Position Paper

The EC Beating Cancer Plan — reflections on the right to be forgotten

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Summary

Insurers are subject to legislative and regulatory requirements when offering and concluding contracts for insurance with consumers. Since insurance operates by pooling the risks of many, the fairness of terms (such as premiums and benefits) is determined not only from an individual consumer's perspective but also by having regard to the larger group of consumers whose risks are pooled together. This pooling is done based on the risk of the insured event happening while seeking to achieve a premium rate and associated benefits that consumers will find attractive. This ensures that there is minimal anti-selection[1] and is dependent on the existence of no, or little, information-asymmetry[2] existing. That is how private insurance operates.

A right to be forgotten that disregards how private insurance works (ie, the pooling of risks) would jeopardise insurance offerings in terms of availability, price, choice or benefits for all consumers. If price is decoupled from risks, some consumers will pay too much relative to the risk they bring to the insurer, while others will underpay for the cover they secure relative to the risks they carry. It is therefore critical that any EU-wide RTBF:

(1) is flexible enough to reflect the many different types of cancer and other factors (such as variations in treatment outcomes in particular member states or regions) affecting the risk associated with a given cancer,

(2) is flexible enough to meet the differing needs and characteristics of countries and markets, and

(3) preserves the ability of insurers to individually determine premiums and benefits based on risk-relevant factors.

Insurance Europe therefore advocates an implementation of any RTBF at EU level via a flexible code of conduct, agreed to by all stakeholders involved, that can be smoothly adapted to scientific developments.

[1] Anti-selection occurs when the price does not reflect the relevant risks so that those consumers with a lower risk attribution realise they overpay and those with a high risk attribution realise they underpay

[2] Information asymmetry occurs where the consumer withholds risk-relevant information from the insurer so that it is not taken into account in the underwriting decision about the premium and benefits offered by the insurer

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Introduction

To benefit cancer survivors and consumers in the long term, any EU-wide right to be forgotten (RTBF) must be flexible enough to reflect the many different types of cancer, treatments, and outcomes in different markets, while preserving the ability to individually determine premiums and benefits based on risk-relevant factors.

The European insurance and reinsurance sector notes the dialogue that has developed on assisting survivors of cancer to improve their quality of life. Insurance Europe and its members have followed the developments related to a right to be forgotten (RTBF) in several member states for many years, as well as the calls made by cancer patient organisations to ensure there is no discrimination against cancer survivors when accessing life insurance for home purchases. Insurance Europe notes the European Commission's intention to develop a code of conduct in cooperation with relevant stakeholders, including insurers.

Insurance Europe is therefore keen to engage in dialogue with the European Commission, European Parliament, cancer patient organisations and academics on how to implement a RTBF that works in practice. To this end, any code of conduct on a RTBF should be based on fair assessment, which would ensure that cancer survivors have access to individual life insurance in connection with a private mortgage when — based on actuarial, scientific and medical data — there is no longer a heightened risk of mortality associated with the prior cancer or its treatment. Insurance Europe stands ready to discuss its ideas with stakeholders and calls on the European Commission and European Parliament to launch a platform for the discussion of a code of conduct as announced in Europe's Beating Cancer Plan.

Most importantly, to benefit cancer survivors and consumers in the long run, it is crucial that any EU-wide RTBF:

(1) is flexible enough to reflect the many different types of cancer and other factors (such as variations in treatment outcomes in particular member states or regions) affecting the risk associated with a given cancer,
(2) is flexible enough to meet the differing needs and characteristics of countries and markets, and
(3) preserves the ability of insurers to individually determine premiums and benefits based on risk-relevant factors.

Insurance Europe therefore advocates an implementation of any RTBF at EU level via a flexible code of conduct, agreed to by all stakeholders involved, that can be smoothly adapted to scientific developments, and it advises against a rigid mechanism embedded in EU legislation that is hard to adapt.

Insurance Europe suggests investing in dialogue between relevant stakeholders to address the issue, to get a better common understanding of problems cancer patients may experience and to ensure a better understanding of how insurance works. Insurance Europe reminds cancer patient stakeholders that insurers and reinsurers are, like any business, subject to various pieces of legislation protecting the rights of individuals that prevent discrimination, as well as sector-specific legislation, such as the Insurance Distribution Directive, which sets out how insurers (and intermediaries) are to interact with, inform and treat consumers. It is therefore regrettable to read incorrect statements that allege that *all* cancer survivors have difficulty accessing financial services or that insurers are not following national and European legislation[3], or even that insurers are not adhering to generally accepted underwriting principles[4]. It suggests a misunderstanding of how insurance works and could give false hope to cancer survivors; points that are all addressed below.

[3] Socca and Meunier (2020), "A right to be forgotten for cancer survivors: A legal development expected to reflect the medical progress in the fight against cancer", Journal of Cancer Policy 25, which wrongly alleges that: "*The issue concerns more than 12 million cancer survivors in Europe. The practices of creditworthiness assessments are mostly self-regulated by private actors, including the collection and the evaluation of health information and data related to the applicant*." link

[4] Prof. Meunier during a public event (February 2021) entitled "14 million reasons to discuss life after cancer: implementing the right to be forgotten across Europe": "*…without any medical justification, cancer survivors are turned away or are imposed excessive premiums by insurance providers when they seek financial services.*", transcript

How does insurance work?

Offering insurance products without weighing the risk policyholders bring, is not compatible with private insurance and would be to the detriment of the many.

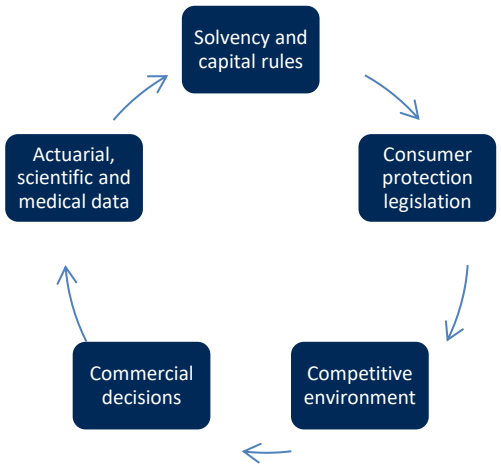
Insurance premiums and benefits are determined based on the risk an applicant brings to the pool of insureds. This risk is assessed based on the relevant information about the person applying for insurance. Therefore, insurers base their decision whether to insure - and how to insure - an applicant on data relevant to the risk taken on by the insurer. This process is known as underwriting.

The probability of the insured event happening (risk), determines the terms and conditions of insurance offered (coverage) and the price at which an insurer can offer the insurance (premium).

In line with European and national laws, insurers (like any business) are prohibited from discriminating against sections of the community, such as on the basis of gender. When applicants get different premium quotes or different levels of coverage offered by the same insurer, this is reflective of the differences in the risk each applicant brings to the pool of insureds with that insurer. This is not discrimination, since different factors are treated differently — in line with their risk addition — and similar factors are treated the same. "Differentiation", as is necessary for modern, private insurance, is not "discrimination", which is prohibited.

Underwriting decisions are a function of:

- ✓ *Laws & regulations, such as solvency/capital reserve rules, consumer protection laws, product-specific legislation*
- ✓ *Actuarial, scientific and medical data*
- ✓ *Commercial decisions*
- ✓ *Competitive environment*



The effects of differentiation can be negative for individuals since they may mean higher premiums or lesser coverage for an individual who brings higher risk of a claim to the insurer. However, this is necessary to be able to develop insurance products that are accessible to large groups of consumers, with the risk of the few spread among the many. This is the concept of mutualisation. Otherwise, the premiums would be too high or the benefits too low compared to the risk, which may disincentivise consumers from getting insurance protection. In the worst case, the products would not have a market, and therefore could not reasonably be offered by insurers.

Further, the type of insurance (eg, individual life assurance in support of a private mortgage) determines what risks are relevant when pricing and determining the benefits under the policy. Therefore, some data will be relevant to some insurance products, whereas other data may be more relevant to others.

Offering insurance products without weighting the risk policyholders bring is not compatible with private insurance and would be to the detriment of the many. As Swiss Re notes in a recent blog-article:

> "*Failing to match risk to prices will result in unaffordable insurance, as insurers would have to increase premium prices significantly. This would undermine the value of the products for the circumstances of many*."[5]

The right to be forgotten (RTBF)

Although some member states have introduced RTBF mechanisms, at European level a flexible code of conduct is preferable to a universal and rigid RTBF due to real and significant variations in care and social-economic outcomes between member states.

Insurers go to great lengths to use current data to continuously ensure product offerings are efficient and attractive. By way of example, insurers in some markets, such as Denmark, have voluntarily agreed to disregard a prior cancer diagnosis after some time and subject to certain caveats. In other markets — in which a RTBF has been introduced in a more formalised way — insurers have been part of the dialogue to achieve a RTBF that works in that market. This is the case in France, Belgium, the Netherlands and Luxembourg. In yet other markets, such as Sweden, insurers have voluntarily agreed to explain to consumers in plain language if medical reasons have led to coverage being rejected or terms varied for a risk-based reason. And in Italy, some insurers, in collaboration with the Italian federation of associations of cancer patients and survivors, signed a protocol that establishes that the distribution channel staff be adequately trained, thus facilitating the assessment and underwriting of cancer survivors' coverage.

Treatment options and availability tend to differ between member states. As the European Commission concedes:

> "*…When it comes to accessing high-quality cancer care, and particularly for timely diagnosis and treatment, patients are still faced with substantial differences in the standards of care, leading to unacceptable disparities across the EU. For instance, survival rates following treatment for breast cancer vary by 20% between countries and the five-year survival for colon cancer ranges from 49% to 68%*"[6].

One EU-wide fit for all markets is therefore inadvisable, since there are real and significant variations in care and social-economic outcomes between member states.

In some markets (France, the Netherlands and Luxembourg), the current designs of RTBF mechanisms are centred on the requirement that the insurance applicant must determine whether a prior diagnosis and treatment should be reported to the insurer. In other markets (Belgium), an applicant must make full disclosure and it is for the insurer to then determine when this information must be disregarded for the purposes of pricing and the benefits under the contract. The former approach places additional stresses on the applicant, who must determine whether to report to the insurer, since non-disclosure of material facts may lead to the coverage being voided. It also introduces additional costs to the provision of insurance within the scope of a RTBF, as the insurer needs to provide more guidance to the applicant. In contrast, where the obligation to disregard submitted information is placed on the insurer, it spares the applicant that stress and uncertainty when the contract is concluded, and likewise avoids that stress for loved ones in the event of a claim, placing the responsibility instead on the insurer.

Introducing a universal and rigid RTBF is inadvisable for these reasons. It is also right that those systems already implemented are respected, as they reflect the many differences between markets. However, ensuring that all insurers — including those in markets in which there is no RTBF mechanism — adhere to a code of conduct that

[5] J. Turner, Swiss Re (18 August 2021), "The Right to Forget Cancer", link

[6] European Commission (February 2021), "Beating Cancer Plan", p.16

affords the flexibility to meet local needs and differences, ensures that accommodations made for one group of insureds will not disproportionately impact others.

The stage at which cancer can be deemed to no longer carry an increased risk of mortality depends on factors such as the type of cancer diagnosed, age at diagnosis, stage at diagnosis, treatment forms, etc. Therefore, there should be no rigid timetable of, say, 10 years, for when a cancer survivor is deemed no longer at heightened risk of mortality. The relevant determinant — in line with actuarial, medical and scientific evidence — is the risk arising from the prior cancer diagnosis.

Current position — risk-related impact of cancer

A prior cancer diagnosis carries long-term risks. Only a few cancers are not associated with an excess mortality risk within 10 years of diagnosis and survivors of childhood cancer are at risk of chronic health conditions in adulthood. Several factors are relevant to determine the risk of recurrence or consequent morbidities and mortality.

The data on the risks arising from a prior cancer diagnosis and treatment makes for difficult and uncomfortable reading. However, to achieve an equitable method of pricing for the many — using risk-based underwriting techniques — generally accepted and current data is used by insurers and reinsurers. In the Netherlands, the insurance sector, cancer patient representatives and cancer data scientists concluded together, using data in the Netherlands Cancer Registry and reinsurers' manuals, that there are only a few cancers where an excess mortality risk is not associated with a prior cancer diagnosis within 10 years of diagnosis[7].

Cancer survival data from Italy finds:

> "*…a small but non negligible excess risk of death was still present even after 15 years since diagnosis for women with breast cancer and men with prostate and bladder cancers. In both sexes, a clear long-term excess risk of death emerged for most smoking-related cancers … and for hemolymphopoietic neoplasms, except for Hodgkin lymphoma…*"[8] and
>
> "*Excess cancer mortality risk …remained for >15 years for breast and prostate cancers*." [9]

The long-term impacts of cancer types and forms of treatment on cancer survivors is gaining attention. In research reported by the European Society of Cardiology, it was found that:

> "*The risk of death from cardiovascular diseases is several times that of the general population in the first year of [cancer] diagnosis; sometimes, this risk decreases, but for most, this risk increases as [cancer] survivors are followed for ten years or more*."[10]

Similarly, the longer-term impact on childhood cancer survivors also reveals previously little-understood consequences of treatment and types of cancer. By way of example, the WHO notes the risks to survivors of childhood cancer of suffering altered genes, predisposing them to future cancer recurrence, may be as high as 12%[11].

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[7] Data from the Dutch Insurance Association, Verbond van Verzekeraars Nederland, and the Nederlandse Federatie van Kankerpatiëntenorganisaties, in cooperation with the Dutch Cancer Registry, link

[8] Dal Maso (2019), "*Prognosis and cure of long-term cancer survivors: A population-based estimation*", Cancer Medicine 2019; 8:4497–4507 (p.4504)

[9] Ibid (p.4506)

[10] European Society of Cardiology press release (25 November 2019), "Cancer patients are at higher risk of dying from heart disease and stroke" link

[11] WHO (2020), "WHO Report on Cancer: setting priorities, investing wisely and providing care for all" (p.96): "*approximately 12% of childhood cancer survivors are expected to carry alterations in cancer-predisposing genes, requiring close long-term follow-up*" link

There is also growing evidence of cardiovascular disease in adult life for survivors of childhood cancer. Research into longer-term outcomes for German survivors of childhood cancer found:

> "*… a substantially elevated burden of traditional CVRF [cardiovascular risk factors] and CVD [cardiovascular disease] in a large German CCS [childhood-cancer survivors] cohort compared to the general population. Cardiovascular disease occurs prematurely and increases with age without reaching a plateau over time. The considerably increased prevalence for hypertension and dyslipidaemia in this young adult CCS indicates a high burden of cardiovascular morbidity and mortality in the long term*." [12]

Research from the US underscores the multitude consequences on quality of life that survivors of childhood cancer may face in adulthood:

> "*The percentage of survivors with 1 or more chronic health conditions prevalent in a young adult population was extraordinarily high. These data underscore the need for clinically focused monitoring, both for conditions that have significant morbidity if not detected and treated early, such as second malignancies and heart disease, and also for those that if remediated can improve quality of life, such as hearing loss and vision deficits.*"[13]

The above underlines the need to continue to permit insurance to be based on actuarial, medical and scientific evidence. Each cancer patient, although forming part of a wider statistic, is very individual. The age at diagnosis, the cancer type, the form of treatment, the duration of treatment and so on are all factors that are relevant to determine the risk of recurrence or consequent morbidities and mortality.

Implications of a rigid European RTBF

Requiring insurance to be offered without reference to relevant risk factors jeopardises insurance provision, as it decouples pricing and benefits from the risk that is taken on by insurers. This will have a knock-on effect on product terms, pricing or availability in the longer term and will likely impact all consumers.

Insurance Europe understands that the objectives of cancer patient organisations, including the European Cancer Organisation (ECCO), include a:

> "*call for the right of cancer survivors, when accessing financial services, not to declare their cancer ten years after the end of the active treatment and five years if they had cancer under 18, to be codified across European countries by 2025.*"[14].

Insurers are willing to discuss how the sector can support cancer survivors while operating within the legal and regulatory requirements that determine insurers' responsibilities. Among those responsibilities are the need to treat consumers fairly and without discrimination, while ensuring commitments to pay future claims can be kept by adhering to solvency and capital requirements. Because of those responsibilities, insurers must be able to continue to underwrite based on risk-relevant factors.

Requiring insurance to be offered without reference to relevant risk factors jeopardises insurance provision.

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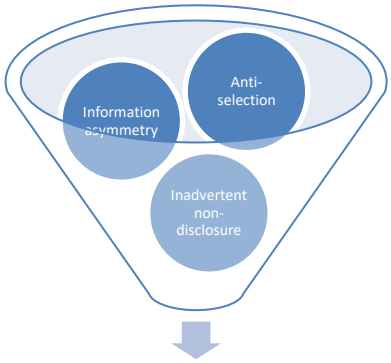
[12] J. Faber *et al* (2018), "*Burden of cardiovascular risk factors and cardiovascular disease in childhood cancer survivors: data from the German CVSS-study*", European Heart Journal, Volume 39, Issue 17, 1 May 2018, pp.1555–1562, link

[13] M. M. Hudson MD *et al* (2013), "*Clinical Ascertainment of Health Outcomes Among Adults Treated for Childhood Cancer*" (p.2381), JAMA Network, 12 June 2013 — Vol. 309, No.22, pp.2371-2381, link

[14] European Cancer Organisation (November 2020), "*Free from Cancer: Achieving Quality of Life for All Cancer Patients and Survivors*", link



The long-term consequences for consumers and insurers of existing RTBF mechanisms have not yet been assessed

- **Anti-selection** By way of example, a lack of medical information about cancer survivors due to a poorly designed RTBF could cause an increase in premium rates for the wider body of insureds. Potential market distortion due to anti-selection by some policyholders and pricing based on a flat premium — rather than a risk-based premium — could have unintended impacts on product design, availability or pricing. This is because consumers who bring a lower risk to the insurer will reflect on whether they pay too much and stop taking out insurance, while consumers who carry higher risks of the insured event happening may come to realise they are getting a very good deal and buy more insurance. The consequence is that insurance pricing becomes imbalanced relative to the risks and will impact product design, pricing and availability in the longer term. Anti-selection has been seen in various markets including the US, Germany and the UK[15].

- **Information asymmetry** With an RTBF there is a risk that the lack of information on the likely prevalence and severity of claims arising from the policyholders who benefit from it hides the true extent of the impact of such claims. That has potential implications for other policyholders — in terms of a heightened risk of anti-selection — and for the financial security of insurers because the risk-based underwriting decisions are based on incomplete information. This may be a low risk in the short term, but it could have severe implications for certain types of insurance products in the longer term as more claims materialise.

- **Inadvertent non-disclosure of material facts** The design of some existing RTBF, for instance in the Netherlands and France, does not require the disclosure of a prior cancer diagnosis to insurers if 10 years has passed since treatment ended. This means the responsibility to judge when this timeframe expires is placed on individual cancer survivors. There is evidence that this is a stressful burden on them, with insurers also reporting that it requires more customer assistance on their part to guide applicants through the rules. The consequences are additional costs, but — more importantly — the risk of an applicant failing to disclose what should have been disclosed leading to the claim being rejected for (inadvertent) non-disclosure.

- **Unknown consequences** The reality is that the consequences of existing RTBF mechanisms are not yet fully understood. There is insufficient data available to determine whether a RTBF for one group of consumers (here, cancer survivors), will have (or is having) a detrimental effect on other groups of consumers and product pricing, design or availability. Similarly, it is currently unclear to what extent existing RTBF mechanisms have increased access to insurance. The mechanisms so far introduced are all too recent (since 2015) and affect life assurance, which is a long-term product, meaning unpriced claims may not have materialised yet.

[15] Oxera study (October 2012), "*Why the use of age and disability matters to consumers and insurers*", p. 8 (figure 2.1), link

- **Significance of a small risk** What a consumer considers a "small" risk of mortality may be different from what an insurer understands to be a "small" statistical difference for insurance underwriting purposes[16]. Therefore, a 0.1% increased risk of mortality may not seem significant to a consumer, but this may mean the difference between a product at an attractive price or at a price at which consumers would not choose to purchase; it may even mean an insurer will not offer the product at all. The mortality risks differ from cancer to cancer and its impact differs from product to product.

Conclusions

An EU-wide RTBF that disregards risk-based underwriting may jeopardise insurance offerings and conflict with insurers' legislative and regulatory obligations.

Insurers are subject to legislative and regulatory requirements when offering and concluding contracts for insurance with consumers. They include: the fair treatment of all consumers through legislation to ensure consumers are not discriminated against on the basis of protected features (eg, gender); legislation covering solvency and capital reserves to protect the continued operation of insurers; and legislation on how insurers (and intermediaries) interact with, inform and treat consumers.

Since insurance operates by pooling the risks of many, the fairness of terms (such as premiums and benefits) is determined not only from an individual consumer's perspective but also by having regard to the larger group of consumers whose risks are pooled together. This pooling is done based on the risk of the insured event happening while seeking to achieve a premium rate and associated benefits that consumers will find attractive. This ensures that there is minimal anti-selection[17] and is dependent on the existence of no, or little, information-asymmetry[18] existing. That is how private insurance operates.

A right to be forgotten that disregards how private insurance works (ie, the pooling of risks) would jeopardise insurance offerings in terms of availability, price, choice or benefits for all consumers. If price is decoupled from risks, some consumers will pay too much premium relative to the risk they bring to the insurer, while others will underpay for the cover they secure relative to the risks they carry. It is therefore critical that any EU-wide RTBF:

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(3) preserves the ability of insurers to individually determine premiums and benefits based on risk-relevant factors.

[16] There is a difference between the way patients and clinicians look at mortality risk (life expectancy) and the way insurers do (excess mortality). Imagine that a healthy person has a survival rate of 99.9% (a mortality risk of 1 per 1000). Imagine that a cancer survivor has a survival rate of 99.8% (so the mortality risk is 1 per 1000 higher than the mortality rate of a healthy person = an excess mortality of 100%). This means that the mortality risk of the cancer survivor is twice as high as expected..

[17] Anti-selection occurs when the price does not reflect the relevant risks so that those consumers with a lower risk attribution realise they overpay and those with a high risk attribution realise they underpay

[18] Information asymmetry occurs where the consumer withholds risk-relevant information from the insurer so that it is not taken into account in the underwriting decision about the premium and benefits offered by the insurer