



ACTUARIAL ASSOCIATION OF EUROPE

RIGHT TO BE FORGOTTEN & EU BEATING CANCER PLAN

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Right to be forgotten & EU beating cancer plan

- As part of the EU beating cancer plan and the review of the Consumer Credit Directive (CCD), the European Parliament has called for the introduction of a EU-wide right to be forgotten (RTBF) for persons with a prior diagnosis of certain communicable and non-communicable diseases, including cancer. The RTBF would mean that **former cancer patients who have overcome their illness would not be required to disclose the prior diagnosis of cancer when applying for life insurance.**
- The topic has been growing rapidly in EU and also globally as NGO's representing cancer survivors have been actively bringing out the 'end the discrimination' aspect.
- AAE published a short paper on key topics on December 2023 and had a discussion with DG FISMA already in October presenting the key issues.



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KEY MESSAGES ON THE RIGHT TO BE FORGOTTEN

RTBF roundtable presentation January 2024

Link to the publication: <https://actuary.eu/memos/key-messages-on-the-right-to-be-forgotten/>

Main messages for the RTBF Code of Conduct work

We already have comprehensive actuarial work and similar cases from history?

- The **Society of Actuaries in Ireland published a study on 2023** Spring looking at the ‘Consideration of the potential impacts of the introduction of a Right to be Forgotten framework for Cancer Survivors in Ireland when applying for Life Insurance products (main results at the end of the presentation).
- The EU rules on **gender-neutral pricing in insurance (2012)** can be considered to have a number of similar characteristics as the RTBF. The consequences of this regulation have been studied in several publications. Also at the time an AAE study looked closely at the usage of age & disability as rating factors in insurance and found that there would be profound consequences for the availability of some types of insurance on a private voluntary basis if restriction were made.
- Just recently in **Denmark the Mona Case** has resulted with a recommendation that **BMI should not be used anymore in the underwriting process.**

Discriminating or Differentiating?

- ‘**actuarial fairness**’ - customers bearing the same risk are charged the same price
- **Understanding the risk profile requires differentiating of data** as insurers need to analyze and quantify their risk profile in several ways – this need has nothing to do with discrimination itself
- **People might feel discriminated for several reasons** – if a CoC is put in place having ‘ending discrimination’ as one of the main starting points quite likely outcome is that the same argument will be used for other ‘discriminative’ reasons, like for other severe illnesses or even for car models.

Main messages for the RTBF Code of Conduct work

Restricting the use of data?

- One of the main points in RTBF is to restrict the access to data after some period and by that safeguard cancer survivors' rights. From insurers point of view **restrictions of data most likely leads to pricing higher the same risk** or introducing stricter underwriting conditions.
- We currently have initiatives on '**open insurance**' in EU. Can these contradict or even harm this CoC initiative which goes to opposite direction?
- **Generative AI models**, especially when channeled to internet search history and social media data will **create indirect ways to learn a lot from customers**. The EU AI act is addressing some of the issues, but one possible outcome is that cancer history comes indirectly in the underwriting process even though the insurer would not be especially deciding to use or not to use it.
- We have **examples in insurance where customers are rewarded on 'being active and healthy'** – Cancer survivors might not be applicable to these schemes even with the help of the CoC.

Main messages for the RTBF Code of Conduct work

Can this be managed only by a policy for the private side?

- RTBF has a **direct link to public health coverage** and the actual need for (private) insurance, which differs amongst member states in the EU – this should be well enough understood before any policy setting.
- Harmonizing RTBF rules across EU most likely **requires also harmonizing some of the customs like the health side clinical practices** as these have a lot of impact to insurers underwriting practices.

CoC's relation to EU and national legislation and supervisory guidance's?

- **Solvency II** regulation has many articles **requiring insurers to fully understand their risk profile** – the main principle being, first understand and analyze then decide on actions (like use of simplifications in SCR, use shorter internal policies to manage the risk, keep the governance structure lighter on it, etc.)
- The **CoC part IV** on action to support implementation – **List of actions is something where insurers already have existing obligations** – cross check might be needed.
- **National insurance policy law or National supervisory practices might already have own interpretations or policies** – How should an insurer look the CoC against these?

Main messages for the RTBF Code of Conduct work

All insurance products included in the CoC or just some certain ones?

- There should be **evidence-based arguments when justifying the RTBF** to different insurance products. Now there seems to be analysis looking the relation between cancer and mortality. This means basically only those insurance products where the mortality cover plays an elementary part.
- A distinction between **essential and non-essential insurance** products might bring insight to where the CoC would bring the most importance – EIOPA has studied this angle for instance in the work relating to insurance guarantee schemes.

Possible market impact if introducing the CoC?

- The evidence shows that Cancer is one of the top (if not the top) causes of payout on Critical Illness and disability products across Europe. Insurers across Europe will pay hundreds of millions to Cancer sufferers. In the event that these **products become unviable or unaffordable** then a risk is run that **Cancer sufferers are less protected financially than they are today**.
- Insurers could be more cautious and **lower the risk sums offered or stricter the underwriting conditions** – This could bring a new kind of **protection gap** for consumers.
- **Lowering the age limit** in some of the insurance products (like mortality cover) might become as a market practice to lower the overall risk insurer is exposed to. This might bring difficulties to elderly people.

Society of Actuaries in Ireland 2023

a study on looking at the ‘Consideration of the potential impacts of the introduction of a Right to be Forgotten framework for Cancer Survivors in Ireland when applying for Life Insurance products

The Society of Actuaries in Ireland (SAI) formed a working group in 2022 to look at the potential impacts of introducing a RTBF framework in Ireland. They published their report in April 2023. It is available here: [Paper - Right to be Forgotten framework for Cancer Survivors | Society of Actuaries in Ireland](#)

They analysed anonymised application data from the period 28th August 2014 to 24th June 2022. This represented data from three of the six main Irish life insurers and is believed to be a representative data set for the life insurance market in Ireland overall.

Key Findings:

- An estimated 17,000 cancer survivors applied for life insurance in Ireland over the almost 8-year period (1.7% of total applications).
- An estimated 10,000 (62% of the 17,000 cancer survivors applying for life insurance cover) of these applicants declared they ended cancer treatment 5 or more years ago.
- The data indicated that cancer survivors do not get an automatic decision at point of sale, but instead were primarily referred to a manual underwriting process. However, the report acknowledges that the reason for being referred for manual underwriting might not be solely due to the cancer declaration.
- It does appear from the case studies carried out, offers of cover are available in the market for many cancer survivors but it does depend on the type and severity of the cancer and the duration since treatment ended.

Underwriting outcomes – case studies

The Working Group carried out a survey of notional application case studies with all 6 insurers offering life insurance to retail customers in Ireland covering 7 cancer types. The case studies focused on Life insurance cover only and did not ask about other insurance types e.g. Disability or Critical Illness.

For each test case each insurer was asked if they would offer life cover (both 5 years post completion of treatment and 10 years post completion of treatment) and on what terms i.e. with:

- No Extra Premium
- Extra Premium
- No Terms Available (i.e., the case would be postponed or declined)

The following slide shows the outcomes for the Breast Cancer case study. All case studies are shown in the report. The Case Studies suggest that the factors insurers take into account in making their underwriting decision includes:

1. Type / site of the Cancer – the case studies show different underwriting decisions for different types of cancer.
2. Severity of the Cancer – the case studies show more offers of life cover where the cancer suffered has been less severe e.g. earlier stage.
3. The duration since treatment ended – the case studies show that there were more offers of life cover available 10 years post completion rather than 5 years post completion of treatment.

Case study example – breast cancer

Average number of new cases per year	Proportion diagnosed <50	Proportion diagnosed <65	Stage / Description	Outcome 5 years post-completion of treatment			Outcome 10 years post-completion of treatment		
				No Extra Premium	Extra Premium	No Terms Available	No Extra Premium	Extra Premium	No Terms Available
3,906	23% (898)	61% (2,382)	IA Small tumour, no spread	4/6 insurers	2/6 insurers		6/6 insurers		
			IIA Slightly larger tumour / early nodal spread		6/6 insurers		2/6 insurers	4/6 insurers	
			IIIA Slightly larger tumour still, slightly wider nodal spread		5/6 insurers	1/6 insurers	1/6 insurers	5/6 insurers	
			More advanced Large tumour / wider spread			6/6 insurers		3/6 insurers	3/6 insurers

- For the earlier stage test case, 10 years post completion of treatment all insurers indicated they would provide terms at standard rates. If the same test case was 5 years post completion of treatment 4 out of the 6 insurers indicated they would provide terms at standard rates while 2 others would charge an additional premium.
 - For the test cases at a later stage, the outcomes vary with less insurers offering terms at standard rates 10 years post completion of treatment and none doing so 5 years post completion of treatment.
 - For the most advanced test case no terms were indicated as being available 5 years post treatment while 3 out of 6 would offer terms with an additional premium payable after 10 years post completion of treatment.
- Note case study examples for all 7 cancer types reviewed are included in the report.

The report notes that different groups of consumers will be impacted in different ways by a Right to be Forgotten Framework for cancer survivors

- Cancer survivors: Life Insurance products will likely become more affordable for some cancer survivors. For some cancer survivors the cost of their life insurance may not change (as they are currently being offered standard premiums). However, the application process may be improved for some through the introduction of an RTBF framework. It may help to change perceptions of accessibility of life insurance, leading to more cancer survivors applying for cover.
- Other consumers who have never been diagnosed with cancer: are likely to see an increase in premiums if an RTBF framework is introduced (i.e., cross-subsidising for consumers who meet the RTBF criteria). Some consumers may consider this to be unfair.
- Consumers that have recovered from other illnesses or diseases: may feel unfairly treated as they would still be required to declare their prior condition.

The report also notes features of the Irish insurance market which could result in a RTBF framework having a bigger or lessor impact (e.g. product mix) on consumers compared to other countries as well as a list of potential practical and operational considerations.

Right to be forgotten & EU beating cancer plan

- The EU discussions started fully on Q4/2023 when HaDEA (European Health and Digital Executive Agency), DG FISMA and DG SANTE started roundtables in order to get interested EU stakeholders agreeing on a Code of Conduct.
- AAE started participating on the roundtables on January and made a presentation (slide deck end of these slides) bringing up evidence that was available, especially from the short paper and the work from the Society of Actuaries in Ireland.
- The Roundtable #9 took place on April 10th still lacking a common agreement on the detailed parameters.... Still a lot has been achieved:
 - Coverage changed from 'all insurance products' to 'mortgage loan or professional loan life cover'
 - Two stage implementation process where EU organisations are signatories to the CoC but all the implementation will be done in a national level by the national organizations. Crucial parameters like waiting period, maximum age or sum might be left to national level as no consensus found.
 - The rtbf waiting period was the far most biggest issues as NGO's said that only maximum of 5y is acceptable and the industry that below 10y is not possible.
 - Insurance companies are asked to adhere (comply with it) the CoC when ready in each country. There's still expectations that everything would be ready on Autumn 2025.
 - The 'Actuarial evidence' highlighted in the discussion. This will be looked also in the national discussions and if/when the rtbf work in EU level is reviewed.
 - There still might be one roundtable on April. Commissions is also putting up a seminar on this to bring visibility to it on 14th May.

Roundtable participants

- DG FISMA
- DG SANTE
- HaDEA
- Deloitte (Commission's consultant)
- Association of European Cancer leagues(ECL)
- Actuari Association of Europe (AAE)
- Bureau Européennes Unions de Consommateurs(BEUC)
- Cancer Patients Europe(CPE)
- Eurofinas
- European Association of Co-operative Banks (EACB)
- European Savings Banks Group (ESBG)
- Europa Donna
- Europa Uomo
- European Banking Federation(EBF)
- European Cancer Organisation(ECO)
- European Cancer Patient Coalition(ECPC)
- European Federation of Insurance Intermediaries(BIPAR)
- European Federation of Investors and Financial Service Users (Better Finance)
- European Mortgage Federation(EMF)
- European Society for Medical Oncology(ESMO)
- European Initiative on Ending Discrimination against Cancer Survivors
- Insurance Europe (IE)
- Reinsurance Advisory Board (RAB)
- Youth Cancer Europe

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