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Cancer survivorship and European access to Insurance

The legal, ethical and technological debate of risk mitigation

Dissertation to obtain a Master's Degree in Law and Financial Markets

Supervisor: Professor Margarida Lima Rego

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Lisbon, 14 December 2023

In the sunset of dissolution, everything is illuminated by the aura of nostalgia, even the guillotine.

Milan Kundera

To my mother,
for the unrivalled support
throughout my entire journey.

To Miguel,
a sunny, simple happiness
that didn't arrive for just a quick visit.
Unmatched influence.

To Petra, Ana, João and Tiago,
the people onto which friendship, inspiration
and love perspire of.

To all my remaining friends,
for their patience, motivation and support more than in these
last few months, but in all my years.

To professor Margarida Lima Rego,
for her guidance and even more for setting an example
of excellence in my professional life.

Special Mentions (*Menções Especiais*)

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Index of acronyms and abbreviations

AI	Artificial Intelligence
CCD	Consumer Credit Directive
Charter	Charter of Fundamental Rights of the European Union
CJEU	Court of Justice of the European Union
CNPD	Portuguese National Commission for Data Protection *(Comissão Nacional de Proteção de Dados)*
ECHR	European Court of Human Rights
ECJ	European Court of Justice
EHDS	European Health Data Space
EIOPA	European Insurance and Occupational Pensions Authority
EPFIA	European Federation of Pharmaceutical Industries and Associations
EPSR	European Pillar of Social Rights
ESMO	European Society for Medical Oncology
EU	European Union
GDPR	General Data Protection Regulation
IDD	Insurance Distribution Directive
ML	Machine Learning
OECD	Organisation for Economic Cooperation and Development
RTBF	Right to be Forgotten
TEU	Treaty on European Union
TFEU	Treaty on the Functioning of the European Union
USA	United States of America
WHO	World Health Organization

Abstract

Cancer survivors are exposed to the phenomenon of financial toxicity namely within Insurance. This issue brings forward the root question of the relation between the Insurance model and the key idea of non-discrimination, in particular: *how can private Insurance work within a society which is driven by a non-discrimination ideal?*

This key discussion will be the starting point for this dissertation. Throughout these chapters, the debate will be heightened with the introduction of different variables given that one cannot look at a subject which affects society from a single point of view. Insurance brings forward not solely juridical thinking but also ethical, and as of the last few decades, technological. This debate is not without its challenges and hurdles, in particular in the technological sector, which due to the inherent relation of insurance with data, is a current debate given the potential for prejudice perpetuation within Big Data.

Key words: insurance - right to be forgotten - cancer survivors - European Union law - anti-discrimination - ethics - statistical discrimination - artificial intelligence - machine learning - big data

Resumo

Os sobreviventes de cancro estão expostos ao fenómeno da toxicidade financeira (*financial toxicity*), nomeadamente no âmbito dos Seguros. Esta problemática suscita a questão basilar da relação entre o modelo de Seguros e a ideia-chave de não-discriminação, nomeadamente: *como é que o setor segurador privado pode funcionar numa sociedade que se orienta por um ideal de não-discriminação?*

Esta reflexão central será o ponto de partida da presente dissertação. No decurso destes capítulos, o debate será aprofundado com a introdução de diferentes variáveis, uma vez que não se pode abordar um tema que afeta a sociedade de um único ponto de vista. Os Seguros suscitam uma reflexão não apenas jurídica, mas também ética e, a partir das últimas décadas, tecnológica. Este debate não está isento de desafios e obstáculos, nomeadamente no setor tecnológico, que devido à relação inerente dos seguros com os dados, assume-se como um debate atual dado o potencial de perpetuação de preconceitos no *Big Data*.

Key words: seguros - direito ao esquecimento - sobreviventes de cancro - direito da União Europeia - anti-discriminação - ética - discriminação estatística - inteligência artificial - *machine learning* - *big data*

Introduction

Insurance as a sector is permeated by a form of permitted discrimination[1] fostered by a desire for financial stability in the presence of uncertainty[2]. The present dissertation attempts to analyse this sector in connection with its treatment of cancer survivors and the impacts it had on the lives of this ever growing demographic, in short, it addresses the intersection between two areas of Law: *(i)* Insurance Law, and *(ii)* Human Rights Law, specifically, the principle of equality and non-discrimination. Through three lenses, legal, ethical and technological, the consequences of discrimination in the access to insurance for cancer survivors and, as a result, the recently established right to be forgotten at European level for the private insurance sector will be discussed.

The introductory background on this dissertation will be given by the analysis of the *status quo* of the socioeconomic consequences of cancer survivorship and the evolution of cancer survivorship statistics as a means of laying down a factual ground for the debate.

The legal focus will provide the current framework for this discussion, as this is the method used by a society reliant on the legislator to establish its ethical principles. The balancing act between the European legislative trend of anti-discrimination, sustained by the EU equality, anti-discrimination and consumer protection driven rights, against the sustainability of a private sector of the economy, essential for the financial stability of society will be put forward. The pillars of the Treaty on the Functioning of the European Union (TFEU) will give the basis to the analysis of the new and potential European conquests such as the Europe Beating Cancer Plan, the European Health Data Space, the new Draft Proposal for a Council Directive regarding anti-discrimination, and highlighting the newly adopted Consumer Credit Directive as the vehicle for the enactment of the right to be forgotten for cancer survivors at an EU level.

Moving beyond this introductory motto, the ethical question raised behind the legislative development of insurance's reliance on discrimination will take a step further

[1] Rego, M. (2015). *Statistics as a basis for discrimination in the insurance business*. Law, Probability and Risk 14. P.123.
[2] European Central Bank (2009). *The importance of insurance companies for financial stability.* ECB Financial Stability Review. P.165-166.

by focusing on the right established for cancer survivors, leaving out other discriminated classes. The question of where the line must be drawn remains at large.

In the third lense, algorithmic solutions will be examined as the means of establishing the newly foreseen right to be forgotten to cancer survivors, not foregoing the necessary discussions generated by this new digital age regarding a new form of indirect bias, which could be more easily perpetuated in Insurance algorithms.

The battle against bias and the survival of Insurance will set the tone throughout the present dissertation whilst also providing the concluding remark to the arguments brought forward.

Circling back, and as an introductory remark on this dissertation, and alongside the development of society there was a simultaneous development of the risks human nature has had to endure. Consequently, Insurance as a sector saw its bloom with the association of risk coverage to the idea of protection of one's financial security[3]. Insurance grew from a sector mainly directed to the wealthier strata of society, into a sector directed to the masses. Nonetheless, the masses corresponded, unlike what one might ponder, to a limited segment of the population. Discrimination incurred within Insurance as it incurred within society[4]. The prejudice borne by individuals in their daily life, as such, permeated concurrently into their financial life[5].

The discrimination most easily thought of would be directly linked to the discrimination that gave way to the term *suspect classification* which *refers to a class of individuals that have been historically subject to discrimination*[6]. The commonly agreed classifications within the US relate to race, religion, national origin and alienage[7], with a

[3] *The parties have recourse to insurance to obviate a certain state of exposure to uncertainty. (...) the insurance contract serves precisely this purpose: that of implicating the patrimony of the insurer, instead of the patrimony of the insured, for certain patrimonial effects associated with that exposure.* (Source: Martins, M. (2010). *O Seguro de Vida enquanto tipo contratual legal*. Wolters Kluwer Portugal – Coimbra Editora. P.126).

[4] *E.g.*, the phenomena of redlining in the United States of America, which has been defined as *credit discrimination based upon the characteristics surrounding the borrower's dwelling* with, in the past, this behaviour being a *commonplace in an industry which provides a service as vital as property insurance has devastating implications for the housing opportunities of minorities* (Source: Gilmore, J. (1985). *Insurance Redlining & the Fair Housing Act: The Lost Opportunity of Mackey v. Nationwide Insurance* Companies. Catholic University Law Review, Volume 34, Issue 2. P.563-564).

[5] Pak, TY., Kim, H. and Kim, K.T. (2020). The long-term effects of cancer survivorship on household assets. Health Econ Rev 10, 2. P.2.

[6] Legal Information Institute. *suspect classification*. Cornell Law School, *in:* https://www.law.cornell.edu/wex/suspect_classification.

[7] *Idem*.

bigger emphasis on race due to the nations' history[8]. Notwithstanding, the European Union, in contrast, has had a bigger focus on sex[9] as a suspect classification, with numerous legislative and judicial decisions reflecting on the matter[10].

With regards to the health sector, discrimination within it has also been linked with discrimination arising from other areas. Notably, one can easily grasp how sex can lead to differentiations in health insurance from a patriarchal view of society. If women are the ones to bear the children, they could bear a higher premium due to its associated costs. However, it is not deemed fair since children are both parents responsibility and thus male and female should equally endure the cost that is reflected on the premium[11].

Discrimination regarding physical characteristics isn't the sole driver of this disparity. Wealth discrimination poses a serious issue as well since, for instance, with the increase in the prices of cancer medicines, according to the 2018 WHO Technical Report, there was a reflection on a less accessible care for patients and therefore a disparity in survival[12].

These discriminations, amidst others, that put cancer survivors on the spotlight within the European Union, are the driver of the present dissertation. However, we must begin by questioning:

Are Insurers capable of portraying an anti-discriminatory arena for cancer survivors without jeopardising the economic position its private status grants them?

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[8] The United States of America, amidst many other Occidental nations, have perpetrated racist institutions such as slavery. Even after the Cold War, the legacy of slavery ensued and, with this, iconic historical moments of resistance occurred such as the Underground Railroad, the Selma march, and the Montgomery Bus Boycott. Notwithstanding these efforts, we must recall that the Civil Rights Act that foresees the prohibition of discrimination was only signed in 1964 and even with this formal legislative matter in place, the reality is far from perfect, thus making race and the discrimination perpetrated still a very complex subject that is not solved as we can grasp by the surge of movements such as the Black Lives Matter.

[9] This theme will be dealt in more depth in Chapter II.

[10] Rego, M. (2022). *Discrimination Bans and Insurance Law*. Insurance and Human Rights, AIDA Europe. Research Series on Insurance Law and Regulation 5; Rego, M. (2015). *Statistics as a basis for discrimination in the insurance business*. Law, Probability and Risk 14.

[11] Following the *Test-Achats* Ruling (Judgment of the Court (Grand Chamber) of 1st March 2011, *Association Belge des Consommateurs Test-Achats ASBL and Others v Conseil des ministres* (Case C-236/09), the ECJ revoked article 5 (2) of the Gender Directive, thus making it impossible for insurers to differentiate individuals based on sex. As a consequence, sex can no longer be used as an actuarial factor for underwriting policies within the EU and this issue was resolved from a consumer perspective. For further information refer to: Rego, M. (2022). *Discrimination Bans and Insurance Law*. Insurance and Human Rights, AIDA Europe. Research Series on Insurance Law and Regulation 5. P.8 and following; Rego, M. (2015). *Insurance Segmentation as unfair discrimination: what to expect next in the wake of Test-Achats.* Proceedings of the 16th Annual Conference on Insurance Law Association of Serbia. *Insurance law, governance and transparency: basics of the legal certainty*. AIDA Serbia 2015; Torella, E. (2012). *Gender equality after Test Achats.* ERA Forum 13.

[12] World Health Organization (2019). *Technical Report on Pricing of cancer medicines and its impacts*. Information Session for Member States and Non-State Actors in Official Relations. P.41 and following.

Chapter I

Evolution and socioeconomic consequences of Cancer Survivorship

§1. Evolution of Cancer Survivorship statistics

Throughout the decades of medical developments, cancer[13] has remained one of the leading diseases which affects an ever-growing number of the population[14] and does not possess a straightforward cure. Numerous therapies and methods have been implemented as a means to fight the disease[15]. Nevertheless, survivors still face a risk of relapse, namely in the subsequent five years of the end of treatment, which poses an added health risk against survival of diseases which do not possess this characteristic.

Regardless of what was previously stated, and the predominant conceptions in civil society, the trends in cancer survivorship statistics have slowly confirmed an increase in the five-year cancer survival rates[16], indicating also an increase in cancer prevalence in society[17]. Through the following figure we can analyse this tendency of survival in the United States where all types of cancer, apart from cervix uteri, have faced an increase in its 5-year survival rates since 1970-77 to 2007-2013.

[13] Cancer is a term used to describe *more than 100 forms of the disease* since *almost every tissue in the body can spawn malignancies; some even yield several types* (Source: Weinberg, R. A. (1996). *How Cancer Arises*. Scientific American, 275(3). P.62.).

[14] *According to the International Agency for Research on Cancer (IARC), new cancer cases are projected to increase from 3.9 million in 2018 to 4.7 million by 2040, with the highest rates predicted in the elderly population* (Source: Working document from the European Parliament' Special Committee on Beating Cancer, *on Inputs of the Special Committee on Beating Cancer (BECA) to influence the future Europe's Beating Cancer Plan,* of 27 October 2020. P.2).

[15] *Progress against cancer has accelerated in the past decade because of advances in early detection, surgical techniques, and targeted therapies, despite slowing momentum for other leading causes of death. Some recent treatment breakthroughs are particularly notable because they are for historically difficult-to-treat cancers, such as metastatic melanoma and lung cancer.* (Source: Siegel, R., Miller, K., Fuchs, H., Jemal, A. (2022). *Cancer statistics, 2022 CA: A Cancer Journal for Clinicians.* American Cancer Society. Volume 72, Number 1. P. 29-30).

[16] *(...) aggregate five-year survival rates for all cancers increased from 50.3 to 67 percent* (Source*: Cancer death rates are falling; five-year survival rates are rising*. Our World in Data, *in*: https://ourworldindata.org/cancer-death-rates-are-falling-five-year-survival-rates-are-rising).

[17] *(...) in populations of western countries, the number of individuals living after a cancer diagnosis (i.e. cancer prevalence) is growing by approximately 3% annually* (Source: Scocca, G., Meunier, F. (2021). *Towards an EU legislation on the right to be forgotten to access to financial services for cancer survivors.* European Journal of Cancer 162 (2022). P.134).

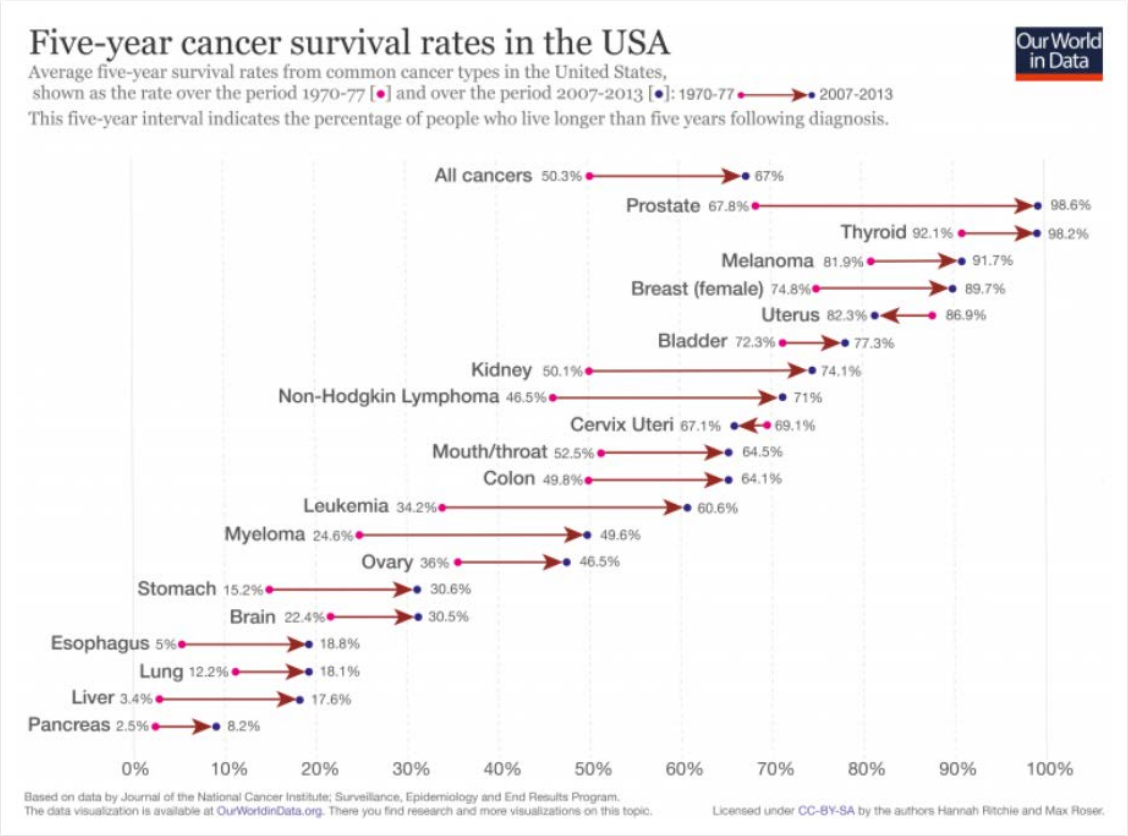

Figure I- Five-year cancer survival rates in the USA. Source: *Cancer death rates are falling; five-year survival rates are rising*. Our World in Data, *in*: https://ourworldindata.org/cancer-death-rates-are-falling-five-year-survival-rates-are-rising.

The European Union has not fallen outside this trend, with the 5-year survival rates increasing[18] – even though not at the same pace in all EU Member States[19]. The below table showcases an example of this disparity within the EU, with five-year survival rates for colon cancer from 2010-2014 ranging from almost 70% at its highest (Iceland), to 50% at its lowest (Croatia). This outcome variation is being highly fought against at an European level, namely through the pathways which are being built by the European Beating Cancer Plan that designed measures such as *i)* establishment by 2025 of an EU network which connects National Comprehensive Cancer Centres of all EU Member States[20], *ii)* launch of an EU platform to expand access for all to cancer treating medicines,

[18] *Recent developments in cancer diagnosis and treatment have dramatically improved survival rates and quality of life for cancer patient* (Source: Communication from the commission to the European Parliament and the Council on *Europe's Beating Cancer Plan*, of 3 February 2021. P. 18).

[19] *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* (Source: Communication from the commission to the European Parliament and the Council on *Europe's Beating Cancer Plan*, of 3 February 2021. P.16).

[20] According to the Europe Beating Cancer Plan, "*this action will help deliver higher-quality care and reduce inequalities across the EU, while enabling patients to benefit from diagnosis and treatment close to*

and *iii)* launch of a *"Cancer Diagnotic and Treatment for All"*[21] initiative to increase access to new methods of diagnosis and treatment.

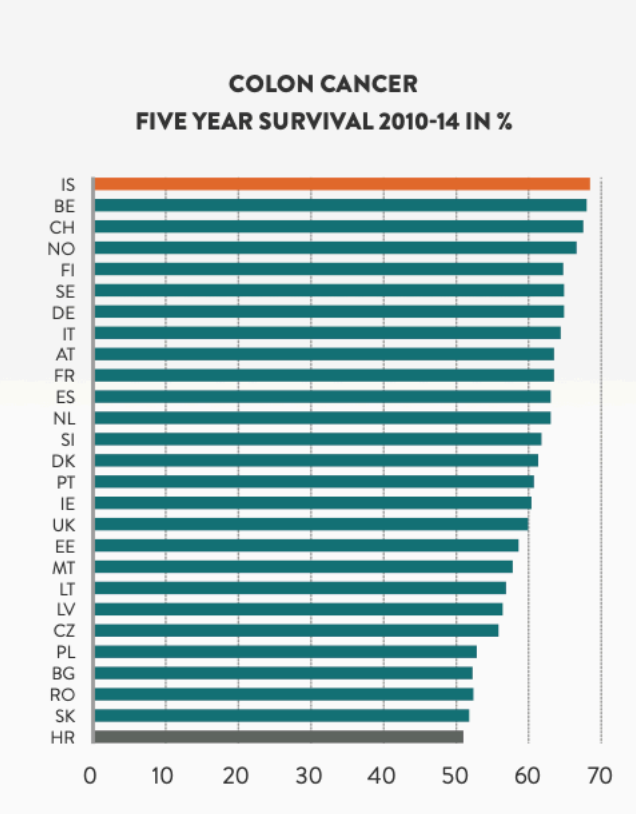

Figure II – Colon Cancer Five Year Survival Rate 2010-2014. Source: *in* European Federation of Pharmaceutical Industries and Associations (EPFIA). *Comparator Report Cancer in Europe.* P.3.

To add to this trend, and even though a larger number of people are dying from cancer today[22], this premise alone does not grant us much valuable information. Specifically, a statistical analysis taking into account solely these factors is flawed. To fully understand this scenario, other premises need to be put forward, in particular*: (i)* the notion that there is a larger number of people today than 20 years ago[23], and *(ii)* that the

home." (Source: Communication from the commission to the European Parliament and the Council on *Europe's Beating Cancer Plan*, of 3 February 2021. P.17).

[21] Communication from the commission to the European Parliament and the Council on *Europe's Beating Cancer Plan*, of 3 February 2021. P21.

[22] *Cancer is a leading cause of death worldwide, accounting for nearly 10 million deaths in 2020* (Source: World Health Organization. *Cancer, in*: https://www.who.int/news-room/fact-sheets/detail/cancer), in comparison with *the estimated 5.2 million deaths from cancer* in 1990 (Source: Pisani, P., Parkin, D., Bray, F., Ferlay, J. (1999). *Estimates of the worldwide mortality from 25 cancer in 1990*. Int J Cancer. 83(1).).

[23] In Europe we have risen from 721.50 million in 1990 to 745.17 million in 2021 (Source: Ritchie, H., Rodés-Guirao, L., Mathieu, E., Gerber, M., Ortiz-Ospina, E., Hasell, J., Roser, M. *Population Growth*. Our World in Data, *in*: https://ourworldindata.org/population-growth).

highest incidence is found among the oldest members of the population[24] who traditionally can be less resilient when compared with a younger individual when fighting this disease[25].

If we take into account all these factors, and correct the population in our analysis, we will comprehend that the mortality rates have actually dropped over the last decade[26][27].

Therefore, it is evermore relevant to discuss the socioeconomic consequences of the restriction of access to financial services to cancer survivors[28] given not merely the growing rate of cancer incidence, but mostly the consequent survival rates.

How can a considerably growing sector of our society be restricted from accessing basic financial products such as life insurance that are compulsory when taking out a loan for a house? One could argue, in extreme, the clash of this restriction with the fundamental right to housing displayed in numerous constitutional instruments throughout Europe[29]. However, there is not yet consensus along the political spectrum on the extent that this fundamental right has in the State's scope of activity. Additionally, it can be deemed a weak argument given the literal nature specified by the provisions which tend to indicate more of an "access to adequate housing" and not *per se* the right to ownership of a house. Notwithstanding, there are other legal mechanisms to argue against this restriction, notably the right of non-discrimination, in particular, financial discrimination, which seems to be the path the European legislator chose to undertake with the approval of the newly revised Consumer Credit Directive[30].

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[24] *We see that globally the majority of cancers occur in older populations. Approximately 70% of cancer cases occur in those aged over 50*. (Source: Roser, M., Ritchie, H. (2019). *Cancer*. Our World in Data, *in:* https://ourworldindata.org/cancer).

[25] *Almost half - 46% in 2017 - of all people who died from cancer are 70 or older. Another 41 percent are between 50 and 69 years old - so that 87% of all cancer victims are older than 50 years*. (Source: Roser, M., Ritchie, H. (2019). *Cancer*. Our World in Data, *in:* https://ourworldindata.org/cancer).

[26] (...) *age-standardized cancer death rates are falling globally. Death rates which correct for ageing show a 17 percent decline from 1990 to 2016*. (Source: *Cancer death rates are falling; five-year survival rates are rising*. Our World in Data, *in*: https://ourworldindata.org/cancer-death-rates-are-falling-five-year-survival-rates-are-rising).

[27] *Once the population growth and ageing have been accounted for, the number of cancer deaths has in fact decrease since the mid 1990s.* (Source: European Federation of Pharmaceutical Industries and Associations (EPFIA). *Comparator Report Cancer in Europe*. P.1).

[28] This exposition will be given in further detail in point 2 of the present Chapter.

[29] Such as: *(i)* Article 65 of the Portuguese Constitution; *(ii)* Article 47.2 of the Italian Constitution; and *(iii)* Article 20, section 1 of the German Constitution, amidst others.

[30] European Parliament (2022). *Deal on new rules to protect consumers from taking on too much debt*. Press Releases, *in: https://www.europarl.europa.eu/news/en/press-room/20221128IPR58027/deal-on-new-rules-to-protect-consumers-from-taking-on-too-much-debt*.

In order to develop this thesis, we must first paint the full picture of financial discrimination and its resulting implications on survivors before diving onto the legal, ethical and technological problems that arise in this stage.

§2. Socioeconomic consequences of cancer survivors

Survivorship of a disease such as cancer comes along with an associated financial burden. Notwithstanding the efforts within the European Union to establish itself as an organization constituted by States which put universal access to free, or extensively cost-reduced, health care at the top of its priorities, the financial consequences that can arise from the fight against this disease are still visible.

The economic burden that arises from this disease does not stop at the medical related expenses but the financial consequences which arise from patients being unable to work, either temporarily (sickness leave) or permanently (permanent absence due to declaration of unfit to work or death), and the support given by friends and family members through means of unpaid care which cannot be economically quantified must also be taken into account. In sum,

quantification of the economic burden of cancer in the EU needs not only an estimation of the costs of cancer to health-care systems, but also an estimation of the lost earnings associated with the inability to work (due to illness or premature death) and the costs of unpaid care provided by patients' friends and relatives[31].

Studies on the costs of cancer have been done both at State and EU level. It is prudent to analyse it as a whole, taking into account as abovementioned not merely the health care costs but also the remaining costs for the patient and society which result from patients being unable to work and with the costs of unpaid care given by individuals in close proximity to the patients. The following graph details by EU country (before Brexit) both the healthcare costs, productivity losses (associated with both the declaration of unfit to work - on a temporary or permanent basis - and with the mortality associated with the disease) and informal care costs provided by relatives and friends of the patient.

[31] Fernandez, R., Leal, J., Gray, A., Sullivan, R. (2013). *Economic burden of cancer across the European Union: a population-based cost analysis.* Lancet Oncology 2013, Volume 14. P. 1165.

	Cancer-related health-care costs							Productivity losses		Informal care costs	Total costs	
	Primary care	Outpatient care	Accident and emergency	Inpatient care	Drugs	Total	Percentage of total health-care expenditure	Mortality	Morbidity		Total	Percentage of gross domestic product
Austria	33	53	22	750	343	1202	4%	750	136	550	2638	0·95%
Belgium	34	70	9	550	346	1010	3%	1047	604	553	3214	0·94%
Bulgaria	10	12	2	56	44	124	5%	119	26	31	300	0·86%
Cyprus	<1	1	1	12	22	36	4%	53	5	15	109	0·65%
Czech Republic	29	77	14	284	194	598	5%	446	166	122	1331	0·94%
Denmark	4	55	11	299	205	574	2%	1010	380	277	2241	1·00%
Estonia	8	10	7	27	10	61	6%	61	34	17	172	1·25%
Finland	21	145	20	460	157	804	5%	464	77	166	1511	0·88%
France	114	176	19	3716	3025	7051	3%	4990	2299	2543	16 883	0·90%
Germany	710	1689	29	9760	2705	14 893	5%	11 607	2213	6414	35 126	1·48%
Greece	57	126	25	584	453	1244	5%	917	86	348	2596	1·12%
Hungary	26	19	5	121	221	393	5%	416	48	122	980	1·07%
Ireland	32	30	13	417	127	619	4%	603	63	162	1447	0·89%
Italy	487	452	115	4136	1664	6854	5%	3966	143	5491	16 454	1·08%
Latvia	5	7	2	34	11	60	5%	88	20	23	191	1·03%
Lithuania	8	8	4	30	9	59	3%	100	40	29	228	0·85%
Luxembourg	4	7	1	53	26	91	3%	57	18	26	191	0·53%
Malta	1	1	<1	6	7	16	4%	12	1	9	38	0·63%
Netherlands	172	250	13	1351	356	2143	3%	2519	706	983	6350	1·11%
Poland	129	368	15	619	267	1399	6%	1306	386	550	3641	1·17%
Portugal	43	65	28	182	247	564	3%	1118	98	268	2048	1·22%
Romania	19	62	2	133	205	421	6%	643	81	112	1257	1·06%
Slovakia	28	71	3	92	112	306	5%	180	88	53	627	1·00%
Slovenia	3	7	5	82	47	145	4%	147	72	42	406	1·14%
Spain	776	340	208	1275	1515	4114	4%	2838	482	1581	9016	0·86%
Sweden	47	244	40	408	233	971	3%	923	478	397	2769	0·95%
UK	153	1072	44	2916	1054	5241	3%	6186	682	2334	14 442	0·91%
Total for European Union	2954	5419	659	28 357	13 604	50 994	4%	42 565	9431	23 216	126 205	1·07%

Data are millions of euros, unless otherwise stated. No adjustment for price differentials. Totals do not match sum of costs because of rounding.

Table 1: **Costs of cancer in the European Union in 2009, by country**

Figure III - Costs of cancer in the EU in 2009. Source: Fernandez, R., Leal, J., Gray, A., Sullivan, R. (2013). *Economic burden of cancer across the European Union: a population-based cost analysis.* Lancet Oncology 2013, Volume 14. P. 1167.

Through a superficial analysis of the table above, the prevalence of over 50% of the costs in the productivity losses and informal care costs portray a problem for society. Although the total financial burden on the EU is shown at a little over 1% of the gross domestic product, it is worrisome the impact it has on society, both through loss of productivity but also for the economic loss that arises from the lives of individuals who support survivors through informal care and thus see a reduction in their work/leisure time. This also affects both productivity levels of society and economic aspects with less time to spend money on other activities. Most importantly, the financial burden it puts onto patients and consequently, on survivors is worrisome.

The evolution of cancer related costs in the EU is in an increasing tendency, with a study in 2018 (9 years after the abovementioned data) portraying an amount of 199 billion euros in Europe (the EU Member States alongside Iceland, Norway, Switzerland and the United Kingdom)[32] in comparison with the 126 billion in the EU (plus United Kingdom) in 2009. Notwithstanding the increase in costs, a dissection of this number is necessary to understand the true nature of this tendency.

The graph below dissects a 2018 analysis of the European cost of cancer. An analysis achieved both by the sum of the direct costs which arise from this disease, namely health expenditure on care and cancer drugs, and additionally the informal care alongside the indirect costs resulting from productivity. We can understand from both the studies presented, the relevance of the input of these variables onto our data analysis for a better understanding of the effective cost of cancer. Through these studies, we can take into account not merely the costs for the health sector in *stricto sensu*, but to the society and its economy as a whole.

[32] Hofmarcher, T., Lindgren, P., Wilking, N., Jonsson, B. (2020). *The cost of cancer in Europe 2018*. European Journal of Cancer 129. P.41.

Total cost of cancer (in million €) in Europe in 2018, by country and component.

Country	Direct costs			Informal care costs	Indirect costs		Total costs
	Health expenditure on cancer care	Share of total health expenditure	Cancer drugs[a]		Productivity loss from premature mortality	Productivity loss from morbidity	
Austria	2553	6.4%[b]	952	398	1080	281	4312
Belgium	3240	6.9%[b]	1024	693	1406	1244	6583
Bulgaria	320	7.1%[b]	216	43	174	49	587
Croatia	249	6.8%[b]	149	94	200	427	969
Cyprus	90	6.3%	–	24	40	9	163
Czechia	1084	7.0%	174	192	436	341	2053
Denmark	1499	4.8%	513	764	946	726	3934
Estonia	96	5.8%	5	24	61	75	255
Finland	844	4.0%	331	337	559	154	1895
France	18,707	7.1%	5184	3288	7116	4542	33,652
Germany	25,537	6.8%	7584	5141	11,516	4370	46,564
Greece	942	6.5%	44	314	607	159	2022
Hungary	618	7.1%	388	167	497	91	1372
Iceland	69	3.8%	21	20	44	40	173
Ireland	1139	5.0%[b]	308	180	526	113	1957
Italy	10,374	6.7%	4517	5165	4924	284	20,748
Latvia	111	6.4%[b]	26	33	92	39	274
Lithuania	196	6.4%[b]	55	34	113	82	426
Luxembourg	221	6.9%[b]	7	33	90	37	380
Malta	74	6.5%[b]	–	12	26	2	114
Netherlands	5309	6.9%	1072	982	2485	1387	10,163
Norway	1575	4.2%	366	362	609	666	3212
Poland	2185	7.0%	583	582	1775	784	5327
Portugal	991	5.4%	404	371	655	192	2208
Romania	712	7.1%[b]	351	159	598	160	1629
Slovakia	428	7.1%[b]	166	72	257	173	930
Slovenia	234	6.4%	105	77	166	139	616
Spain	5245	4.9%	2841	2529	3440	950	12,164
Sweden	1907	3.7%	572	491	830	960	4189
Switzerland	4366	6.0%	801	597	1716	477	7157
United Kingdom	11,691	5.0%	3249	3213	6633	1465	23,002
Europe	102,607	6.2%	32,008	26,389	49,615	20,418	199,029

Notes: Totals of Europe and costs do not match sums of costs because of rounding. No adjustment for price differentials. Cancer drug expenditure do not include confidential rebates. Data on cancer drugs for Cyprus and Malta could not be obtained, and for Estonia, Greece, and Luxembourg they only include retail sales but not hospital sales.

[a] Cancer drug expenditure are a subset of the health expenditure on cancer care.

[b] Estimated share based on data from similar countries; see Ref. [10].

Figure IV - Total costs of cancer in 2018 in Europe. Source: Hofmarcher, T., Lindgren, P., Wilking, N., Jonsson, B. (2020). *The cost of cancer in Europe 2018*. European Journal of Cancer 129. P.44

From the analysis of the figure above we can sustain the thesis of the relevance of the input of the data points since, from the 199 billion total cost, 96 billion amounts to non-related health-care system costs. Almost 50% of the cancer related expenditure results from indirect and informal care costs which makes it clearer the need for initiatives to attempt to diminish and tackle the impact this disease has on society. Notwithstanding the relevance of the values presented, the real costs could be much higher, namely in the informal care division, since estimates given by this study were deemed *rather crude*[33] since the study *might have missed a large share of patients below the age of 50, and it*

[33] Hofmarcher, T., Lindgren, P., Wilking, N., Jonsson, B. (2020). *The cost of cancer in Europe 2018*. European Journal of Cancer 129. P.47.

had to impute data for half the countries[34]. More in-depth studies were deemed necessary to fully conceptualize the effective economic burden it brought to the European society.

From the above analysis, cancer survivors are already put in a disadvantageous financial starting place from a health status they cannot control. Their access to insurance was deemed vital by the European Union[35], and previously by a limited number of EU Member States[36], in order to enable them the consequent access to financial services, in particular, to housing loans which foresee a mandatory life insurance policy associated. However, these measures must not be analysed lightheartedly. The measures established at both a national and European level – which we will dive into further in subsequent chapters – pose numerous questions on their viability given the burden allocated solely to insurers. Relevant stakeholders in the sector, namely Insurance Europe, have come forward opposing this view of establishing a right to be forgotten since *a right to be forgotten 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*[37]. The balancing act between the European trend of legislating an anti-discrimination mentality and provision of access to financial services to cancer survivors through allocation of burden onto the private sector versus the survival of private Insurance is the key issue that will be discussed, directly or indirectly, throughout the present dissertation.

2.1. Risk assessment on cancer survivors and consequent access to financial services

As previously exposed, insurance is a key financial asset in an individual's life. When we are discussing risk assessment of cancer survivors, the reality begins to morph itself into a complex arena. More so if Insurers truly attempt to measure the risks associated in an even more specified way, since *much current data on long term prognosis is based on US population*[38]. This circumstance imposes the need, mainly in the European Union given its state unified approach, to establish an adequate database for cancer survivors' data available to Insurers.

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[34] Hofmarcher, T., Lindgren, P., Wilking, N., Jonsson, B. (2020). *The cost of cancer in Europe 2018*. European Journal of Cancer 129. P.47.
[35] European Parliament (2022). Resolution of 16 February 2022 *on strengthening Europe in the fight against cancer - towards a comprehensive and coordinated strategy* (2020/2267(INI)). Paragraph 125.
[36] Namely, but not limited to, Luxembourg, France, Belgium and Portugal.
[37] Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.1.
[38] Saul, H., Liu, L., Meunier, F. (2018). *Call for action to end discrimination against cancer survivors*. Journal of Cancer Policy, Volume 17, P.2.

Until recently, insurers – given their inability to fully assess the risk of cancer survivors – typically took the prudent path and indirectly created hurdles to access to their services to cancer survivors[39]. However, due to medical, technological and statistical developments, insurers have now been creating new mechanisms and actuarial methods to be able to provide insurance policies targeted to survivors[40]. Currently, to narrow the risk assessment, Insurers utilize a measure denominated *conditional survival, which improves with time from diagnosis*[41]. Nevertheless, even with the application of this measure, *novel tools to derive a fair rating of risk in this population*[42] are crucial for the creation of an even playing field. Scocca and Meunier go further and point out that *the lack of specific criteria uniformly applied by private actors contributes to generate a fragmented assessment practice, mainly self-regulated by the same companies, including reinsurance companies, with a lack of transparency and monitoring control*[43], emphasizing the need for further investigation on the impacts these hurdles of access cause in survivors.

The risk assessment performed by insurers is not discriminative *per se* and differences in underwriting calculations between cancer survivors and non-cancer patients are only justified when strictly relevant, given the existent legislative anti-discriminative framework. In fact, several factors are taken into account for determining the risk associated for the specific individual, namely *(i) the age of the patient at diagnosis, type of treatment carried out (…), current treatment status, occurrence of concomitant diseases,* and *amount of time passed since the diagnosis/end of treatment*[44] before differentiating from another cancer patient statistics. Actuarial science

[39] *Banks and insurers have difficulties assessing the risks associated with such a complex disease and its risk of relapse. Adopting a precautionary approach in the interest of their business, insurers often applied a principle of caution and denied cancer survivors' applications in order to maintain their solvency.* (Source: Scocca, F., Meunier, F. (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. P.2).

[40] Weber, A., Schmidt, N., Wünsch, H, and Schilling, A. (2022). *Remember to Forget – Insuring Cancer Survivors and the Right to be Forgotten.* Gen Re Business School. Underwriting Focus, December 2022. P.7.

[41] Saul, H., Liu, L., Meunier, F. (2018). *Call for action to end discrimination against cancer survivors*. Journal of Cancer Policy, Volume 17, P.2..

[42] Saul, H., Liu, L., Meunier, F. (2018). *Call for action to end discrimination against cancer survivors*. Journal of Cancer Policy, Volume 17, P.2..

[43] Scocca, F., Meunier, F. (2021). *Towards an EU legislation on the right to be forgotten to access to financial services for cancer survivors.* European Journal of Cancer 162 (2022). P.134

[44] Weber, A., Schmidt, N., Wünsch, H, and Schilling, A. (2022). *Remember to Forget – Insuring Cancer Survivors and the Right to be Forgotten.* Gen Re Business School. Underwriting Focus, December 2022. P.8.

mechanisms are used to allow high risk individuals to be covered whilst balancing the economic viability for insurers.

Although the performed risk assessment and subsequent differentiations are based on medical statistical data, the consequences brought by it, in particular, the financial issues borne by cancer survivors, are discussed around the world, with the USA categorizing it as *financial toxicity*[45]. This concept describes the financial hardship brought to an individual or household due to a cancer diagnosis, either due to productivity losses and medical expenses or, in the other side, difficulty in accessing financial services. This hardship is described in studies both at national[46], European[47] and American level[48]. In any scenario, the existence of considerable hurdles to the access of financial services following a cancer diagnosis, which tend to get to a critical extreme in the housing loans, health and life insurance sectors is perceivable.

As previously indicated, in the European Union, stricto sensu *discrimination against cancer survivors when accessing insurance*[49] is against the law[50], with a relevant stakeholder in the Insurance sector of the European Union, Insurance Europe, stating that *Insurance Europe's members report that most cancer survivors are able to access insurance despite a prior cancer diagnosis*[51]. However, the problem arises from the *differentiation resulting in variations to the terms of the contract arising from a prior cancer diagnosis*[52] which, even if not directly, forbids certain classes of society from lower income households from accessing these services due to economic barriers.

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[45] *Financial Toxicity and Cancer Treatment (PDQ) – Health Professional Version*. National Cancer Institute in: https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq.

[46] Irish Cancer Society (2022). *The Right to be Forgotten beyond cancer: Access to financial products and services*. Research conducted by Core Research, 2021.

[47] *Right to be Forgotten.* European Cancer Patient Coalition *in: https://ecpc.org/policy/the-right-to-be-forgotten/.*

[48] *Financial Toxicity and Cancer Treatment (PDQ) – Health Professional Version*. National Cancer Institute in: https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq; and Pak, TY., Kim, H. and Kim, K.T. (2020). The long-term effects of cancer survivorship on household assets. Health Econ Rev 10, 2.

[49] Insurance Europe (2021). *Response to Nivel survey on access to financial products for cancer survivors.* P.1

[50] *National and European anti-discrimination legislation and/or contract law prevents insurers from discriminating against consumers. It is therefore not permitted to treat a cancer survivor differently from any other consumer solely based on the factor that the person has an impact on the risk insured* (Source: Insurance Europe (2021). *Response to Nivel survey on access to financial products for cancer survivors*. P.2). For example, article 15 of the Portuguese Decree-Law no. 72/2008, April 16 2008 (*Regime Jurídico do Contrato de Seguro*) establishes a general prohibition of discrimination in connection with insurance contracts.

[51] *Idem.*

[52] *Idem.*

Given the problem, this is not a discrimination *per se* issue when it comes to insurers. Private insurance works from the possibility of discriminating insurers based on their underwritten risk, and through this, a premium is calculated that accurately covers the individual risk. The supported thesis will be elaborated in following chapters, but an initial note must be presented. If legislative acts begin infiltrating the insurance sector due to this European trend of anti-discrimination[53], private insurance as we know it might come to an end. If we begin foregoing the possibility of statistical discrimination[54], which has already been done for gender[55], and now for cancer diagnosis[56], individuals who have lower risk profiles will have to bear a higher cost, with the possibility of the insurance model becoming unfeasible if the trend expands to other categories. The issues begin to rise: Who should bear these costs? Individuals, insurance companies or the States? Should the strive for a complete anti-discriminatory society allow for the demise of a part of a financial sector that has been, for decades, built on statistical discrimination? If a balancing act is desired, where is the line drawn?

[53] The use of the expression "European trend of anti-discrimination" intends to showcase the wider notion of discrimination that go beyond the discrimination provision already set in numerous legislative acts and through this, expanding the anti-discrimination mentality to an absolute extreme, not allowing for instrumental discrimination such as statistical discrimination which has been the basis of private insurance since its inception.

[54] For further developments on discrimination and, in particular, statistical discrimination, please refer to "*Chapter IV - Ethical Debate on Discrimination within Insurance*" of the dissertation.

[55] Due to the Gender Directive, Council Directive 2004/113/EC of 13 December 2004 *implementing the principle of equal treatment between men and women in the access to and supply of goods and services;* and the consequent *test-achats* ruling, Judgment of the Court (Grand Chamber) of 1 March 2011, *Association Belge des Consommateurs Test-Achats ASBL and Others v Conseil des ministres* (Case C-236/09).

[56] Position of the European Parliament adopted at first reading on 12 September 2023 with a view to the adoption of Directive (EU) 2023/... of the European Parliament and of the Council *on credit agreements for consumers* and repealing Directive 2008/48/EC.

Chapter II

European Union Legislative framework

§1. The Pillars of the TFEU, the TEU and the Charter of Fundamental Rights of the European Union

The European Union is known for its diverse and considerable volume of legislation[57] which materializes itself in the form of hard law instruments such as Treaties, Directives and Regulations or soft law mechanisms such as Opinions, Communications, amidst others[58].

Focusing on the instruments which target the debated problematic, the three base mechanisms that paved the way for the Union's intrinsic relation with anti-discrimination, equality, health promotion and consumer rights were the Treaty on European Union, the Treaty on the Functioning of the European Union and the Charter of Fundamental Rights of the European Union.

The Treaty on European Union[59], which originated in the Maastricht Treaty[60] that *marked a further step along the path to the political unification of Europe*[61] through the creation of the European Union, is now a consequence of the Lisbon Treaty of 2007. This Treaty features in its article 2, a mention to the anti-discrimination and equality view that the EU has fostered since its inception,

> *The Union is founded on the values of respect for human dignity, freedom, democracy, **equality**, the rule of law and respect for human rights, including the rights of persons belonging to minorities. These values are common to the Member States in a society in which pluralism, **non-discrimination**, tolerance, justice, solidarity and equality between women and men prevail.*

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[57] *(...) in 2019, there have been 54 acts falling into the category of "ordinary legislative procedure" which include European Parliament and Council (...) There were 172 "other legislative acts" which only involved the European Council* (Source: McCarthy, M. (2019). *How Much EU Legislation Is Adopted Annually?*. Statista, *in:* https://www.statista.com/chart/18838/adopted-legislative-acts-by-the-european-union/).

[58] Europa Nu. *Legal Instruments*. EU Monitor, *in:* https://www.eumonitor.eu/9353000/1/j9vvik7m1c3gyxp/vh75mdhkg4s0.

[59] Treaty on European Union of 13 December 2007 - consolidated version (OJ C 202, 7.6.2016).

[60] Treaty of Maastricht on 7 February 1992.

[61] *Treaty on the Functioning of the European Union*, Eur-Lex. Last updated on 15.12.2017 *in*: https://eur-lex.europa.eu/EN/legal-content/summary/treaty-on-the-functioning-of-the-european-union.html.

These views of equality, non-discrimination and pledge of fundamental rights are embodied in numerous articles of this instrument, notably article 3, paragraph 3 and article 6, paragraph 2 and 3. To further develop the notions, the Treaty on the Functioning of the European Union[62] has established, from its conception, a very ample view of what it sought for the Union and its citizens, from an economic, social and cultural perspective[63]. The Treaty is sub-divided in seven parts: *(i)* Principles; *(ii)* Non-Discrimination and Citizenship of the Union; *(iii)* Union Policies and Internal Actions; *(iv)* Association of the Overseas countries and territories; *(v)* The Union's External Action; *(vi)* Institutional and Financial Provisions; and *(vii)* General and Final Provisions.

The evolution of the divisions move from wider and more abstract concepts (*e.g.* the scope of the Treaty and the general principles which outline and govern the action of the Union in Part I) to more in depth notions that will be implemented and which range from the free movement of goods, persons, services and capital to public health and consumer protection in Part III (which we will endeavour to analyse below).

At last, in this macro legislative web, the Union possesses the Charter of Fundamental Rights of the European Union[64] which became legally binding with the Lisbon Treaty and has in its origins the thesis that *the Union is founded on the indivisible, universal values of human dignity, freedom, equality and solidarity*[65]. The Charter foresees articles protecting the right to personal data (article 8), human dignity (article 1) and non-discrimination related to, amongst others, genetic features or disability (article 21). The restriction on the scope of these rights within the Union is expressly limited to not allow for circumvention of the aim of the Charter with other legal instruments (article 52).

Now that we have established a general overview of the basis on which the Union founded its course of action we will delve onto the main principles which can, at first glance, be in clash with the risk assessment method of cancer survivors. Notwithstanding this first approach, it is mandatory to balance the rights of the companies as private commercial entities and the citizens in todays' market economy which rules our society.

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[62] Treaty on the Functioning of the European Union of 13 December 2007 - consolidated version (OJ C 202, 7.6.2016).
[63] Preamble of the Treaty on the Functioning of the European Union of 13 December 2007 - consolidated version (OJ C 202, 7.6.2016).
[64] Charter of Fundamental Rights of the European Union of December 2000 with consequent wording alteration in 2009 with the Lisbon Treaty (OJ C 202, 7.6.2016).
[65] Preamble of the Charter of Fundamental Rights of the European Union (OJ C 202, 7.6.2016).

1.1. Health Promotion Principle

The emphasis on health promotion, outlined in article 168 of the TFEU on Public Health, has been one of the objectives within the Union[66] since its foundation with manifestations of this principle, notably the creation of the European Health Data Space[67] and, more pertinently for the present discussion, the Europe's Beating Cancer plan[68].

Since the principles' inception, the EU has worked alongside stakeholders, namely the WHO[69], and has expanded its role in health promotion through the Treaties of Maastricht[70] and Amsterdam[71].

The essence of the health promotion principle, emphasized by the critical state of the health sector after Covid-19[72], was put on blast, and thus it developed into complex and meaningful initiatives. Notwithstanding the latest developments conquered through the last twenty decades, the root issues remain. To name a few, *(i) oversimplified approaches*; *(ii) infrastructure deficits*; and *(iii) lack of healthy public policies*[73]. To tackle these issues, and to achieve the goals of this principle, the EU must realise that *a truly health-promoting Union requires a more social Union*[74].

In 2021, the Regulation (EU) 2021/522[75], following the Covid-19 pandemic, was published, thereby establishing the EU4Health programme 2021-2027[76]. This was the fourth established programme in the EU for health promotion[77] in accordance with the

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[66] Ziglio, E., Hagard, S., and Griffiths, J. (2000). *Health promotion development in Europe: achievements and challenges.* Health Promotion International, Volume 15, Issue 2, June 2000. P.144; European Commission. *Health Promotion*. Public Health, *in:* https://health.ec.europa.eu/other-pages/basic-page/health-promotion_en.

[67] European Commission. *European Health Data Space*. Public Health, *in: https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en.*

[68] Developed in point 3 of Chapter II.

[69] For instance, *The World Health Organization (WHO) and European Commission have announced today the launch of a landmark digital health partnership.* (Source: World Health Organization (2023). *The European Commission and WHO launch landmark digital health initiative to strengthen global health security*. News release, *in: https://www.who.int/news/item/05-06-2023-the-european-commission-and-who-launch-landmark-digital-health-initiative-to-strengthen-global-health-security).*

[70] Treaty of Maastricht of 7 February 1992.

[71] Treaty of Amsterdam of 2 October 1997.

[72] OECD/European Union (2022). *Health at a Glance: Europe 2022: State of Health in the EU Cycle.* OECD Publishing, Paris. P.3.

[73] Ziglio, E., Hagard, S., and Griffiths, J. (2000). *Health promotion development in Europe: achievements and challenges.* Health Promotion International, Volume 15, Issue 2, June 2000. P.145.

[74] Godziewski, C. (2022). *What role for health promotion in the European Health Union?* The Progressive Post, FEPS, 26 October 2022, *in: https://progressivepost.eu/what-role-for-health-promotion-in-the-european-health-union/.*

[75] Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 *establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027, and repealing Regulation (EU) no. 282/2014.*

[76] *Idem.*

[77]Decision no. 1786/2002/EC of the European Parliament and of the Council of 23 September 2002 *adopting a programme of Community action in the field of public health (2003-2008);* Decision no.

principle set by article 168 of the TFEU, and it focused its efforts on four main goals: *(i)* fight against communicable and non-communicable diseases at an EU level through health promotion and disease prevention, *by reducing health inequalities, by fostering healthy lifestyles and by promoting access to healthcare*[78]. This goal is the foundation for measures such as the Europe Beating Cancer Plan[79]; *(ii)* identifying cross-border threats and establishing coordination and prevention strategies[80] – namely by *reinforcing the role of the European Centre for Disease Prevention and Control (ECDC)*[81]; *(iii)* focusing on the 3 A's: accessibility, availability and affordability, when it comes to medicine and medical devices[82]; and *(iv)* improving resilience and efficiency of health systems[83]. The following measures established on this objective are particularly relevant for the question posed - *supporting integrated and coordinated work between Member States (…), promoting the implementation of best practices and promoting data sharing,* and *advancing digital transformation*[84]. In synergy with other established programmes, the EU4Health Programme, alongside, for instances, the Digital Europe Programme[85], has established the newly founded European Health Data Space[86]. This health data space is foreseen in the Digital Europe Programme Regulation where it not only establishes its goal of giving back control to EU citizens over their personal health data but also foster

1350/2007/EC of the European Parliament and of the Council of 23 October 2007 *establishing a second programme of Community action in the field of health (2008-13)*; and Regulation (EU) no. 282/2014 of the European Parliament and of the Council of 11 March 2014, *on the establishment of a third Programme for the Union's action in the field of health (2014-2020) and repealing Decision no. 1350/2007/EC.*

[78] Article 3 (a) of Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 *establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027, and repealing Regulation (EU) no. 282/2014*

[79] European Commission. *A cancer plan for Europe, in: https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/promoting-our-european-way-life/european-health-union/cancer-plan-europe_en.*

[80] Article 3 (b) of Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 *establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027, and repealing Regulation (EU) no. 282/2014.*

[81] Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 *establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027, and repealing Regulation (EU) no. 282/2014.* P.3.

[82] Article 3 (c) of Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 *establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027, and repealing Regulation (EU) no. 282/2014.*

[83] European Commission. *EU4Health programme 2021-2027 - a vision for a healthier European Union.* Public Health, *in: https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en.*

[84] Article 3 (d), (i), (ii) and (v) of Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 *establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027, and repealing Regulation (EU) no. 282/2014.*

[85] Regulation (EU) 2021/694 of the European Parliament and of the Council of 29 April 2021 *establishing the Digital Europe Programme and Repealing Decision (EU) 2015/2240.*

[86] Proposal COM (2022) 197 final, of 3 May 2022, for a Regulation of the European Parliament and of the Council *on the European Health Data Space.*

the improvement and availability of more quantity and quality of data for research, disease prevention and individualized care in the EU[87].

Through all the aforementioned objectives, the EU4Health Programme aims to *pave the way to a European Health Union*[88]. Pursuant to both the Communication of 11 November 2020[89] and the European Commission's website[90], the current key actions of the European Health Union are: *(i) crisis preparedness*; *(ii) reform of the EU pharmaceutical legislation*; *(iii) Europe's Beating Cancer Plan*; and *(iv) a comprehensive approach to mental health*[91].

The European Pillar of Social Rights (EPSR), is an initiative which impacts the state of health promotion and protection in the EU and was firstly proclaimed in 2017 at the Gothenburg Summit by the European Parliament, the Council and the Commission[92]. The EPSR is composed of 20 principles divided in three areas: *equal opportunities and access to the labour market; fair working conditions; and social protection and inclusion*[93]. Although some principles impact directly[94] or indirectly[95] the health status of individuals, principle 16 is the one strictly foreseeing health care, with the European Commission associated actions being the Europe's Beating Cancer Plan and a new comprehensive approach to mental health[96]. Adding to this, the accessibility, availability and affordability is still considerably diverse[97] in EU Member States. Taking into account

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[87] Regulation (EU) 2021/694 of the European Parliament and of the Council of 29 April 2021 *establishing the Digital Europe Programme and Repealing Decision (EU) 2015/2240*. P.30.

[88] European Commission. *EU4Health programme 2021-2027 - a vision for a healthier European Union*. Public Health, *in: https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en*.

[89] European Commission (2020). *Building a European Health Union: Reinforcing the EU's resilience for cross-border health threats.* Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions.

[90] European Commission. *Europe Health Union, in*: https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/promoting-our-european-way-life/european-health-union_en.

[91] *Idem.*

[92] European Commission. *European Pillar of Social Rights - Building a fairer and more inclusive European Union*. Employment, Social Affairs & inclusion, *in: https://ec.europa.eu/social/main.jsp?catId=1226&langId=en*.

[93] European Commission. *The European Pillar of Social Rights in 20 principles.* Employment, Social Affairs & Inclusion *in*: https://ec.europa.eu/social/main.jsp?catId=1606&langId=en.

[94] For example, Principle 10 (Healthy, safe and well-adapted work environment and data protection) and Principle 18 (Long Term Care) (Source: European Commission (2023). *European Pillar of Social Rights: From Principles to Action for a strong social Europe.* Factsheet).

[95] For example, Principle 9 (Work-life balance), Principle 15 (Old age income and pensions) and Principle 20 (Access to essential services) (Source: European Commission (2023). *European Pillar of Social Rights: From Principles to Action for a strong social Europe.* Factsheet).

[96] European Commission. *The European Pillar of Social Rights in 20 principles.* Employment, Social Affairs & Inclusion *in*: https://ec.europa.eu/social/main.jsp?catId=1606&langId=en.

[97] Scholz, N. (2020). *Addressing health inequalities in the European Union: Concepts, action, state of play*. EPRS |European Parliamentary Research Service. P.1.

these considerations, it cannot be denied that *people's health status, their social situation and economic conditions are closely interconnected*[98]. Thus, we can argue that if the EPSR objectives are fulfilled, health of individuals in the EU may also take a significant improvement, even if foregoing the express 16th principle of the EPSR. The below table showcases this thesis with only 10% of health inequity being attributed to quality of health care and 64% being directly related to financial and socio-economic reasons.

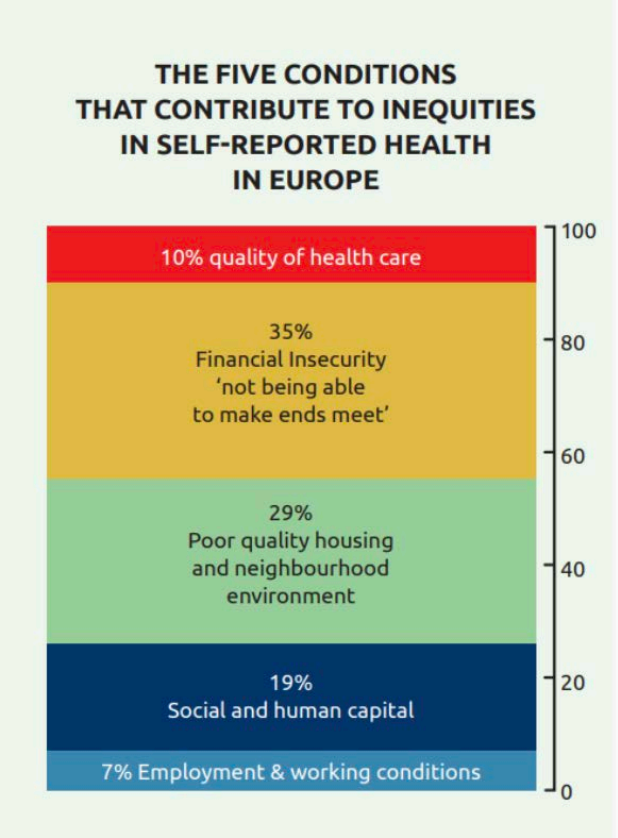

Figure V – The five conditions that contribute to inequities in self-reported health in Europe. Source: EuroHealthNet (2020). *The European Pillar of Social Rights: A key vehicle to improving health for all*. P.2.

To add to this data, we can find in the *OECD Health at a Glance: Europe 2022: State of Health in the EU Cycle* report[99] a critical contemporary statistical document. The report dove into several health determinants and analysed key public health issues in Europe, namely the consequences of the pandemic in non-Covid health care, the trends in mortality, risk factrs, health expenditure, quality of care, resilience and the 3 A's,

[98] EuroHealthNet (2020). *The European Pillar of Social Rights: A key vehicle to improving health for all*. P.4.
[99] OECD / European Union (2022). *Health at a Glance: Europe 2022: State of Health in the EU Cycle*. OECD Publishing, Paris.

accessibility, affordability and availability in the health care sector[100]. In its analysis, it found discrepancies in the quality, accessibility, affordability and availability of health care between States in Europe[101] even though there has been, since the Union's inception, the principle of health promotion and protection instituted in the founding charters and legal texts.

Following the OECD analysis, the existence of severe discrepancies in accessibility, affordability and availability of health care which are still dependent on the Member State the citizen is resident on is confirmed[102]. As such, this poses a dire consequence, not only for citizens diagnosed with cancer – who will not have access to treatments, medicines and ultimately, medical resources – but also for local insurers who, despite having different survival rates than other EU Member States, will have to cover the risk to the same extent as the latter. This can be an argument put forward against the newly established EU right to be forgotten. If the EU wishes for every citizen to be treated the same regardless of its home state, it needs to ensure that there is identical access to healthcare for all Member States so that the statistical discrimination that would typically be used to calculate the risk to be covered would be alike, thereby putting all insurers on equal footing in terms of foreseeable losses. Lastly, this newly established right brings forward a competition issue regarding the larger burden put onto local insurers versus multinational ones where the losses can be more easily scattered. Through this, the EU may be fostering the creation of a barrier to the entry to new or permanence of existing national insurers in the market due to its unsustainability, thus fueling the creation of a sector with players too big to fail. This would be exacerbated for insurers who sole branch is life insurance, however if new provisions regarding prohibition of use of statistical discrimination and actuarial factors continue, this issue may be posed for other insurance branches as well.

1.2. Non-discrimination

Non-discrimination[103] is one of the enshrined rights in the EU. This view is now set out in various European texts, including article 10 of the TFEU, articles 2 and 3 of

[100] *Idem*.
[101] OECD / European Union (2022). *Health at a Glance: Europe 2022: State of Health in the EU Cycle.* OECD Publishing, Paris. P.170 and following.
[102] Scholz, N. (2020). *Addressing health inequalities in the European Union: Concepts, action, state of play*. EPRS |European Parliamentary Research Service. P.4.
[103] The concept of non-discrimination will be used interchangeably with anti-discrimination in this paper.

TEU and articles 7, 8 and 21 of the Charter of Fundamental Rights of the European Union. Following the provisions mentioned, *any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited*[104].

The EU is no longer a mere economic driven cluster of institutions, with social policy at the forefront of many initiatives[105] which do not contribute to the initial economic market integration objective. Non-discrimination law is no longer restricted to gender and nationality with the expansion to other classes such as race, religion[106] and, relevant to this discussion, cancer survivorship. In the Insurance sector we have witnessed the impacts of this anti-discrimination trend that completely disregards the way private insurance works[107], thus discarding the validity of any form of statistical discrimination and the mathematics of actuarial sciences. We have witnessed this in a first moment with gender, through the *Test-Achats* case[108] and now through the introduction of a provision in the Consumer Credit Directive which foresees a right to be forgotten for cancer survivors[109]. Anti-discrimination in social sectors is necessary and the transformation of society onto an egalitarian state is the ideal social European view. However, if the legislative trend begins to strive for absolute refusal of discrimination, Insurance will end, and more harm than good will be done to society.

1.3. Consumer Rights

The European Union is known for its expansive view regarding consumer protection[110]. Although the directives enacted in the last decades[111] have taken centre

[104] Article 21 of the Charter of Fundamental Rights of the European Union of December 2000 with consequent wording alteration in 2009 with the Lisbon Treaty (OJ C 202, 7.6.2016).
[105] Eurofund (2023). *Social policies, in: https://www.eurofound.europa.eu/en/topic/social-policies.*
[106] European Union Agency for Fundamental Rights. (2018). *Handbook on European non-discrimination law.* Publications Office of the European Union. P.21.
[107] Huang, S., Salm, M. (2019). *The effect of a ban on gender-based pricing on risk selection in the German health insurance market.* Health Economics, Volume 29, Issue 1. P.16.
[108] Judgment of the Court (Grand Chamber) of 1st March 2011, *Association Belge des Consommateurs Test-Achats ASBL and Others v Conseil des ministres* (Case C-236/09).
[109] Article 14 (4) of the position of the European Parliament adopted at first reading on 12 September 2023 with a view to the adoption of Directive (EU) 2023/... of the European Parliament and of the Council *on credit agreements for consumers* and repealing Directive 2008/48/EC.
[110] European Commission (2020). *New Consumer Agenda: European Commission to empower consumers to become the driver of transition*. Press release, *in:* https://ec.europa.eu/commission/presscorner/detail/en/IP_20_2069.
[111] For instance, Directive 2011/83/EU of the European Parliament and of the Council of 25 October 2011 *on consumer rights, amending Council Directive 93/13/EEC and Directive 1999/44/EC of the European Parliament and of the Council and repealing Council Directive 85/577/EEC and Directive 97/7/EC of the*

stage has the flag of consumer protection, they have, as its basis, provisions in the TFEU[112] and in the Charter of Fundamental Rights[113].

The consumer protection idea, within the scope of health and economic interests of citizens, is brought forward by the newly established right to be forgotten for cancer survivors foreseen in the revised Consumer Credit Directive approved in September 2023[114]. An idea which seems to have at its foundations, article 169 (1) of the TFEU which establishes that *in order to promote the interests of consumers and to ensure a high level of consumer protection, the Union shall contribute to protecting the health, safety and economic interests of consumers*.

It is worth to remark that this protection mentality was not present in the EU's inception, with the first major step being taken only in 1962 with the creation of the European Consumer Organisation in Brussels[115]. In 1993, the Maastricht Treaty set out for the first-time consumer protection as a new independent policy of the Union[116]. Following this legislative steppingstone, the consumer protection framework densified itself by, amongst others, the publication of the Unfair Commercial Practices Directive[117], the Consumer Rights Directive[118] and the Unfair Contract Terms Directive[119], all of which have been thoroughly amended by Directive 2019/2161[120]. These legislative texts laid the foundations for the consumer arena as we know it and which has consequently expanded for other specific areas such as financial services[121]. For the question posed, the

European Parliament and of the Council, and Directive (EU) 2019/2161 of the European Parliament and of the Council, of 27 November 2019 *amending Council Directive 93/13/EEC and Directives 98/6/EC, 2005/29/EC and 2011/83/EU of the European Parliament and of the Council as regards the better enforcement and modernization of Union consumer protection rules.*

[112] Article 4.2(f); Article 12; Article 114 (3); and Article 169 (1).

[113] Article 38.

[114] Please refer to Chapter III for development on the newly established right to be forgotten for cancer survivors under the Consumer Credit Directive.

[115] The European Consumer Organisation. *History*. BEUC, *in:* https://www.beuc.eu/about-beuc/history.

[116] Sajn, N. (2019). *Protecting European consumers.* European Parliament. Briefing. P.3.

[117] Directive 2005/29/EC of the European Parliament and of the Council of 11 May 2005 *concerning unfair business-to-consumer commercial practices in the internal market and amending Council Directive 84/450/EEC, Directives 97/7/EC, 98/27/EC and 2002/65/EC of the European Parliament and of the Council and Regulation (EC) No 2006/2004 of the European Parliament and of the Council.*

[118] Directive 2011/83/EU of the European Parliament and of the Council of 25 October 2011 *on consumer rights, amending Council Directive 93/13/EEC and Directive 1999/44/EC of the European Parliament and of the Council and repealing Council Directive 85/577/EEC and Directive 97/7/EC of the European Parliament and of the Council.*

[119] Council Directive 93/13/EEC of 5 April 1993 on unfair terms in consumer contracts.

[120] Directive (EU) 2019/2161 of the European Parliament and of the Council, of 27 November 2019 *amending Council Directive 93/13/EEC and Directives 98/6/EC, 2005/29/EC and 2011/83/EU of the European Parliament and of the Council as regards the better enforcement and modernization of Union consumer protection rules.*

[121] For instance, Directive 2008/48/EC of the European Parliament and of the Council of 23 April 2008 *on credit agreements for consumers and repealing Council Directive 87/102/EEC.*

Consumer Credit Directive of 2008[122] is a relevant legislative piece given that it was enacted to *strengthen consumer rights when concluding a credit agreement*[123], thereby expanding the scope of consumer protection for consumer credits, although not covering, amongst others, mortgage loans[124][125]. These specific loans are relevant since they create the biggest financial impact for cancer survivors given their hurdles to access due to mandatory insurance[126]. As will be further developed below, the revised Consumer Directive will now grant survivors the right to be forgotten with insurers when contracting certain loans, however, due to its exclusion of mortgage loans falls short of already established national legislation provisions[127].

§2. Development of Discrimination Bans within EU and the New Draft Proposal for a Council Directive regarding anti-discrimination

As previously exposed, it is known that the EU did not begin with a social goal centred on fundamental rights, but instead the economic desire of a sole internal market was the key objective[128]. Some scholars such as Belavusau and Henrard, outline the EU development of non-discrimination in three stages: *(i)* before the Treaty of Amsterdam; *(ii)* from the Treaty of Amsterdam until the Treaty of Lisbon; and *(iii)* from the Treaty of Lisbon until the current day[129].

In the first stage, the idea of non-discrimination focused solely on nationality and gender, with *the original rationale for including a prohibition of discrimination* being *the realization of the single economic market*[130]. The goal was for citizens of all Member States, both male and female, to be considered equal with no competitive advantages

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[122] Directive 2008/48/EC of the European Parliament and of the Council of 23 April 2008 *on credit agreements for consumers and repealing Council Directive 87/102/EEC.*

[123] European Commission. *Consumer Credit, in:* https://commission.europa.eu/business-economy-euro/banking-and-finance/consumer-finance-and-payments/retail-financial-services/credit/consumer-credit_en.

[124] Article 2 (2) paragraph a) of Directive 2008/48/EC of the European Parliament and of the Council of 23 April 2008 *on credit agreements for consumers and repealing Council Directive 87/102/EEC.*

[125] Regulated at the EU level by Directive 2014/17/EU of the European Parliament and of the Council of 4 February 2014 *on credit agreements for consumers relating to residential immovable property and amending Directives 2008/48/EC and 2013/36/EU and Regulation (EU) No 1093/2010.*

[126] Irish Cancer Society (2022). *The Right to be Forgotten beyond cancer: Access to financial products and services*. Research conducted by Core Research, 2021. P.4.

[127] For further information, please refer to sub-chapter 2 of Chapter III.

[128] European Union Agency for Fundamental Rights. (2018). *Handbook on European non-discrimination law*. Publications Office of the European Union. P.20.

[129] Belavusau, U., and Henrard, K. (2019). *EU anti-discrimination law beyond gender*. Oxford, UK; Portland, Oregon: Hart Publishing. P.6-11.

[130] Belavusau, U., and Henrard, K. (2019). *EU anti-discrimination law beyond gender*. Oxford, UK; Portland, Oregon: Hart Publishing. P.6

being granted in one versus the other, namely for countries where there was a bigger wage gender gap[131]. The 70s jurisprudential boom led by the CJEU's anti-discrimination views on gender and nationality in a series of judgments[132] brought to life articles from the EEC Treaty[133]. This was possible due to the direct effect of article 119 of the EEC Treaty which has allowed for the Court to develop *its doctrine of sex equality as a general principle of EU law*[134]. However, with the enactment of the Treaty of Amsterdam[135], the CJEU could not depend on the direct effect since the article's new formulation now required the existence of secondary legislation[136]. Nonetheless, the Treaty of Amsterdam was a relevant mark for the development of EU anti-discrimination law for two reasons: *(i)* the establishment of total gender equality in its article 3(2); and *(ii)* the inclusion in its article 13 of more protected classes of discriminated individuals, namely race and ethnicity, religion, disability, age and sexual orientation. This evolution in the second phase marked the establishment of the EU as more than an economic coalition of States, with human rights becoming a key principle of EU law[137].

In order to materialize the anti-discrimination principles set forward on the key treaties and charters of the EU onto clear rules, the EU enacted in this phase a number of secondary legislation, in the form of directives, to attempt to eliminate discrimination:

i) Council Directive 2000/43/EC implementing the principle of equal treatment between persons irrespective of racial or ethnic origin ("Racial Equality Directive");
ii) Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation ("Employment Equality Directive");
iii) Council Directive 2004/113/EC implementing the principle of equal treatment between men and women in the access to and supply of goods and services ("Gender Directive"); and

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[131] *Idem.*
[132] *One of the earliest examples is Elaine Vogel-Polsky, the lawyer who litigated the landmark Defrenne cases (1971, 1976 and 1978)* (Source: Belavusau, U., and Henrard, K. (2019). *EU anti-discrimination law beyond gender*. Oxford, UK; Portland, Oregon: Hart Publishing. P.7).
[133] The European Economic Community Treaty, also known as the Treaty of Rome of 25 March 1957.
[134] Belavusau, U., and Henrard, K. (2019). *EU anti-discrimination law beyond gender*. Oxford, UK; Portland, Oregon: Hart Publishing. P.7
[135] Treaty of Amsterdam of 2 October 1997.
[136] Article 19 TFEU.
[137] EUR-Lex. *Fundamental rights and non-discrimination, in:* https://eur-lex.europa.eu/EN/legal-content/summary/fundamental-rights-and-non-discrimination.html.

iv) Directive 2006/54/EC of the European Parliament and of the Council implementing the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation ("Recast Directive").

Alongside this legislative process, the CJEU continued its mandate. Although some landmark judgments were produced[138], the new classes of discrimination foreseen in the established provisions did not produce a considerable amount of jurisprudence during this phase.

The last phase, launched by the Treaty of Lisbon, fostered the anti-discrimination arena as we now understand it. Through the Treaty of Lisbon, the Charter of Fundamental Rights of the European Union became binding given its newly rank of primary EU law[139]. As such, fundamental rights are now one of the core principles of the EU alongside economic and monetary integration.

Notwithstanding all the developments brought forward over the last decades in the fight against discrimination in the EU, the EU has yet to adopt the draft proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation[140]. However, the political climate changed from the time of the 2000's directives and with more States entering the EU and having a seat at the negotiation table, agreement on such an anti-discrimination view is thorny. Additionally, the decrease of central-left combined with the rise in right-wing governments[141] can help to comprehend the current standstill.

The 2008 draft proposal intended to legislate anti-discrimination in a wider scope namely in the *fields of social protection, social advantage, education and goods and services, including housing*[142], thereby expanding the scope behind the current sole labour

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[138] The landmark judgments foresaw age discrimination (Case C-144/04 *Werner Mangold v Rudiger Helm*), extension of the applicability of EU anti-discrimination law (Case C-303/06 *Coleman v Attridge Law and Steve Law*), race (Case C-54/07 *Centrum voor de Gelijkheid van Kansen en Racismebestrijding v firma Feryn BV*), and sexuality in the Framework Equality Directive (Case C-267/06 *Maruko v Versorgungsanstalt der deutschen buhnen*).

[139] Belavusau, U., and Henrard, K. (2019). *EU anti-discrimination law beyond gender*. Oxford, UK; Portland, Oregon: Hart Publishing. P.12.

[140] Proposal COM (2008) 426 final, of 2 July 2008, for a *Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation.*

[141] Politico (2023). *Europe swings right - and reshapes the EU*. 5 December 2023, *in*: https://www.politico.eu/article/far-right-giorgia-meloni-europe-swings-right-and-reshapes-the-eu/; Armstrong, M. (2023). *Where Europe's Far-Right Has Gained Ground*. Statista, *in:* https://www.statista.com/chart/6852/right-wing-populisms-enormous-potential-across-europe/.

[142] Bell, M. (2009). *Advancing EU Anti-Discrimination Law: the European Commission's 2008 Proposal for a New Directive.* The Equal Rights Review, Vol. Three. P.7.

market focus. For the proposal, discrimination *is understood to include direct and indirect discrimination, harassment, instructions to discriminate and denial of reasonable accommodation*[143][144].

Although expansive in its scope, the proposal foresees exceptions to the prohibition of discrimination. In particular, article 2 (7) establishes the possibility of discrimination if *in the provision of financial services Member States may permit proportionate differences in treatment where, for the product in question, the use of age or disability is a key factor in the assessment of risk based on relevant and accurate actuarial or statistical data*. By not considering cancer survivorship a disability, the establishment of a right to be forgotten for cancer survivors does not contradict this potential exception to be enacted by the proposal. However, if the anti-discrimination EU view is to be considered in a global spectrum, disabled persons should not be affected in their access to financial services just like cancer survivors won't be anymore - to a certain extent - in the European Union. If the *whole point of law is to require suppliers to treat each person as an individual, not as a member of a group*[145] then how can discrimination in access to financial services be allowed for disabled persons but not for cancer survivors? Where will the line be drawn? The discussion of the metaphorical drawing of a line is key because its inexistence would mean the total unfeasibility of private insurance and, thus, unforeseeable consequences for the future of insurance[146]. Insurance is a key part of the financial system, being one of its three sectors, it represents a significant amount of economic value both for corporations and for individuals[147]. At the moment, a report from Munich Re Group on the German market considered that this *still amount to a contained risk*[148]. However, Insurance Europe considered that *the consequences of existing RTBF mechanisms are not yet fully understood*[149]. It can be argued that an extreme anti-discriminatory view could destroy the workings of private insurance which would not come as a benefit for society since, without the aid of insurance, the gaps in

[143] Proposal COM (2008) 426 final, of 2 July 2008, for a *Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation.* Recital 12.
[144] Please refer to sub-chapter 1.1. of Chapter IV for a deeper analysis on direct and indirect discrimination.
[145] Bell, M. (2009). *Advancing EU Anti-Discrimination Law: the European Commission's 2008 Proposal for a New Directive.* The Equal Rights Review, Vol. Three. P.14.
[146]Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.7.
[147] *The insurance industry is Europe's largest institutional investor, with a portfolio equivalent to 61% of GDP* (Source: Insurance Europe. *Value of Insurance, in: https://insuranceeurope.eu/value-of-insurance).*
[148] Munich RE (2023). *The "Right to be forgotten" and its impact on life insurance business. An assessment from an insurance medicine perspective.* P.6.
[149]Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.7.

the social economies of the EU Member States would not have a way to be surpassed by the private citizen and real structural changes would need to be achieved for citizens to keep their economic status, health and welfare.

§3. Europe Beating Cancer Plan and the European Health Data Space

Just as we have established above, cancer is one of the main health concerns within the European Union, with an estimate that, unless serious action is taken, it will become the leading cause of death in the EU by 2035[150]. As such, the European Commission, together with the European Parliament established the necessity of tackling the matter in a comprehensive manner thus implementing the Europe Beating Cancer Plan[151], which took its place as a *key pillar of a strong European Health Union*[152].

The Europe Beating Cancer Plan pursues 4 main areas of intervention: *(i) prevention; (ii) early detection; (iii) diagnosis and treatment;* and *(iv) quality of life of cancer patients and survivors*[153].

One of the key issues pointed out in the Plan relates to the access to financial services for cancer survivors[154]. The Commission, in response, established an initiative in order to *address fair access for cancer survivors to financial services (including insurance), via a code of conduct and a reflection on long-term solutions*[155], whereas the right to be forgotten already established in a number of EU Member States was later deemed as a solution for the problem.

Alongside the establishment of this Plan, and with the materialization of the goal of the European Health Union behind, the discussions on the key idea of a European Health Data Space (EHDS) also arose, stemming from the strategy established by the Union with regards to data[156] which foresaw the constitution of a single market for

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[150] *Unless we take decisive action, lives lost to cancer in the EU are set to increas by more than 24% by 2035(...) in* Communication from the commission to the European Parliament and the Council on *Europe's Beating Cancer Plan*, of 3rd February 2021. P.4.
[151] Presented on 3 February 2021 by the European Commission (Source: Europe's Beating Cancer Plan: A new EU approach to prevention, treatment and care. European Commission, dated 3 February 2021, *in: https://ec.europa.eu/commission/presscorner/detail/en/ip_21_342.).*
[152] *Idem.*
[153] Communication from the commission to the European Parliament and the Council. *Europe's Beating Cancer Plan*. P.4.
[154] Communication from the commission to the European Parliament and the Council. *Europe's Beating Cancer Plan*. P.20.
[155] Communication from the commission to the European Parliament and the Council on *Europe's Beating Cancer Plan*, of 3rd February 2021.P.21.
[156] European Commission (2020). *A European strategy for data*. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions.

data[157]. The vision of taking advantage of the Data economy and fostering a joint market for data which would benefit both private parties as well as commercial entities, was welcomed by numerous sectors of activity[158]. The Commission has put forward a proposal for a regulation on the EHDS[159] which follows a clear EU path that comprises on *building a stronger European Health Union, implementing the European Pillar of Social Rights, improving the functioning of the internal market, promoting synergies with the EU digital internal market agenda, and delivering an ambitious research and innovation agenda*[160].

With regards to health, and with the development of the proposal for the EHDS, Insurers also saw a rising benefit giving its necessity for data as a means of fine tuning the risk assessments, thus allowing for a swifter underwriting process[161].

The EHDS distinguishes health data into primary and secondary use. The former *means data used to support healthcare delivery to the patient*[162], while the latter *refers to uses such as scientific research, policy-making, regulatory purposes or public health monitoring*[163]. Although there is a wide scope of the possibilities to which health data for secondary use can be shared, it is not clear that insurers will be able to obtain these anonymised data sets directly[164]. In fact, pursuant to article 35 of the proposed regulation for the EHDS, it is prohibited to take *decisions in relation to a natural person or groups of natural persons to exclude them from the benefit of an insurance contract or to modify their contributions and insurance premiums*[165]. The possibility of a mere use for update of statistical data sets is not clear but the total exclusion of insurers from the secondary use of health data seems unreasonable. Discrimination is prohibited in the EU[166] and, consequently, insurers would not be able to actively discriminate a natural person or

[157] European Commission (2022). Proposal for a Regulation of the European Parliament and of the Council *on harmonised rules on fair access to and use of data (Data Act)*.
[158] For instance, refer to Insurance Europe (2022). *Response to consultation on EC proposal on the establishment of a European Health Data Space*.
[159] Proposal COM (2022) 197 final, of 3 May 2022, for a Regulation of the European Parliament and of the Council *on the European Health Data Space.*
[160] Proposal COM (2022) 197 final, of 3 May 2022, for a Regulation of the European Parliament and of the Council *on the European Health Data Space.* P.5.
[161] Insurance Europe (2021). *EU Health Data Space must benefit consumers and ensure a level playing field for companies*. Big Data, *in: https://www.insuranceeurope.eu/news/2402/eu-health-data-space-must-benefit-consumers-and-ensure-a-level-playing-field-for-companies.*
[162] BEUC (2023). *Factsheet: A European Health Data Space*. BEUC-X-2023-029. P.1.
[163] *Idem.*
[164] Insurance Europe (2022). *Response to consultation on EC proposal on the establishment of a European Health Data Space*. P.3.
[165] Article 35 (b) of the Proposal COM (2022) 197 final, of 3 May 2022, for a Regulation of the European Parliament and of the Council *on the European Health Data Space.*
[166] Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.3.

groups of natural persons from the information they obtain. The use of data is the mere basis of insurance and the benefit that can arise from a more accurate assessment appears to outweigh the negative of increasing certain premiums of high-risk individuals.

As the provision is currently drafted the modification of premiums could not occur either to reduce or increase it which doesn't seem fair given the pool like system, reliant on the Law of large numbers[167], insurance companies use in their underwriting practices. More data and more information allow for the building of up-to-date statistical analysis on the data sets, thus creating more accurate risk assessments and making each policyholder bear solely their true fair share of risk.

Insurers are obliged by European Law to, pursuant to article 82 and 84 of the Solvency II Directive[168], ensure the appropriateness, completeness and accuracy of both the data and the methods applied. Thus this prohibition appears to go against the EU legislative path given that it would inhibit access for insurers to up-to-date data which hinders the contracting consumers. In sum, access to anonymised health data, could *enable insurers to offer more affordable rates or to offer insurance for risks that were previously uninsurable, due to information gaps that can now be filled due to the increased availability of data*[169].

Notwithstanding this prohibition, the resulting research and statistics from scientific institutions will be able to become more detailed and rely on EU citizens data and not on external States, thus allowing insurers to obtain information specified to the European society and produce more accurate risk assessments.

As such, the existence of an ever-growing number of data and, consequently, an even more tailored made and sophisticated risk model, allows for *insurers to offer more competitive rates, or to offer insurance for risks that were previously uninsurable, due to information gaps which today are filled in by the increased availability of data*[170]. These processes of analysing data allow insurers to extract, from vast amounts of raw data,

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[167] *The law of large numbers states that if the amount of exposure to losses increases, then the predicted loss will be closer to the actual loss. The use of the law of large numbers allows the number of losses to be predicted better. (*Source: Tinungki, G. (2018). *The Application Law of Large Numbers that Predicts the Amount of Actual Loss in Insurance of Life.* Journal of Physics: Conference Series, Volume 979. The 2nd International Conference on Science (ICOS) 2-3 November 2017. P.1.).

[168] Directive 2009/138/EC of the European Parliament and of the Council of 25 November 2009 *on the taking-up and pursuit of the business of Insurance and Reinsurance (Solvency II).*

[169] *EC Proposal for European Health Data Space welcomed; further work needed to avoid legal uncertainty*. Insurance Europe, dated 3 August 2022, in: https://www.insuranceeurope.eu/news/2687/ec-proposal-for-european-health-data-space-welcomed-further-work-needed-to-avoid-legal-uncertainty.

[170] Insurance Europe (2019). *Q&A on the use of big data in insurance*. P.1.

designated as Big Data[171], valuable information that aids the development of the industry, notably, its insertion in the technological space by the adoption of complex algorithms and new methods that foster the revolution that is Insurtech[172].

As such, and even with the prohibition for secondary use, Insurance Europe, in its response to the consultation by the European Commission on the EHDS[173], was still able to put forward benefits for the establishment of this digitalised data space, notably,

The possibility for individuals to receive their electronic health data immediately, free of charge and in machine-readable format is welcomed, as consumers will be able to easily share their data with their own insurer, thereby facilitating easier and faster compensation[174].

The benefit put forward by Insurance Europe relates to the second stage of insurance, not the underwriting and risk assessment process but the secondary stage of compensation when the insurance policy is already contracted[175]. This use would be categorized as primary use, where individuals possess control over their own data, and which is not prohibited under the draft proposal[176].

[171] The concepts of Big Data and the technologic consequences of its use within the Insurance market will be dealt in depth in Chapter V.
[172] *Insurtech refers to the use of technology innovations in the insurance sector aimed to improve customer experience, simplify business processes, develop new products and increase competition* (Source: Koprivica, M. (2018). *Insurtech: challenges and opportunities for the insurance sector*. In 2nd International Scientific Conference ITEMA. P.619).
[173] Insurance Europe (2022). *Response to consultation on EC proposal on the establishment of a European Health Data Space*.
[174] Insurance Europe (2022). *Response to consultation on EC proposal on the establishment of a European Health Data Space*. P.2.
[175] Insurance Europe (2022). *Response to consultation on EC proposal on the establishment of a European Health Data Space*. P.2.
[176] *Idem.*

Chapter III

The Right to Be Forgotten in the Consumer Credit Directive

§1. Consumer Credit Directive Proposal

Following the approval, on 12 September of 2023, by the European Parliament of the newly revised Consumer Credit Directive[177], on 9 October of 2023, the Council of the European Union has followed along onto officially adopting the Directive[178]. The Consumer Credit Directive covers consumer loans to certain extents, restricting its scope through the value of the loan as well as the type of consumer loan involved.

The existing CCD covers most types of consumer loans with values ranging from EUR 200 and EUR 75.000[179] whilst the newly adopted expands this scope by covering consumer loans below EUR 200 and between EUR 75.000 and EUR 100.000[180]. In addition, the new CCD covers new types of loans such as *buy-now-pay-later schemes, payday loans, short-term overdraft facilities, interest-free credits and loans offered through crowd-lending platforms*[181].

Through the amendments of the initial draft of the new CCD by the European Parliament, the RTBF for cancer survivors was proposed in the revised Consumer Credit Directive draft proposal[182]. Article 14 paragraph 4 of the draft Directive reads

Member States shall require that personal data concerning consumers' diagnoses of oncological diseases are not used for the purpose of an insurance policy related to a credit agreement after a period of time determined by the Member States, not exceeding 15 years following the end of the consumers' medical treatment[183].

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[177] Legislative Observatory European Parliament. *2021/0171 (COD) Consumer credits, in:* https://oeil.secure.europarl.europa.eu/oeil/popups/ficheprocedure.do?reference=2021/0171(COD)&l=en.

[178] *Asking for a loan will be safer in the EU after the Council's final approval of the Consumer Credit Directive*. Council of the European Union, 9 October 2023, *in*: https://www.consilium.europa.eu/en/press/press-releases/2023/10/09/asking-for-a-loan-will-be-safer-in-the-eu-after-the-council-s-final-approval-of-the-consumer-credit-directive/.

[179] Article 2 (2) paragraph b) of Directive 2008/48/EC of the European Parliament and of the Council of 23 April 2008 *on credit agreements for consumers and repealing Council Directive 87/102/EEC.*

[180] Article 2 (2) paragraph c) of position of the European Parliament adopted at first reading on 12 September 2023 with a view to the adoption of Directive (EU) 2023/... of the European Parliament and of the Council *on credit agreements for consumers* and repealing Directive 2008/48/EC.

[181] Gökten, M., De Groen, W. *The revision of the Consumer Credit Directive: Does it go far enough?* European Credit Research Institute. P.2-3.

[182] Insurance Europe (2022). *Consumer Credit Directive: Including right to be forgotten for persons with prior diagnosi would be bad for consumers*. Risk-based underwriting, *in: https://www.insuranceeurope.eu/news/2706/consumer-credit-directive-including-right-to-be-forgotten-for-persons-with-prior-diagnosis-would-be-bad-for-consumers.*

[183] Position of the European Parliament adopted at first reading on 12 September 2023 with a view to the adoption of Directive (EU) 2023/... of the European Parliament and of the Council *on credit agreements for consumers* and repealing Directive 2008/48/EC.

As a consequence of its approval in the EU Parliament and the Council, the CCD officially introduced in the European Union the RTBF for cancer survivors when underwriting insurance policies linked to consumer credit once a certain period has elapsed through the abovementioned provision. Once the Directive is published in the Official Journal of the European Union (EUR-Lex) its status will be binding[184] and Member States will have to begin the transposition on their national legislation.

The RTBF provision established a period which shall not exceed 15 years with the precise period being defined at national level. In view of the discretionary nature of the directive's provision, the European Society for Medical Oncology ("**ESMO**") is calling on Member States to adopt a 5-year period for cancer survivors when transposing the newly adopted CCD onto their national legislation[185].

The provision foresees a RTBF strictly for insurance linked to consumer credit agreements. The EU intention is to fight financial toxicity for cancer survivors in the access to financial products but health insurance is still not covered under this right.

1.1. Right to be Forgotten as an established solution

The Right to be Forgotten as a legal mechanism stems from the Google Spain SL, Google Inc v Agencia Española de Protección de Datos, Mario Costeja González judgment[186], being firstly enacted in European legislation through the General Data Protection Regulation[187].

The RTBF, foreseen in article 17 of the General Data Protection Regulation, relates to Data Protection Law in a wider sense and is traditionally included in the definition of ARCO[188] Rights. The regulation grants EU citizens the right to have their data erased by the data controller if one of the following criteria is met:

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[184] Article 288 and 297 (1) of the TFEU.

[185] ESMO (2023). *The Right to be Forgotten: ESMO Calls on EU Countries to Ensure Equal Financial Rights for Cancer Survivors*, *in:* *https://www.esmo.org/newsroom/press-releases/the-right-to-be-forgotten-esmo-calls-on-eu-countries-to-ensure-equal-financial-rights-for-cancer-survivors*. .

[186] Judgment of the Court (Grand Chamber) of 13 May 2014, *Google Spain SL, Google Inc v Agencia Española de Protección de Datos (AEPD), Mario Costeja González* (Case C-131/12).

[187] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 *on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC* (General Data Protection Regulation).

[188] ARCO Rights means *the Right of access, rectification, cancellation and opposition of the Holders regarding their personal data* (Source: *ARCO Rights*. Humanquality, in: https://www.humanquality.com.mx/en/arco-rights/).

(i) the personal data is no longer necessary for the purposes it was collected and/or processed;
(ii) the data subject withdraws its consent and there is no legal ground for processing;
(iii) the data subject objects to the processing and there are no overriding legitimate grounds for the maintenance of such activity;
(iv) the personal data has been unlawfully processed;
(v) the personal data has to be erased to comply with any and all legal obligations that may be applicable; and
(vi) the personal data has been collected in relation to the provision of society services to a child[189].

However, this RTBF is not absolute with the General Data Protection Regulation foreseeing reasons for the overturn of this right, such as the data being used for compliance with legal obligations or to perform an activity that is being carried out in the public interest or for public health purposes[190].

The transposition of the RTBF mechanism from this general Data Protection Law notion to the Insurance Law field was suggested to protect cancer survivors financial life and as a mechanism to combat the financial toxicity associated with a cancer diagnosis[191]. In addition, it was sustained that *such a measure remedies the fragmented national practices in creditworthiness assessment and ensures equal access to credit for cancer survivors*[192]. From its inception at national level[193] to its inclusion in the Europe Beating Cancer Plan the RTBF saw its enactment in the newly adopted CCD, thus forever changing the paradigm.

§2. Established national legislation on Cancer survivors' access to Insurance

[189] Article 17(1) of Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 *on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC* (General Data Protection Regulation).
[190] Article 17 (3) paragraph b) and c), respectively, of Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 *on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC* (General Data Protection Regulation).
[191] European Parliament (2022). Resolution of 16 February 2022 *on strengthening Europe in the fight against cancer - towards a comprehensive and coordinated strategy* (2020/2267(INI)). Paragraph 125.
[192] Scocca, G., Meunier, F. (2021). *Towards an EU legislation on the right to be forgotten to access to financial services for cancer survivors.* European Journal of Cancer 162 (2022). P.135.
[193] Detailed in the following sub-chapter.

In the last seven years, as we will subsequently showcase, Member States have been pushing forward national legislative enactments of the right to be forgotten for cancer survivors. As of September 2023, Belgium, France, Luxembourg, Portugal, Romania, Spain, and the Netherlands had adopted the right to be forgotten for cancer survivors in their access to financial services. Italy, Cyprus and Ireland have begun the legislating process but they have yet to enact any legal texts[194].

2.1. France

The catalyst of the Right to be Forgotten in Insurance was France, through the enactment of Law no. 2016-41 of 26 January[195], in particular, its article 190. The integration of this provision must comply with the standards set forth in the AERAS[196] Convention and the French Public Health Code.

The Convention, emergent from a cooperating effort from relevant public and private stakeholders (*e.g.*, State, professional organizations, insurance companies, etc.) [197], *aims to facilitate access to insurance and loaning for people presenting an aggravated risk due to their state of health or a handicap with*[198]. To facilitate this, a reference table was included in the Convention to define *for each pathology, the period after which former patients can take out an insurance policy without any cover exclusions or having to pay an extra premium*[199].

From this milestone, developments have erupted such has *(i)* the obligation of insurers to provide a document to potential applicants informing them on the established

[194] ESMO. *Securing equal treatment and non-discrimination in financial services for European cancer survivors.* Right to be Forgotten, *in: https://www.esmo.org/policy/right-to-be-forgotten.*
[195] Law no. 2016-41 of 26 January 2016 modernising our healthcare system (*LOI n.º 2016-41 du 26 janvier 2016 de modernisation de notre système de santé*).
[196] Insuring and Loaning with Aggravated Health Risk *(S'Assurer et Emprunter avec un Risque Aggravé de Santé*).
[197] European Cancer Patient Coalition. *Factsheet on the Right to be forgotten in the EU National Legislations: Legal Background and current status from France, Belgium, Luxembourg and the Netherlands.* P.2.
[198] *Idem.*
[199] *Idem.*

right to be forgotten[200], *(ii)* new penalties for non-compliance with the legal time limit[201], and *(iii)* inclusion of new pathologies in the AERAS Convention table[202].

Via the AERAS Convention mechanism, individuals who cannot get access to loans given their high risk classification are granted loans by credit institutions limited by the following conditions: *(i)* mortgages amounts limited to a maximum of €320,000 (three hundred and twenty thousand euros) with a maximum borrower age at end of term of 71 years old; and *(ii)* personal loans amounts limited to a maximum of €17,000 (seventeen thousand euros) for maximum terms of 4 year and a maximum borrower age at time of the loan application of 50 years old[203].

Lastly, it is worth nothing that the French legal framework foregoes the necessity of the medical questionnaire in certain instances such as *(i)* consumer loans with a maximum amount of €17,000 (seventeen thousand euros), and *(ii)* real estate loans with a maximum amount of €200,000 (two hundred thousand euros)[204].

2.2. Belgium

Belgium enacted the right to be forgotten for cancer survivors through Law no. C - 2019/40839, of 4 April in 2019 (*Loi relative aux assurance*)[205] which entered into force on February 2020. The RTBF was generally granted after ten years from end of treatment[206] - with specific cancer pathologies having a shortened period[207], reviewed

[200] Enacted through Decree no. 2017-147 of 7 February 2017, *relating to sanctions applying to insurance organisations for non-compliance with the provisions of article L.1141-5 of the French Public Health Code*.
[201] Enacted through Decree no. 2017-173 of 13 February 2017, *specifying the procedures for informing applicants for creditor protection insurance if they present an increased risk due to their state of health or disability.*
[202] Such as *kidney cancer, leukaemia, prostate cancer, cystic fibrosis and hepatitis C* (Source: European Cancer Patient Coalition. *Factsheet on the Right to be forgotten in the EU National Legislations: Legal Background and current status from France, Belgium, Luxembourg and the Netherlands.* P.2.).
[203] European Cancer Patient Coalition. *Factsheet on the Right to be forgotten in the EU National Legislations: Legal Background and current status from France, Belgium, Luxembourg and the Netherlands.* P.2.
[204] *Idem.*
[205] Law no. C- 2019/40839 of 4 April 2019, amending Law of 4 April 2014 on insurance and introducing a right to be forgotten for certain personal insurance policies (*Loi C-2019/40839 du 4 avril 2019, modifiant la loi du 4 avril 2014 relative aux assurances et instaurant un droit à l'oubli pour certaines assurances de personnes*).
[206] Article 61/2 §1 of Law no. C- 2019/40839 of 4 April 2019, amending Law of 4 April 2014 on insurance and introducing a right to be forgotten for certain personal insurance policies (*Loi C-2019/40839 du 4 avril 2019, modifiant la loi du 4 avril 2014 relative aux assurances et instaurant un droit à l'oubli pour certaines assurances de personnes*).
[207] For further information on these specific periods please refer to the reference table adopted in May 2019, Doc. No. C-2019/12990.

every two years by the Belgian Health Care Knowledge Centre[208] - solely for insurance relating to mortgage and professional loans.

Assuralia[209], stepping further in the development of this idea through a code of conduct which applies the RTBF to guaranteed income insurance, obliged its members to expand the application of RTBF for cancer survivors for mortgage and professional loans to this form of insurance[210].

2.3. Luxembourg

On the 1 of January 2020, the RTBF entered into force in Luxembourg through the Convention «Droit a L'oubli» S'assurer et emprunter avec un risque de sante aggrave en raison d'une pathologie cancereuse ou d'une infection virale a l'hepatite C ou d'une infection par le VIH, signed in the 29 of October of 2019. The Convention was entered into by and between the Ministry of Health, the Association of Insurance and Reinsurance Companies alongside eight insurance companies[211].

The Luxembourg convention covers outstanding balance insurance foreseeing two mechanisms for its applicability, the *(i) right to be forgotten without reporting obligation*, or the *(ii) right to be forgotten with reporting obligation, without additional premium*[212]. The first mechanism is triggered when an individual is deemed recovered from cancer, without relapse, once a ten year period has elapsed since the end of treatment, with the period shortened to half if the diagnosis had been determined before the age of eighteen[213]. The latter mechanism is applied in two scenarios: *(i)* given that individuals with HIV cannot be medically considered "cured" within the meaning applied in this convention, the reporting obligation is maintained but insurance companies now cannot exclude them nor apply an additional premium higher than 100%; and *(ii)* for specific types of cancers and for viral hepatitis C diagnosis, the obligation to report is maintained if the individual is considered cured. Insurance companies in this scenario no

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[208] European Cancer Patient Coalition. *Factsheet on the Right to be forgotten in the EU National Legislations: Legal Background and current status from France, Belgium, Luxembourg and the Netherlands.* P.3.
[209] Belgium association of insurance undertakings.
[210] *Entrée en vigueur le 1er février du droit à l'oubli pour toute nouvelle assurance revenu garanti*. Assuralia, 26 January 2022, *in*: Entrée en vigueur le 1er février du droit à l'oubli pour toute nouvelle assurance revenu garanti (assuralia.be).
[211] *Introduction au Luxembourg d'un droit à l'oubli pour personnes guéries d'un cancer).* Le gouvernement luxembourgeois, *in:* https://gouvernement.lu/fr/actualites/toutes_actualites/communiques/2019/10-octobre/29-schneider-droit-oubli.html.
[212] *Idem*.
[213] *Idem.*

longer have the ability to charge additional premiums nor exclude individuals from accessing insurance and, if the conditions are met, the insurers cannot take into account the cancer diagnosis thus allowing a shorter period of access to insurance for individuals[214].

2.4. Spain

Following the entry into force of Royal Decree-Law 5/2023[215], after its publication on the 29 of June in the Official State Gazette, Spain has officially adopted the RTBF for cancer survivors onto its national legislation, thus enacting the European Parliament's intent onto its jurisdiction.

The threshold for being able to not declare the cancer diagnosis is of five years from the end of treatment - without relapse[216]. In addition, the Royal Decree-Law grants the government powers to modify this period in line with new developments in the field of medicine and for specific pathologies[217].

To consummate the importance of this provision, alongside the prohibition of differentiation for insurance policies, the Royal Decree-Law classifies as null and void any clause or agreement which excludes any individual due to its cancer diagnosis once the five year period has elapsed with the waiver by the party from this provision also being deemed as null and void[218].

The five year period being set as the general rule makes Spain go beyond the European Parliament's initial intent, given its set of a period of a maximum of fifteen years in the new CCD, and make a stand on its consumer focused interest.

2.5. Romania

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[214] *Introduction au Luxembourg d'un droit à l'oubli pour personnes guéries d'un cancer).* Le gouvernement luxembourgeois, *in:* https://gouvernement.lu/fr/actualites/toutes_actualites/communiques/2019/10-octobre/29-schneider-droit-oubli.html.

[215] Real Decreto-ley 5/2023, de 28 de junio, *por el que se adoptan y prorrogan determinadas medidas de respuesta a las consecuencias económicas y sociales de la Guerra de Ucrania, de apoyo a la reconstrucción de la isla de La Palma y a otras situaciones de vulnerabilidad; de transposición de Directivas de la Unión Europea en materia de modificaciones estructurales de sociedades mercantiles y conciliación de la vida familiar y la vida profesional de los progenitores y los cuidadores; y de ejecución y cumplimiento del Derecho de la Unión Europea.*

[216] Article 210 (2*)* of *Ley General para la Defensa de los Consumidores y Usuarios y otras leyes complementarias, aprobado por Real Decreto Legislativo 1/2007, de 16 de noviembre*.

[217] Article 210 (3) of *Ley General para la Defensa de los Consumidores y Usuarios y otras leyes complementarias, aprobado por Real Decreto Legislativo 1/2007, de 16 de noviembre*.

[218] La Moncloa. *What is the right to be forgotten regarding cancer?*, *in*: https://www.lamoncloa.gob.es/lang/en/gobierno/news/Paginas/2023/20230710_forgotten-regarding-cancer.aspx.

In July 2022, Romania enacted the Cancer Survivors Law[219] which, amidst other measures such as the national plan to prevent and combat cancer, implemented the right to be forgotten for cancer survivors. In Romania, the general period to be able to invoke the RTBF when underwriting an insurance policy is of seven years[220]. However, if the diagnosis occurred before the age of eighteen the period shortens to five years[221].

2.6. The Netherlands

The Netherlands, through a Decree of 2 of November 2020, followed the above Member States in their rights conquest, thus establishing the RTBF for cancer survivors[222] in underwriting life and funeral insurance policies, which entered into force on the 1st of January of the following year.

The timeframes for application of this right follow the same trend as other national acts with the general period being ten years of remission which is reduced to half if the applicant is less than 21 at the time of diagnosis[223]. An exception on this general rule is done for specific types of cancer which are qualified in a table developed by the Dutch Association of Insurers, the NFK[224] and the Dutch Cancer Registry[225].

The Netherlands focused on these policy types which can be, but not necessarily, consequently linked to credit agreements instead of opting for a direct mandatory link between these in the legislative provisions like the European CCD draft. Notwithstanding, the underlying objective is the same, to allow cancer survivors a fair access to insurance in order to obtain, amidst others, house loans thus fighting financial toxicity associated with this diagnosis.

2.7. Portugal

Draft Law 691/XIV/2.ª[226] began the legislative road to the enactment of the Portuguese RTBF not only for cancer survivors but also for individuals with aggravated

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[219] *Nicoleta Pauliuc. Romanian Senator, National Liberal Party.* European Cancer Organisation, *in:* https://www.europeancancer.org/2-standard/553-nicoleta-pauliuc.
[220] *Idem.*
[221] *Idem.*
[222] *Staatsblad van het Koninkrijk der Nederlanden*, of 2 November 2020.
[223] European Cancer Patient Coalition. *Factsheet on the Right to be forgotten in the EU National Legislations: Legal Background and current status from France, Belgium, Luxembourg and the Netherlands.* P.4.
[224] Nederlandse Federatie van Kankerpatiënten (Dutch Federation of Cancer Patients).
[225] *The Netherlands announce the adoption of the Right to be Forgotten.* European Cancer Patient Coalition, *in*: https://ecpc.org/the-netherlands-announce-the-adoption-of-the-right-to-be-forgotten/.
[226] *Projeto de Lei n.º 691/XIV/2ª*, of 19 February 2021.

health risk (e.g. diabetes, HIV, and other pathologies), later being adopted and promulgated by the President of the Republic[227]. Moreover, Law no. 75/2021, of 18 November came into force on 1 of January 2022.

The enacted Law modifies both the legal framework for insurance contracts[228] and the legislative act that first introduced the ban on discriminatory practices on the ground of disability and aggravated health risk[229].

An RTBF for both access to insurance and for house and consumer loans was introduced through this Law, in particular, in its article 3 paragraph 2, it stipulated that no health information regarding the diagnosis can be collected by the insurance company or credit institutions:

(i) 10 years after the end of treatment, without relapse;

(ii) 5 years after the end of treatment in case of diagnosis prior to the age of 21, without relapse; and

(iii) 2 years of continuous and effective treatment in case of aggravated health risk or mitigated disability.

Individuals covered by this Law can neither *(i)* be subject to higher premiums nor excluded from any insurance contract collaterals[230], and *(ii)* no information shall be collected and subject to treatment in a pre-contractual stage[231].

Notwithstanding its initial efforts to go beyond the mere stipulation of a RTBF for cancer survivors, the fact remains that the legislative enactment is yet to be fulfilled[232]. The legal provisions set forth provided for a national agreement on access to credit and insurance between the Government and the relevant stakeholders[233] (*i.e.*, insurance companies and credit institutions), which has yet to be celebrated. Following the provisions set forth on article 6 of the Portuguese Law, the CNPD[234] will have to issue a legal opinion prior to the adoption of this national agreement. Although this is not a usual provision in Portuguese national law, according to an opinion from the CNPD[235], it could

[227] Portuguese Law no. 75/2021, of 18 November.
[228] Portuguese Decree-Law no.72/2008, of 16 April (*Regime Jurídico do Contrato de Seguro*).
[229] Portuguese Law no. 46/2006, of 28 August.
[230] Article 3 (1) paragraph a) of Portuguese Law no. 75/2021, of 18 November.
[231] Article 3 (1) paragraph b) of Portuguese Law no. 75/2021, of 18 November.
[232] ECO Seguros (2023). *PS faz ultimato: Direito ao esquecimento até 30 de junho de 2024, in*: https://eco.sapo.pt/2023/11/16/ps-faz-ultimato-direito-ao-esquecimento-ate-30-de-junho-de-2024/.
[233] Article 6 of Portuguese Law no. 75/2021, of 18 November.
[234] National Commission for Data Protection (*Comissão Nacional de Proteção de Dados*).
[235] *Comissão Nacional de Proteção de Dados* (CNPD). Legal Opinion 2021/75, of 9 June 2021.

be justified due to the sensitive nature of the data. This agreement, amongst other key stipulations, will foresee a reference table for each pathology which will be updated every 2 (two) years so as to keep up to date with scientific and medical developments[236].

§3. Consequences of the RTBF in Insurance

Stakeholders in the sector, namely Insurance Europe, have put forward foreseeable consequences of the approval of the right to be forgotten. There are six key points worth mentioning:

(i) Less access to insurance protection for all consumers;

(ii) Increased risk of consumer detriment;

(iii)Disappearance of some products;

(iv) Uncertainty for consumers;

(v) Opaque system; and

(vi) Less certainty about insurers' ability to pay future claims[237].

In opposition to the right to be forgotten enacted in the new CCD, Insurance Europe supports the preliminary thesis of the European legislator, the code of conduct. Supported in the EU Beating Cancer Plan, this would allow fair access for cancer survivors to financial services whilst still being flexible enough to adapt to new scientific developments, unlike the strict mechanism set out in the new CCD provisions, in particular recital 47, articles 2.(25a), 14.4 and 18.3b[238].

A necessity to postpone the European RTBF until relevant data that would allow for an unbiased and factual evaluation of the consequences of the establishment of the RTBF for cancer survivors in the Member States which have implemented this right was supported by Insurance Europe[239]. Only then, we argue, would a RTBF at European level be adequately analysed and be able to balance the benefits it would bring to the individuals covered by it against the detriment it could cause to the remaining consumer

[236] Thoroughly defined in article 15-A of Portuguese Decree-Law no.72/2008, of 16 April (*Regime Jurídico do Contrato de Seguro*).

[237] Insurance Europe (2022). *The Consumer Credit Directive: The use of risk-based underwriting and the impact of a right to be forgotten.* P.2.

[238] *Insurance Europe has come forward expressly against these provisions, stating their non-supportive position regarding the CCD II text* (Source: Insurance Europe (2022). *The Consumer Credit Directive: The use of risk-based underwriting and the impact of a right to be forgotten.* P.1).

[239] Insurance Europe (2022). *Risk-based underwriting: Frequently asked questions on the right to be forgotten.* P.1.

market[240]. An assessment of the proportionality is currently not possible given this lack of data and thus the balancing act is a blind-sided mission.

It is worth to dive deeper onto some of the issues posed above. For instances, regarding the access to insurance and the increased risk of consumer detriment stated above in point *(i)* and *(ii)* we can recall the phenomenon of adverse selection. Adverse selection can summarily be described as the situation where given the absence of pricing and risk selection according to the represented risk class, a progressive degradation of the mass of insured risks is observed[241]. The market will begin to push out low risk individuals which grant some stability to the insurance system and lure high risk ones for the potential benefits accrued[242]. Adverse selection is thus one of the greatest issues of private insurance since it affects the mechanism of risk pooling so deeply. To fight against this issue, insurers created numerous mechanisms such as *simply refusing to sell policies to individuals with known health conditions, such as preexisting condition exclusions, and charging higher premiums based on health status or health risk, such as experience rating[243]*. Aside from adverse selection which contaminates risk pooling mechanisms[244], we have additional threats to the viability of private insurance such as moral hazard and information asymmetries, to name a few.

Circling back to the pending issue resulting from the RTBF for cancer survivors, and as we can infer from the points above, just as point *(i)* and *(ii)* seem a clear risk, we can argue that the consequent point *(iii)* above (*Disappearance of some products*) can be the destination onto which we are headed towards if the RTBF is not carefully legislated.

Another relevant point can be the burden of the disclosure being put onto cancer survivors. The argument of *putting the responsibility on the insurer may be the favoured approach as it prevents the risk of accidental non-disclosure*[245], in particular, since insurers are better trained to assess if the information disclosed can fall onto the RTBF

[240] Insurance Europe (2022). *Risk-based underwriting: Frequently asked questions on the right to be forgotten*. P.1.
[241] Poças, L. (2022). *A Lei 75/2021, o direito ao esquecimento e os seguros*. Revista de Direito Comercial. P.138.
[242] *Idem.*
[243] Roberts, J., Weeks, E. (2018). *Healthism: Health-Status Discrimination and the Law*. Cambridge University Press. P.100.
[244] Insurance and Reinsurance Stakeholder Group - Own-Initiative Report (2023). *Advice on the right to be forgotten (RTBF)*. IRSG-23/15. P.5.
[245] Weber, A., Schmidt, N., Wünsch, H, and Schilling, A. (2022). *Remember to Forget – Insuring Cancer Survivors and the Right to be Forgotten.* Gen Re Business School. Underwriting Focus, December 2022. P.10.

scope or not[246]. Placing the burden onto insured individuals can lead to a bigger trend of non-disclosure due to technical unawareness or misunderstanding of the scope of the RTBF on the part of the individuals[247]. This can result in the non-acceptance of insurance claims due to non-disclosure[248] and, in the end, create an even bigger legal and financial uncertainty to cancer survivors.

Scholars are divided in the support of this RTBF, with Portuguese scholars such as Luís Poças coming forward stating their opposition to the new national legislation and the idea of stipulating a RTBF for cancer survivors in insurance[249]. The argument of the preexistence of a ban on discriminatory practices is put forward with the intent of showcasing the solution previously adopted as the more coherent with the workings of the private insurance market.

Other solutions can and are being put forward as a replacement for the RTBF such as codes of conduct[250]. We argue for the possibility of agreements between States and relevant stakeholders for mitigation of economic dire consequences, and even for the reliance on State financing' given its ownership of the social view of society[251].

These rigid measures implemented at EU level disregard the particularities of a system which relies on statistical data discrimination[252] and, if the trend continues, can risk creating a private insurance sector which is inaccessible or unattractive to most[253]. The ability for insurers to commit to pay future claims goes hand in hand with their ability to *continue to underwrite based on risk-relevant factors*[254].

The balancing act between the survivability of the private insurance market and the necessity of protecting cancer survivors against financial toxicity does not seem to have found its equilibrium with the enactment of a RTBF at an EU level.

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[246] Weber, A., Schmidt, N., Wünsch, H, and Schilling, A. (2022). *Remember to Forget – Insuring Cancer Survivors and the Right to be Forgotten.* Gen Re Business School. Underwriting Focus, December 2022. P.10.
[247] *Idem.*
[248] *Idem.*
[249] Poças, L. (2022). *A Lei 75/2021, o direito ao esquecimento e os seguros*. Revista de Direito Comercial.
[250] Weber, A., Schmidt, N., Wünsch, H, and Schilling, A. (2022). *Remember to Forget – Insuring Cancer Survivors and the Right to be Forgotten.* Gen Re Business School. Underwriting Focus, December 2022. P.10; Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.1.
[251] Applicable for EU Member States with a strong political view of Social State.
[252] Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.8.
[253] *Idem.*
[254] Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.6.

Chapter IV

Ethical Debate on Discrimination within Insurance

§1. Discrimination and Ethics

The basis of the insurance sector lies within discrimination, in particular a specific method, statistical discrimination[255]. Given this, and the human development against discrimination so as to enforce the equality principle (even if egality is argued to be the first steppingstone)[256], the ethical debate on discrimination within Insurance is posed.

The problematic is thus set: how can discrimination be ethical? And how has the world developed new methods of controlling it? The tracing of the ethical line within discrimination is the undiscovered oasis that gives rise to numerous theses. Although philosophical discussions on discrimination have not developed as one might think – that is not to say there hasn't been philosophers studying the topic (*e.g.* Cavanagh, Eidelson, Khaitan) – the wider philosophical concept of ethics gives rise to reflections amongst legal theorists regarding discrimination[257], and, in a narrower scope, discrimination within Insurance. Legal theorists might invoke these notions and concepts when engaging in discussions that go beyond the *stricto sensu* scope of what the Law currently legislates – which can typically leave behind moral and/or political significances when it comes to discrimination. This is where, as it customarily occurs, Philosophy leaves its mark on Law.

Before diving further into the complexity that lies within the ethical debate on discrimination one must first establish what is discrimination. Several authors develop a concept of discrimination which can expand or restrict its scope. Scholar Kasper Lippert-Rasmussen perceives this concept has a "*differential treatment plus something else*"[258] with something else, in his view, being referred to "*differential treatment on the basis of membership of a socially salient group*"[259]. This definition of discrimination is aligned with anti-discrimination law, both at a European and national level which typically categorize these groups as the groups which are regularly affected by discrimination, namely, groups defined by gender, sexuality, race, nationality and religion[260]. These

[255] Rego, M. (2022). *Discrimination Bans and Insurance Law*. Insurance and Human Rights, AIDA Europe. Research Series on Insurance Law and Regulation 5. P.34.
[256] European Commission. *Non-discrimination, in: https://commission.europa.eu/aid-development-cooperation-fundamental-rights/your-rights-eu/know-your-rights/equality/non-discrimination_en.*
[257] Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.2.
[258] *Idem.*
[259] *Idem.*
[260] *E.g.* article 21 (Non-discrimination) of the EU Charter of Fundamental Rights.

groups, since they have been historically subject to discrimination, are classified as suspect classifications within Law. The Fourteenth Amendment's Equal Protection Clause established in the United States of America invokes this definition[261], alongside case law such as Brown v. Board of Education of Topeka[262], where the doctrine of Plessy v. Ferguson[263] upholding "separate but equal" was reversed, thereby prohibiting states in the USA from segregating public school students based on race. In the European Union the anti-discrimination landmarks occur, on the other hand, to a greater extent in the legislative side given the civil law system predominance[264].

Considering the establishment of the wide concept of discrimination, we can begin to understand the different kinds of discrimination, in particular the ones which are at the roots of the insurance discussion namely *(i)* the direct and indirect discrimination, and *(ii)* the statistical discrimination.

1.1. Direct and Indirect Discrimination

When discrimination is being discussed, it is necessary to delineate the concepts one is referring to. One of the prevalent divisions of the concept revolves around the dichotomy of direct versus indirect discrimination. The European framework foresees this distinction in its directives regarding anti-discrimination and equality, namely in Council Directive 2000/43/EC of 29 June 2000, *implementing the principle of equal treatment between persons irrespective of racial or ethnic origin*, in its article 2 (2). The provisions set forth distinguish direct discrimination to be the discrimination as we understand it, where *one person is treated less favourably than another is, has been or would be treated in a comparable situation*[265], whereas indirect discrimination takes place when *an apparently neutral provision, criterion or practice would put persons of a racial or ethnic origin at a particular disadvantage compared with other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary*[266]. These classes of discrimination typically arise when susceptible classes of individuals which have been historically subject to

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[261] Legal Information Institute. *suspect classification*. Cornell Law School, *in: https://www.law.cornell.edu/wex/suspect_classification*.
[262] Brown v. Board of Education of Topeka, 347 U.S. 483 (1954).
[263] Plessy v. Ferguson, 163 U.S. 537 (1896).
[264] For further information on this please refer to Chapter II *European Union Legislative framework.*
[265] Article 2 (2) a) of Council Directive 2000/43/EC of 29 June 2000, *implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.*
[266] Article 2 (2) b) of Council Directive 2000/43/EC of 29 June 2000, *implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.*

discrimination are involved, and are classified as suspect classifications. These classifications involve characteristics like race, ethnicity, religion and gender to name a few.

Direct discrimination focuses on causation, to be concrete, *the causation of the less favourable treatment and comparability of situations*[267], whilst indirect discrimination does not have causation at its basis but instead is *an effect-related concept*[268]. In sum, the apparently neutral provision indirectly discriminates a group of individuals without a legitimate or proportionate aim for such a difference. The exceptions given at EU level for making discriminatory provisions valid and effective focus mainly on a sense of "greater good" and "justifiable measures". In particular, in the Council Directives 2000/43[269] and 2000/78[270] its foreseen that this exception is allowed when *such a characteristic constitutes a genuine and determining occupational requirement, provided that the objective is legitimate and the requirement is proportionate*[271].

If one moves further into the analysis outside of the legal scope *per se*, and into the ethical notions, direct discrimination appears to be the *core* discrimination definition. When one comes across the wording discrimination it typically associates the word with the more general meaning that is direct discrimination. Although discussed in the last decades[272] defining precisely the term of discrimination is still not a black and white arena.

The EU framework foresees the summarised notion of being treated worse in a comparable situation than another individual[273]. The idea of differential treatment is one of the key features of this notion alongside the existence of a poorer outcome/treatment than another in a comparable situation[274]. However, even something which in theory

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[267] Maliszewska-Nienartowicz, J. (2014). *Direct and Indirect Discrimination in European Union Law - How to Draw a Dividing Line?* International Journal of Social Sciences, III (I). P.42.
[268] Maliszewska-Nienartowicz, J. (2014). *Direct and Indirect Discrimination in European Union Law - How to Draw a Dividing Line?* International Journal of Social Sciences, III (I). P.43.
[269] Council Directive 2000/43/EC of 29 June 2000, *implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.*
[270] Council Directive 2000/78/EC of 27 November 2000, *establishing a general framework for equal treatment in employment and occupation.*
[271] Article 4 and Article 4 (1) of Council Directive 2000/43 and Council Directive 2000/78, respectively.
[272] Maliszewska-Nienartowicz, J. (2014). *Direct and Indirect Discrimination in European Union Law - How to Draw a Dividing Line?* International Journal of Social Sciences, III (I). P.43.
[273] E.g., in article 2 (2) a) of Council Directive 2000/43/EC of 29 June 2000, *implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.*
[274] E.g., Article 2 (2) b) of Council Directive 2000/43/EC of 29 June 2000, *implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.*

appears simple, such as identifying differential from equal treatment, is not an unambiguous answer.

An interesting thesis revolves around the idea that the features indicated above are not necessarily cumulative to be able to define an action as discriminatory. In particular, discrimination can be merely the differential treatment without a bad outcome attached to it. For instance, the common practice in the nightclub market where females are not charged an entry fee and male are. At first glance this appears to not be discriminatory given the benefit that is granted to females. However, and going against scholars like Friedman[275], it should be argued that the fight against discrimination occurs at all levels and, as a consequence, differential treatment, even without a poor outcome, should be eliminated[276].

A generic definition of direct discrimination is put forward by Thomsen, where he argues that an individual engages in direct discrimination against another if:

> *(i) She treats persons with property P (P-persons) differently than she treats or would have treated others (non-P-persons);*
>
> *(ii) The treatment of P-persons is worse for P-persons with respect to good G than the treatment of non-P-persons is or would be for non-P-persons; and*
>
> *(iii)The difference in treatment is explainable by P-persons possessing or the agent believing that they possess P and non-P-persons not possessing P.*[277]

To complement this generic definition, Thomsen suggests the introduction of a *restriction on the properties that can be targets of discrimination*[278], specifically *those identity-carrying groups that have been socially, economically or politically disadvantaged*[279]. This notion is transported to legal definitions such as suspect classification which we have discussed in previous chapters. A key fault with this

[275] Friedman B., Nissenbaum H. (1996). *Bias in computer systems.* ACM Transactions on Information Systems, Vol.14, No.3.
[276] *I.e.*, although women can benefit from this monetary exemption, the discriminating nature of this practice is still vivid and arguably deterring the development of the gender equality movement by playing onto the idea that women can still be considered objects to be used for business profit.
[277] Thomsen, F. *Direct discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.24.
[278] Thomsen, F. *Direct discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.25.
[279] *Idem.*

definition, which focuses on previously disadvantaged groups, is that any novel form of discrimination tends to be excluded[280]. We argue for the application of a more flexible criteria so as to be able to cover direct discrimination cases in an ever-evolving society[281].

Morality can be inputted into this definition so as to allow this flexibility. However, it is clear the ambiguity it could bring as all the discussions which arise have been, at the deeper side of them, discussed for centuries as far back as the Socrates and Aristoteles eras. The biggest takeaway from a discussion on the notions of discrimination are that they are not absolute, and the way in which we tend to ascertain the existence of this uncertainty revolves around the *awareness that there are several different senses of discrimination*[282] which leads to a need of a case by case analysis.

Something which could give the impression of a simple definition one can intuitively describe is an evolving phenomenon and onto which the enemy is the static and the rigid.

On the other side of the spectrum, there's the phenomenon of indirect discrimination which scholars such as Eidelson question its classification as discrimination *per se*[283]. Indirect discrimination has been linked to law since the concept was firstly brought to life in this field - firstly in the USA[284] and subsequently in the EU[285] which we have presented above.

The debate around these forms of discrimination tends to ascertain the existence of direct discrimination whilst, at the same time, arguing the *legitimacy of legal regulation of indirect discrimination*[286]. The close link of indirect discrimination to morality, and thus its consequent ambiguity, alongside the tests it must pass to be qualified as such (*e.g. disproportionate impact on a protected group* and *disproportionate means of achieving an aim*[287]), tend to make it of difficult applicability.

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[280] *Idem.*
[281] Thomsen, F. *Direct discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.26.
[282] Thomsen, F. *Direct discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.28.
[283] Khaitan, T. *Indirect Discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.30.
[284] Through the landmark case *Griggs v. Duke Power Company* (Griggs v. Duke Power Co., 401 U.S. 424 (1971)).
[285] Firstly enacted in the Council Directive 97/80/EC of 15 December 1997, *on the burden of proof in cases of discrimination based on sex.*
[286] Khaitan, T. *Indirect Discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.40.
[287] *Idem.*

1.2. Statistical Discrimination

Statistical discrimination, contrary to non-statistical discrimination, is often labeled as *instrumental discrimination*[288] given its objective, autonomous of discrimination. On the other hand, non-statistical discrimination tends to *rely on some non-instrumentational distinction of important between classes of, typically, people*[289]. For the latter we can think of typical cases of gender discrimination where the reason for discrimination stems from the idea that there are roles in society that each gender should fulfil, thus leading women to being excluded of activities and even rights. This idea is also easily applied to cases of racial discrimination where the discriminating party believes in the fundamental difference between races or even in the superiority of one race over the other.

Once the distinction between these kinds of discrimination is achieved, there ought to be a further analysis of the former distinction, given its impact in the question of this dissertation, and in Insurance as a sector.

Statistical discrimination focuses on inferring certain characteristics from others. It is worth to distinguish, like Schauer emphasized, that *the important relationship is an indicative or correlative one, and that the soundness of a statistical indicator is independent of the existence (or not) of a causal relationship between the indicator and the target, or vice versa*[290]. The distinction between correlation and causation[291] is key, as well as the accuracy and reliability of the correlations.

The strength of the correlations made in statistical discrimination, we argue, are vital to support the application of statistical discrimination in society and, most importantly, in Law and related fields. The problem within this arises, for instances, when we understand that the data that is being used for the inference of these correlations is taken from a society which is permeated by prejudice and bias[292]. A prime example of this bias within our society which is being fought against by the European system, is seen in jurisprudence

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[288] Schauer, F. *Statistical (and non-statistical) discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.43.
[289] *Idem*.
[290] Schauer, F. *Statistical (and non-statistical) discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.46.
[291] *A correlation between variables, however, does not automatically mean that the change in one variable is the cause of the change in the values of the other variable. Causation indicates that one event is the result of the occurrence of the other event (…).*(Source: *Corrrelation and causation. Australian Bureau of Statistics, in: https://www.abs.gov.au/statistics/understanding-statistics/statistical-terms-and-concepts/correlation-and-causation).*
[292] Favaretto, M., Clercq, E., Elger, B. (2019). *Big Data and discrimination: perils, promises and solutions. A sistematic review.* Journal of Big Data. P.6.

from the European Court of Human Rights and European Court of Justice, in regards to gender, sexual orientation, and race by attempting to make individuals equal pursuant to the non-discrimination provisions established at an European level, notably in articles 14 of the European Convention of Human Rights[293], 21 of the Charter[294] and 10 of the TFEU[295]. The following are cases which clearly showcase this trend: *i)* in *Defrenne*[296], the ECJ upheld the principle of equal pay between man and woman; *ii)* in *Geoffrey Léger*[297], the ECJ considered the permanent prohibition of blood donation for men who had sexual relations with another man may amount to discrimination if the two indicators established by the court are not fulfilled, *a)* the principle of proportionality, *b)* the existence of scientific proof factually classifying the persons as a high risk of contracting severe infectious diseases (*e.g.* HIV), and *c)* the inexistence of effective detection methods or onerous methods for protecting the recipients; and *iii)* in *Beeler*[298], ECHR held that *domestic legislation curtailing male widowers' access to public benefits versus those accessible to female widows was held to be discriminatory on the basis of sex under Article 14 when read in conjunction with Article 8*[299].

Circling back to statistical discrimination and the inherent bias within society, and when considering a thesis against it, individuals must recognize the associated cost of foregoing the use of these indicators. In the words of Schauer, *the avoidance of an*

[293] *The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.*(Source: Article 14 of the Convention for the Protection of Human Rights and Fundamental Freedoms (*Rome, 4.XI.1950*)).

[294] 1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited. (Source: Article 21 of the Charter of Fundamental Rights of the European Union of December 2000 with consequent wording alteration in 2009 with the Lisbon Treaty (OJ C 202, 7.6.2016)).

[295]*In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation*. (Source: Article 10 of the Treaty on the Functioning of the European Union of 13 December 2007 - consolidated version (OJ C 202, 7.6.2016)).

[296] Judgment of the Court of 8 April 1976, *Defrenne v. Société Anonyme Belge De Navigation Aérienne Sabena* (Case 43/75).

[297] Judgment of the Court of 29 April 2015, *Geoffrey Léger v Ministre des Affaires sociales, de la Santé et des Droits des femmes and Établissement français du sang* (Case C-528/13).

[298] Judgment of the Court (Grand Chamber) of 11 October 2022, *Beeler v. Switzerland* (Application no. 78630/12).

[299] Jelić, I., Smith, H. (2022). *Gender Equality and Discrimination on the Grounds of Sex: A guide on the relevant jurisprudence of the European Court of Human Rights*. The AIRE Centre, p. 155.

instrumentally efficient and statistically justified discrimination comes at a cost that must be paid or borne by someone[300].

Harcourt, in his 2005 paper, supported the alternative use of randomization or individualization, thereby foregoing statistical discrimination used in actuarial sciences as an effective method of prediction in criminal law[301]. This idea can be extended to law and public policy, however, one cannot forego the cost it entails. Schauer, in opposition, argues that *the morality of decision by categories and by generalizations, even with its consequent apparent disregard for the fact that decision-making by generalization often seems to produce an unjust result in particular cases*[302]. The latter approach takes the cost of injustice in specific cases for the global efficiency of the system, whilst the former favours individual justice over the associated efficiency costs. Although egality, and consequently, equality, is the desired societal destination, individualization and randomization in a globalized and technological world with regards to every situation incurred in fields such as law, insurance and public policy may not be deemed sufficiently effective to be considered feasible due to its economic impact.

Schauer put forward an idea that there must be a distinction made between statistical discrimination with race, ethnicity, national origin, religion, gender or sexual orientation as the basis and the remaining statistical discrimination[303]. The aversion to the former is not aversion to *statistical discrimination qua statistical discrimination*[304], the latter, but aversion to this type of discrimination given it historical and moral background. As such, for the former, the solution must be in the elevation of the standard of accuracy for its indicators and even its prohibition, but not the prohibition of statistical discrimination as a whole. The consequences of this route of action would be more nefarious than benign for society, with sectors such as insurance being brought to a point of inefficiency that their sole existence would be called into question.

§2. The ethical question Insurance poses

[300] Schauer, F. *Statistical (and non-statistical) discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.50.
[301] Harcourt, B. (2005). *Against prediction: Sentencing, policing, and punishing in an actuarial age*. Chicago Public Law and Working Theory Working Paper no. 94. The University of Chicago, Law School.
[302] Schauer, F. (2003). *Profiles, Probabilities and Stereotypes ix.* Harvard University Press, as cited in Harcourt, B. (2005). *Against prediction: Sentencing, policing, and punishing in an actuarial age*. Chicago Public Law and Working Theory Working Paper no. 94. The University of Chicago, Law School. P.13.
[303] *Idem.*
[304] Schauer, F. *Statistical (and non-statistical) discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.52.

At the core of private insurance lies a known form of permitted discrimination[305]. However, the line States set is continuously mutating to reflect society's views of a more egalitarian society. There is a general anti-discrimination prohibition without fair justification provision widely legislated through numerous jurisdictions[306]. However, the existence of a complete hardcore prohibition of discrimination is a rare sight. We can see hardcore prohibitions now in place for, by way of example, gender in the European Union[307]. The balance between the anti-discrimination trend and the profitability of a private business thus *remains a normative mystery*[308]. The ethical discussions around this topic – even if limited – tend to focus on direct statistical discrimination, typically leaving out the pressing issue of indirect statistical discrimination. There is a wide consensus, as a consequence of legislative efforts to impose the general principle of non-discrimination, that the issue no longer revolves around intentional discrimination *per se*, given the illegality within it, with the indirect statistical discrimination now taking centre stage[309]. However, how can the line be accurately drawn if this form of discrimination occurs *when insurers discriminate based on a characteristic (such as the size of a car engine*) *that correlates with a protected class (such as gender)*[310].

With this evolving mentality within discrimination law, insurance - namely private insurance - tends to evoke this ever growing debate of *what separates admissible criteria of differentiation from inadmissible forms of discrimination?*[311]. The root of private insurance revolves around accurate statistical findings and a scientific method of data analysis described as actuarial sciences[312]. Given the rationality behind the applied methods, it can be discussed if ethics as a place in this. It is a fact insurance is discriminating in its practices - it is its root model. The classification of risk according to

[305] Rego, M. (2022). *Discrimination Bans and Insurance Law*. Insurance and Human Rights, AIDA Europe. Research Series on Insurance Law and Regulation 5. P.34.
[306] *E.g.*, in article 15 of Portuguese Decree-Law No. 72/2008, of 16 April and article 13 of the Constitution of the Portuguese Republic of 1976.
[307] As a result of the Test-Achats ruling (Judgment of the Court (Grand Chamber) of 1st March 2011, *Association Belge des Consommateurs Test-Achats ASBL and Others v Conseil des ministres* (Case C-236/09)), which prohibited any form of discrimination due to gender - even if it resulted in any form of benefit for the typically disadvantaged group (women).
[308] Avraham, R. *Discrimination and Insurance, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.337.
[309] *Idem.*
[310] Avraham, R. *Discrimination and Insurance, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.339.
[311] Alexander, L. (1992). *What Makes Wrongful Discrimination Wrong? Biases, Preferences, Stereotypes, and Proxies.* University of Pennsylvania Review, 141. P.151, *in* Rego, M. (2015). *Statistics as a basis for discrimination in the insurance business.* Law, Probability and Risk, 14. P.122.
[312] Sherris, M. (2000). *Principles of Actuarial Science*. Michael Sherris.

specific characteristics individuals bear allows for a more tailored made insurance policy and premium to be paid[313], thus fighting the main issues which can be fostered in the insurance market, *(i)* adverse selection, which can lead to *(ii)* less access to insurance for individuals[314].

For insurance to be considered ethical in the sense where no discrimination is allowed, the rational methodology which fosters these tailored made policies would vanish and a one-policy-for-all system would need to be applied. This cannot be supported in a developed financial system where insurance occupies its share[315]. The ideal non-discriminating society and the existence of private insurance can and should coexist. One can argue that the rational discrimination line should be expressly drawn but if one examines the way in which current insurance legislation prohibits discrimination, it is easily acknowledged the existence of this line. Any intention to further strengthen and restrict the ability of insurers to make a fateful risk analysis will result in a worse market outcome for consumers. Prohibiting any kind of discrimination in its *lato sensu* is not sustainable nor defensible. How can one argue that discriminating based on age, for example, in car insurance, is discriminating younger individuals to a place where it is unethical and not a mere rational and valid syllogism?

The potential unethical effects of insurance given its discrimination driven methodology could be diminished by an update in the data sets used by insurers[316]. A deeper analysis of data and how it impacts the potential bias and discrimination in insurance will be achieved in Chapter V of this dissertation, but it is worth to give an introductory remark regarding the use of bias data.

We argue that updating the data sets used to analyse an individual's risk through the law of large numbers is a fundamental first step towards establishing a private insurance market that strikes a balance between *(i)* the private interest of insurers, and *(ii)* the optimal premium to be paid by consumers in relation to their risk. This achievement is not without the effort to take into account a reduction in discriminatory factors purported by years of prejudice in society which, even without expressly taking into account the discriminatory characteristic, still remain discriminatory due to what is called

[313] Insurance Europe. *How the losses of the few are spread among the many.* Risk-based underwriting, *in: https://www.insuranceeurope.eu/priorities/2473/risk-based-underwriting-incl-ec-beating-cancer-plan.*
[314] Insurance Europe (2021). *The benefits of risk-based underwriting.*
[315] Insurance Europe. *Value of Insurance, in: https://insuranceeurope.eu/value-of-insurance.*
[316] For further solutions, please refer to Chapter V of this dissertation.

social identifiers[317] that allow the permeation of prejudice to supposedly "clean" or "non-discriminating" datasets.

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[317] For further information, please refer to Chapter V of this dissertation.

Chapter V

RTBF in Insurance: Algorithms as a solution?

§1. Algorithms and Big Data in Insurance

The new era we have entered, entitled by David Brooks as *data-ism*[318], revolves around the phenomena of data, in particular, data as both the match and the gasoline of technological development. Given its key role in society's development, data is currently the *world's most valuable resource*[319], surpassing oil. A second age of enlightenment is reached, pursuant to philosophy professor Byung-Chul Han thesis, with the imperative being that everything must be transformed into data and information considering data *is* transparency[320]. However, Han does not advocate for such a thesis of dependency in transparency because in his hypothesis *trust means establishing a positive relationship with the Other, even in ignorance*[321] and thus *transparency dismantles trust*[322]. Other authors, see this new age as a move towards a *Knowledge Based Society*[323], where *in order to extract better knowledge we need a bigger amount of data*[324][325]. Regardless of the classification we award to this new age, the root of it remains in the reliance and dependency on large amounts of data, *i.e.*, in Big Data.

1.1. What is Big Data?

The term Big Data was formulated in the early 2000s with Roger Magoulas coining the term[326], and Doug Laney classifying it through the notorious 3 (three) V's: *(i)* Volume; *(ii)* Velocity; and *(iii)* Variety[327]. Following the development of this field, these 3 Vs have now almost doubled into the following 5Vs: *Volume, velocity, variety, veracity*

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[318] Brooks, D. *The Philosophy of Data* (2013). New York Times, 4 of February of 2013, *in: https://www.nytimes.com/2013/02/05/opinion/brooks-the-philosophy-of-data.html.*
[319] *The world's most valuable resource is no longer oil, but data.* (2017). The Economist, May 6 2017, *in:* https://www.economist.com/leaders/2017/05/06/the-worlds-most-valuable-resource-is-no-longer-oil-but-data.
[320] *Idem.*
[321] Han, B. (2015). *The Transparency Society*. Stanford University Press. P.47.
[322] Han, B. (2015). *The Transparency Society*. Stanford University Press. P.48.
[323] Ularu, E. G., Puican, F. C., Apostu, A., Velicanu, M. (2012). *Perspectives on big data and big data analytics*. Database Systems Journal, 3(4). P.3.
[324] *Idem.*
[325] iCohen. J. (2013). *What privacy is for*. Harvard Law Review, 126/1904. P.1920; Ferguson, A. (2015). *Big data and predictive reasonable suspicion*. University of Pennyslvania Law Review, 163/2. P.352.
[326] *Idem.*
[327] Laney, D. (2001).*3D Data Management: Controlling Data Volume, Velocity, and Variety*. Gartner, file no 949.

and value[328] (additional characteristics have been put forward but the 5 mentioned tend to gather the most consensus).

From the early 2000s until the present day, the amount of data grew at an inconceivable rate with a statistic from 2018 stating that *over the last two years alone 90 percent of the data in the world was generated*[329]. As such, traditional methods of data analysis which were designed for smaller amounts of data are no longer appropriate. Methods such as *sampling, data condensation, density-based approaches, grid-based approaches, divide and conquer, incremental learning, and distributed computing have been presented*[330] as a response to the issues of analyzing these large volumes of data. A data analysis method which was formulated to reduce *the input data volume to accelerate the process of data analytics*[331], the principal components analysis, is one of the main data analysis methods for this new age. There is a clear research trend in the past decade to try and use *efficient methods to reduce the computation time of input, comparison, sampling, and a variety of reduction methods will play an important role in big data analytics*[332].

These data analysis methods can, from the raw data sets in Big Data, which are classified as unrefined, discover patterns, correlations and/or information which grants them knowledge through what scholars call "data mining". Data mining attempts *to understand the meaning from collected data*[333].

Through this, Big Data grants efficiency to individuals and/or institutions which can process these amounts of data in an adequate way since it grants a better vision of the specific matter that they are analysing. In the Insurance sector, Big Data allows for an even more extensive knowledge of risks and the correlations it can make through algorithms - detailed further in subsequent sub-chapters - allows for an even greater

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[328] Patgiri, R., Ahmed, A. (2016). *Big Data: The V's of the Game Changer Paradigm*. IEEE 18th International Conference on High Performance Computing and Communications; IEEE 14th International Conference on Smart City; IEEE 2nd International Conference on Data Science and Systems. P.18.

[329] Marr, B. *How much data do we create every day? The Mind-blowing stats everyone should read*. Forbes, 21 of May 2018 *in: https://www.forbes.com/sites/bernardmarr/2018/05/21/how-much-data-do-we-create-every-day- the-mind-blowing-stats-everyone-should-read/?sh=6c031c3a60ba.*

[330] Tsai, C., Lai, C., Chao, H. Vasilakos, A. (2015). *Big data analytics: a survey*. Journal of Big Data. Springer. P.1.

[331] *Idem.*

[332] Tsai, C., Lai, C., Chao, H. Vasilakos, A. (2015). *Big data analytics: a survey*. Journal of Big Data. Springer. P.26-27.

[333] Tsai, C., Lai, C., Chao, H. Vasilakos, A. (2015). *Big data analytics: a survey*. Journal of Big Data. Springer. P.4.

predictability in the field of actuarial sciences[334]. In addition, through Big Data, insurers can fight problematics such as adverse selection[335][336] given the reduction of information asymmetry[337].

Notwithstanding these benefits, Big Data is not without its flaws. Due to a *great deal of modern-day inequality (…)* being *attributed to what sociologists call "institutional" discrimination*[338], a mere input of raw unrefined data in this data analysis methods tends to aggravate the prejudice within the data which result from decades of discrimination within society. In particular, if data is inputted into mechanisms of data analysis without meticulous ethical handling it *can reproduce existing patterns of discrimination, inherit the prejudice of prior decision makers, or simply reflect the widespread biases that persist in society*[339].

Alongside data mining and knowledge discovery, Big Data is employed nowadays to generate choices (*i.e.*, within Machine Learning or Artificial Intelligence). Data mining and knowledge discovery, like abovementioned, are methods which can find patterns, correlations and information. However they do not make decisions[340] *per se* like an algorithm which decides whether to acquire securities or sell them. Regardless of the technique, to be able to comprehend and analyse through a set of unstructured or structured data and properly structure information is immensely valuable[341] in era where data is flowing, as stated, at inconceivable rates[342].

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[334] Leal, A. (2017). *Aspetos jurídicos da análise de dados na Internet (big data analytics) nos setores bancário e financeiro: proteção de dados pessoais e deveres de informação*. P.88, *in* Cordeiro, A., Oliveira, A., Duarte, D. (2017). *Desafios da Tecnologia Financeira*. Edições Almedina, S.A.

[335] Leal, A. (2017). *Aspetos jurídicos da análise de dados na Internet (big data analytics) nos setores bancário e financeiro: proteção de dados pessoais e deveres de informação*. P.89, *in* Cordeiro, A., Oliveira, A., Duarte, D. (2017). *Desafios da Tecnologia Financeira*. Edições Almedina, S.A.

[336] OECD (2020). *The impact of Big Data and Artificial Intelligence (AI) in the Insurance Sector*. P.14.

[337] Martinez, P. (2006). *Direito dos Seguros.* Apontamentos, Principia, Lisboa. P.57.

[338] Barocas, S., Selbst, A. D. (2016). *Big Data's Disparate Impact*. 104 California Law Review 671. P.673.

[339] Barocas, S., Selbst, A. D. (2016). *Big Data's Disparate Impact*. 104 California Law Review 671. P.674.

[340] JavaTPoint. *KDD vs Data Mining, in: https://www.javatpoint.com/kdd-vs-data-mining.*

[341] *Big Data: What is and why it matters.* SAS *in:* https://www.sas.com/pt_pt/insights/big-data/what-is- big-data.html; Saidali, J., Rahich, H., Tabaa, Y., Medouri, A. (2019). The combination between Big Data and Marketing Strategies to gain valuable Business Insights for better Production Success. Procedia Manufacturing, Volume 32; Najafabadi, M., Villanustre, F., Khoshgoftaar, T., Seliya, N., Wald, R., Muharemagic, E. (2015). *Deep learning applications and challenges in big data analytics.* Journal of Big Data 2.

[342] SAP. *What is Big Data?, in: https://www.sap.com/products/technology-platform/what-is-big-data.html;* Deloitte. *Data: a small four-letter word which has grown exponentially to such a big value, in:* https://www2.deloitte.com/cy/en/pages/technology/articles/data-grown-big-value.html; Statista (2021). *Volume of data/information created, captured, copied and consumed worldwide from 2010 to 2020, with forecasts from 2021 to 2025, in:* https://www.statista.com/statistics/871513/worldwide-data-created/.

1.2. Machine Learning

Given the scope of this dissertation, the primary focus of the following analysis will be Artificial Intelligence (AI) and Machine Learning (ML)[343] due to their decision making capabilities and the associated bias still perpetuated within it. Machine Learning is a field within AI, with its origins going back to the 1950s with the work of Alan Touring[344].

Machine Learning through the input of data sets produces, not mere decisions, but *prediction of y from x*[345]. It is within these predictions that the prejudice ensues. Within Machine Learning reside 3 (three) methodologies: *(i)* supervised machine learning; *(ii)* unsupervised machine learning; and *(iii)* reinforcement learning[346]. Each methodology allows for a different kind of problem solving, supervised machine learning is *commonly used in classification and regression problems*, whilst unsupervised is *commonly used in segmentation and clustering problems*, and, lastly, reinforcement learning is *similar to supervised learning, but reward mechanism in place instead of labeled output*[347].

The predictive characteristic of ML can also be one of its biggest defects[348], thus the importance of the quality of data it uses. EIOPA has put forward additional challenges which can occur in or due to AI and ML like *(i) transparency and explainability issues; the potential impact of some AI use cases on the fair treatment of consumers;* and *(iii) limited financial inclusion of high-risk or vulnerable consumers*[349]. The key point for this dissertation is, however, that a machine learning algorithm is only as good as the date it uses as its source[350]. The problematic around the bias which data sets can possess might

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[343] Here presented separately but there is a scholar consensus that machine learning (ML) is a part of the wider notion of Artificial Intelligence (AI).
[344] Turing, A. (1950). *Computing Machinery and Intelligence*. Mind, Volume LIX, Issue 236. P. 433-460.
[345] Mullainathan, S., & Spiess, J. (2017). *Machine Learning: An Applied Econometric Approach*. The Journal of Economic Perspectives, 31(2). P.88.
[346] DeBrusk, C. (2018). *The Risk of Machine Learning Bias (and how to prevent it)*. Risk Journal, Rethinking T actics. P.3.
[347] *Idem.*
[348] In the sense it can predict decisions and/or outcomes that can potentially be inherently bias if the data which is inputted into the training algorithm is "*contaminated*".
[349] EIOPA. *Artificial Intelligence and Big Data, in*: https://www.eiopa.europa.eu/browse/digitalisation-and-financial-innovation/artificial-intelligence-and-big-data_en.
[350] *Ensuring you have good data quality prior to running machine learning algorithms is a crucial step within the overall data science and machine learning workflow* (Source: McDonald, A. (2022). *Data Quality Considerations for Machine Learning Models*. Towards Data Science, *in:* https://towardsdatascience.com/data-quality-considerations-for-machine-learning-models-dcbe9cab34cb).

be resolved with their identification and removal[351][352]. This idea of an external control of the inputted data is thus on the forefront of the debate[353].

Silva and Kenney putted forward the following bias categories: *Training Data Bias; Algorithmic Focus Bias; Algorithmic Processing Bias; Interpretation Bias; Non-Transparency of Outcomes Bias; Automation Bias; Consumer Bias; Feedback Loop Bias*[354].

Friedman and Nissenbaum supported the thesis that for bias to occur it must fulfil the following two cumulative indicators: *(i)* for discrimination to be biased it cannot merely occur individually, it must be systemic; and *(ii)* if there is no unfair outcome that arises out of this discrimination, bias is not considered to be present[355]. As previously stated, we argue against this idea, in particular in its applicability in the insurance market. Bias should not be, in any scenario, dependent on the existence of a negative outcome.

One can argue on the extent of what is classified as a negative outcome. For instances, when it comes to the standard market practice of nightclubs exempting women from paying entrance fees, it can be seen as a discrimination without negative outcome given this exemption. However, if one analyses further the reasoning it understands that this is a direct consequence of the commercialization and objectification of their presence in order to attract male attention. No matter where one stands on the classification of this action, in the fight against discrimination and objectification of women, the loss of this apparent benefit shall be a necessary result. This idea does not intend to disregard the prejudice which women already face in a number of sectors, namely in the workplace in relation with pay disparity[356], but merely strengthen the thesis that for gender disparity to be eradicated all privileges and prejudice which ensue must be revoked. Notwithstanding, this is a thesis which will take decades to accurately set up given the decades and centuries of accumulated prejudice which taint the possibility of beginning on equal footing soon.

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[351] DeBrusk, C. (2018). *The Risk of Machine Learning Bias (and how to prevent it)*. Risk Journal, Rethinking Tactics. P.5.
[352] Holm, S., Petersen, E., Ganz, M., Feragen, A. (2023). *Bias in context: What to do when complete bias removal is not an option*. PNAS.
[353] Bynum, T. (2015). *Computer and information ethics*. The Stanford Encyclopedia of Philosophy Archive. Winter 2017 Edition, *in:* https://plato.stanford.edu/archives/win2017/entries/ethics-computer/.
[354] Silva, S., Kenney, M. (2018). *Algorithms, Platforms, and Ethnic Bias: An Integrative Essay*. Phylon (1960-), 55(1 & 2).
[355] Friedman B., Nissenbaum H. (1996). *Bias in computer systems.* ACM Transactions on Information Systems, Vol.14, No.3. P. 333.
[356] E.g., the gender pay gap is still visible in the European Union with an average gap of 14.1%, ranging from 5% in some countries to 19% in others. Source: *The gender pay gap situation in the EU*. European Commission *in: https://ec.europa.eu/info/policies/justice-and-fundamental-rights/gender-equality/equal-pay/gender-pay-gap-situation-eu_en*.

In a succinct matter, we will focus on three types of Machine Learning techniques to be able to comprehend how this bias can be generated: *(i)* Neural Networks; *(ii)* Support Vector Machines; and *(iii)* Decision Trees[357].

Neural network models are a method within the wider notion of machine learning which existence has, at its origin, the imitation of the functioning of the neurons in the brain[358]. Although works on neural networks were already being produced, the groundbreaking point occurred with McCulloch and Pitt's paper in 1943 denominated "Logical Calculus of Ideas Immanent in Nervous Activity"[359]. These networks *learn to perform task by considering examples, generally without being programmed with any task-specific rules*[360].

From these neural networks was created the method of deep machine learning which are multilayered neural networks[361]. In sum, deep learning *refers to the depth of layers in a neural network*[362], with neural networks with *more than three layers*[363] being thus classified as deep machine learning. The following figure can showcase a deep learning algorithm versus a neural network:

[357] Sarker, I. (2021). *Machine Learning: Algorithms, Real-World Applications and Research Directions.* SN Computer Science, 160. P.6.; Wakefield. K. *A guide to the types of machine learning algorithms and their applications*. SAS, *in:* https://www.sas.com/en_gb/insights/articles/analytics/machine-learning-algorithms.html.

[358] Kriegeskorte, N., Golan, T. (2019). *Neural network models and deep learning*. Current Biology 29, R225-R240. Elsevier Ltd. P.231; Dongare, A., Kharde, R., Kachare, A. (2012). *Introduction to Artificial Neural Network*. International Journal of Engineering and Innovative Technology (IJEIT). Volume 2, Issue 1, July 2012. P.189.

[359] Piccinini, G. (2004). *The First Computational Theory of Mind and Brain: A Close Look at Mcculloch and Pitts's "Logical Calculus of Ideas Immanent in Nervous Activity*". Synthese 141. P.175.

[360] OECD (2020). *The impact of Big Data and Artificial Intelligence (AI) in the Insurance Sector*. P.18.

[361] *Idem.*

[362] Kavlakoglu, E. (2020). *AI vs. Machine Learning vs. Deep Learning vs. Neural Networks: What's the Difference?* IBM, 27 May 2020, *in*: https://www.ibm.com/cloud/blog/ai-vs-machine-learning-vs-deep-learning-vs-neural-networks.

[363] *Idem.*

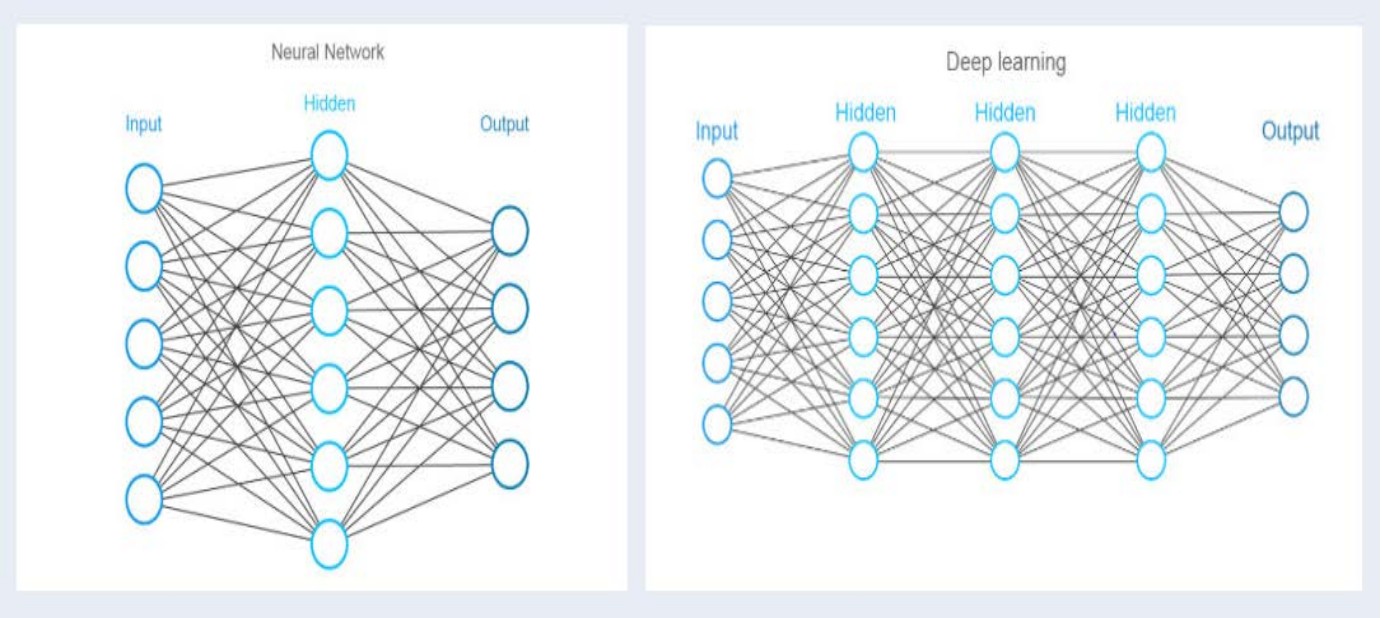


Figure VI - Neural Networks vs. Deep Learning. Source: EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.15

Another machine learning method are support vector machine algorithms, which are supervised learning algorithms[364], used for classification and regression problematics[365], although more predominant in the first scenario. For a clearer notion, the following graph presents the support vector machine algorithm in a 2 dimensional manner,

[364] DeBrusk, C. (2018). *The Risk of Machine Learning Bias (and how to prevent it).* Risk Journal, Rethinking Tactics. P.3.
[365] JavaTpoint. *Support Vector Machine Algorithm, in:* https://www.javatpoint.com/machine-learning-support-vector-machine-algorithm.

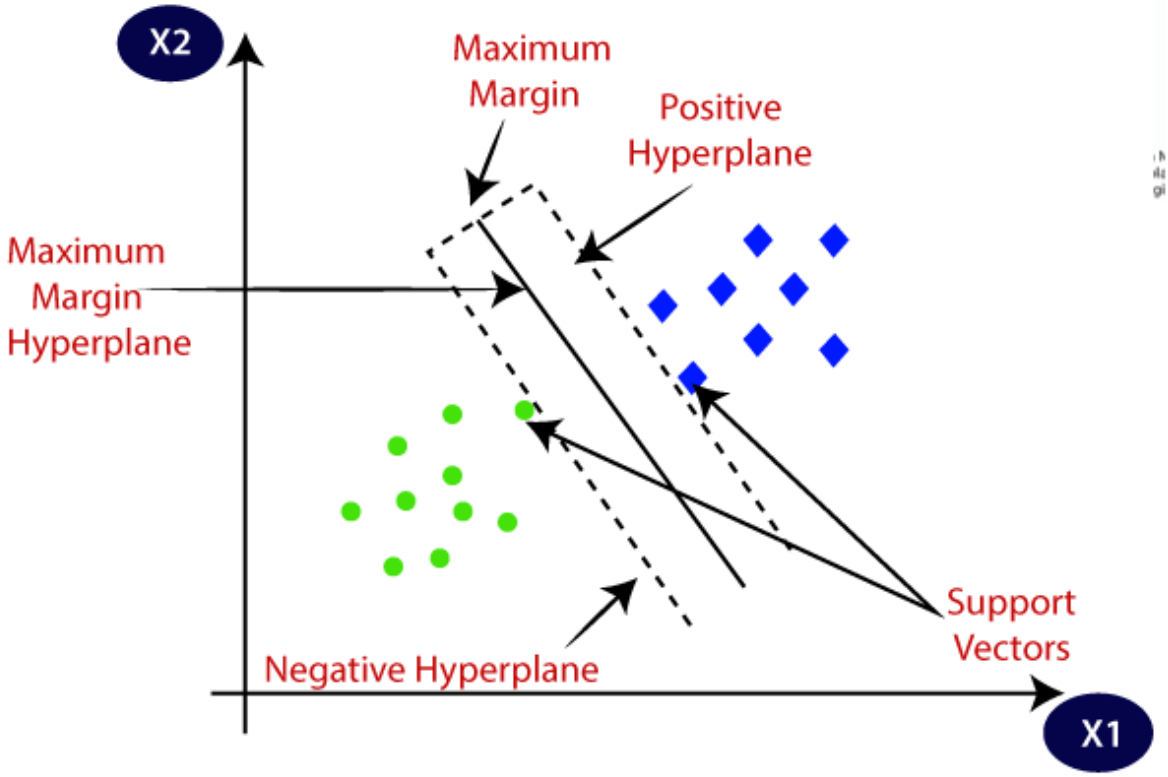


Figure VII - Support Vector Machine Graphic representation. Source: JavaTpoint. *Support Vector Machine Algorithm, in:* https://www.javatpoint.com/machine-learning-support-vector-machine-algorithm

Support vector machine algorithms have, as their main purpose, the creation of the optimum line or decision boundary (the hyperplane[366]) which *can segregate n-dimensional space into classes so that we can easily put the new data point in the correct category in the future*[367], in a simplified way, a data segmentation method[368]. Given its classification as a superior classification algorithm[369] it is relevant to analyse. The

[366] Gandhi, R. (2018). *Support Vector Machine - Introduction to Machine Learning Algorithms.* Towards Data Science, *in:* https://towardsdatascience.com/support-vector-machine-introduction-to-machine-learning-algorithms-934a444fca47; JavaTpoint. *Support Vector Machine Algorithm, in:* https://www.javatpoint.com/machine-learning-support-vector-machine-algorithm.

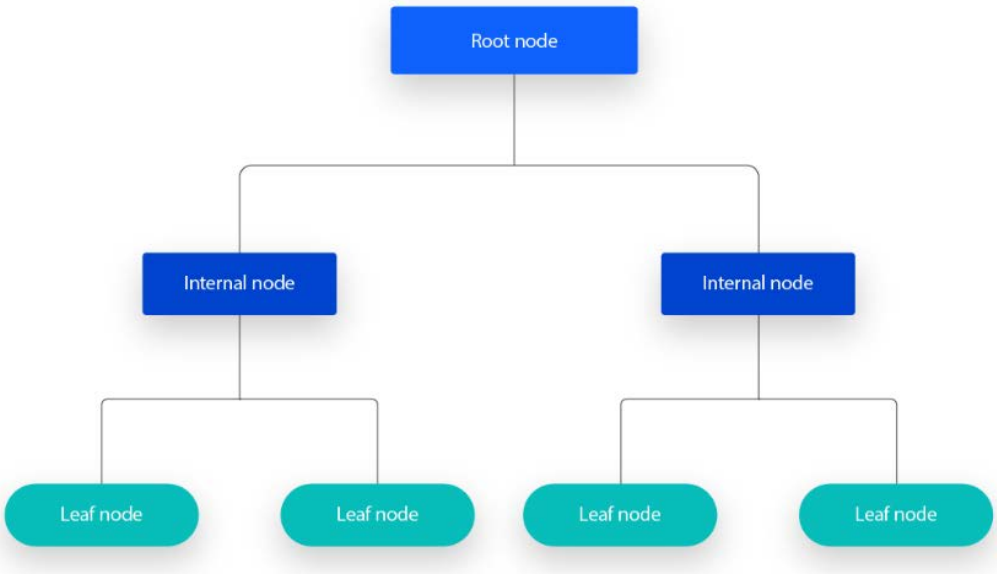
[367] JavaTpoint. *Support Vector Machine Algorithm, in:* https://www.javatpoint.com/machine-learning-support-vector-machine-algorithm.

[368] Gaye, B., Zhang, D., Wulamu, A. (2021). *Improvement of Support Vector Machine Algorithm in Big Data Background*. Mathematic Problems in Engineering, Volume 2021. Hindawi. P.2.

[369] Rustam, Z., Ariantari, N. (2018). *Support Vector Machines for Classifying Policyholders Satisfactorily in Automobile Insurance.* Journal of Physics: Conference of Series 1028. P.2.; Gandhi, R. (2018). *Support Vector Machine - Introduction to Machine Learning Algorithms.* Towards Data Science, *in:* https://towardsdatascience.com/support-vector-machine-introduction-to-machine-learning-algorithms-934a444fca47.

maximization of the margin distance allows for a better classification of future data points[370] and through this, the aim of support vector machines is fulfilled[371].

Lastly, decision trees, alongside support vector machine algorithms, fall into the category of supervised machine learning[372]. This *non-parametric supervised learning method*[373], is traditionally applied for *classification and regression tasks*[374]. In order to comprehend this machine learning model, the following two figures below showcase how this hierarchical tree structure can be utilized,



[370] Gandhi, R. (2018). *Support Vector Machine - Introduction to Machine Learning Algorithms.* Towards Data Science, *in:* https://towardsdatascience.com/support-vector-machine-introduction-to-machine-learning-algorithms-934a444fca47.
[371] Wakefield. K. *A guide to the types of machine learning algorithms and their applications.* SAS, *in:* https://www.sas.com/en_gb/insights/articles/analytics/machine-learning-algorithms.html; Gandhi, R. (2018). *Support Vector Machine - Introduction to Machine Learning Algorithms.* Towards Data Science, *in:* https://towardsdatascience.com/support-vector-machine-introduction-to-machine-learning-algorithms-934a444fca47.
[372] DeBrusk, C. (2018). *The Risk of Machine Learning Bias (and how to prevent it).* Risk Journal, Rethinking Tactics. P.3.
[373] Sarker, I. (2021). *Machine Learning: Algorithms, Real-World Applications and Research Directions.* SN Computer Science, 160. P.6.
[374] *Idem.*

Figures VIII-A and VIII-B - Decision Trees. Source: IBM. *Decision Trees, in:* https://www.ibm.com/topics/decision-trees.

Decision trees are essentially, a *graphical representation for getting all the possible solutions to a problem/decision based on given conditions*[375]. They are traditionally weaker than other algorithms[376], but they still possess an important and relevant place in *data mining and knowledge discovery tasks*[377] since they are easily understood and thus useful for showcasing all the potential outcomes[378] without the need for significant data cleaning[379].

Even taking into account solely the abovementioned models, one can still easily confuse these types of machine learning methods and the wider notions of *(i)* machine learning, *(ii)* artificial intelligence, and even *(iii)* the stricter notion of deep machine learning. The figure of the Russian nesting dolls below can aid in the clarification process and more clearly portray these differentiations,

[375] JavaTpoint. *Decision Tree Classification Algorithm, in: https://www.javatpoint.com/machine-learning-decision-tree-classification-algorithm.*
[376] IBM. *Decision Trees, in:* https://www.ibm.com/topics/decision-trees.
[377] *Idem.*
[378] Wakefield. K. *A guide to the types of machine learning algorithms and their applications*. SAS, *in:* https://www.sas.com/en_gb/insights/articles/analytics/machine-learning-algorithms.html.
[379] JavaTpoint. *Decision Tree Classification Algorithm, in: https://www.javatpoint.com/machine-learning-decision-tree-classification-algorithm.*

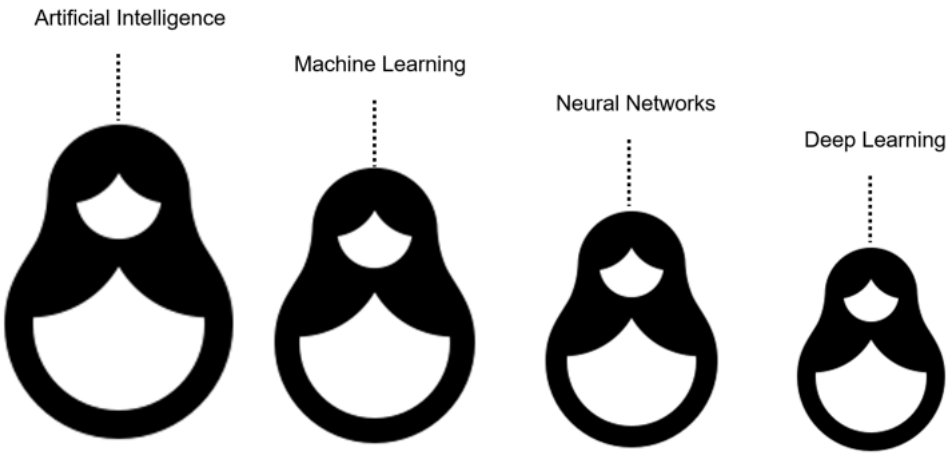


Figure IX - AI Russian Dolls. Source: Kavlakoglu, E. (2020). *AI vs. Machine Learning vs. Deep Learning vs. Neural Networks: What's the Difference?* IBM, 27 May 2020, *in*: https://www.ibm.com/cloud/blog/ai-vs-machine-learning-vs-deep-learning-vs-neural-networks.)

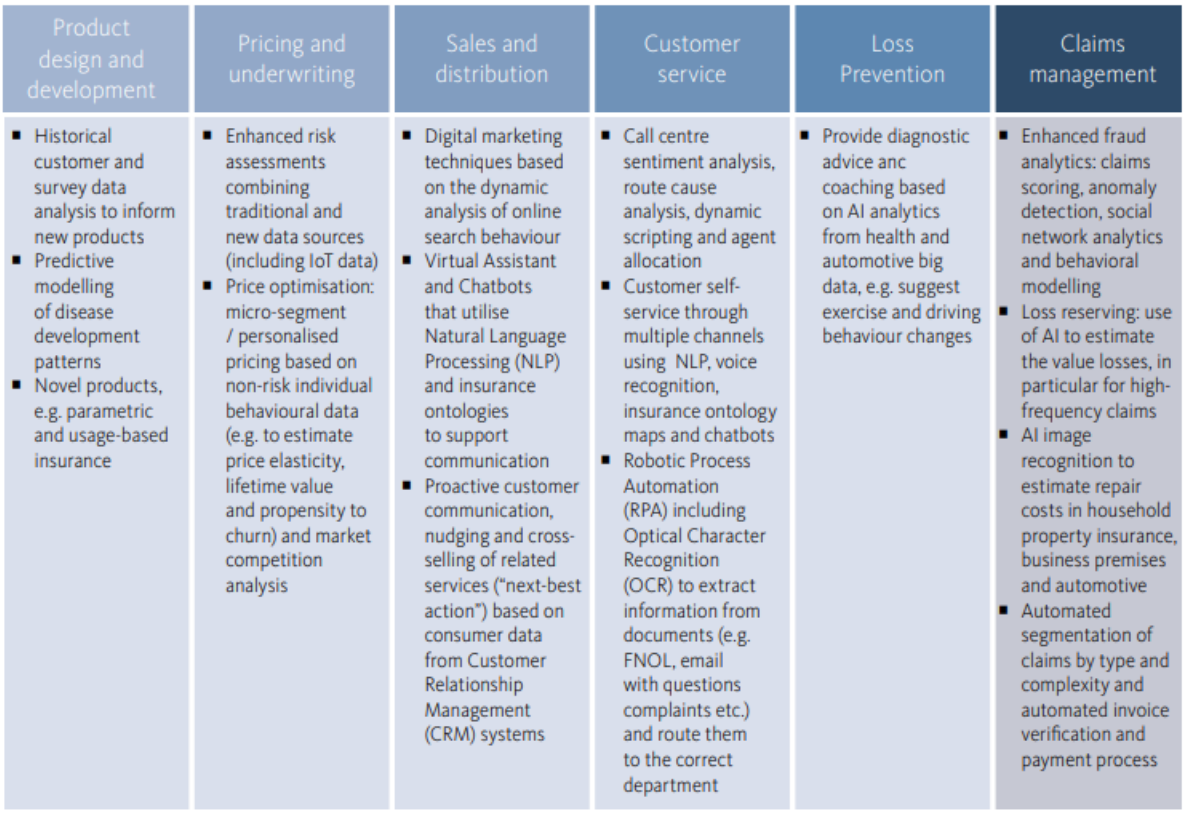
Artificial intelligence is the wider notion which encompasses all the others and, as we analyse deeper onto each concept, we understand that they become more limited, with each encompassing the other in a sequential manner.

1.3. Machine Learning and Insurance

The advent of the entrance of machine learning in the financial system[380], and its predicted exponential growth[381], allowed for, amongst others, the improvement of *the accuracy of prediction and financial data analysis*[382]. In particular, given the field that is Insurance, and coupled with Big Data, machine learning models *could represent a step-change improvement in the ability to accurately monitor and evaluate risk*[383].

In a recent EIOPA report, AI was showcase as useful across all of the value chain through the following figure:

[380] Xie, M. (2019). *Development of Artificial Intelligence and Effects on Financial System.* Journal of Physics: Conf. Series 1187. P.1.
[381] *Global spending on AI is forecast to double over the next four years, growing from $50.1 billion in 2020 to more than $110 billion in 2024 (*Source: OECD (2021). *Artificial Intelligence, Machine Learning and Big Data in Finance: Opportunities, Challenges, and Implications for Policy Markers.* P.19); *The potential impact of AI is estimated to drive global GDP to USD 15.7 trillion by 2030* (Source: OECD (2020). *The impact of Big Data and Artificial Intelligence (AI) in the Insurance Sector*. P.18).
[382] Xie, M. (2019). *Development of Artificial Intelligence and Effects on Financial System.* Journal of Physics: Conf. Series 1187. P.1.
[383] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.14.



Product design and development	Pricing and underwriting	Sales and distribution	Customer service	Loss Prevention	Claims management
▪ Historical customer and survey data analysis to inform new products ▪ Predictive modelling of disease development patterns ▪ Novel products, e.g. parametric and usage-based insurance	▪ Enhanced risk assessments combining traditional and new data sources (including IoT data) ▪ Price optimisation: micro-segment / personalised pricing based on non-risk individual behavioural data (e.g. to estimate price elasticity, lifetime value and propensity to churn) and market competition analysis	▪ Digital marketing techniques based on the dynamic analysis of online search behaviour ▪ Virtual Assistant and Chatbots that utilise Natural Language Processing (NLP) and insurance ontologies to support communication ▪ Proactive customer communication, nudging and cross-selling of related services ("next-best action") based on consumer data from Customer Relationship Management (CRM) systems	▪ Call centre sentiment analysis, route cause analysis, dynamic scripting and agent allocation ▪ Customer self-service through multiple channels using NLP, voice recognition, insurance ontology maps and chatbots ▪ Robotic Process Automation (RPA) including Optical Character Recognition (OCR) to extract information from documents (e.g. FNOL, email with questions complaints etc.) and route them to the correct department	▪ Provide diagnostic advice anc coaching based on AI analytics from health and automotive big data, e.g. suggest exercise and driving behaviour changes	▪ Enhanced fraud analytics: claims scoring, anomaly detection, social network analytics and behavioral modelling ▪ Loss reserving: use of AI to estimate the value losses, in particular for high-frequency claims ▪ AI image recognition to estimate repair costs in household property insurance, business premises and automotive ▪ Automated segmentation of claims by type and complexity and automated invoice verification and payment process

Figure X - AI in Insurance value chain. Source: EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P.9.

As one can understand from the figure above, through the application of AI and ML in Insurance, both the insurer and the insured can draw advantages for themselves. For instance, through a bigger quantity of data provided now and the ability of these methods to process such information[384], there is now an increase in *prediction accuracy, automation, new products and services and cost reduction*[385].

In addition, within Insurance, the machine learning models specified above, in particular, neural networks and deep learning, are seen as potentially efficient algorithms since they are *able (...) to develop, without or with limited human intervention, very accurate assessments, increasing the efficiency and speed of decision making and*

[384] EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P.10.
[385] *Idem.*

therefore reducing operational costs[386]. However, as we have understood above, given the mechanism of neural networks and deep learning models which comprises one or more hidden layers[387], transparency of decisions and the causal relationship established by the algorithm from the input and the output layer can be challenging to explain[388].

However, with regards to this transparency issue, the duties which arise under GDPR regarding information and data, in particular due to article 13 (*Information to be provided where personal data are collected from the data subject*) and article 14 (*Information to be provided where personal data have not been obtained from the data subject*) of the GDPR[389], are quite extensive which forces insurance companies to *inform consumers about the types, sources and purposes of the use of personal data in their BDA processes in compliance with the requirements*[390]. EIOPA considers this opacity issue to be covered by the GDPR provisions[391]. However, there is debate around two points: *(i)* are consumers capable of understanding how their personal data is being processed, and for what purposes it is being used? and *(ii)* how can insurers explain how certain algorithms, in particular black box algorithms[392], function whilst complying with GDPR requirements if it's not easy to determine its functioning?[393]

Point *(ii)* above is one of the trickiest issues to resolve. Given the specificities of ML, there is a widely known *difficulty in decomposing the output of a ML model into the*

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[386] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.15.
[387] Please refer to Figure VI bove regarding deep learning algorithms.
[388] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.15.; EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P.7.
[389] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 *on the protection of natural persons with regard to the processing of personal data and on the free movement of such data,* and repealing Directive 95/46/EC (General Data Protection Regulation); EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.44.
[390] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.43-44.
[391] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P. 48.
[392] *The Artificial Intelligence black box problem is based on the inability to fully understand why the algorithms behind the AI work the way they do.* (Source: Garcia, O. (2020). *"Black box". There's no way to determine how the algorithm came to your decision.* Towards Data Science, *in:* https://towardsdatascience.com/black-box-theres-no-way-to-determine-how-the-algorithm-came-to-your-decision-19c9ee185a8).
[393] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P. 48.

underlying drivers of its decision[394]. This problematic is more vivid within deep machine learning algorithms[395] since decision trees and bayesian networks are evidently more explainable *thus making the process of decision making more transparent and any biases easier to detect*[396].

OECD sustained that improving this transparency, defined in the area as explainability[397], can increase the confidence in the sector's stakeholders, in particular the supervisory authorities and consumers[398].

In addition to the opacity and explainability issue above, EIOPA gathered information from stakeholders to ascertain the following main challenges in connection with Big Data algorithms,

[394] OECD (2021). *Artificial Intelligence, Machine Learning and Big Data in Finance: Opportunities, Challenges, and Implications for Policy Markers.* P.42.
[395] OECD (2020). *The impact of Big Data and Artificial Intelligence (AI) in the Insurance Sector.* P.18.
[396] *Idem.*
[397] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union; OECD (2021). *Artificial Intelligence, Machine Learning and Big Data in Finance: Opportunities, Challenges, and Implications for Policy Markers;* EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union.
[398] OECD (2021). *Artificial Intelligence, Machine Learning and Big Data in Finance: Opportunities, Challenges, and Implications for Policy Markers.* P.42.

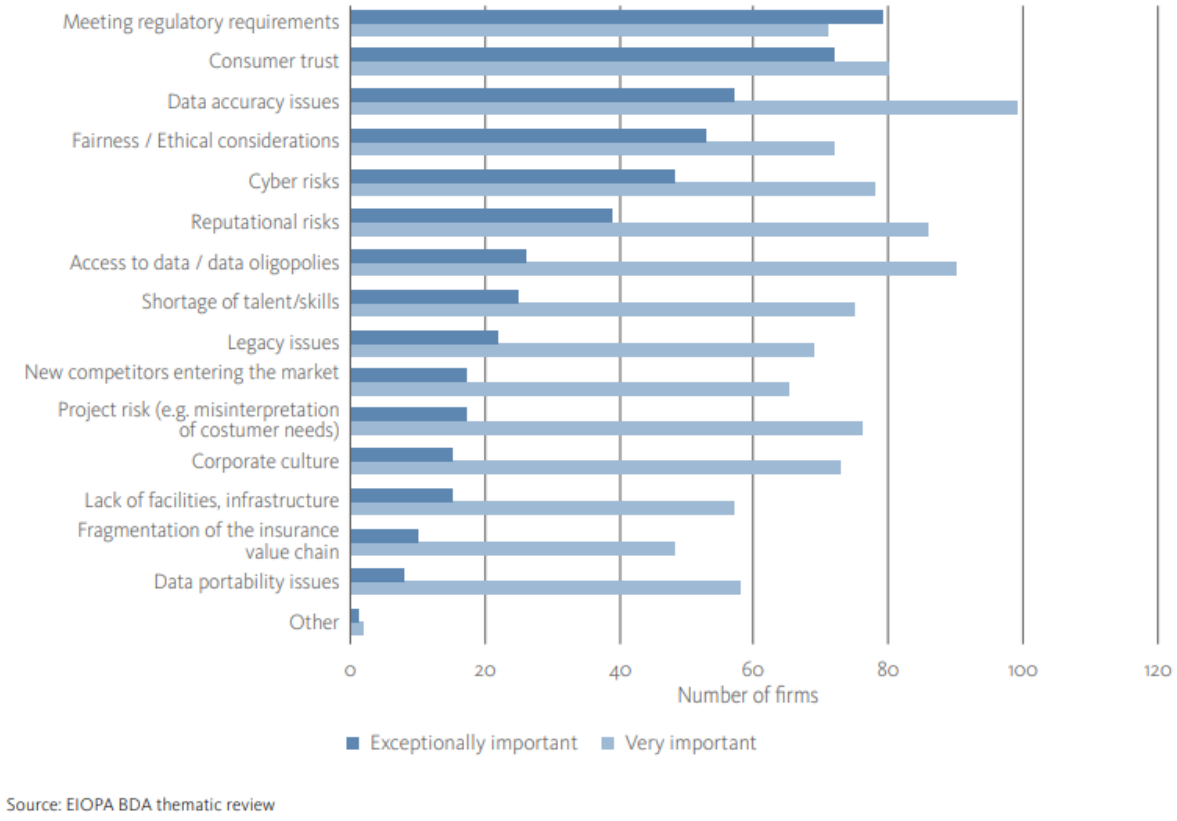

Figure XI - Challenges within Big Data and Insurance. Source: EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.47.

From the abovementioned challenges, both data accuracy issues and fairness/ethical considerations, due to the impact bias data can have on underwriting and pricing[399], are the key issues in connection with this dissertation[400]. These issues arise not only due to data sets which are biased in themselves, but also *if the output is based on correlations which are falsely assumed to be causations, then the decision-making process would be biased as well*[401].

Given its awareness of both the challenges and the benefits of AI and ML within Insurance[402], EIOPA established its strategy for 2023-2026 to *support consumers, the*

[399] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.47.
[400] For further information, please refer to sub-chapter 2 - Algorithmic Accountability.
[401] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.47.
[402] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.45-48; EIOPA (2023). *EIOPA's Digital Strategy: Support consumers, markets and the supervisory community through digital transformation.* EIPOA-23/328. P.8-9.

supervisory community, and the industry to mitigate the risks and seize the opportunities of the digital transformation[403]. To guide its activity in the sector, EIOPA put forward in 2021 the following AI Governance Principles, in line with the challenges it gathered have arisen from AI entrance into Insurance: *(i) Human oversight*; *(ii) Robustness and performance*; *(iii) Data governance and record keeping*; *(iv) Transparency and explainability*; *(v) Fairness and non-discrimination*; and *(vi) principle of proportionality*[404].

In the following sub-chapters it will be put forward how some of these governance principles can be complied when considering correlation and patterns of ML and, subsequently by taking into account all of the characteristics of these algorithms, how can the RTBF be implemented.

§2. Correlation and Patterns in AI and ML

As explained above, ML and AI algorithms learn from patterns[405]. These patterns can perpetuate prejudice in the decisions and predictions present in the outcomes of the AI and ML algorithms if the datasets in themselves are prejudiced[406]. However, it must be emphasized that these prejudice may not be blatant[407].

For instance, a way in which we could perpetuate prejudice against gender, namely females, traditionally arose in motor insurance since females would incur in a lower premium given that statistically they did not have as many accidents as their male counterparts[408]. This statistic cannot be interpreted without considering the decades of prejudice against female driving for most of the decades of collected data, or more precisely, uncollected data[409]. Although this could be considered almost a beneficial

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[403] EIOPA (2023). *EIOPA's Digital Strategy: Support consumers, markets and the supervisory community through digital transformation.* EIPOA-23/328. P.9.
[404] EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P. 15.
[405] Please refer to sub-chapter 1.2 *Machine Learning* of Chapter V *RTBF in Insurance: Algorithms as a solution?*
[406] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.96.
[407] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.79.
[408] *The National Highway Traffic Safety Administration reports that men cause an average of 6.1 million accidents per year in the US, and women cause 4.4 million accidents per year.* Source: *Who causes more car accidents: Men or Women?* Malman Law *in: https://www.malmanlaw.com/malman-law-injury-blog/who-causes-more-car-accidents-men-or-women/.*
[409] *(...) we are living in a world that has been designed for men because for the most part, we haven't been collecting data on women. This is the gender data gap*. (Source: Perez, C. (2020). *We Need to Close the*

discrimination, the reality is that it exacerbates the potential discrimination within algorithms since it creates additional difficulty in bias identification[410]. This occurs due to what we can denominate as social identifiers and, with these, *algorithms can discriminate on the basis of a social category, intentionally and unintentionally, even when they are not explicitly fed social category data*[411]. Social identifiers can be understood by algorithms through correlations in historical data even if they are not present expressly[412]. As such, the mere erasure of sensitive categories (*i.e.*, suspect classifications) does not prevent the perpetuation of discrimination.

Although able to perpetuate bias, we must give the proper ennoblement to patterns since through them we can achieve three things which aid in the knowledge of the world and the functioning of AI mechanisms:

- *Patterns across people make prediction possible.*
- *Patterns make imputation of missing data possible.*
- *Proxy variables can pinpoint variables that are not represented in the data set*[413].

Circling back to correlations and patterns which occur in ML and AI algorithms, and even when suspect classification characteristics are removed, much of the data used is still prejudiced since *data about race, ethnicity, immigration status, and gender identity are encoded in many other aspects of a person's life*[414]. In sum, *algorithms for the most part are reflecting back the bias in our own world*[415][416]. O'Neil has dubbed these ML and

Gender Data Gap By Including Women in our Algorithms. Time, *in*: https://time.com/collection/davos-2020/5764698/gender-data-gap/).

[410] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.78.

[411] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.88.

[412] Example of Facebook which does not directly ask users for their race or ethnicity but through a proxy that analyzes their interactions can estimate what is denominated by them as a "*Multicultural Affinity*" which then grants advertisers to be able to target their ads. (Source: Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.90).

[413] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.84.

[414] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P.82.

[415] Shah, H. (2018). *Algorithmic accountability*. Philosophical Transactions, Royal Society Publishing. P.2.

[416] Matthews, J. (2020). *Patterns and Antipatterns, Principles, and Pitfalls: Accountability and Transparency in Artificial Intelligence.* AI Magazine. Association for the Advancement of Artificial Intelligence. P. 84.

AI algorithms as "weapons of math destruction"[417] given this perpetuation of prejudice due to algorithmic bias[418][419]. Thus, navigating AI and ML within anti-discrimination and transparency provisions needs to be on the forefront of the debate to ensure bias does not ensue in regulated activities.

Now that the building blocks of prejudice in data and consequently in the outputs of AI and ML algorithms are laid down, the accountability for these actions needs to be discussed since *human influences* are *embedded into algorithms, such as criteria choices, training data, semantics, and interpretation*[420][421].

On 2017, the Association for Computing Machinery delivered a statement establishing the following seven principles as the key for algorithmic transparency and accountability: *(i) Awareness*; *(ii) Access and redress*; *(iii) Accountability*; *(iv) Explanation*; *(v) Data Provenance*; *(vi) Auditability*; *(vii) Validation and Testing*[422].

With connection to this issue, some scholars have argued for more transparency in the design of these algorithms[423] whilst others have argued this to be insufficient[424], backing instead the thesis of auditing algorithms[425]. Transparency advocates tend to support the principle of a system which is transparent - both the inputs and the functioning of it[426]. Numerous methods for this achievement are put forward such as *(i) analysis of*

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[417] O'Neil, C. (2016). *Weapons of math destruction: how big data increases inequality and threatens democracy*. Crown New York.
[418] *Idem.*
[419] *(...) algorithmic decision-making can potentially entail corruption risks due to the discretion of those who design these systems and the data with which the algorithms are trained. Both of these elements can result in systems that do not serve the common good, but rather perpetuate generational inequalities, prejudice, private gain and other exclusionary practices.* (Source: Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.9).
[420] Diakopoulos, N. (2013). *Algorithmic Accountability Reporting: on the investigation of black boxes.* Tow Center for Digital Journalism. Columbia Journalism School. P. 10.
[421] Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.5.
[422] Association for Computing Machinery (2017). *Statement on Algorithmic Transparency and Accountability*. US Public Policy Council (USACM). P.2.
[423] Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.10;
[424] Kroll, J. A., Huey, J., Barocas, S., Felten, E. W., Reidenberg, J. R., Robinson, D. G., & Yu, H. (2017). *ACCOUNTABLE ALGORITHMS*. University of Pennsylvania Law Review, 165(3). P.662.
[425] Sandvig, C., Hamilton, K., Karahalios, K, Langbord, C. (2014). *Auditing Algorithms: Research Methods for Detecting Discrimination on Internet* Platforms. Paper presented to "*Data and Discrimination: Converting Critical Concerns into Productive Inquiry*," a preconference at the 64th Annual Meeting of the International Communication Association; O'Neil Risk Consulting & Algorithmic Accountability (ORCAA). *How do you know your AI is working well for everyone? in: https://orcaarisk.com/.*
[426] Diakopoulos, N. (2013). *Algorithmic Accountability Reporting: on the investigation of black boxes.* Tow Center for Digital Journalism. Columbia Journalism School. P. 11 and following; Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.10.

input data, (ii) statistical analysis of outcomes, (iii) sensitivity testing[427]. Additionally, *while there is a natural inclination to demand greater algorithmic transparency, the literature indicates there is no clear linear relationship between transparency* and *accountability*[428]. As such, transparency as of itself does not seem sufficient. Given the complexity associated with algorithms, we argue that explainability is a principle which seems to encompass more of what is needed within the sector[429]. However, *the level and type of explainability also depends on the model's use*[430]. In particular, and given EU legislation[431], insurers need to make the mechanisms which made them arrive to a decision both transparent and understandable [432].

For the second thesis, auditing algorithms as a means to ensure a gold standard within these models is the thesis supported in herein. Specialized consulting firms such as O'Neil Risk Consulting & Algorithmic Accountability have established a model for algorithmic audit which focuses on: *(i)* its Ethical Matrix framework; *(ii)* identification of priority-issues in connection with fairness and performance; *(iii)* drafts recommendations in relation to risks; and *(iv)* produces an algorithmic audit report[433].

It is our stance that it would be adequate for insurers (alongside other entities which work closely with these algorithms) to be mandated to give, perhaps annual audits, to ensure compliance with the tight regulations within EU and its anti-discrimination attentive legal framework, and for no institutional and statistical discrimination being unknowingly perpetuated.

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[427] Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.12.

[428] Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.10.

[429] EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P. 39; EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review.* Publications Office of the European Union. P.7.

[430] Lael, B. (2020). *Speech by Governor Brainard on supporting responsible use of AI and equitable outcomes in financial services*. Federal Reserve Board, *in*: https://www.federalreserve.gov/newsevents/speech/brainard20210112a.htm.

[431] For instance, the "right to explanation" under articles 13 to 15 of the GDPR (Source: Selbst, A., Powles, J. (2017). *Meaningful information and the right to explanation*. International Data Privacy Law, Volume 7, Issue 4.)

[432] OECD (2021). *Artificial Intelligence, Machine Learning and Big Data in Finance: Opportunities, Challenges, and Implications for Policy Markers.* P.42.

[433] ; O'Neil Risk Consulting & Algorithmic Accountability (ORCAA). *How do you know your AI is working well for everyone? in: https://orcaarisk.com/.*

In sum, should an insurance company choose to pursue the technological road and take advantage of the *datafied* society we now live in, it must also ensure it has in place a continuous self-assessment (or even external assessment through audits) of the mechanisms it's using.

§3. Can the RTBF for cancer survivors truly be implemented within algorithms?

Taking into account the existence of correlation, patterns and social identifiers in AI and ML algorithms which are being employed within Insurance[434] the question of the viability of a right to be forgotten for cancer survivors remains.

On the consumer side, given the existence of patterns and correlations, even if specific data is erased there is still a potential risk of discriminating cancer survivors based on patterns of, for example, health related characteristics which - although not directly - are able to infer the existence of problematic triggers[435] that, in turn can reject or increase an individual's premium. In addition to these correlations, uncertainty bias is another challenge to overcome and is verified when one group is under represented in the sample, and, taking into account the risk aversion characteristic of algorithms, it will favor decisions which its more confident on[436].

On the other side of the spectrum, questions are raised regarding *(i)* the efficiency of deletion (*i.e.., how to delete individual data points without retraining the model*)[437], *(ii)* the removal of data without any compromise to the model accuracy[438], and *(iii)* the impact deletion has on explanation frameworks[439].

Alternative methods to the model retraining must be adopted so as to balance the duty to comply with the right to be forgotten by insurers with the efficiency of these

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[434] EIOPA (2019). *Big Data Analytics in motor and health insurance: a thematic review*. Publications Office of the European Union. P.15 and following; OECD (2020). *The impact of Big Data and Artificial Intelligence (AI) in the Insurance Sector*. P.24 and following*;* EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance*. Publications Office of the European Union. P.9 and following.

[435] (...) *it is widely acknowledged that simply removing certain variables from a model does not ensure predictions that are, in effect, uncorrelated to those variables*. (Source: Goodman, B., Flaxman, S. (2017). *European Union Regulations on Algorithmic Decision Making and a "Right to Explanation"*. AI Magazine. Association for the Advancement of Artificial Intelligence. P. 53).

[436] Goodman, B., Flaxman, S. (2017). *European Union Regulations on Algorithmic Decision Making and a "Right to Explanation"*. AI Magazine. Association for the Advancement of Artificial Intelligence. P. 54.

[437] Pawelczyk, M., Leeman, T., Biega, A., Kasneci, G. (2023). *On the Trade-off between Actionable Explanations and the Right to be Forgotten*. Published as a conference paper at ICLR 2023. P.1.

[438] Pawelczyk, M., Leeman, T., Biega, A., Kasneci, G. (2023). *On the Trade-off between Actionable Explanations and the Right to be Forgotten*. Published as a conference paper at ICLR 2023. P.1-2.

[439] Pawelczyk, M., Leeman, T., Biega, A., Kasneci, G. (2023). *On the Trade-off between Actionable Explanations and the Right to be Forgotten*. Published as a conference paper at ICLR 2023. P.2.

algorithms in the sector. Scholars such as Golatkar, Achille and Soatto have proposed *a method for "scrubbing" the weights clean of information about a particular set of training data*[440]. Alternatively, and as a consequence of the complexity of erasing data in ML algorithms[441], scholars argue that to achieve a complete erasure of data, *data controllers and processors must (1) continuously trace all the digital locations where the relevant data, including the derivative data is archived, and (2) individually evaluate whether the data should be deleted or de-indexed within a reasonable period of time*[442].

Other methods used are functional encryption, anonymization, pseudonymization and trusted environments but they still remain unpractical given the reduction of quality and/or the impact in costs[443].

In sum, a number of methods are put forward as a means to implement this RTBF in practice. Nevertheless, given the challenges we have presented on both sides - consumer and insurer - the applicability of this right is still not flawless and remains to be perfected.

§4. Solution or a step backwards?

AI and ML algorithms, in this *datafied* society, are the present and the future[444], with *the challenge for regulators and supervisors alike* residing *in allowing the European insurance sector to take advantage of the innovation offered by digital economy, whilst, at the same time, protecting the interests of consumers and citizens*[445].

To tackle these issues within the use of Big Data and algorithms and to allow, at the same time, for the RTBF (for cancer survivors in this dissertation, but also for other classifications in the wider sense) to be implemented, the EU has implemented numerous rules to protect citizens such as,

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[440] Golatkar, A., Achille, A., Soatto, S. (2020). *Eternal Sunshine of the Spotless Net: Selective Forgetting in Deep Networks.* Proceedings of the IEEE/CVF Conference on Computer Vision and Pattern Recognition. P.1.

[441] Zhao, Z. (2022). *The Application of the Right to be Forgotten in the Machine Learning Context: From the Perspective of European Laws.* Catholic University Journal of Law and Technology, Volume 31, Issue 1. P.94.

[442] *Idem*.

[443] Malle, B., Kieseberg, P., Schrittwieser, S., Holzinger, A. (2016). *Privacy Aware Machine Learning and the "Right to be Forgotten".* ERCIM NEWS, Number 107, Special theme: Machine Learning. P.23.

[444]EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P.4.

[445] EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P.11.

(i) Requirement for clear and freely given consent for companies to process data of citizens (Article 7 of the GDPR);

(ii) Right to explanation upon consumer request to the data controller (article 13 to article 15 of the GDPR);

(iii) Transparency obligations with regard to information provided to consumers[446], in particular, it must be *concise, transparent, intelligible and easily accessible form using clear and plain language*[447]*;*

(iv) Right of a data subject to object to an automated decision which is based solely on automated processing (article 21 of the GDPR); and

(v) Duty of insurance distributors to act honestly, fairly and professionally when selling services and products with the obligation to act in the best interests of consumers (article 17 of the IDD[448])[449].

Notwithstanding, scholars have come forward with the thesis that *the EU official goal of data protection is to promote the data analysis and to create a considerable amount of revenue from it*[450].

If we circle back and consider all the points established within this Chapter, the following four main ideas are supported in this dissertation:

(i) Transparency by itself is not enough[451]. Explainability is the more adequate criteria for the standard to be applied to algorithms[452];

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[446] Additional transparency requirements for insurance providers *per se* can be found in the Solvency II Directive (Directive 2009/138/EC of the European Parliament and of the Council of 25 November 2009 *on the taking-up and pursuit of the business of Insurance and Reinsurance).*

[447] Article 12 (1) of Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 *on the protection of natural persons with regard to the processing of personal data and on the free movement of such data*, and repealing Directive 95/46/EC (General Data Protection Regulation).

[448] Article 17 of the Directive (EU) 2016/97 of the European Parliament and of the Council, of 20 January 2016, *on insurance distribution* (IDD).

[449] *Financial service providers are obliged to act honestly and fairly when using Big Data to create services and products and also when using big data to sell those services and products to you.* (Source: EIOPA. *Use of Big Data by financial institutions, in*: https://register.eiopa.europa.eu/Publications/Other%20Documents/Big%20Data%20Factsheet-final.pdf).

[450] Zhao, Z. (2022). *The Application of the Right to be Forgotten in the Machine Learning Context: From the Perspective of European Laws.* Catholic University Journal of Law and Technology, Volume 31, Issue 1. P.90.

[451] Kroll, J. A., Huey, J., Barocas, S., Felten, E. W., Reidenberg, J. R., Robinson, D. G., & Yu, H. (2017). *ACCOUNTABLE ALGORITHMS*. University of Pennsylvania Law Review, 165(3). P.658.

[452] EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P.43.

(ii) Auditing algorithms (external audits)[453] is an additional step to ensure effective compliance of insurers with applicable regulation, namely but not limiting, anti-discrimination provisions[454] and erasure of prejudice in data[455]; and

(iii) The benefits arising to insurers and consumers out of the use of Big Data and its applications in Artificial Intelligence and Machine Learning are considerable[456] thus the challenges which occur due to consumer protection and anti-discrimination must be promptly answered so as to allow for an even deeper development of this sector.

As a final note, a reinforcement must be made on the necessity of insurance companies to integrate a continuous assessment on the data they input onto algorithms, in particular, given the new provision which enacts a RTBF for cancer survivors across the EU in the access to insurance. For a RTBF to be enacted and for cancer survivors to not face discrimination - directly or indirectly - when subscribing an insurance policy, all the correlations and patterns must be duly erased so the application of a RTBF can be, in practice, what intends in theory.

[453] Williams, B. A., Brooks, C. F., Shmargad, Y. (2018). *How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.* Journal of Information Policy, 8. P. 108.

[454] For instance, article 15 of the Portuguese Decree-Law no. 72/2008, April 16th 2008 (*Regime Jurídico do Contrato de Seguro*) establishes a general prohibition of discrimination in connection with insurance contracts.

[455] Kossow, N., Windwehr, S., Jenkins, M. (2021). *Algorithmic transparency and accountability*. Transparency International. P.9.

[456] EIOPA (2021). *Artificial Intelligence Governance Principles: Towards ethical and trustworthy artificial intelligence in the European insurance sector. A report from EIOPA's Consultative Expert Group on Digital Ethics in Insurance.* Publications Office of the European Union. P. 9 and following.

Concluding Remarks

Cancer survivorship is steadily increasing[457], thus highlighting the phenomenon of what we have presented as *financial toxicity*[458]. This toxicity presents itself in the Insurance sector in particular due to its model being rooted in statistical discrimination[459].

This dissertation begins by presenting a narrower scope by focusing on the issue of statistical discrimination and financial consequences associated with cancer survivorship, mainly given the framework of the European Union as of today. However, as one can grasp from the body of this dissertation, the core issue discussed is broader.

The EU is attempting to move towards a non-discriminating society through its legislative acts[460], with the implementation of the RTBF for cancer survivors in the access to insurance products for consumer credit agreements solely as the latest conquest[461]. This legislative trend poses the following question underlying this entire dissertation: *What is the line that should be drawn between the non-discrimination principle and the existence of private insurance?*

In an attempt to answer this central question, three areas were brought upon: *(i)* legal, *(ii)* ethical, and *(iii)* technological. Through the aid of these areas, the thesis of necessity of balancing the ways of private insurance in an ever-developing society - aware of its inherent prejudice[462] - was put forward. We argue that, even though measures such as the RTBF for cancer survivors in the access to insurance for consumer credit agreements are beneficial, and one could even argue they should go further to fully address the issue and extend its scope to mortgage loans, the research onto its potential dire consequences is not - as of yet - sufficient[463]. Further research is needed to determine the consequences of the enactment of this RTBF for cancer survivors and, in particular, for future developments of the non-discrimination principle at a sector level before proceeding to any further restrictions.

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[457] European Federation of Pharmaceutical Industries and Associations (EPFIA). *Comparator Report Cancer in Europe*. P.3.
[458] Pak, TY., Kim, H. and Kim, K.T. (2020). The long-term effects of cancer survivorship on household assets. Health Econ Rev 10, 2. P.2.
[459] Rego, M. (2022). *Discrimination Bans and Insurance Law*. Insurance and Human Rights, AIDA Europe. Research Series on Insurance Law and Regulation 5. P.34.
[460] *E.g.*, Council Directive 2004/113/EC of 13 December 2004 *implementing the principle of equal treatment between men and women in the access to and supply of goods and services* ("Gender Directive").
[461] Article 14 paragraph 4 of the Position of the European Parliament adopted at first reading on 12 September 2023 with a view to the adoption of Directive (EU) 2023/... of the European Parliament and of the Council *on credit agreements for consumers* and repealing Directive 2008/48/EC.
[462] Barocas, S., Selbst, A. D. (2016). *Big Data's Disparate Impact*. 104 California Law Review 671. P.674.
[463] Insurance Europe (2021). *The EC Beating Cancer Plan – reflections on the right to be forgotten.* P.7.

Given the long-term maturity of the type of policies we are considering (*i.e.*, life insurance), there are clear limitations on a short-term analysis of the potential side effects of RTBF[464]. Nevertheless, a report by Munich Re[465] was able to support the feasibility of a RTBF as it is initially legislated, without prejudice to being restricted solely to cancer and a remission period of 10 years[466].

Alongside this research limitation, an added hurdle is brought forward by the use of Big Data in the implementation of this anti-discrimination provisions. Data is inherently biased if collected from a prejudiced society like ours, and inputted onto machine algorithms - like the ones becoming increasingly used within Insurance[467] - without any filtering and auditing of its quality[468].

Following the enumeration of all these obstacles, we can put forward our thesis which focuses on three main ideas: *(i)* statistical discrimination is not inherently wrong, nor should it be made illegal, since its process and purpose is independent from discrimination *stricto sensu*[469]; *(ii)* the benefits which arise from the insurance sector and its economic value[470] must be taken into account since they also grant financial stability to citizens[471]; and *(iii)* a maximization of insurance can be achieved through machine learning if strict accountability provisions are put in place to ensure quality of data in order to overcome inherent prejudice embedded in data[472].

As such, the line that must be drawn is the line that can adequately reach the ideal of an egalitarian society without foregoing the existence of private insurance as a mechanism for the financial stability of citizens. In sum, we argue for alternatives to absolute prohibitions to insurers of apparent discriminating factors - characterized as actuarial factors for insurance purposes[473] - such as national agreements between States

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[464] Insurance Europe (2022). *Risk-based underwriting: Frequently asked questions on the right to be forgotten*. P.1.
[465] Munich RE (2023). *The "Right to be forgotten" and its impact on life insurance business. An assessment from an insurance medicine perspective.* P.6.
[466] *Idem.*
[467] Insurance Europe (2021). *AI in the insurance sector*. P.1.
[468] Please refer to Chapter V of this dissertation.
[469] Schauer, F. *Statistical (and non-statistical) discrimination, in* Lippert-Rasmussen, K. (2017). *The Routledge handbook of the ethics of discrimination*. Routledge, p.43.
[470] Insurance Europe. *Value of Insurance, in: https://insuranceeurope.eu/value-of-insurance.*
[471] European Central Bank (2009). *The importance of insurance companies for financial stability*. ECB Financial Stability Review. P.165-166.
[472] Bechtold, E., Ferreira, R. (Zurich Insurance Group), Azafrani, R., Bucher, C., Klebôn, F., Madani, S. (Microsoft Corp.) (2021). *Artificial Intelligence and Algorithmic Liability: A techonology and risk engineering perspective from Zurich Insurance Group and Microsoft Corp*. White Paper July 2021. P.8 and following.
[473] Rego, M. (2022). *Discrimination Bans and Insurance Law*. Insurance and Human Rights, AIDA Europe. Research Series on Insurance Law and Regulation 5. P.3.

and stakeholders (*i.e.*, insurance and reinsurance companies), or investment in research and development of machine learning algorithms which can truly erase correlations and patterns present in data and in the subsequent trained models. Only through measures such as these can we attempt to preserve private insurance and its key role in the functioning of society[474].

[474] *Social insurance is widely used to redistribute wealth and income from the rich to the poor. While private insurance is not designed to address social inequality, its relevance for income and wealth distribution is obvious (...)* (Source: Schanz, K. (2020). *The role of insurance in mitigating social inequality*. The Geneva Association. P. 7).

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