ver





Inquérito sobre Desvantagens Devidas a um Diagnóstico de Cancro Infantil

Caro/a participante, Este inquérito pretende criar uma base de dados de experiências de sobreviventes de cancro infantil e juvenil no que respeita a discriminação e desvantagens em aspetos do dia a dia (por exemplo, ao candidatar-se a um seguro) em resultado do seu diagnóstico de cancro.

Agradecemos sinceramente a sua participação e as valiosas informações que nos fornece!

Muito obrigado por participar neste inquérito!
Todos os dados serão tratados de forma confidencial.

Quando submeter este formulário, este não irá recolher automaticamente os seus dados, como o nome e o endereço de e-mail, a menos que o forneça por si próprio.

* Obrigatório

1. **Insira o seu primeiro nome:** *

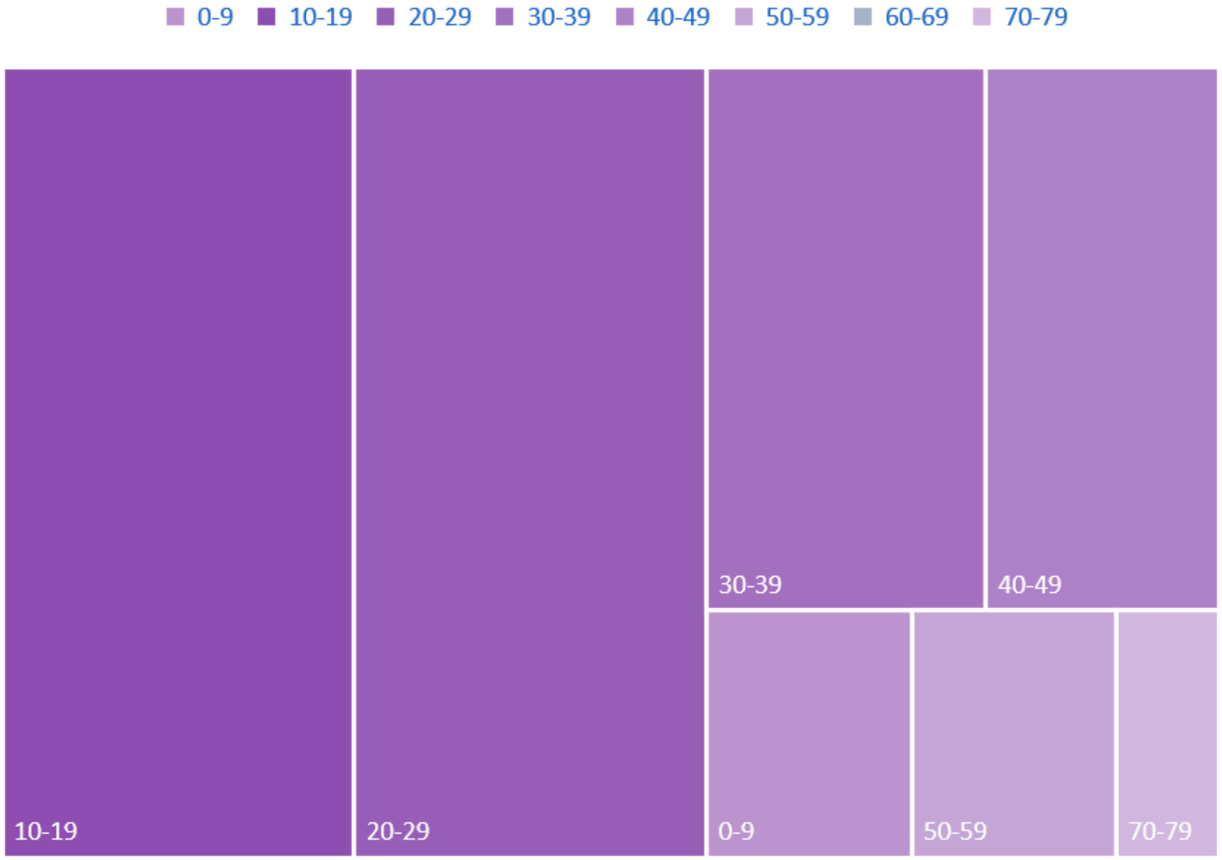
Introduza a sua resposta



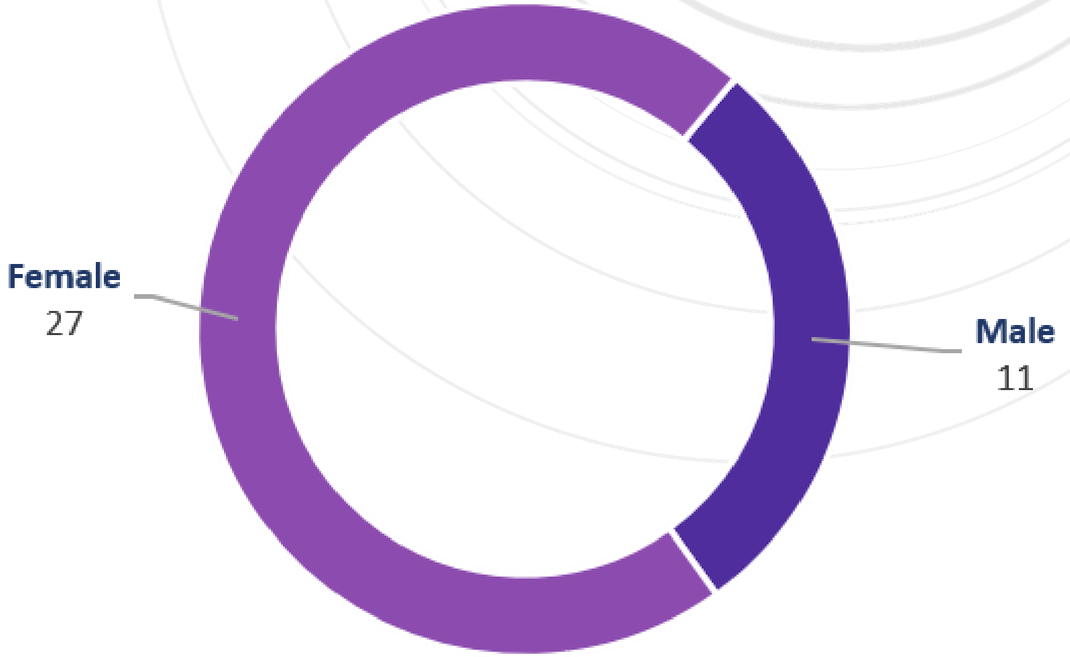
Discrimination Survey

IN PROGRESS

Age Distribution



Gender Balance



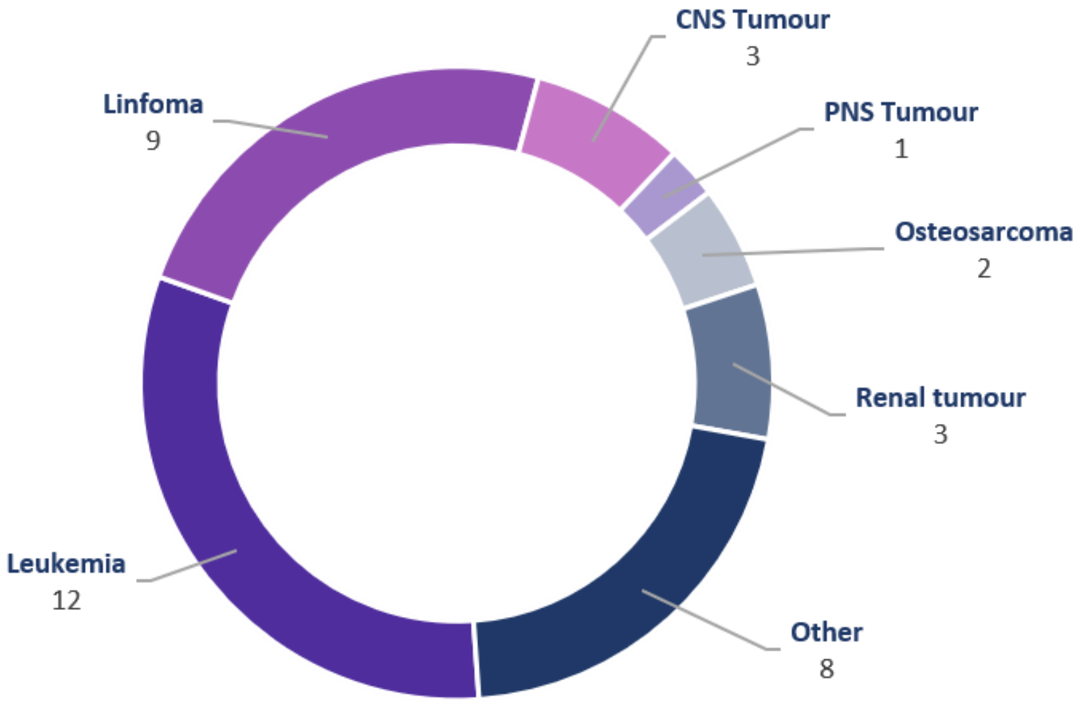
National Cancer Hub PT
NCH PT

REPÚBLICA PORTUGUESA SAÚDE
DGS Direção-Geral da Saúde
AICIB AGÊNCIA DE INVESTIGAÇÃO CLÍNICA E INOVAÇÃO BIOMÉDICA

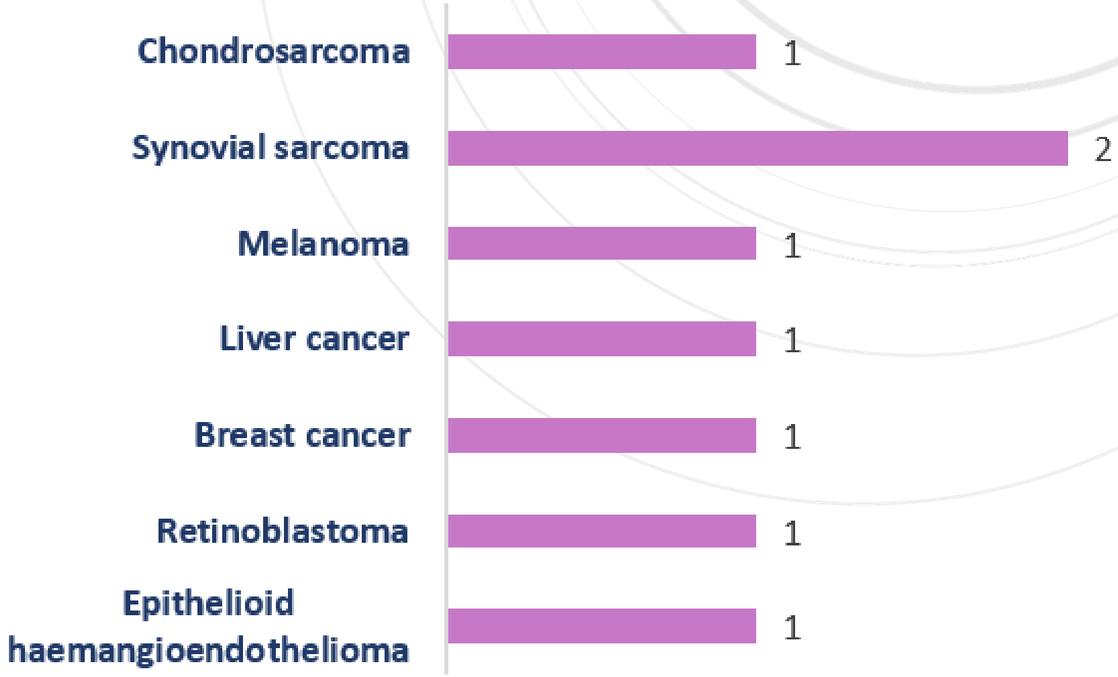
Discrimination Survey

IN PROGRESS

Diagnosis



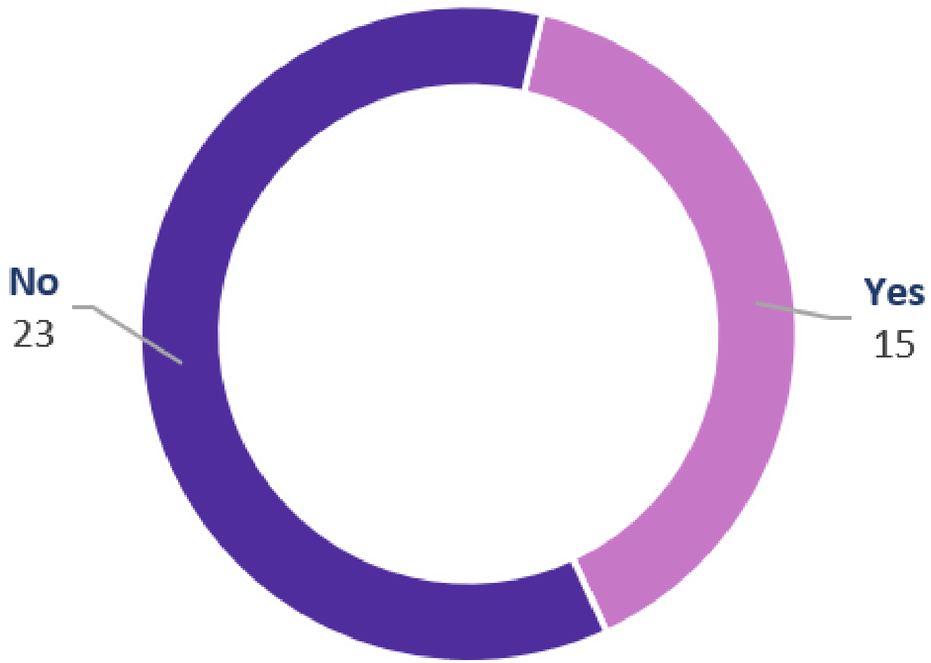
"Other" cancer types referred



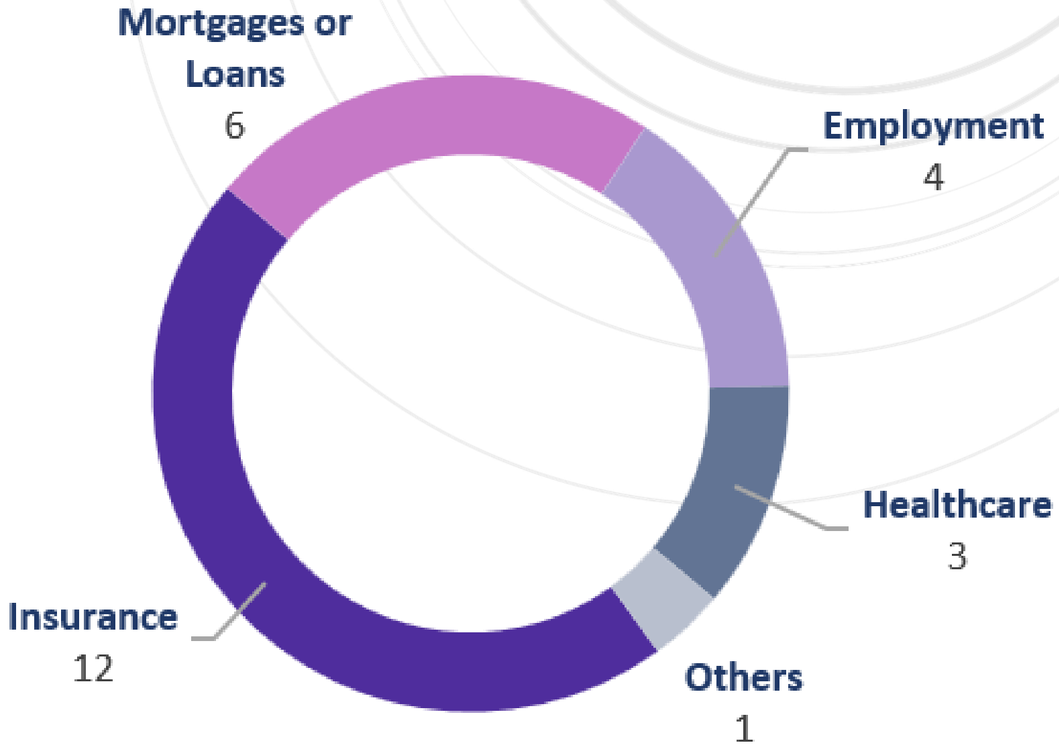
Discrimination Survey

IN PROGRESS

Have you ever endured any disadvantage due to your cancer diagnosis?



In which area(s) did the disadvantage occur?



Discrimination Survey

IN PROGRESS

"At a **private hospital**, they told me that knee surgery would be a more complicated process because of my medical history, and that **it would be better to have it done in the public system."**

"Increase in the mandatory **insurance premium** for a bank loan. Increase in the loan interest rate."

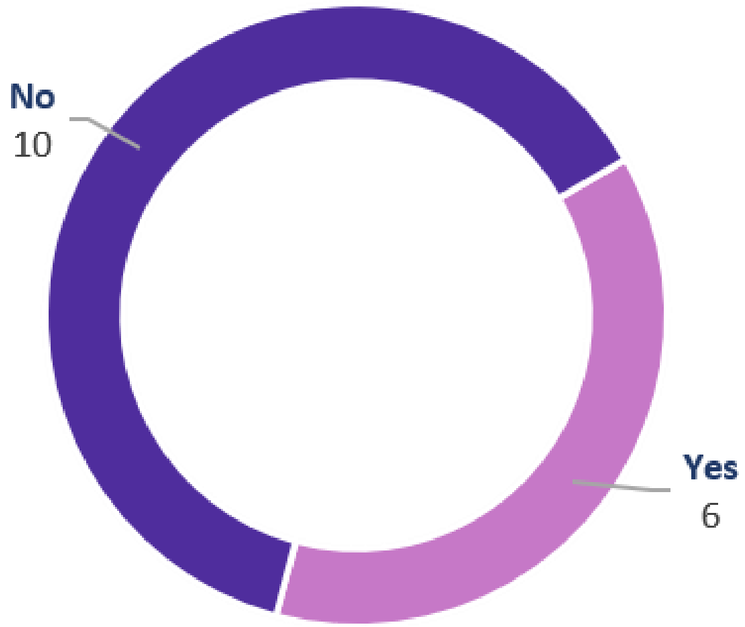
"**Several insurers wouldn't even consider it**, and the one that agreed required a medical declaration of cure and still **charged triple the usual amount**. For home loans, most banks don't grant credit under the disability regime."

*"**Health insurance with a much higher annual cost**, mainly focused on chemotherapy treatments, even though I had the illness more than 20 years ago."*

Discrimination Survey

IN PROGRESS

Did you try to take any measure against this disadvantage?



"I contacted several insurers. None of them would give me insurance. I felt discriminated against **and lost the deposit I had paid for the house I wanted to buy."**

"'Useless' is the only word that comes to mind."

"There was no legal recourse."

"I learned more about defending patients' rights, joined several patient associations and began my journey as a patient advocate."

Network of NCMHs

17 NCMHs Implemented

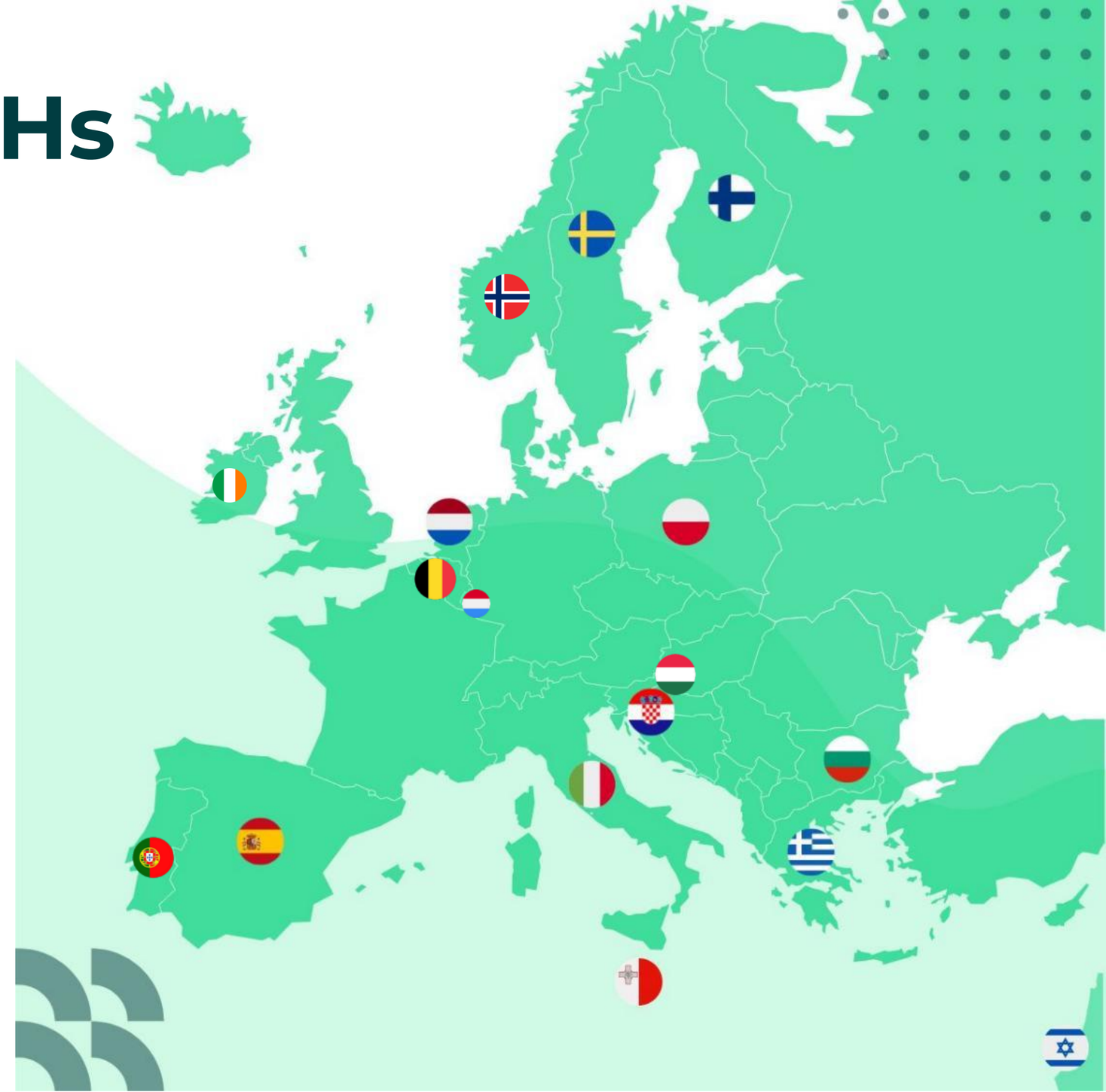
Bulgaria, Greece, Malta, Netherlands, Poland, Croatia, Finland, Israel, Italy, Spain, Sweden, Luxembourg, Portugal, Belgium, Norway, Hungary, Ireland

NCMH-like structures in development

Cyprus; Lithuania, Romania, Germany, France

Structures in Planning Phase

Türkiye, Austria, Czech Republic, Denmark, Estonia, Latvia, Slovakia, Slovenia



Ending discrimination against cancer survivors

ECHoS
Cancer Mission Hubs

AICIB
AGÊNCIA DE INVESTIGAÇÃO CLÍNICA E INOVAÇÃO BIOMÉDICA

Thank you for your attention

www.aicib.pt

11:30 - 12:30

Ending discrimination against cancer survivors

Session II

From Commitment to Advancing the Right to be Forgotten Across Europe - National Perspective

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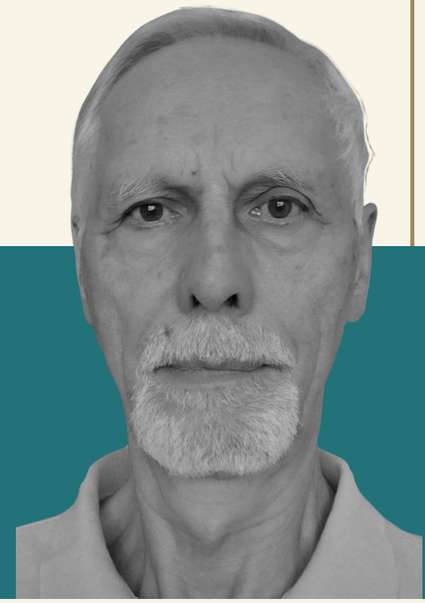

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Patient Advocate, HOP (Cancer Patients Voice), **CZ**

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From Commitment to Advancing the Right to be Forgotten Across Europe

The German Perspective

Dr. med. Gabriele Calaminus

University Hospital Bonn, Germany
WG Cancer Survivorship GPOH

Prof. Dr. med. Inken Hilgendorf

University Hospital Jena, Germany
German Foundation for Young Adults with Cancer



The Right to be Forgotten as a Human Right, 21 October 2026

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In collaboration with Irish Cancer Society

Establishing the Medical and Paediatric Survivorship Case

Gabriele Calaminus

Senior Consultant Paediatric Haematology and Oncology, University Hospital Bonn

Germany



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Ending discrimination against cancer survivors

In collaboration with Irish Cancer Society

Questions for this Talk

Cure, care and the Right to Be Forgotten

01 Why is the **medical definition of "cure"** important to the debate on the Right to Be Forgotten?

02 How should **evidence about life after childhood cancer inform** survivors' rights and reintegration?

03 How should **policymakers distinguish between the need for long-term clinical follow-up and evidence of continuing oncological risk**?

04 For access to insurance and credit, should a **past cancer diagnosis alone justify treating all survivors as high risk?**

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Definition of Cure and Care after Childhood Cancer

The Erice Statement separates the original cancer from later health needs

CURE

Refers to a cure of the original cancer—regardless of any remaining limitations, late effects, or long-term effects associated with treatment.

CARE

Includes personalized follow-up examinations, as well as comprehensive, age- and culturally sensitive information on diagnosis, treatment, curability, and residual risks.

Cure means definite cure from the original cancer
Care addresses any lasting clinical and psychosocial effects

Jankovic … Calaminus et al. J Cancer Surviv. 2018;12:647–650. Erice Statement revised in 2016

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Ending discrimination against cancer survivors

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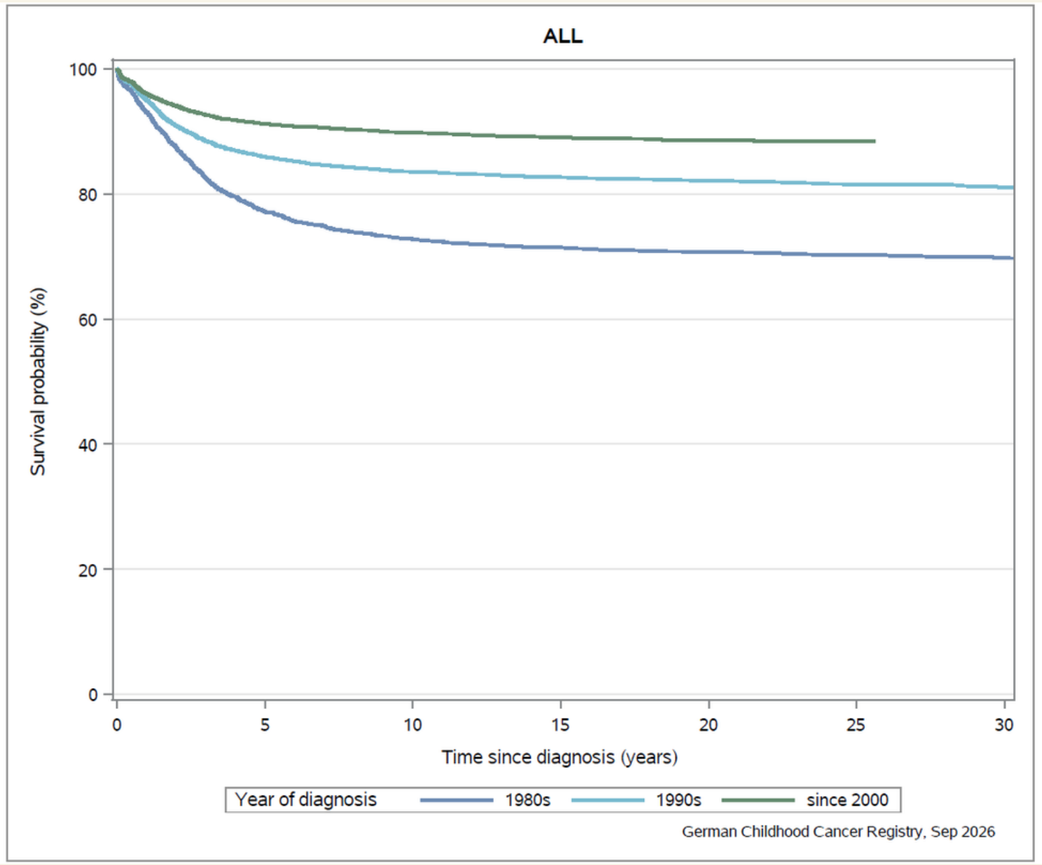
Acute Lymphoblastic Leucemia in Children and Adolescents (ALL)

A Disease Model for High Cure Rates and High Long-Term Survival

Data from the German Childhood Cancer Registry, Sept.2026



Improvements in treatment

Significant improvements in treatment are evident when comparing the cohorts

High survival rates for ALL

Once a person is cured, the cancer should no longer be treated as an ongoing disease

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Ending discrimination against cancer survivors

In collaboration with Irish Cancer Society

VersKIK: Long-term Health and Care After Childhood Cancer in Germany

Selected Study Population: childhood ALL survivors and age-matched controls, using statutory health insurance records
Only ALL survivors over 18 Yrs and at least 5 years from Diagnosis and continuously insured

6,948 people with an ALL diagnosis → 4,117 younger than 18

↓

2,831 aged at least 18 on 1 January 2017 → 92 less than five years since diagnosis

↓

2,739 at least five years since diagnosis → 573 without continuous statutory health insurance records

↓

2,166 with continuous statutory health insurance records, 2017–2021

Matched comparison group: 6,498 people

Trocchi, … Calaminus et al. Deutscher Kongress für Versorgungsforschung. 2024. doi:10.3205/24dkvf313.

VersKIK

German statutory health insurance records, 2017–2021

Average numbers of healthcare use per person-year

Events per person-year	ALL	Comparison	Rate ratio (95% CI)
Outpatient visits	5.73	4.89	1.17 (1.15–1.20)
Inpatient hospitalisations	0.23	0.17	1.34 (1.21–1.49)
Work-incapacity episodes	1.24	1.04	1.19 (1.13–1.24)

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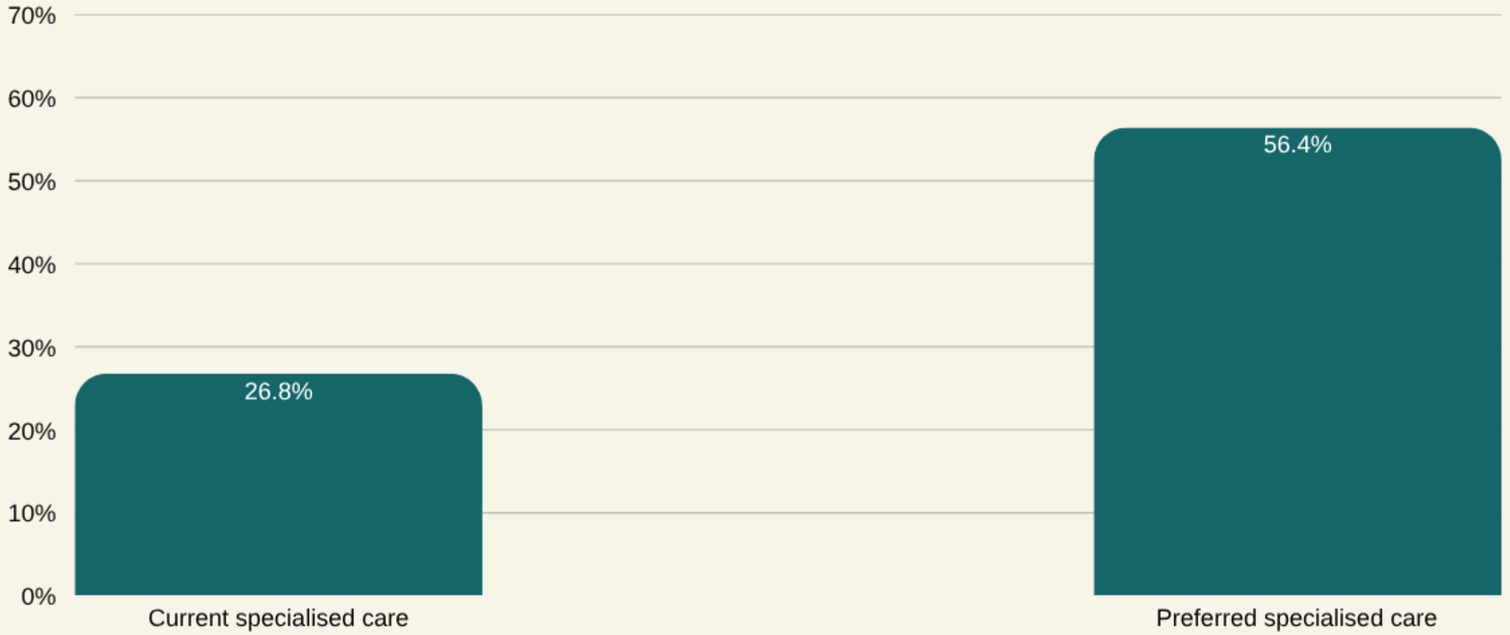
How do Survivors See their Care Situation?

German survivor-led online survey across diagnoses



69.3%

felt insufficiently informed about late effects (235 of 339).

Psychological support in adult care: 5.8% current, 17.9% preferred (n = 172).

Among 172 respondents in adult follow-up

Adapted from Figure 3. Care comparison: n = 172. Self-selected survey; not an ALL prevalence estimate.

Luedersen et al. Cancers. 2026;18:2951. doi:10.3390/cancers18182951.

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Questions for This Talk and Comments from the Paediatric Oncology Perspective

Cure, care and the Right to Be Forgotten

01 Why is the **medical definition of "cure"** important to the debate on the Right to Be Forgotten?

Cure is cure from the original disease and therefore this should no longer be taken into account

02 How should **evidence about life after childhood cancer inform survivors' rights and reintegration?**

Health services research in cooperation with survivors is the key to evaluate their living situation within the context of their social, and health political enviroment. This will produce the evidence to better understand the needs. It will create a profound base to improve care and support structures.

Questions for This Talk and Comments from the Paediatric Oncology Perspective

Cure, care and the Right to Be Forgotten

03 How should policymakers **distinguish between the need for long-term clinical follow-up and evidence of continuing oncological risk?**

Here it should be noted that long term care has to address both, the general health risks including risk for secondary cancer defined by the individual risk of the survivor.
There is no continuing oncological risk in terms of the primary cancer, if cure has been achieved.

04 For access to insurance and credit, should a past cancer diagnosis alone justify treating all survivors as high risk?

Not at all

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From Survivorship Evidence to Social Protection and Legislative Change

Prof. Dr. med. Inken Hilgendorf

University Hospital Jena, Germany
German Foundation for Young Adults with Cancer

Germany



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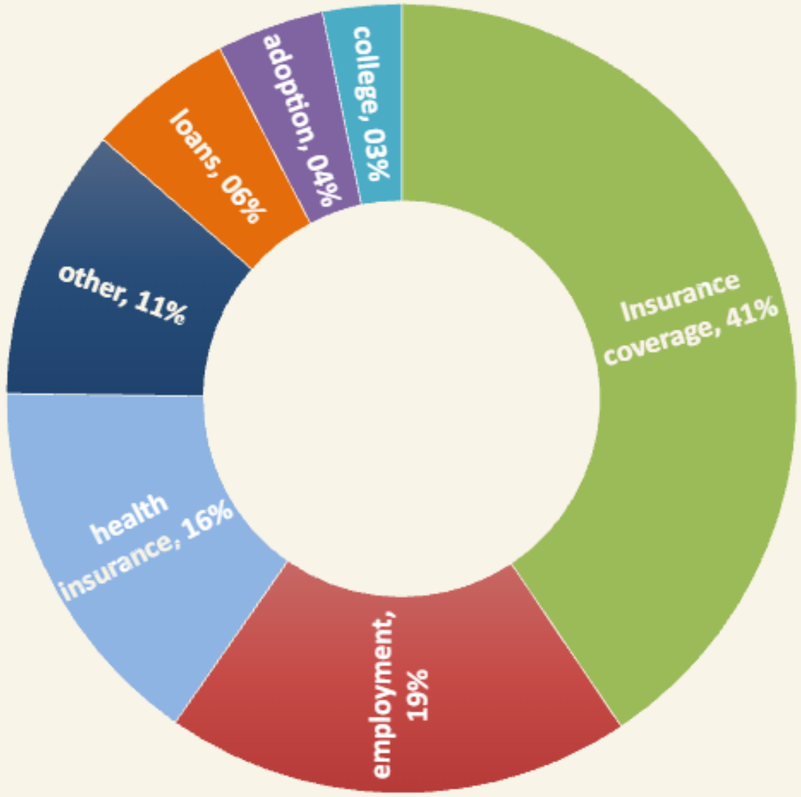
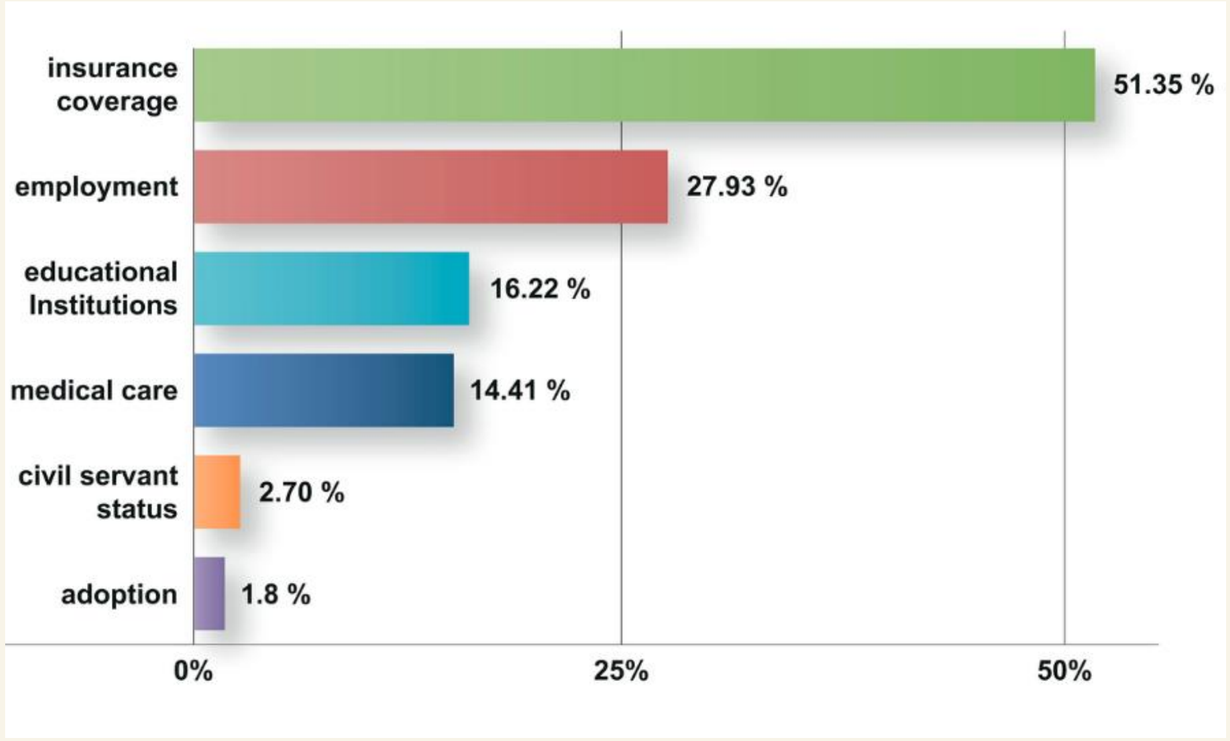
Practical Difficulties Faced by Young Adults Following Cancer

Results of a survey conducted by the German Foundation for Young Adults with Cancer & Survivor Germany





- Figure 1: modified illustration https://www.dgho.de/publikationen/schriftenreihen/junge-erwachsene/dgho_bro_gpsr_22_web.pdf
- Figure 2: Hessing et al. J Adolesc Young Adult Oncol, 15(1), 23-28, 2026

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Young Cancer Survivors Face Obstacles

Social stigmatization following the medical stigma of cancer

Survivors encounter barriers involving:

- securing insurances or
- financial products: loans and mortgages
- pursuing careers in the civil service
- family formation, including adoption and foster-care procedures.



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

© Picture: Youth Cancer Europe

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Our Campaign to Implement the Right To Be Forgotten in Germany

Germany's Long Journey

- **Since 2022: Campaigning actively for a RTBF** including discussions with politicians, education, policy advocacy, research, and raising of awareness in the general public
- **06/24: Joint satellite symposium** with the German Society for Hematology and Oncology e.V. (DGHO) at the Berlin Health Policy Congress on the topic: 'Right to be Forgotten – Stopping Discrimination Against Cancer Patients in Germany Now'
- **08/24:** Meeting with the **German Insurance Association**
- **09/24:** Press Conference with the DGHO presenting the 22nd volume of the health policy series: "RTBF– Ending Discrimination Against Young Adults with Cancer"[1] and launch of an intensive media outreach campaign
- **07/25: Joint position paper** with the DGHO on the draft law for implementing Directive (EU) 2023/2225

GERMAN FOUNDATION FOR YOUNG ADULTS WITH CANCER

[1]https://www.youthcancereurope.org/yce-hosts-eu-parliament-event-to-end-financial-discrimination-against-cancer-survivors/
[2]https://www.dgho.de/publikationen/schriftenreihen/junge-erwachsene/dgho_bro_gpsr_22_web.pdf

Developments Regarding the Right To Be Forgotten in Germany

2026 - The campaign is moving forward





- **01/26:** **Meeting** with Susanne Hierl (CDU, member of the German Parliament)
- **02/26:** Press Release about RTBF for World Cancer Day
- **04/26:** **Motion for a resolution** was adopted as part of the passage of the law implementing the Consumer Credit Directive II - joint statement with the DGHO, Survivor Germany and the Children's Cancer Association, on the draft of the Second Act Amending the General Equal Treatment Act
- **07/26:** The Foundation advocated for a **legal RTBF for the NRW State Parliament's** Committee on Labour, Health and Social Affairs - SPD Presidency adopted a resolution supporting a statutory RTBF extending substantially beyond credit-linked insurance

An important political Step – Legislative Implementation is Still Pending

Summary of the last month



© Picture: Bundesrat | Dirk Deckbar

- **22.09.26:** 3 Federal States submitted a **motion for a resolution** on the RTBF to the Federal Council
- **02.10.26:** Committee on Family, Senior Citizens, Women, and Youth and the Health Committee recommended deleting the passage regarding adoption efforts
- **14.10.26:** **Joint statement** of the Foundation with the DGHO, GPOH, Children's Cancer Association and Survivor Germany on maintaining the adoption efforts in the resolution
- **16.10.26:** Federal Council approved the **motion for a resolution on RTBF,** including consideration of insurance, credit, and adoption, and explicitly requiring medical evidence on relapse, long- term risk, cure, and remission to establish the framework conditions

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Our Demands

GERMAN FOUNDATION FOR YOUNG ADULTS WITH CANCER

The German Foundation for Young Adults with Cancer calls for:

- **A legally binding RTBF, allowing survivors to move on without discrimination after a defined remission period.**
- **Broad legal coverage, ensuring protections apply across insurance, credit, employment, and adoption.**
- **Increased awareness and destigmatisation, so that young survivors are not treated as lifelong "risk patients."**

Every child, adolescent and young adult who survives cancer should be able to live, work, and plan their future on equal terms with their peers.

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Enough words have been exchanged. Let me finally see some action!

J. W. Goethe

Dr. Gabriele Calaminus
Gabriele.Calaminus@ukbonn.de
Working Group Cancer Survivorship GPOH

Prof. Dr. Inken Hilgendorf
Inken.Hilgendorf@med.uni-jena.de

https://junge-erwachsene-mit-krebs.de/en/right-to-be-forgotten/nt



GERMAN FOUNDATION FOR YOUNG ADULTS WITH CANCER

11:30 - 12:30

Ending discrimination against cancer survivors

Session II

From Commitment to Advancing the Right to be Forgotten Across Europe - National Perspective

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Hugo Soares
AICIB, Co-Coordinator of ECHoS project and the Portuguese National Cancer Hub, **PT**



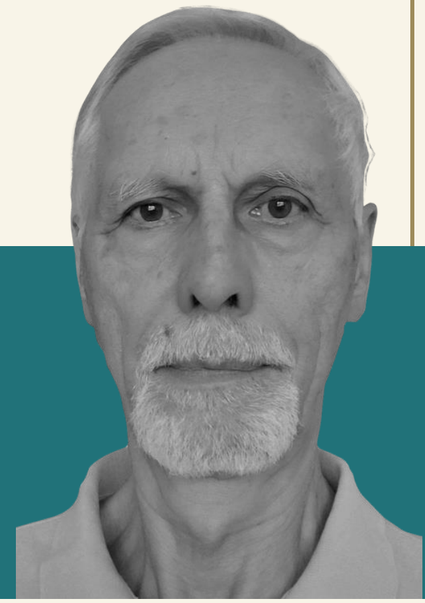
Emma Harte
Policy and Campaigns Manager, Irish Cancer Society, **IE**



Prof. Dr. Inken Hilgendorf
Deputy Director, Clinic of Internal Medicine II, Jena University Hospital, **DE**



Dr. Gabriele Calaminus
Lead Long term follow-up and Quality of Life research Unit, University Bonn, **DE**



Pavel Trcka
Patient Advocate, HOP (Cancer Patients Voice), **CZ**

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From Commitment to Advancing the Right to be Forgotten Across Europe

The Polish Perspective

Prof. Piotr Rutkowski

Maria Sklodowska-Curie Memorial Cancer Center and Institute of Oncology
Warsaw

Poland



The Right to be Forgotten as a Human Right, 21 October 2026

The right to be forgotten
In Poland

The Right to be Forgotten as a Human Right

Ending Discrimination Against Cancer Survivors

21.10.2026

Krajowy Ośrodek Monitorujący

Maria Sklodowska-Curie
National Research Institute of Oncology



12:30 - 13:00

Cancer Inequalities Facts & Figures
From Evidence to Fairer Rules

Ending discrimination against cancer survivors

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Caroline Berchet
OECD health economist working on cancer care and inequalities

Luigino Dal Maso
Head of the Cancer Epidemiology Unit, CRO Aviano, IRCCS, National Cancer Institute, **IT**

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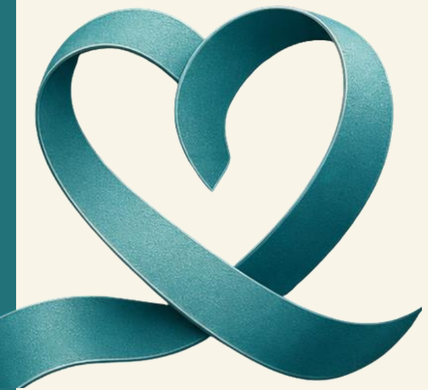
From Evidence to Fairer Rules

Caroline Berchet

OECD health economist working on cancer care and inequalities



Beating Cancer Inequalities in Europe

The Right to Be Forgotten as a Human Right
21 October 2026

Caroline Berchet, Health Economist (PhD), OECD



The European Cancer Inequalities Registry at a glance

Cancer burden and care
between EU countries and regions

Identification of trends

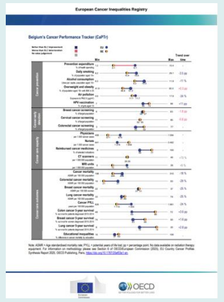
Identification of disparities

Identification of inequalities

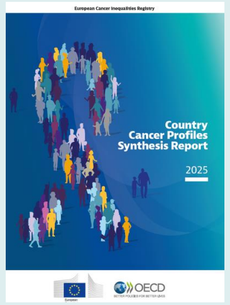
29 Country Cancer Profiles



Cancer Performance Tracker



Synthesis Report



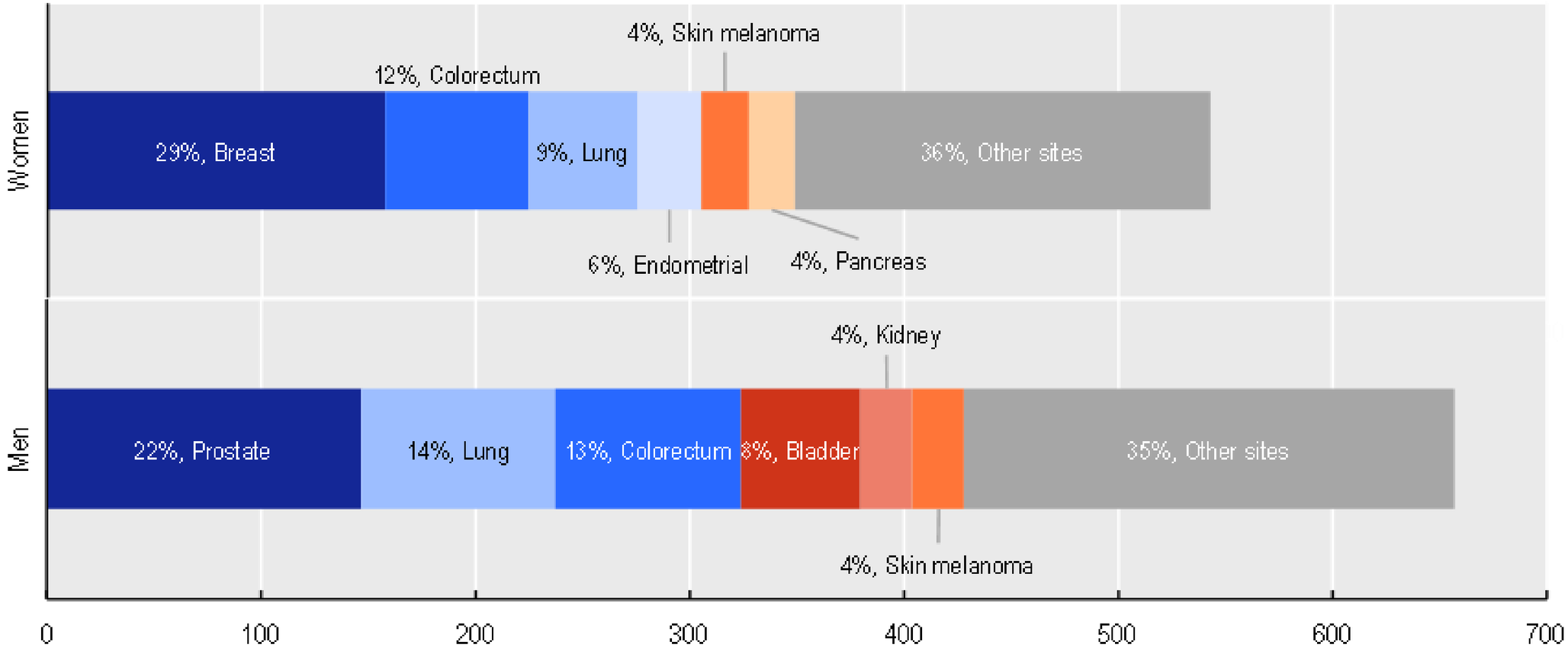
NEW report on Delivering High Value Cancer Care

Released in Feb 2026



Every minute, five people find out they have cancer in the EU

An estimated new cancer cases were diagnosed in 2024 in the EU

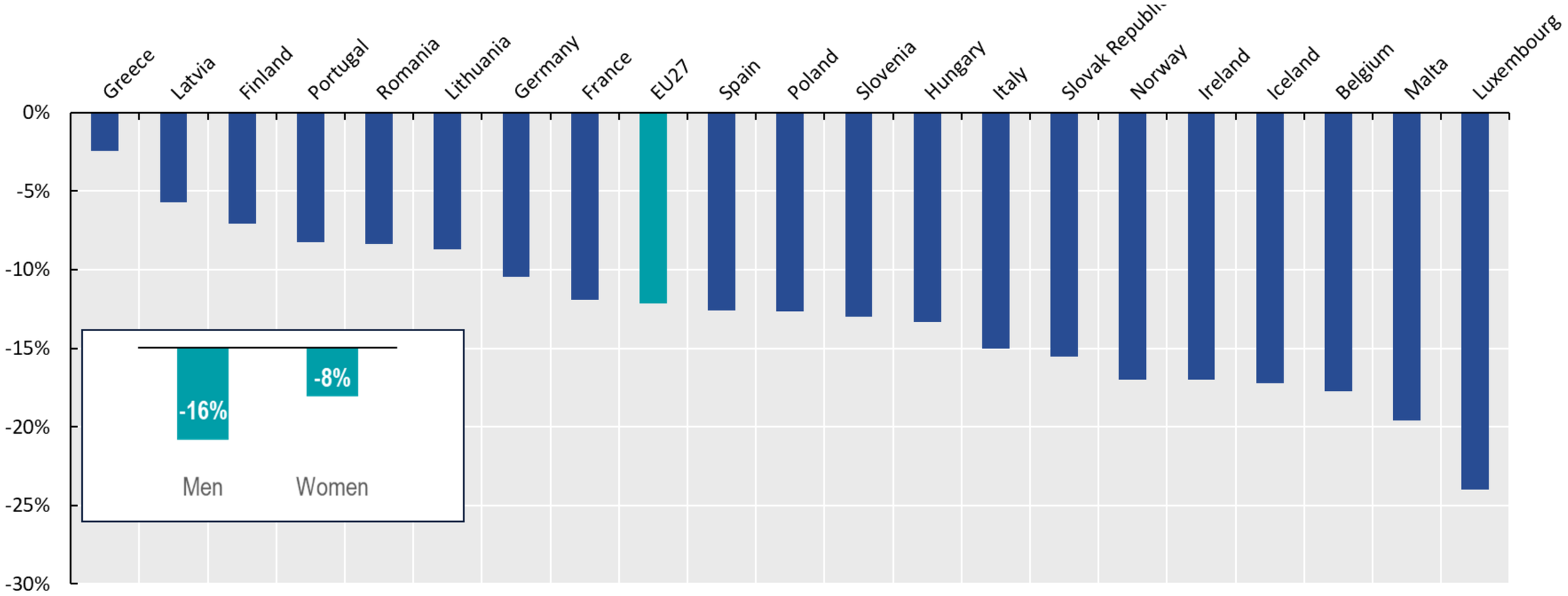


Source: European Cancer Information System (ECIS). From https://ecis.jrc.ec.europa.eu/. © European Union, 2026.

Europe’s Beating Cancer Plan is supporting key improvements in cancer control, but challenges remain

Cancer mortality rates fell in nearly all countries

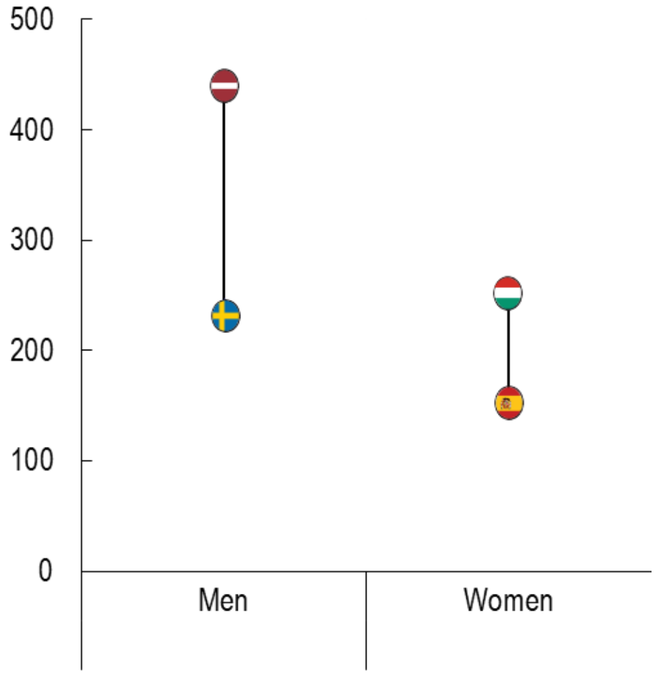
Age-standardised cancer mortality rates between 2011-2021



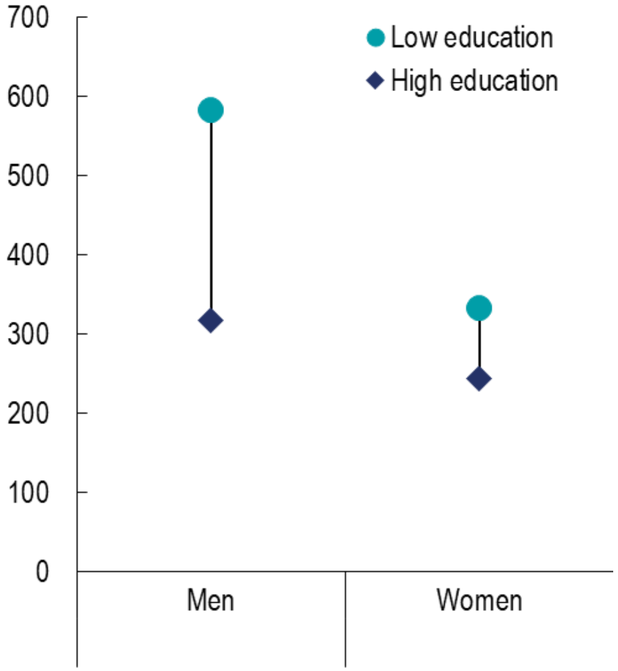
Source: Eurostat Database.

Mortality gaps across countries and between population groups vary by almost two-fold

Cancer mortality rates among men varied by between EU countries



Cancer mortality rates were among men with lower versus higher education



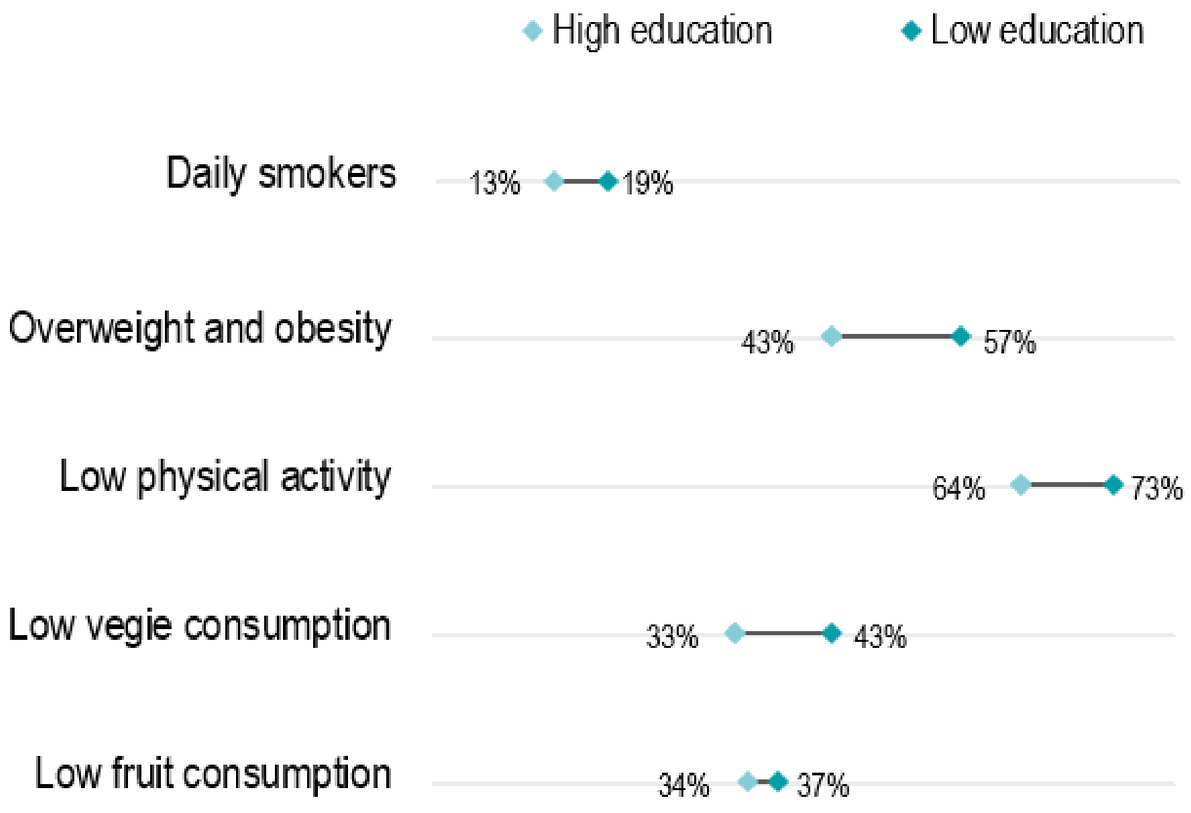
Source: European Commission/IARC/Erasmus MC (2024); Eurostat Database. Notes: Figures refer to age-standardised mortality rates per 100 000 people

Risk factors are falling, but gaps between populations remain large

from 22% to 19% between 2012-22

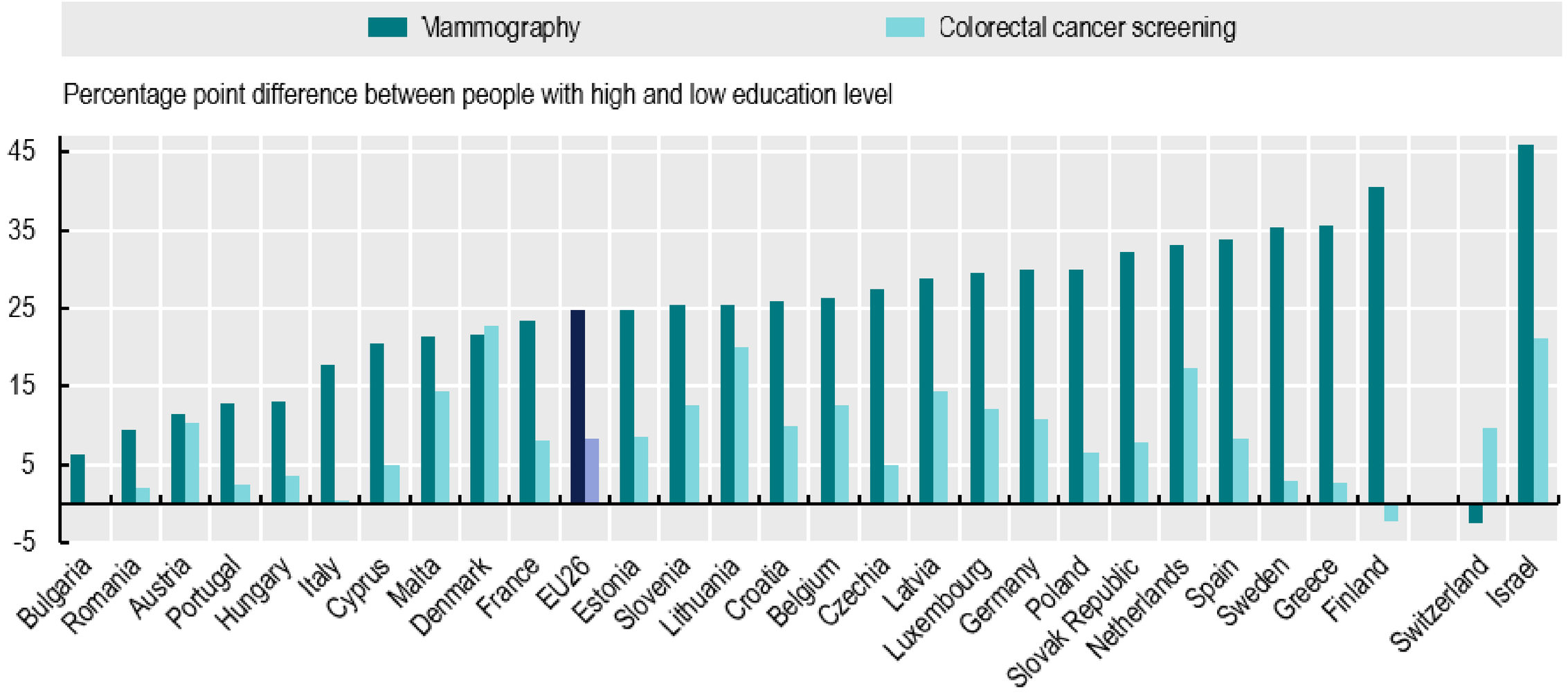
in two out of three countries between 2010 and 2022

from 56% to 64% between 2013-23



Source: OECD 2025

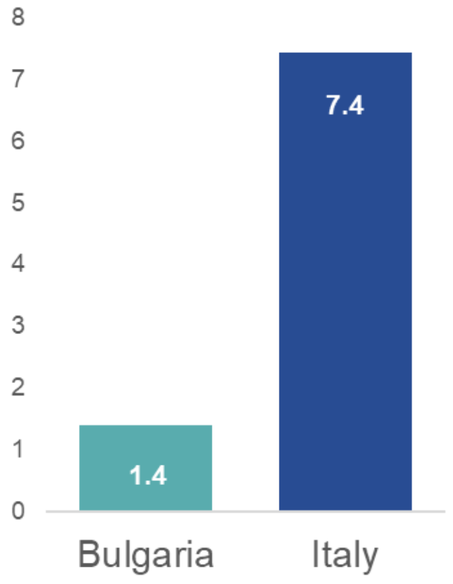
Population-based screening programs are in place but large inequalities remain by population groups



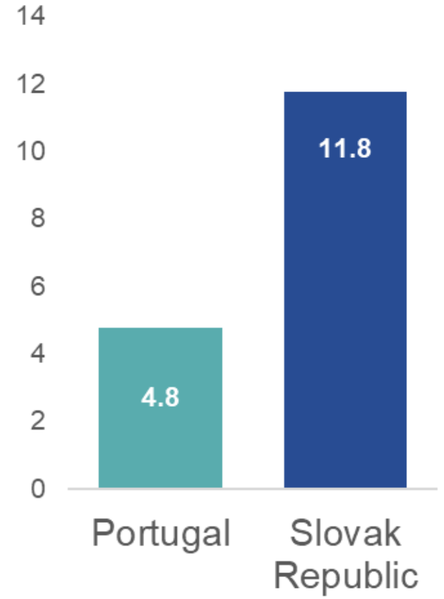
Source: OECD 2026.

Workforce and access to therapies for cancer care vary by up to 6-fold across EU countries

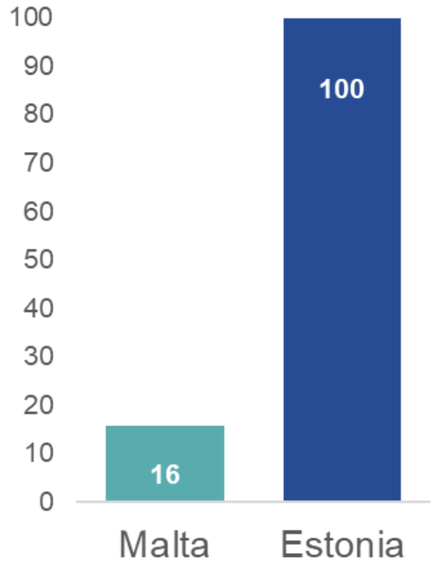
Medical, clinical or radiation oncologists per 100 000 people



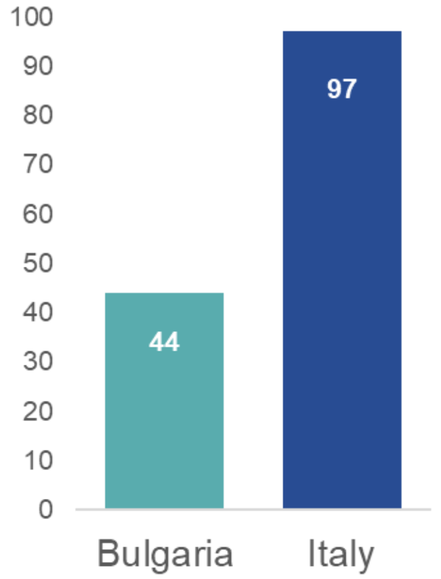
Supply of radiotherapy equipment per 1 000 000 people



Share of cancer biosimilars reimbursed



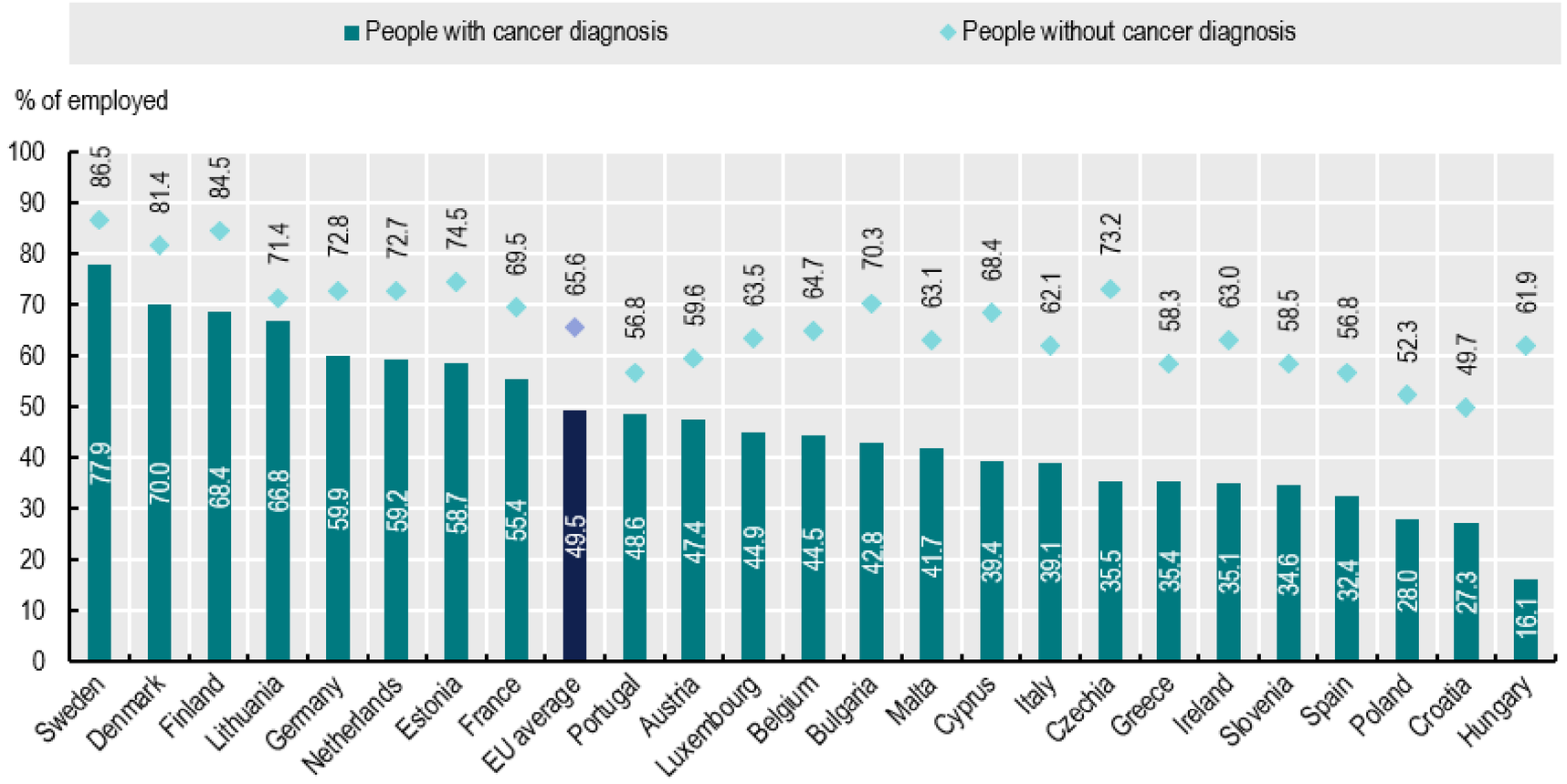
Share of essential paediatric cancer medicines available



Source: OECD Health Statistics 2024; Hofmarcher, Berchet and Dedet (2024), “Access to oncology medicines in EU and OECD countries”; Vassal et al., (2021) “Access to essential anticancer medicines for children and adolescents in Europe.”

Cancer diagnosis reduces the likelihood of employment by 14%

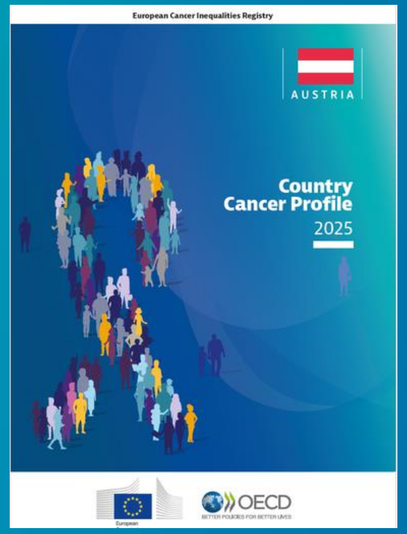
The employment gap between individuals living with a cancer diagnosis and those without is highest in Central and Eastern European countries

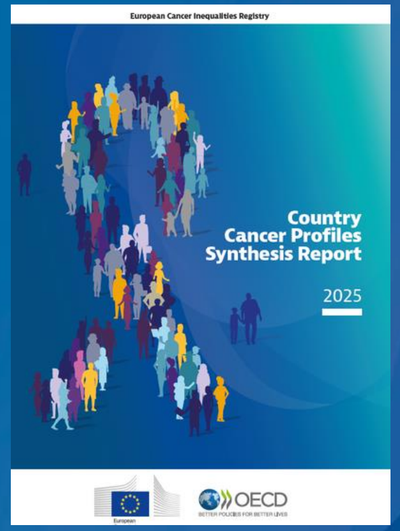


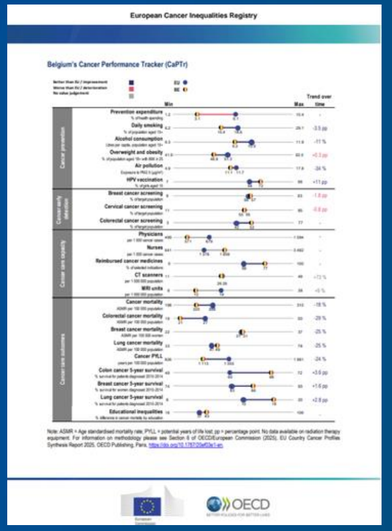
Source: OECD 2026

Thank you

Caroline.berchet@oecd.org







European Commission

OECD
BETTER POLICIES FOR BETTER LIVES

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From Evidence to Fairer Rules: Cancer Inequalities Facts & Figures

Luigino Dal Maso

Cancer Epidemiology Unit,
CRO Aviano, IRCCS, National Cancer Institute, IT

CRO AVIANO
IRCCS CRO
Istituto di ricovero e cura a carattere scientifico
"Centro di Riferimento Oncologico" di Aviano
REGIONE AUTONOMA FRIULI VENEZIA GIULIA



The Right to be Forgotten as a Human Right, 21 October 2026

FUNDINGS



Italian Foundation for Cancer Research - A.I.R.C, NGO

I HAVE NO DISCLOSURES TO DECLARE

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Scientific Contributors

IRCCS CRO
Istituto di ricovero e cura a carattere scientifico "Centro di Riferimento Oncologico" di Aviano
REGIONE AUTONOMA FRIULI VENEZIA GIULIA

L Dal Maso, F Giudici, D Serraino, F Toffolutti

A Andreotti, S Guzzinati, M Zorzi



F.A.V.O.
Federazione italiana delle Associazioni di Volontariato in Oncologia

Scientific work is the result of **the involvement** – in the planning, implementation and discussion of the research – **of those who have experienced the illness.**
Working method: **nothing about us without us**

NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

AB Mariotto

FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

L Botta, R Capocaccia, G Gatta, A Trama

EUROCARE
Survival of cancer patients in Europe

ISTITVTO SVPERIORE DI SANITA

R De Angelis, E Demuru, S Francisci, D Pierannunzio, S Rossi, A Tavilla

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WHY ARE WE INTERESTED IN CANCER "CURE" ?

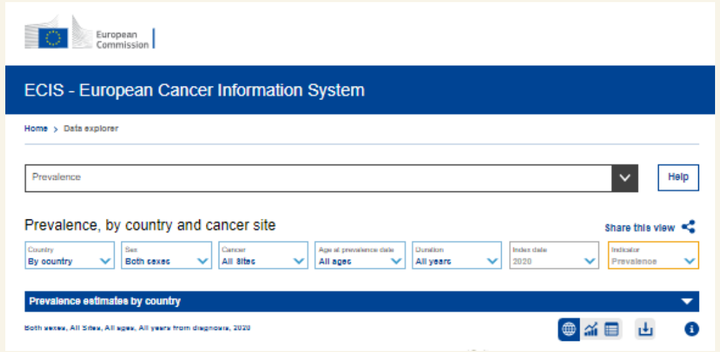
In Europe in 2020 there was 23.7 million cancer survivors

5% of the total population (448 mln)

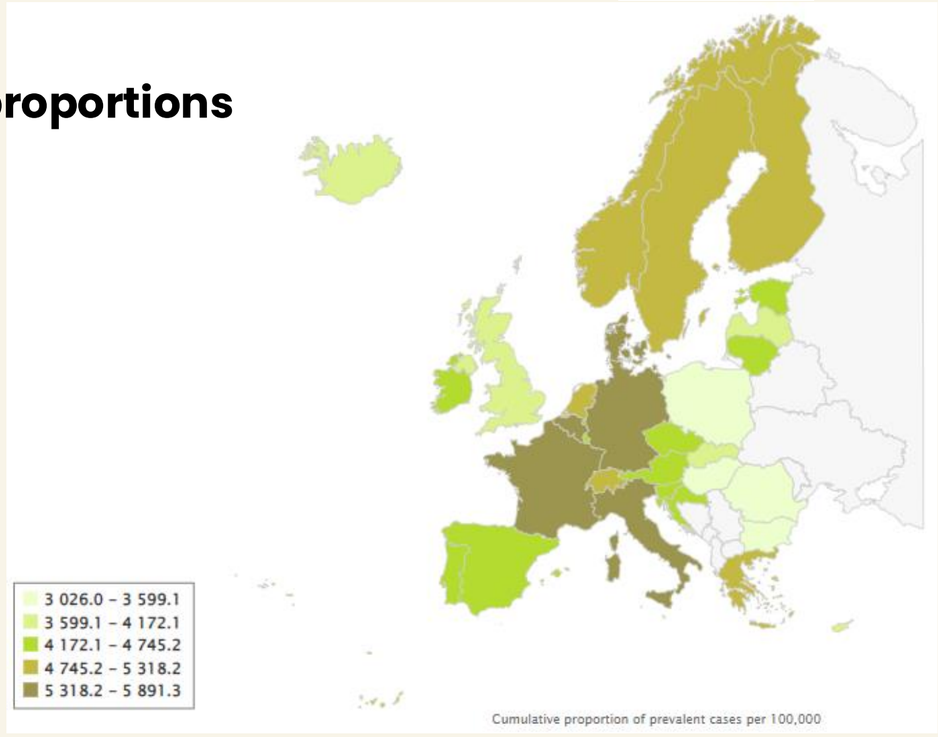
Estimates are accessible for consultation on the EUROPEAN CANCER INFORMATION SYSTEM (ECIS)
https://ecis.jrc.ec.europa.eu/

EUROCARE-6 Study





Wide differences in prevalence proportions



European Network of Cancer Registries

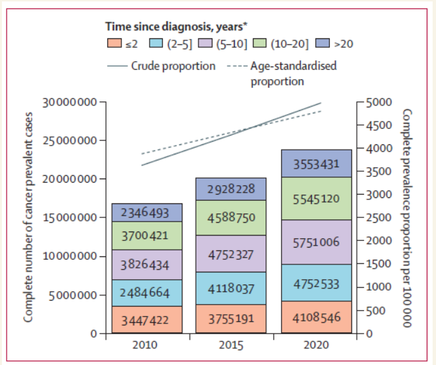


Figure 3: Change in estimated complete cancer prevalence between Jan 1, 2010, and Jan 1, 2020, in Europe (European pool of 29 countries in EUROCARE-6)

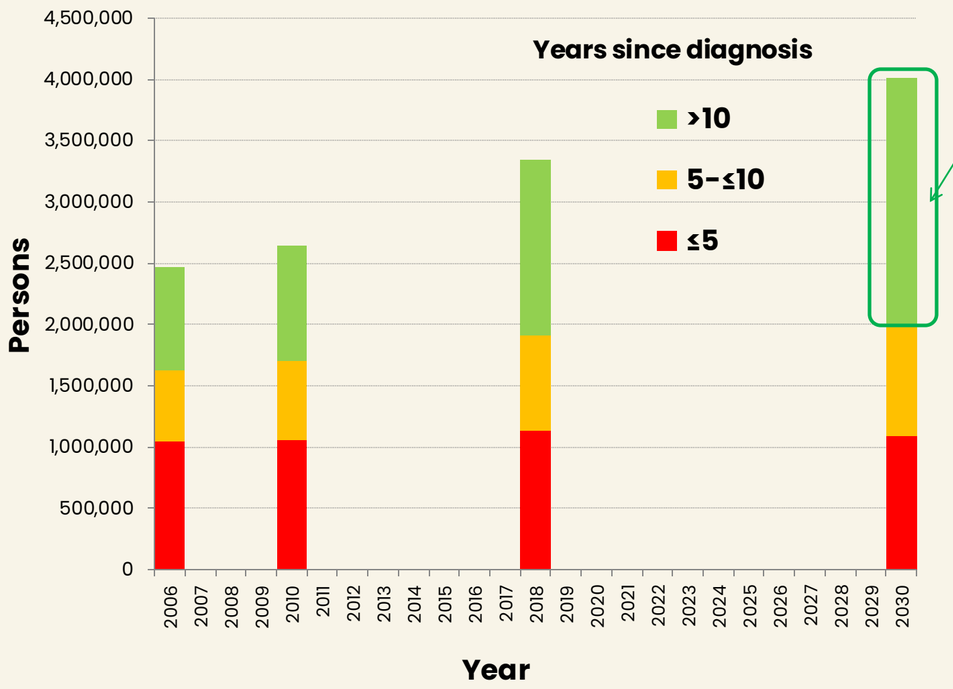
De Angelis et al. Lancet Oncol 2024

WHY ARE WE INTERESTED IN CANCER "CURE" ?

In Italy, the number of persons living after a cancer diagnosis (cancer prevalence) is increasing

…by 2030, there will be 4 million people in Italy, approximately 6.5% of the total population,

…of whom 2 million will have been diagnosed more than 10 years earlier.



Guzzinati et al. ESMO Open 2024

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MUNICH 2018 ESMO congress

WHEN IS A CANCER PATIENT CURED?

Luigino Dal Maso

PARTIALLY OR TOTALLY UNANSWERED QUESTIONS (10 YEARS AGO):

How many years will I have to wait to consider myself cured?

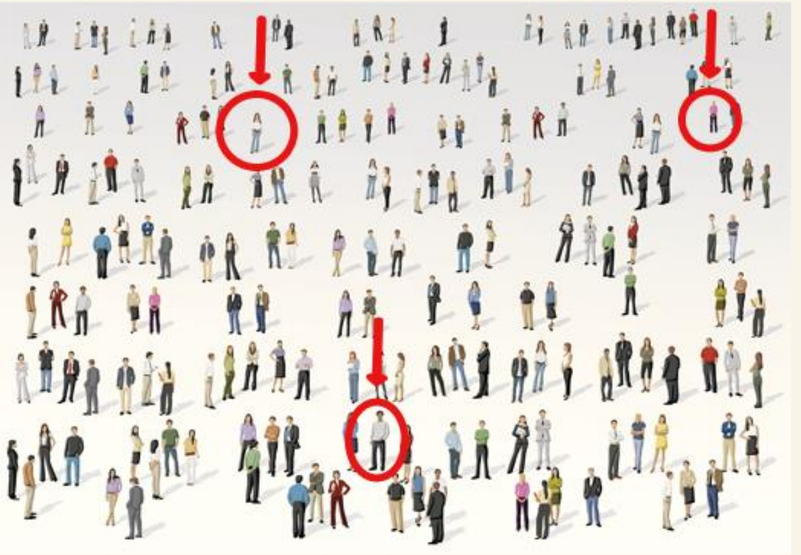
How many patients will be cured from the disease?

How many prevalent patients will not die for the disease?



How to provide an evidence-based risk stratification of cancer patients?

We are interested (can provide) in **measurable definitions of "cancer cure"**.



At **population level**, patients can be considered cured when they reach the same mortality rate (life expectancy) of the general population of the same sex and age.

At **individual level,** a measurable excess risk may remain after the elimination of all 'detectable' malignant cells (complete remission).

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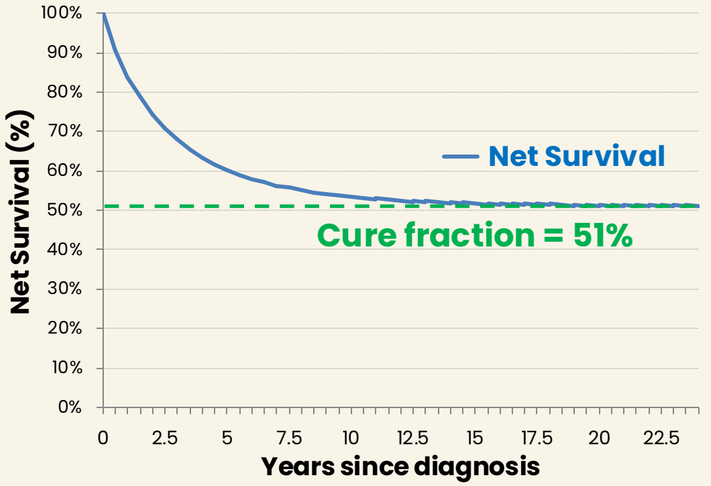
How many patients will be cured from the disease?

Cure fraction:
the percentage of people diagnosed with cancer having the same life expectancy as the general population



The dashed line represents the **cure fraction**: patients that will not die for their cancer

Italian patients diagnosed in 2010

	Age at diagnosis (years)					
Cancer type	**All ages**	**≤44**	**45-54**	**55-64**	**65-74**	**75+**
Breast, all stages	**73%**	77%	82%	77%	72%	60%
Stage I	**99%**	97%	98%	99%	99%	100%
Stage II	**81%**	85%	89%	86%	78%	70%
Stage III-IV	**36%**	59%	50%	40%	27%	23%
Cervix Uteri	**58%**	83%	71%	55%	35%	24%
Corpus Uteri	**69%**	86%	81%	76%	67%	54%
Ovary	**32%**	65%	50%	38%	27%	11%

Dal Maso et al IJC 2024

Giudici et al AmJEpidemiol 2024

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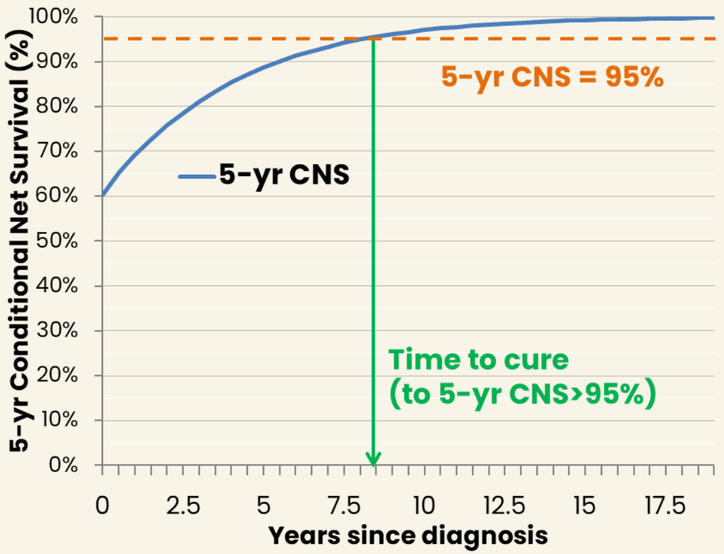
How many years will I have to wait to consider myself cured? (to reach time to cure)

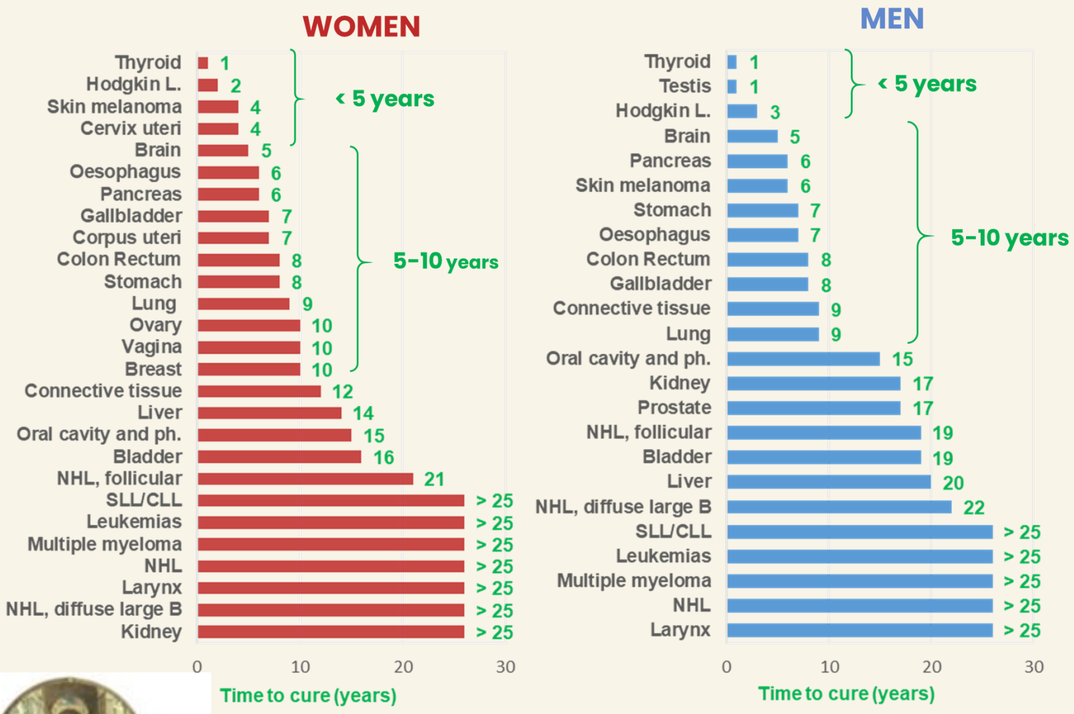
When 5-year Conditioned Net Survival approaches 100%, patients reach the same life expectancy as that observed in the general population.



It is reasonable to assume that **Time to cure** is reached when 5-year CNS becomes higher than 95%, when the residual excess mortality is clinically negligible.

- Substantial differences between cancer types, age at diagnosis, sex
- Below 10 years for many cancers
- Very short (< 3 years) for some cancers types (Thyroid, Testis and Hodgkin lymphoma)

European patients diagnosed in 2000



EUROCARE

Dal Maso et al Int J Epidemiol 2020

EUROCARE-5 STUDY, EUROPEAN POOL

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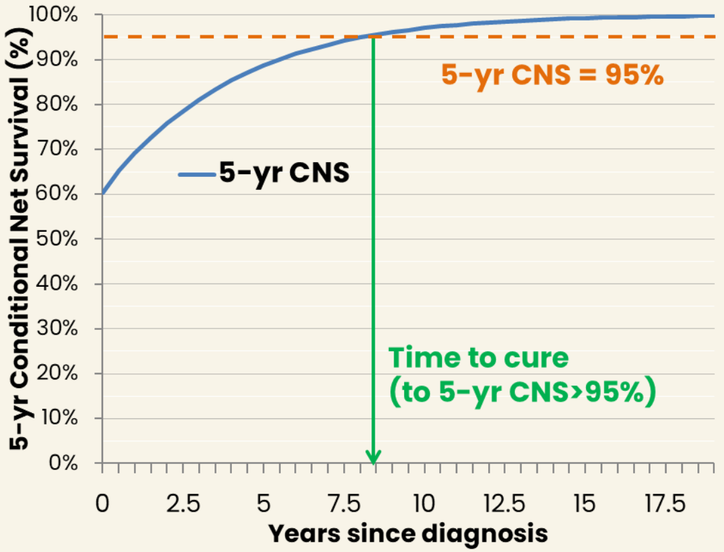


It is reasonable to assume that **Time to cure** is reached when 5-year CNS becomes higher than 95%, when the residual (excess mortality is clinically negligible).

Italian patients diagnosed in 2010

Dal Maso et al. Int J Cancer 2024

Breast cancer

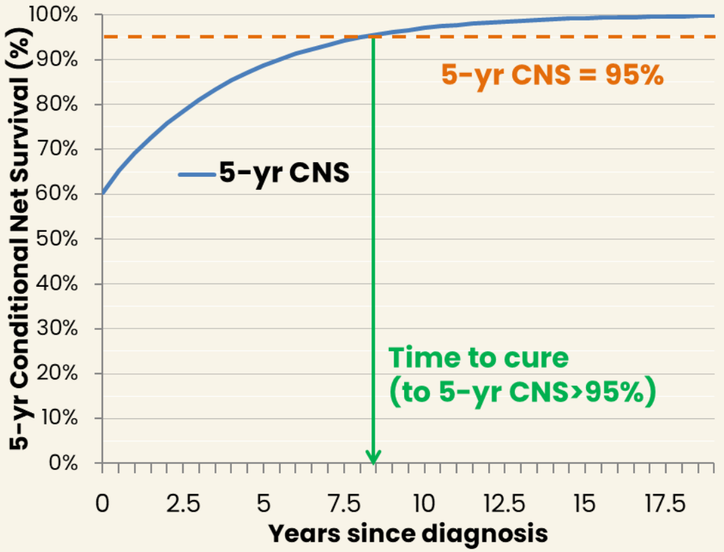
Stage	Age at diagnosis (years)			
	0-44	45-54	55-64	65-74
All	**11**	**5**	**8**	**12**
I	1	1	1	1
II	1	1	1	12
III - IV	12	>15	>15	>15

Colorectal cancer

Stage	Age at diagnosis (years)			
	0-44	45-54	55-64	65-74
All	**6**	**7**	**7**	**8**
I	-	1	1	1
II	-	7	7	10
III - IV	-	7	8	9

How many years will I have to wait to consider myself cured? (to reach time to cure)

When 5-year Conditioned Net Survival approaches 100%, patients reach the same life expectancy as that observed in the general population.



It is reasonable to assume that **Time to cure** is reached when 5-year CNS becomes higher than 95%, when the residual (excess mortality is clinically negligible).

Italian patients diagnosed in 2015

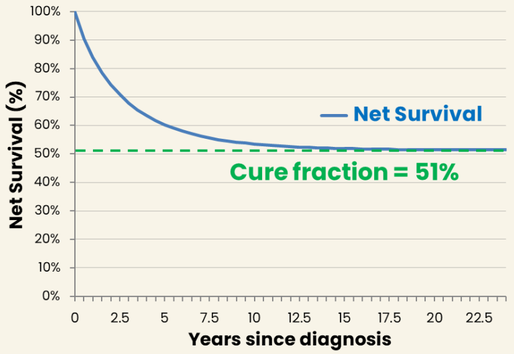
Mancini et al. Cancer Med 2026

Skin Melanoma

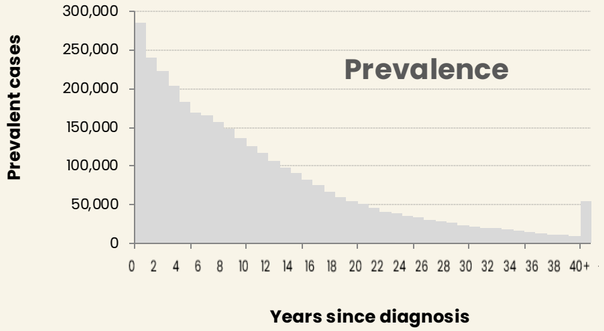
Thickness, mm		Age at diagnosis (years)			
		Men		Women	
		15-54	55-74	15-54	55-74
All		**3**	**5**	**1**	**5**
(63% of cases)	≤1.0	1	1	1	1
(17% of cases)	>1.0 -2.0	5	11	1	6
(12% of cases)	>2.0 – 4.0	9	10	14	10
(8% of cases)	>4.0	7	10	>15	15

How many prevalent patients will not die for the disease?

Appling Cure fraction…

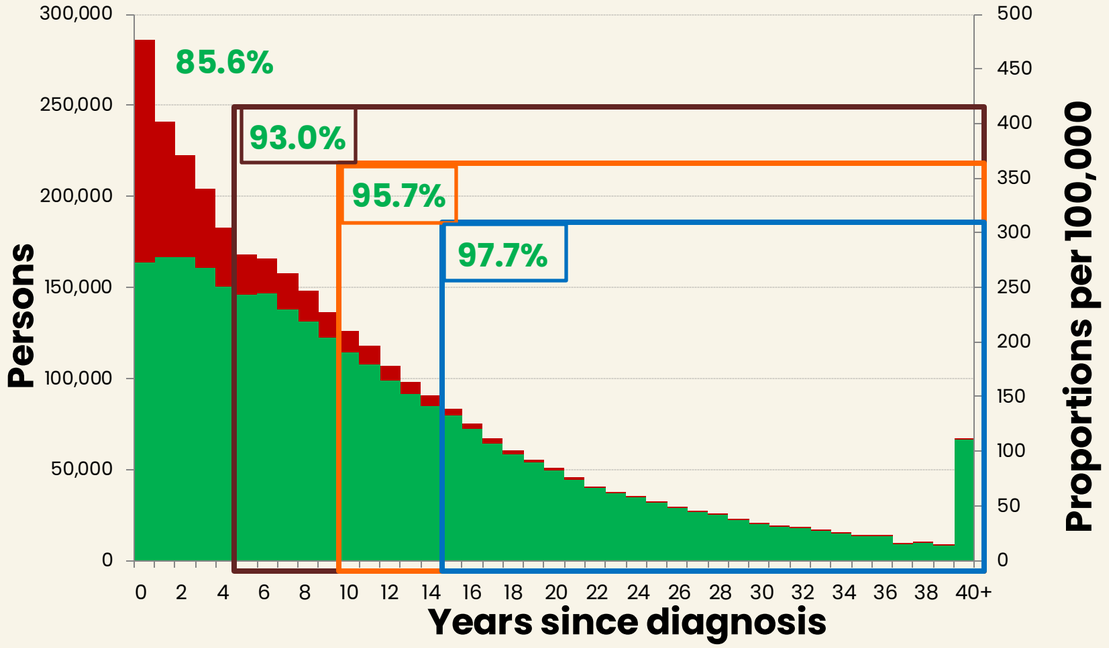


…to the distribution of prevalent cases



Italian patients alive in 2018 after a cancer diagnosis

…in green those will not die for cancer (cure prevalence)



Overall **cure prevalence** was 85.6%, increasing with time since diagnosis to 93% or 96% after 5 or 10 years.

Guzzinati et al. ESMO Open 2024

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How these results on time to cure contribute to the Right to be forgotten?

Italian Experience: Thanks the advocacy of….

On 7 December 2023, a law on the 'right to be forgotten' was adopted.

Law 193/2023 has established that "…information regarding previous cancer diagnoses may not be requested once more than **ten years have elapsed since the conclusion of active treatment for the condition, provided there have been no recurrences or relapses;** this period is reduced to five years for those diagnosed before the age of 21.
The legislation also provides for the possibility of **shorter time limits for specific types of cancer** (Ministerial Decree of 22 March 2024).

DM 22 marzo 2024 (GU n. 96 del 24.04.2024)		
Tipo di tumore	**Specificazioni**	**Anni dalla fine del trattamento**
Colon retto	Stadio I, qualsiasi età	1
Colon retto	Stadio II-III, >21 anni	7
Melanoma	>21 anni	6
Mammella	Stadio I-II, qualsiasi età	1
Utero, collo	>21 anni	6
Utero, corpo	Qualsiasi età	5
Testicolo	Qualsiasi età	1
Tiroide	Donne con diagnosi <55 anni Uomini con diagnosi <45 anni. Esclusi i tumori anaplastici per entrambi i sessi	1
Linfomi di Hodgkin	<45 anni	5
Leucemie	Acute (linfoblastiche e mieloidi) qualsiasi età	5

OPEN ISSUES

- **The epidemiological data on the time to cure** (estimated from the date of diagnosis) **are shorter than those specified by the legislator**.

- The law and guidelines do not explicitly specify what is meant by '**active treatment**'. It will be proposed that the forthcoming grid explicitly clarify that **immunotherapy and adjuvant endocrine therapy should be excluded** from the calculation.

WHAT CANCER REGISTRIES DATA AND ESTIMATES OF LONG TERM SURVIVAL AND CURE TELL US?

- **Several indicators of "cancer cure" are measurable** according to cancer type, sex, age, and other relevant prognostic factors

WHAT ELSE IS NEEDED?

- **More up-to-date and detailed information on relevant indicators of cancer cure** (by country, stage at diagnosis,…)
- **A mutual understanding of the different needs (questions) expressed by patients, epidemiologists, oncologists, and stakeholders**

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- https://ecis.jrc.ec.europa.eu/en

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Thank you

Questions and comments are welcome ...

dalmaso@cro.it



Ending discrimination against cancer survivors

13:00 - 14:00

Ending Discrimination Against Cancer Survivors

The Right to be Forgotten as a Human Right

NETWORKING LUNCH



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14:00 - 14:15

Keynote

The Right To Be Forgotten in Ireland

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Minister of State Robert Troy

Professor, Minister of State at the Department of Finance, **IE**

14:15 - 14:25

Presentation

The UK Experience

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Prof. Mark Lawler

Professor, digital health, Queen's University Belfast and immediate Past Chair, International Cancer Benchmarking Partnership, **IE**

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Opening Remarks

Prof. Mark Lawler

Professor of Digital Health, Queen's University Belfast, UK,
Co-Lead, All Island Cancer Research Institute
Immediate Past Chair, International Cancer Benchmarking Partnership
Co Chair, Lancet Oncology 'Omics and Precision Oncology Commission
Vice Chair Cancer Focus Northern Ireland

Ireland



Righting a Wrong

SO…

Marie, a cancer survivor from **Bordeaux** can **buy that little gîte in Brittany (France)** she's always wanted,

and **Mary in Ballina (Ireland) will now receive a mortgage quote** for her dream cottage in Buncrana

BUT…

Moira from **Ballymena (Northern Ireland) cannot afford the travel insurance** for her once-in-a-lifetime trip to visit her daughter in New Zealand,

and as for Morag in Balmoral (Scotland), Maire in Bangor (Wales) and Marian in Birmingham (England)…

Is this the society we want in the UK in October 2026?

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Irish Cancer Society

THE LANCET Oncology

Cancer Focus NORTHERN IRELAND

NECRET North East Cancer Research & Education Trust

ICBI International Cancer Benchmarking Partnersh

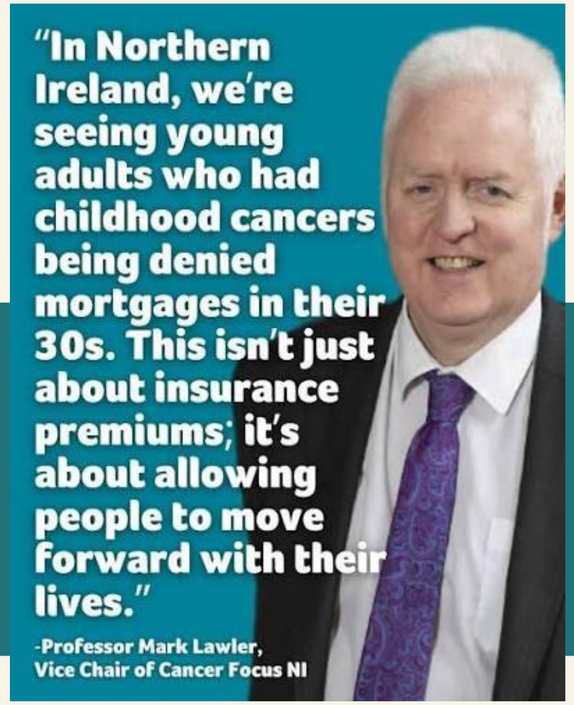
QUEEN'S UNIVERSITY BELFAST

A New Right To Be Forgotten Campaign



Richard Spratt

Chief Executive, Cancer Focus NI



Prof. Mark Lawler

Vice Chair, Cancer Focus NI

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Back on the Political Influence Trail



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QUEEN'S UNIVERSITY BELFAST

Generating the Evidence Base

- **Cancer Focus Northern Ireland** and **Queen's University Belfast**, working with **YouGov**, have generated **robust quantitative and qualitative evidence**
- Will underpin the **Westminster launch** of a **UK-wide Right To Be Forgotten Campaign**



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So the FIGHT Goes on!



There is Life After Cancer

Join us in our mission to embed the **Right To Be Forgotten** in **all 4 nations of the UK**

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Cancer Focus NORTHERN IRELAND

NECRET North East Cancer Research & Education Trust

ICBI International Cancer Benchmarking Partnersh

QUEEN'S UNIVERSITY BELFAST

14:25 - 15:30

Session III

Right To Be Forgotten as a Human Right:

Ending Discrimination Against Cancer Survivors

Ending discrimination against cancer survivors

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Prof. Françoise Tulkens
Former Vice-President of the European Court of Human Rights



Prof. Isabelle Rorive
Professor of Law specialising in equality and non-discrimination



Dr. Grazia Scocca
Legal Expert, EDACS Initiative; IEE-ULB



Prof. Florence Caeymaex
Professor of Ethics and Medical Humanities, Adviser on Ethics and Equality Politics at ULiège

The Right to Be Forgotten as a Human Right

International conference: Ending Discrimination Against Cancer Survivors

Brussels, University Foundation, October 21, 2026

Isabelle Rorive

Full professor at the Law Faculty

Centre Perelman for Legal Philosophy - Equality Law Clinic (ULB)

Royal Academy of Belgium

ULB UNIVERSITÉ LIBRE DE BRUXELLES

Faculté Droit & Crimir

CENTRE PERELMAN DE PHILOSOPHIE DU DROIT

ELC EQUALITY LAW CLINIC

The Different Meanings of the Right to be Forgotten

- Criminal convictions and criminal records
- Digital footprints and online traces
- Medical records and insurance

- A social justice issue (« double penalty »)
- The Right to Move On: Privacy, Reintegration and a Fresh Start

Framing the Legal Issue

Faced with the rising number of cancer cases and the growing number of people who recover from the disease, how should the law approach the tension between a favourable medical prognosis and the prudential approach of insurance companies?

Curable cancer (not comparable to a chronic disease) — complete remission (medical concept).

Beyond Privacy: A Human Rights Perspective

The right to be forgotten is about more than protecting personal data.
It is also about protecting human dignity and personal autonomy.
It is linked to social and economic rights including the right to housing.

Looking Ahead

October 2025: A report spanning more than 150 pages (online)

What are the next steps?

Thank you, delighted to join such a rich panel!

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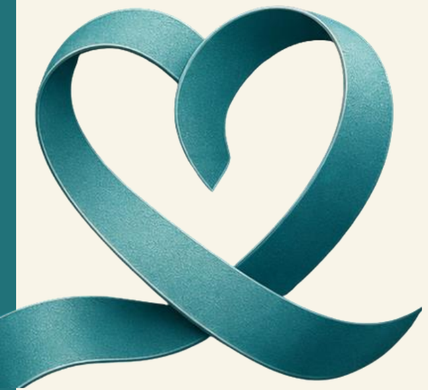
The Right to Be Forgotten as a Human Right: Ending Discrimination Against Cancer Survivors

Grazia Scocca

EDACS, IEE-ULB



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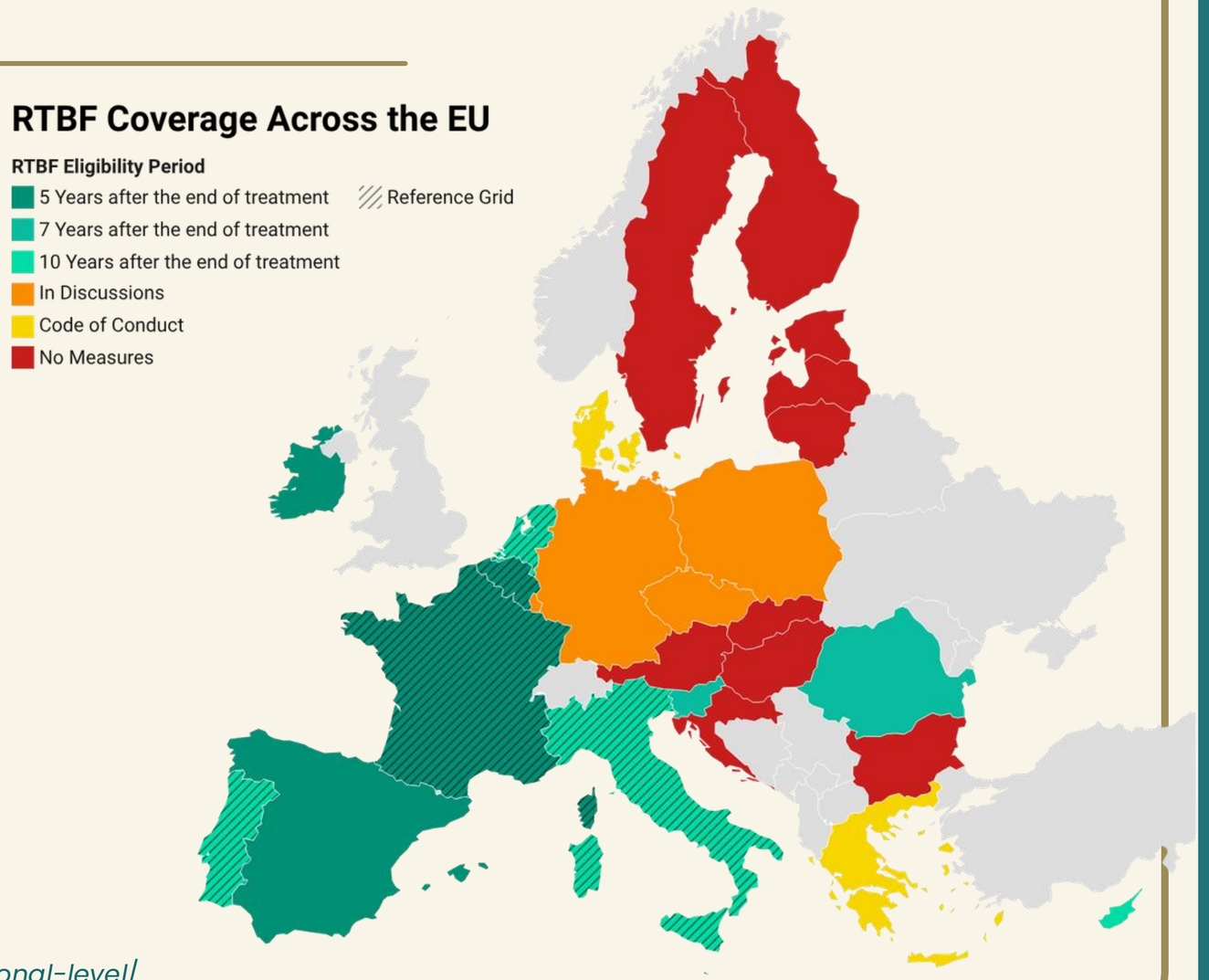
The Current Legal Landscape in Europe

- **11 EU Member States** have adopted binding legislation;
- **4** more others rely on codes of conduct, voluntary practices;
- **2 EU countries** confirm having legislative work in progress.

This confirms both progress and persistent fragmentation across Europe.



Map from EDACS website: *https://endingdiscrimination-cancersurvivors.eu/national-level/*

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Key differentiator	Main differences across Europe
Waiting period	5 years in France, Belgium, Spain and Ireland; 7 years in Romania, Slovenia and Czechia; 10 years in Italy, Netherlands, Portugal, Cyprus and Malta.
Childhood / young-adult cancer	All systems apply a shorter period for diagnosis before age 18/21; Uniform 5-year rule in France, Belgium, Spain and Ireland.
Cancer-specific reductions	France, Belgium, The Netherlands, Portugal, Italy, Romania, Slovenia apply shorter time limits for cancers with favourable prognosis.
Scope of financial products	Protection may cover mortgage, consumer credit, professional loans, life, income-protection or travel-cancellation insurance.
Reference grid with cancer-specific reduced terms	France, Belgium, Netherlands, Portugal, Italy, Romania, Slovenia, Luxembourg
Monitoring / scientific update body	France, Belgium, Italy, Portugal, Romania, Luxembourg, Malta, Spain
Dedicated mediation or individual-complaint mechanism	France, Luxembourg, Belgium, Netherlands

Additional differences concern coverage caps, the inclusion of other diseases (e.g. HIV, hepatitis C and diabetes), and disclosure requirements for cancer history

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Regional Level

- **EU Consumer Credit Directive — Art. 14(4), 2023**
- **Existing Human Rights Frameworks**
- **Ongoing European Commission consultation**

Member States must ensure that cancer-diagnosis data are not used for credit-related insurance after a nationally determined period, capped at **15 years** after the end of treatment. Applies from **20 November 2026**.	Not a uniform European waiting period; does not cover every financial product or every form of discrimination.
ECHR and European Social Charter can support arguments against discrimination and for social protection.	No harmonised, cancer-specific right to be forgotten in insurance and credit.
Considers further measures, including guidance for effective national protection.	A step towards possible future harmonisation, not yet a binding harmonised regime.

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What's Next? Three Priorities

- **Europe needs common minimum standards.** Clear rules on waiting periods, coverage, childhood cancers and evidence-based medical reference tables. Protection should not depend on where a person lives or which insurer they approach.

- **Protection must be enforceable**. People need transparent procedures, accessible complaints mechanisms, effective remedies, and safeguards against indirect ways of obtaining information that should no longer be used.

- **Look beyond mortgages and insurance.** The broader challenge is to ensure that people living with and beyond cancer can participate fully in society, without being permanently defined by their medical history.

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Thank you

Grazia Scocca
grazia.scocca@gmail.com

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The Right to be Forgotten as a Human Right
Ending discrimination against cancer survivors

Fondation Universitaire 21 October 2026

Ethical and philosophical perspective

Florence Caeymaex, Professor of Ethics and Medical Humanities
University of Liege
Royal Academy of Medicine
Belgian Advisory Committee on Bioethics

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The Question

Illness and vulnerability are part of the human condition. From an ethical perspective, what are the consequences of continuing to define someone by a past cancer diagnosis, and how can we ensure that this experience does not become a permanent identity imposed on them?

To explore

- personal and social identity intertwine
- illness challenges one's own personal and social identity
- how healthism works
- why we need to tackle discrimination & promote human rights

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Two introductive remarks

Positionality Statement

I have never faced a serious disease myself, nor experienced severe illness. I draw from philosophers and writers who did

Contextual Remark

A recent parliamentary conference about cancer survivors and their return to work. The social and personal aftermath of cancer as a challenge

Personal Identity & the Self

Philosophy and Ethics of *Care* (Joan Tronto, Carol Gilligan, Pascale Molinier)

The “self” is the faculty to relate with oneself and to reflect on who we are as individual

Such faculty or ability is intrinsically linked to relationality

Without mutual care and expressions of mutual recognition, it is not possible for a human being to fully become his or herself.

We are said to be vulnerable: we are interdependent, our lives depend upon each other.

Social Relationships, Rules & Norms

Inter-subjective interactions are shaped by social rules

The recognition and care we receive or give depend upon our capacity to adapt to shared social rules and norms

Our response to such expectations shapes largely our social identity

No society without norms that apply to many aspects of life: bodily conduct, symbolic and linguistic interactions, ways of learning, working & doing things, physical appearance

They make us socially « recognizable » (or not !)

Illness as an Experience for the Self

Georges Canguilhem (1904-1995) Physician, Philosopher & historian of medicine

Two inseparable aspects

- Disease as deviation or failure from what medicine identifies as the “normal” (vs. pathological)
- Illness as an existential transformation and challenge for the patient, the forming of “another allure of life” (1943)

The irreversible (and continuous) changes a disease imposes to a life (irreversibility of life).

Claire Marin

Violence of illness, violence of Life (Armand Colin, 2015)

"Disease disrupts these two aspects: bodily functions break down (organs damaged, destroyed or attacked; hormonal imbalances; proliferation of cancer cells; destruction of the immune system) and the body's normal functioning deteriorates (gait disturbances, speech difficulties, memory problems, mood disorders). The foundations of my way of being gradually fade away. The individual's scope for action is reduced. […] Disease is the loss of a certain margin of manoeuvre in life upon which the individual's sense of freedom is based" (2015, 54 & 55).

Claire Marin

“It cuts off the spontaneous impulse of consciousness to project itself; it destabilises the individual by preventing them from representing themselves in their usual way. […] Disease cannot be conceived of as a mere digression in an individual’s life. Not only does it call their identity into question during the period of pathological activity, but it can also upend their entire history; it leaves its mark, from scars to the immune response, from physiological after-effects to psychological trauma. It becomes part of a new temporal framework, of which it constitutes the point of reference” (2015, 67 & 68).

Illness as a challenge for intersubjective relations

Human beings are interdependent, relational beings.

The event of a disease (which brings illness) affects not only the person, but potentially the whole human ecosystem of care and recognition the person needs

Social relationships are not devoid of norms

Normal/pathological

Health/Disease (or illness)

Play a major role for one’s place in society

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Claire Marin

“At a certain level, there is no longer any distinction between the disease and the individual. The patient is no longer merely sick; he is his disease. This is, first and foremost, what the medical approach leads him to realise. He is nothing more than a system of symptoms that correspond to the characteristics of his disease. The patient becomes a more or less legible sign, the expression of her/his pathology. The disease speaks through the patient in the first person, relegating her/him to a secondary role. […] The subject’s identity is thus reduced solely to that of a patient” (2015, 80)

Illness as a negative label in the social life

The negative social value of illness (especially in “performance” societies)

Imposing the subject to renegotiate his or her own identity accordingly

Claire Marin

“Although it primarily concerns the individual, it only becomes an ‘illness’ when the individual is identified from the outside as ‘ill’. The ‘recognition’ of illness involves an assessment by the community. It is signalled by a failure in social functioning. Illness is a disruption to our ability to fulfil our role within the community”.

Illness as a Negative Social Value

"[…] Illness is regarded by society as a nuisance; it constitutes an obstacle to activity, a disability. Thus, illness may remain invisible as long as its effects do not impinge upon the individual's effectiveness, the individual being viewed as a 'political' and, above all, an 'economic' being.

[…] In some cases, awareness of the illness only arises with this external observation of the difficulties or the impossibility of continuing with one's usual activities. Illness is therefore socially defined as the inability to be oneself – or, at the very least, to be oneself in the eyes of others. It calls into question social identity and, with it, social organisation itself. If the patient wishes to recover, it is also to reclaim that part of their identity constituted by their social persona. If we wish for them to recover, it is so that the manifestation of a disorder may disappear." (2015, 93-94)

Healthism

Social Pressures

- to reduce the person's identity to his or her illness (labelling through impersonal administrative categorizations)

- upon patients to affirm their personality against the illness and their capacity to return as soon as possible to his or her former social persona (ignoring the changes)

Two aspects of healthism

a normative system that devalues the lives perceived as injured, damaged, disabled, unfit or weakened

Healthism, Discrimination, and HR

Healthism is behind what democratic societies name “discrimination” an unjustifiable difference in treatment of individuals or groups because of some characteristics that are socially perceived as negative

The core idea of human rights :

an ideal of equal and just treatment of each human individual in his or her uniqueness

everyone’s right to participate in society and to find the proper conditions to fully develop one’s own personality whatever the biographical breaks may be

Ending discrimination against cancer survivors

15:30 - 15:50

Ending Discrimination Against Cancer Survivors

The Right to be Forgotten as a Human Right

COFFEE BREAK



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15:50 - 17:00

Session IV

Best Practices: From Adoption to Implementation

Ending discrimination against cancer survivors

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Dr. Iris Pauporté
Director of Research, Innovation, and Scientific Information, The League Against Cancer, **FR**

Prof. Maëlle de Ville de Goyet
Head of Department, Pediatric Hematologist-Oncologist, Cliniques Universitaires Saint-Luc, **BE**

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Cancer survivor and Senior Lawyer at the Office of the State Advocate **MT**

Dr. Amanda Spiteri Grech
Former Member of the Parliament, **MT**

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Best Practices: From Adoption to Implementation

Dr. Iris Pauporté

Director of Research, Innovation, and Scientific Information, The League Against Cancer

France

LA LIGUE CONTRE LE CANCER

The Right to be Forgotten as a Human Right, 21 October 2026

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Right to Be Forgotten: 25 Years of Struggle: From 2001 to 2023

2001 — **Belorgey convention**
Loan insurance

2006 — LA LIGUE CONTRE LE CANCER

2007 — **1st law + AERAS convention**
Loan insurance + specific framework

2015 — **AERAS convention extended**
Right to be forgotten 15 years after treatment

2022 — **2nd law + rights extended**
5 years after treatment + Hepatitis patients

2023 — **EU directive on Consumer Credit Directive II**



3e Plan Cancer – Droit à l'oubli, Paris, 24 March 2015

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From 2025

2025

Work in progress within AERAS framework to extend the right to be forgotten to treatment-related chronic sequelae



LA LIGUE CONTRE LE CANCER

CASE

48-year-old woman,
leukemia in 2008,
transplanted in 2009,
treatment-related sequelae: hypertension and chronic kidney disease.
→ **uncertainty to declare or not sequelae**

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Best Practices: From Adoption to Implementation

Prof. Maëlle de Ville de Goyet

Paediatric Haematologist-Oncologist, Institut Roi Albert II,
Cliniques universitaires Saint-Luc

Belgium



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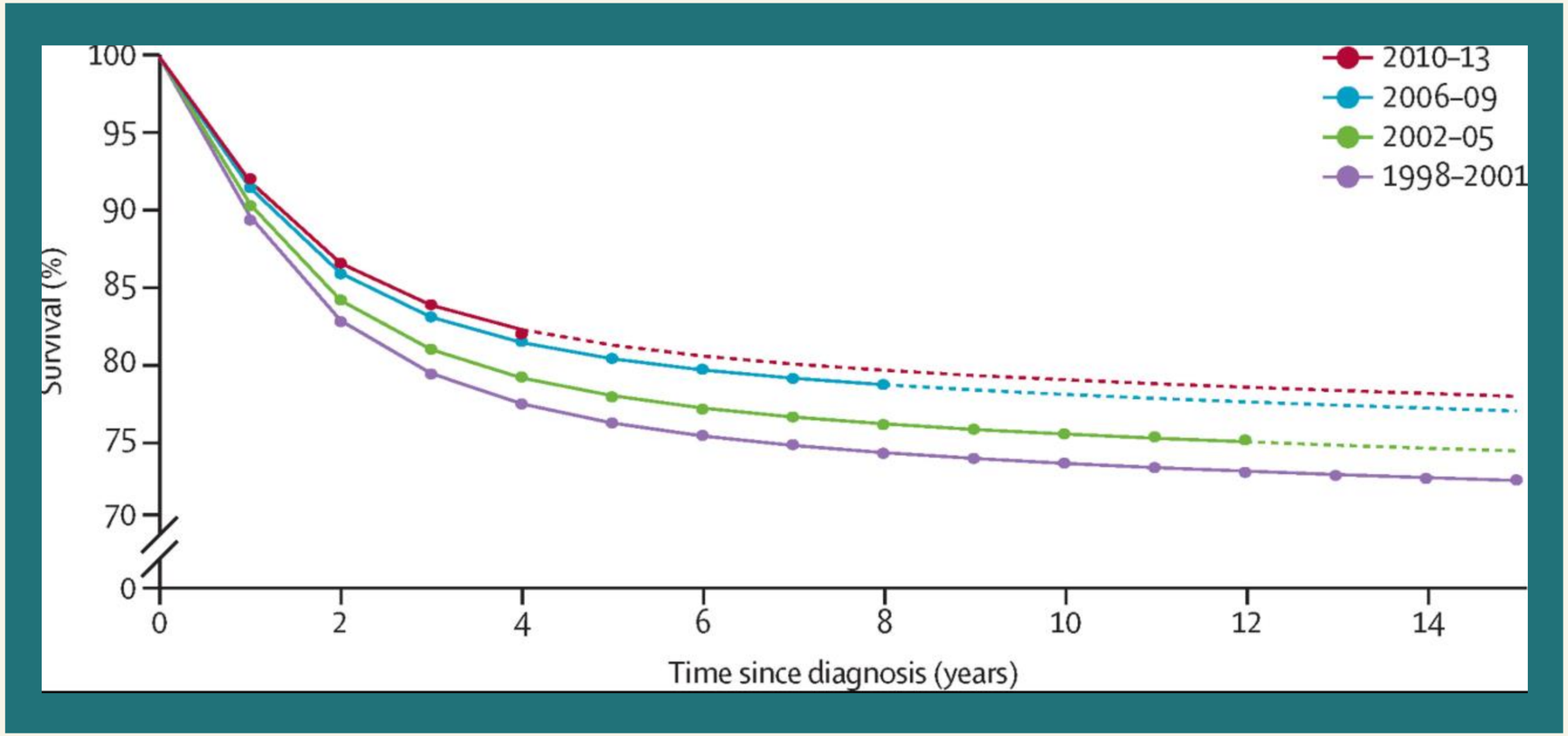
CANCER ET HÉMATOLOGIE
Cliniques universitaires SAINT-LUC
UCLouvain BRUXELLES

Childhood cancer survivorship: Belgium experience



L. Botta, Lancet Oncology, 2022

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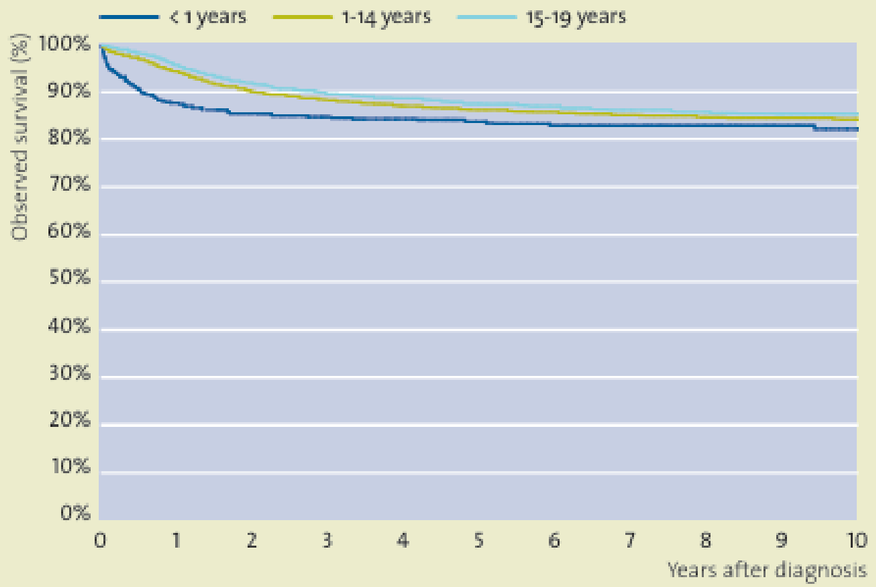
Childhood cancer survivorship: Belgium experience

Figure 10 Cancer in children and adolescents: Observed survival by age group, Belgium 2004-2016



N at risk											
< 1 y	502	440	404	367	329	287	248	221	183	147	117
1-14 y	3,847	3,620	3,300	2,980	2,680	2,356	2,055	1,808	1,574	1,298	1,057
15-19 y	2,282	2,177	2,000	1,800	1,604	1,425	1,263	1,113	936	772	636

Source: Belgian Cancer Registry

Source: Belgian Cancer Registry 02/2019

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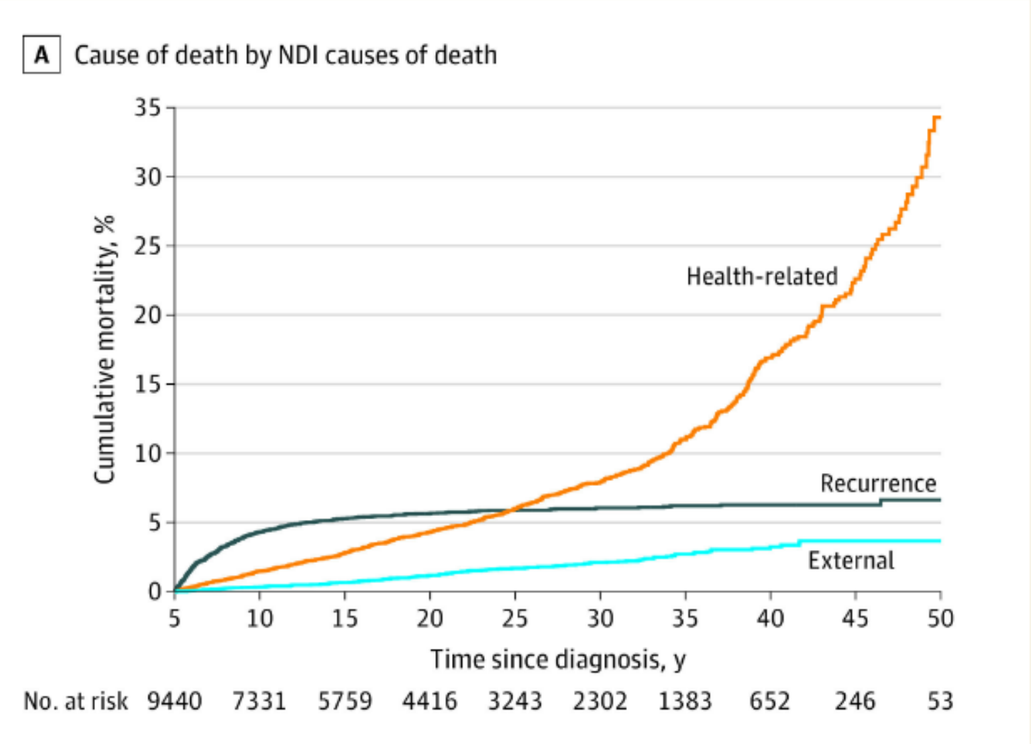
Recurrence and late effects need separate assessment

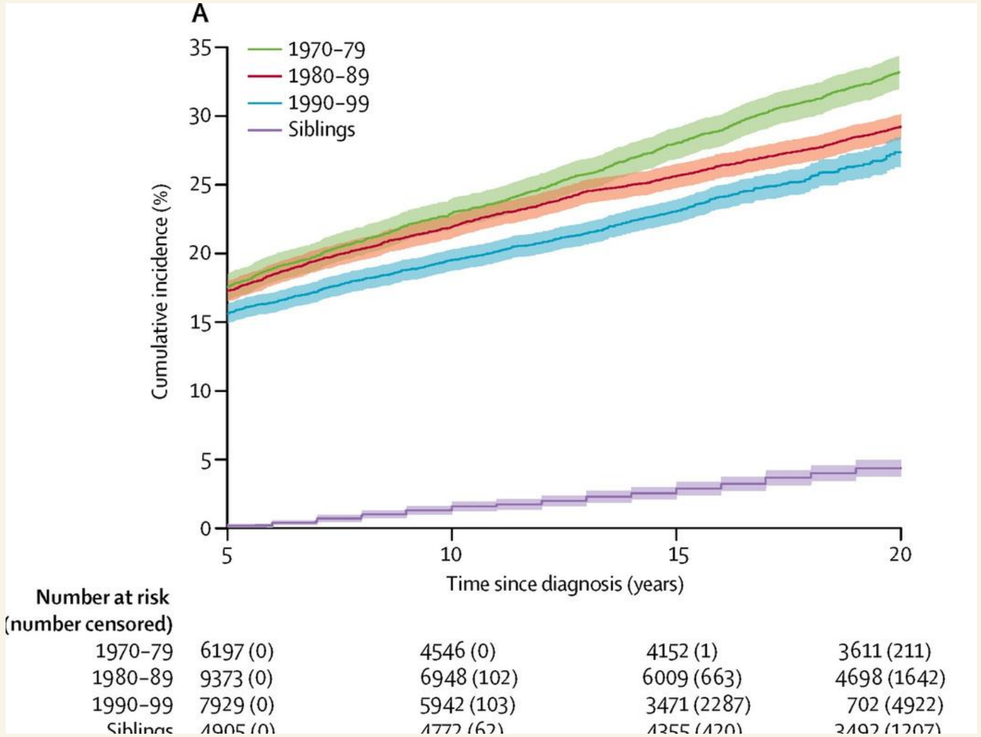
CANCER RECURRENCE

The risk for the original cancer returning.



LATE EFFECTS OF TREATMENT

Long-term consequences that require their own assessment.



Gibson TM , Lancet Oncol 2018

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A Historical Diagnosis Alone Cannot Describe the Full Risk Profile

CLINICAL DIFFERENCES

Cancer type and stage.

Treatments received.

Time elapsed since treatment

Different survivors can have very different trajectories.

IMPLICATIONS FOR FINANCIAL RULES

Reflect improved survival and more precise risk stratification.

Review waiting periods against follow-up evidence.

Avoid treating every historical cancer diagnosis as a permanent indicator of elevated risk.

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Long Team Follow-Up Care Organisation



GOALS

SCREENING FOR LATE EFFECTS

RISK-BASED FOLLOW UP CARE PLAN

EDUCATION AND EMPOWERMENT

PSYCHOSOCIAL SUPPORT

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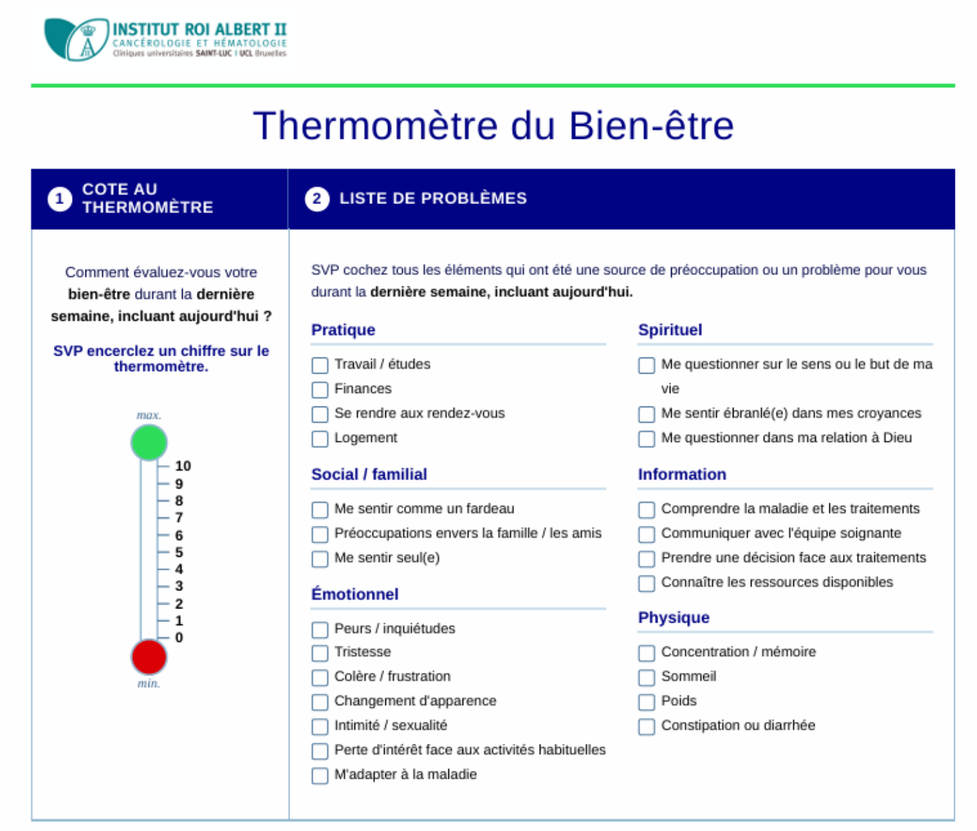
Gibson TM , Lancet Oncol 2018

Long Team Follow-Up Care Organisation



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Thermomètre du Bien-être

1 COTE AU THERMOMÈTRE

Comment évaluez-vous votre **bien-être** durant la **dernière semaine, incluant aujourd'hui ?**

SVP encerclez un chiffre sur le thermomètre.

max.
10
9
8
7
6
5
4
3
2
1
0
min.

2 LISTE DE PROBLÈMES

SVP cochez tous les éléments qui ont été une source de préoccupation ou un problème pour vous durant la **dernière semaine, incluant aujourd'hui.**

Pratique
- ☐ Travail / études
- ☐ Finances
- ☐ Se rendre aux rendez-vous
- ☐ Logement

Social / familial
- ☐ Me sentir comme un fardeau
- ☐ Préoccupations envers la famille / les amis
- ☐ Me sentir seul(e)

Émotionnel
- ☐ Peurs / inquiétudes
- ☐ Tristesse
- ☐ Colère / frustration
- ☐ Changement d'apparence
- ☐ Intimité / sexualité
- ☐ Perte d'intérêt face aux activités habituelles
- ☐ M'adapter à la maladie

Spirituel
- ☐ Me questionner sur le sens ou le but de ma vie
- ☐ Me sentir ébranlé(e) dans mes croyances
- ☐ Me questionner dans ma relation à Dieu

Information
- ☐ Comprendre la maladie et les traitements
- ☐ Communiquer avec l'équipe soignante
- ☐ Prendre une décision face aux traitements
- ☐ Connaître les ressources disponibles

Physique
- ☐ Concentration / mémoire
- ☐ Sommeil
- ☐ Poids
- ☐ Constipation ou diarrhée

MULTIDISCIPLINARY TEAM INCLUDING

SCREENING BY NURSE SPECIALIST

- FINANCIAL SITUATION
  - WORK AND EDUCATION
  - AUTONOMY
  - HOME ENVIRONMENT

MEDICAL ASSESSMENT

EDUCATION/INFORMATIONS (AYAS)

PSY/PHYSIO/DIET/NEUROPHYSIO…

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A Childhood Diagnosis Can Affect Adult Financial Access

The first financial application may come many years after treatment

THE SURVIVOR'S TIMELINE

Cancer during childhood, adolescence or young adulthood.

A first mortgage, life-insurance policy or business loan much later.

The historical diagnosis may have limited relevance to current health.

THE FINANCIAL CONSEQUENCES

Medical questionnaires may bring the past diagnosis back into focus.

Survivors can still face exclusions, higher premiums or refusals.

Paediatric survivorship needs specific consideration.

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Childhood cancer survivors should not be penalised twice by unequal access to financial resources

Recognise the specific risks and needs of childhood cancer survivors.

Update rules as long-term evidence evolves.

Keep insurance decisions separate from the treating physician's role.

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Best Practices: From Adoption to Implementation

Dr. Irina Odnoletkova

Lead investigator ‘Right to be forgotten’, Belgian Health Care Knowledge Centre

Belgium



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The Right To Be Forgotten in Belgium

Introduced in 2020 for outstanding balance insurance

- **Standard waiting period: 5 years after successful treatment**

- Reference tables define shorter waiting periods for selected cancers

- **After the waiting period:**
  - No refusal
  - No premium loading
  - No disclosure of past cancer
  - Income protection insurance
  - Travel cancellation insurance

- **RTBF is extended to:**
  - Income protection insurance
  - Travel cancellation insurance

KCE mission

- **Periodic evaluation** of RTBF reference grids
- **Evidence-based** recommendations



The « Right to be forgotten » programme | KCE

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Waiting Periods in Breast Cancer

TNM prognostig group	Proposed waiting period
In situ (Tis N0 M0)	0 years
Minimally invasive (<T2 and<N2M0)	1 year
Other	Standard (5 years)

~50% of patients

Source: The right to be forgotten in breast cancer: new propositions (2022)

Evidence base:

- Time-to-cure

Impact:
Implemented in Belgian RTBF reference tables (July 2023)

Referentierooster kankeraandoeningen | FOD Economie

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Waiting Periods in Thyroid Cancer

TNM prognostic group	Proposed waiting period
Differentiated, any T, any N, M0	0 years, >90% of patients
Other	Standard (5 years)

Belgian Cancer registry& mortalitydata (15.713 patients, 2004-2023)

Source: Right to be forgotten in thyroid cancer: evidence to inform (2026)

Evidence base:

- Epidemiological approach: Time-to-cure
- Actuarial approach: Standardized Mortality Ratio
- Highly consistent conclusions across methods

Impact:
Implemented in Belgian RTBF reference tables (July 2023)

From Evidence to Legislation: the Belgian RTBF Model

Key elements:

Stakeholder-driven prioritisation

↓

Robust evidence

↓

Independent expert review

↓

Stakeholder consultation

→

Outcome:

Transparent policy recommendations

a. KCE
b. Price Monitoring Office

↓

Translation into legislation

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Thank you

Irina.Odnoletkova@kce.fgov.be

15:50 - 17:00

Session IV

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Dr. Corinne Gail De Gabriele
Cancer survivor and Senior Lawyer at the Office of the State Advocate **MT**

Dr. Amanda Spiteri Grech
Former Member of the Parliament, **MT**

17:00 – 17:10

Final Reflections

Remaining Questions & Priorities for a Europe Without Financial Discrimination

Ending discrimination against cancer survivors

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Kinga Wójtowicz

Moderator & Director of EU Healthcare, RPP Group

17:10 - 17:30

Closing Remarks

Setting the Ambition for the Future

Ending discrimination against cancer survivors

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Prof. Françoise Meunier
Founder, Ending Discrimination Against Cancer Survivors

Prof. Mark Lawler
Professor, digital health, Queen's University Belfast and immediate Past Chair, International Cancer Benchmarking Partnership, **IE**

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17:30 - 18:30

Ending Discrimination Against Cancer Survivors

The Right to be Forgotten as a Human Right

NETWORKING RECEPTION



THE DAY IS PHOTOGRAPHED AND FILMED.
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