

## Genetic ‘Risk Carriers’ and Lifestyle ‘Risk Takers’. Which Risks Deserve our Legal Protection in Insurance?

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**Abstract** Over the past years, one of the most contentious topics in policy debates on genetics has been the use of genetic testing in insurance. In the rush to confront concerns about potential abuses of genetic information, most countries throughout Europe and the US have enacted genetics-specific legislation for insurance. Drawing on current debates on the pros and cons of a genetics-specific legislative approach, this article offers empirical insight into how such legislation works out in insurance practice. To this end, ethnographic fieldwork was done in the underwriting departments of Belgian insurance companies. Belgium was one of the first European countries introducing genetics-specific legislation in insurance. Although this approach does not allow us to speak in terms of ‘the causal effects of the law’, it enables us to point to some developments in insurance practice that are quite different than the law’s original intentions. It will not only become clear that the Belgian genetics-specific legislation does not offer adequate solutions to the underlying issues it was intended for. We will also show that, while the legislation’s focus has been on the inadmissibility of genetic discrimination, at the same time differences are made in the insurance appraisal *within* the group of the asymptomatic ill. In other words, by giving exclusive legal protection to the group of genetic risks, other *non*-genetic risk groups are unintendedly being under-protected. From a policy point of view, studying genetics-specific legislation is especially valuable because it forces us to return to first principles: Which risks deserve our legal protection in insurance? Who do we declare our solidarity with?

**Keywords** Genetics · Insurance · Discrimination · Genetic privacy law · Solidarity · Health care

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Over the past decade the potential of genetics for understanding and controlling health and disease in radically new ways has been widely discussed. This molecular genetics allows us to understand which genes contribute to which diseases. Scientists say that currently there are about four thousand, generally rare diseases—like Huntington’s disease, cystic fibrosis, and Duchenne muscular dystrophy—with so-called genetic markers that can identify people who are at risk of contracting them. That way, new intermediate or in-between health categories have emerged where individuals are identified as “genetically at risk” [33], derived from risk probabilities. Like other predictive risks (e.g. lifestyle), these “genetically at risk” are asymptotically ill, that is, they inhabit an intermediate health state as neither necessarily healthy nor already ill. Experts claim that this knowledge of genetic predisposition heralds the prospect of shifting medical practice from its emphasis on diagnosis and treatment to an exciting new era of prediction. For example, the European Commission foresees a genetic revolution in health care marked by a move towards prevention rather than cure [6, p. 6]. Increased accuracy of genetic risk calculation combined with cheaper and faster genetic detection will also provide a major incentive to apply genetic testing outside medical practice, as for example in insurance practice.

The use of genetic testing by insurance has met with considerable public opposition. While insurers invoke the mutuality principle underlying the private insurance contract and the principle of adverse selection to justify their access to genetic information, patients groups and the public in general invoke the risk of creating a “genetic underclass.” Other arguments include confidentiality doubts, testing deterrence and genetic privacy. Regarding the respect for privacy, it is argued that genetic information is too private to be dealt with by third parties. These issues have been the thrust of ongoing policy debates in the public realm and parliaments in Europe and the US. In recent years, the most prominent strategy to deal with the issue has been the enactment of legislation prohibiting “genetic discrimination.” These laws emphasize genetic information as distinct from other medical information and attempt to prioritize interests in genetic information. A thorough description of the legislation itself can be found elsewhere, see e.g. [26, 28, 30, 35, 47]. To summarize here, currently most European countries have passed some form of genetic discrimination law since 1990 while in the US most states have enacted laws dealing with “genetic” discrimination, “genetic” privacy and “genetic testing” in health or life insurance.

There has been a great deal written on the pros and cons of such genetics-specific legislation [1, 14, 31, 38, 40]. Proponents often make the “genetic exceptionalism” claim, which says, roughly, that genetic test information is *unique*, that is, inherently or qualitatively “sufficiently different from other kinds of health-related information that it deserves special protection or other exceptional measures” [31, p. 61]. A growing number of authors have cautioned however against this “genetic exceptionalism,” arguing that such an approach promotes a “genetic determinism” or “geneticization” [16, 18, 19, 25, 32, 49]. Coined by Lippman in the early 1990s, “geneticization” describes “the growing tendency to distinguish people one from another on the basis of genetics; to define most disorder, behaviours, and physiological variations a wholly or in part genetic in origin” (Lippman, in: [13, p. 876]). Rather than diminishing the power of genetics, they say, the exceptionalist argument enhances “the DNA mystique” and the reduction of our identities and life chances to our genes. Rapp, in her ethnographic study on amniocentesis, finds genetic exceptionalism, or “geneticization,” and genetic discrimination closely linked: “Geneticization is an historically consonant ideology linking individual attributes and social problems as if they could be effectively reshaped or eliminated only in the realm of biomedicine now reduced to genetic diagnosis” [37, p. 215]. For Rapp, genetic discrimination laws follow such a view, in which

human problems are attributed to genetic differentiation. In the same line, Knoppers has claimed that singling out the genetically disadvantaged may in effect prove “more stigmatizing than the original condition” [20, p. 45]. She has argued strongly against incremental, genetics-specific policy interventions like genetics-specific legislation. Moreover, the latter may have unintended consequences. Rothstein [39] for example argues that genetics-specific laws represent poor public policy. While they offer little or no substantive protection, they may even be counter-productive.

Till now however, these genetics-specific laws have remained untested in the courts and their practical effects have been unclear. In a recent article, Everett [10] suggested for anthropological research to analyse the effects of genetics-specific legislation in practice. In this article, we will make a start with this. In an attempt to contribute to the genetics and insurance debates, we have explored this from an empirical sociological angle—by studying the insurance world *from the inside*. To this end, we have been doing qualitative fieldwork in Belgian insurance companies. Belgium was one of the first European countries introducing a legal prohibition on the use of genetics in insurance in the Belgian Insurance Law (1992) [48]. Consequently, studying insurance practice in Belgium since the passing of this law provides us with relevant insight into how genetics-specific legislation works out for insurance practice.

Although this approach does not allow us to speak in terms of ‘the causal effects of the law,’ it enables us to point to some developments in Belgian insurance practice that are quite different than the law’s original intentions. In doing so, we draw on contributions from sociology of law [7, 41] that pay attention for the unintended consequences of legislation. Laws do not dictate their own application but may always introduce new elements in an existing practice. Thereby, they—unintended or unforeseen—reorganise these practices, reorder activities or redefine responsibilities [3]. At the same time, these practices have their existing orderings that, in their turn, may have effects on legislations. To study this mutual relationship between law and society, the concept of “socio-technique” [24], derived from STS studies, has been fruitful. In science and technology studies, it is argued that society is not just an application field of scientific knowledge. Rather, for science to be able to “work” in society, scientific knowledge both embeds and is embedded in social identities, institutions, representations and discourses. The concept of “socio-technique” expresses this relationship between technology and society. In other words, scientific knowledge and society are produced simultaneously, or “co-produced” [17]. By considering legislation here as a “socio-technique” then, we want to encourage a balanced approach to the relationships among legislation and the social practices where it is introduced, as in our case, the insurance practice.

That way, it will not only become clear that the Belgian genetics-specific legislation does not offer adequate solutions to the underlying issues it was intended for. We will also show that while the legislation’s focus has been on the legal and moral impermissibility of genetic discrimination, at the same time differences have also been made in the insurance appraisal *within* the group of the asymptomatic ill. Persons affected by genetic risks are distinguished from those exposed to non-genetic risks. As such, the specific focus of legislators on genetics unintentionally isolates other forms of discrimination, plays them off against one another and increases the social acceptance of practices of *non*-genetic discrimination. In this manner, “genetic exceptionalism,” as expressed in current genetics-specific legislations, is likely to reshape the distribution of responsibilities and the way we consider the criteria for solidarity with the sick. From a policy point of view, studying genetics-specific legislation is especially valuable because it forces us to return to first principles: Which risks deserve our legal protection? Who do we attribute the right to insurance? But first we will explain our methodological approach in more detail.

## Following Insurance Practice in An Era of Genetics-Specific Legislation

To study genetics-specific legislation in insurance, it was not sufficient to focus on the end products – for example, by performing a survey of genetic patients' insurance rates. To get insight on the *co-production* of genetics-specific legislation and insurance, we needed an ethnographic approach. Ethnographic inquiry can be attentive to the internal messiness of any organisation; to the mix-up of all kinds of considerations; to the ways in which institutions contain elements that are not always part of their external conceptions; in short, it can be alert to the specificity of the institution. Moreover, because of its typical inside-perspective, it can be useful to trace the rather *veiled* aspects of institutions or practices. This aspect proved very valuable to us, because while studying a legal ban in insurance, we were in fact tracing for something that was *not even there*, so to say.

In doing so, we started from the version of 'ethnography' that is theoretically aligned with Actor Network Theory (ANT). The point of this approach is to "follow the actors" and to unravel the complex chains of connection of actors constituting the 'thing' one is studying [22]. The material presented here is part of ongoing research on the construction of risks in life insurance [46]. The central focus is on insurers' assemblage work and the considerations involved in transforming applicants into insurance risks. Fieldwork was done by the first author and included observations in the underwriting departments of two Belgian insurance companies.<sup>1</sup> Here underwriters align an insurance premium to an applicant, reflecting his or her mortality risk. Applicants are classified in different risk groups ('standard rate,' 'substandard rate' or 'exclusion'). The medical information is collected from different sources. In principal, all applicants must at least fill in a medical questionnaire. Depending on the applicant's profile, extra information may also be supplied via GP reports, a medical examination by an expert or lab tests.

We started with some introductory interviews with each company's department head, the medical advisors and some underwriters in order to get a first-hand look at the process of underwriting. After a while, we moved on to observation. By following the underwriters, observing their activities and asking them about their present activities, we primarily focused on investigating what underwriters *do*.<sup>2</sup> This implied looking at the "inscription devices" [23] they use in making reference to insurance risks and that help them in coming to closure, such as medical questionnaires, reinsurance handbooks, computer programs and internal policy guidelines. We also opted to study interests and relevant connections within the whole company, all having one or another link with underwriting, such as the claims, actuarial and marketing departments and corporate management. Finally, we explored the significance of the various sites linked to medical underwriting. We collected written sources and held in-depth interviews with several key informants from the national and international insurance fields. We also decided to do fieldwork in two reinsurance companies.<sup>3</sup> Reinsurance companies are an active agent in underwriting medical risks. The role of the reinsurance

<sup>1</sup>The first site was an international bank assurance company. Since this company belonged to the market leaders in Belgian insurance, we opted as a second site for a more average market player. We thought it fruitful to focus as a second case on an insurance company with a different profile in terms of its economic policy and market position. Fieldwork in these companies was done in the period 2001–2004. In order to safeguard anonymity, these insurance companies will be referred to as 'case1' and 'case2'.

<sup>2</sup>For an argument in favour of shifting the attention from thinking to practice, see, for example, Latour [21]. Originally, this perspective on 'do-ing' was elaborated in sociology by Garfinkel [12]. It refers to "the ways in which ordinary people ('ethno') methodically construct their social world".

<sup>3</sup>We studied two reinsurance companies that are ranked in the top ten of the Standard and Poor's AA ranking. Fieldwork in these companies was done in the period 2004–2006.

company is to take on the share of large risks that the insurance company cannot carry alone.<sup>4</sup> This allowed us to elucidate various relevant issues, including the general details of the Belgian and European insurance market, the background of the actors involved in medical underwriting (professional organisations of actuaries, medical advisors and insurers), and the institutional context in which private insurance operates. The material has been analysed using the software program Nvivo.

One major strategy we relied on was following an insurance risk “trajectory” [44] from the initial application to the final risk assessment. This approach enabled us to localise all sorts of considerations that are woven as a fine thread through the underwriting practice, along the different phases in the underwriting process. In doing so, we want to outline the intermingling of commercial, ethical, administrative and other considerations in insurance practice. By drawing on contributions from sociology of insurance [2, 8, 9], we analyse insurance as a “normative technology.” This means first of all that insurance institutions are dovetailing with judgements originating in, for example, epidemiology, clinical medicine, legislation, or public opinion [43]. At the same time, insurance institutions do not (always) simply or passively reflect wider societal visions. Rather, they actively may produce a whole range of moral duties and cultural values, for example on what counts as ‘normal lives’ in insurance. The construction work of underwriting underscores that the insurance assessment of human bodies is a profoundly *political* activity [46]. One of these considerations then may have to do with legislation. As we will demonstrate here, regulatory policy initiatives in the context of genetics can particularly mark insurance practice. So how did Belgian genetics-specific legislation work out in insurance practice? In the next sections, we will explore how insurers assessed genetic, resp. non-genetic predictive risks.

### Slipping Through the Legislative Net

As indicated above, the use of genetic information in insurance was very much determined by Belgian legislation [48]. This law was passed in 1992, while art. 5 and 95 particularly address the use of genetic information, stating that “the medical examination (...) may only depend on the present health condition of the candidate and not on genetic research techniques capable of determining future state of health” (art. 95) and “genetic data cannot be transmitted” (art. 5). Legal commentary (after the law’s enactment) was quite critical of this, and pointed to a lacuna for the law’s interpretation. For example, the law offered no clear definitions of “genetic data” [11, p. 28] or of “genetic research techniques” [34, p. 216]. Consequently, it is unclear whether the Belgian legislator prohibits the use of family history or genetic information from other medical tests, such as blood analysis. How did this turn out in insurance practice then?

Notwithstanding the legal ban on genetic data, the underwriters in our fieldwork sometimes encountered genetic test results or genetic information (on, for example, Down syndrome, cystic fibrosis, Huntington’s disease). In these cases, the underwriting guidelines instructed them to solicit extra advice from the reinsurance company.

Int: Have you encountered files with information on, for example, cystic fibrosis?

<sup>4</sup>In other words, whereas the insurance company is the direct insurer of an individual, the company itself can spread its risks by transferring all or part of those risks to one or more reinsurance companies. In reinsurance jargon, the insurance company is referred to as the “ceding company”. Thereby, at the beginning of each year, the insurance company enters in a “treaty” or contract with a reinsurance company, in which the terms under which the risks covered by the treaty are ceded and accepted.

K: Yes, I've seen that a couple of times. In most of these cases, they were excluded from insurance.

Int: And how did you trace that information?

K: These people had put the genetic test results down in the questionnaire.

Int: And how do you proceed then?

K: In these cases, we usually check that information with control test results from the attending physician, to find out whether he has developed the disease already, whether there are already some symptoms present. And if so, then we rate accordingly. And if no symptoms are available yet, then we will send the file to X [reinsurance company], because for cases like that, that's quite delicate to us, you see. (Case2, underwriter K)

Furthermore, since Belgian law does *not explicitly* prohibit the use of a family history, the two insurance companies we studied asked for family history data in their medical questionnaire, while the underwriters could further deduce information on genetic and familial risks from reports presented by the attending physician or specialist. However, our respondents proved to be reticent in taking this information into account. For one thing, they did not consider it necessary to send back medical questionnaires where the responses about family history had not or had been incompletely filled in. Moreover, this family information was only meant to confirm or negate data on diseases from which the applicant himself was already suffering. As in the case of a person with cardiovascular complaints:

If we establish symptoms for him that have to do with heart problems, we also consider the family history. It is possible, then, [grabs guidelines] where heart infarcts have at least occurred in the family, that we have to charge a higher rate. But if a person indicates that his father suffered from a heart affliction, while this person has no such problems at this point, we do not charge a higher premium. (Case1, underwriter E)

The applicant's current pathology determines whether or not family history should play a role. A *tainted* family history might raise the average already higher premium for a specific disorder (60% instead of 50%). For instance, as one underwriter explained with respect to familial hypercholesterolemia (FH):

When the applicant indicates a family history of FH but he himself has no raised LDL cholesterol level at this point, he will be accepted against a standard premium. But if he proves to have high cholesterol levels and if we also can prove that there are specific relevant conditions in the family, these things are added up and he will end up paying a premium that is slightly higher than the average raised premium for FH. And if he discloses no family history and there are also high cholesterol levels, he will end up with the average higher premium for cholesterol. (Case1, underwriter P)

The above then illustrates that the Belgian prohibition on genetic information in insurance does not serve its intended purpose: some information on genetic data still trickles through. Family history is still used in underwriting as confirming information in rating other risk factors of applicants. As such, the law has not resolved all underlying aspects of the problem, partly by not giving clear definitions on "genetic data." However, this family history only plays a limited role, in confirming other risk factors from the applicant, thereby providing context information. So insurers make no distinction between applicants with a good or bad family history *per se*; these applicants are not penalized just because of their family histories.<sup>5</sup> A family history of disease does not automatically make a person a high risk.

<sup>5</sup> Persons with a family history of Huntington's disease, however, were an exception.

## Beyond the Reach of the Law

How did Belgian insurers deal with predictive *lifestyle* risks? In the course of our fieldwork it became clear that underwriters pay a lot of attention to applicants' lifestyle traits. In checking the information on policy applicants, for instance, they indicate that they mainly encounter "lifestyle risks" or "diseases of civilisation":

Recently we have noticed a lot of depression. And also diseases of luxury such as increased liver values, high blood pressure, increased blood sugar and so on. All this has to do with. . . stress and poor lifestyle habits. These are all things, it seems to me, that can be avoided, which is too bad in a way. (Case1, underwriter E)

The instruments and forms used to request this information also mirror this attention to lifestyle. The medical questionnaire has a separate rubric devoted to questions on weight, blood pressure, alcohol use, smoking behaviour and drug use. Its heading, "major information," has a grey frame to emphasise the rubric's significance. During our observations it became clear that the underwriters attach a great deal of importance to the responses in this rubric:

These questions [points to questionnaire and reads] 'weight, height, smoking behaviour and alcohol use,' we consider them carefully because to us these are major risk selection criteria. This is why we always return the questionnaire when an applicant has failed to respond to these questions. (Case1, underwriter P)

Similarly, the reinsurance guidelines on cholesterol, obesity and high blood pressure emphasise the relevance of predictive lifestyle information. Where these risk factors represent a statistically increased chance that someone will develop a particular disease, they are considered *primary* mortality risks in insurance, as independent bases for assigning a higher premium. In the case of high blood pressure, for instance, an underwriter explains:

High blood pressure is not so bad as such. You do not die from it immediately. But the heart of someone who does not pay attention to it suffers a lot, becomes larger, the muscles weaken. This is how it is with many things. There is always a chance that problems will occur later on. So to us, this is already an increased mortality risk. We have to look at the long-term effects. (Case2, underwriter R)

Aside from the use of lifestyle factors as primary mortality risks, these elements also play a role in the classification of those who are already suffering from an(other) disorder. For instance, lifestyle may play a role in *adjusting* the statistical average of higher premiums for a specific disease. By requesting additional information, via a report from the attending physician or an examination by a medical expert, elements come to light on the specific *circumstances* of the disease. These are taken into account as prognostic factors ( $\pm$ ) in assessing individual rates. Thus it is possible to trace personalised, clinical information, including, for instance, the beginning of an illness, periods of relapse, the course of the illness and response to treatment. In the case of high cholesterol, for example, underwriters may request readings of tests performed at various intervals in order to assess whether the person involved has regularly used his or her medication for stabilising the cholesterol level:

Here we have a letter from the GP with tests that cover the last two years, and as you can see [points to the rubric in the letter]: the blood values are fine throughout. So, I

suspect this man takes his pills regularly, because I do not notice any extremes in the values. In other words, he is controlling his illness well. This is why I will accept him against a better premium. (Case1, underwriter B)

In other words, we are dealing here with compliant behaviour on the part of the client, the patient's reliability and his or her way of dealing with the disease. The applicants' premiums are fixed on the basis of their assumed ability to take responsibility for their health.

The policy on smoking is particularly indicative of the prominent role of lifestyle in medical underwriting. Smoking is used as a risk classification factor for charging smokers a higher premium. The reinsurance statistical studies all point to smokers as a major category. A recent study indicates that in the past smoking was undervalued in premium levels, both as risk factor as such and in combination with other disorders [45, p. 4]. Moreover, smoking has of late become a factor in the calculating of the standard premium as well. If the standard premium used to be put together on the basis of non-medical elements, such as age, insured capital and sex, smoking has been added as a factor:

Before, there used to be a standard premium for smokers and non-smokers combined. And the smokers had to pay a higher premium. But in 1999, the managers said: 'Well, non-smokers clearly have a lower risk. We will reward them with a lower standard premium. (Case1, underwriter K)

In practice this means that, at the start of the application process, the standard premium is calculated on the basis of smoking. If it turns out that applicants are non-smokers, they will get a reduced standard premium. But if they smoke, the higher "standard" premium must be paid. And if they are "heavy smokers" (defined in the guidelines as: "more than 2 packages of cigarettes per day"), they have to pay an additional premium. By basing standard premiums in part on "smoking" behaviour, the policy rewards the non-smokers. When asked, the managers explained that this was a way of pointing out to clients that they are responsible for their health. Aside from being a strategy for penalising unhealthy smokers, this has also become a strategy for attracting healthy clients:

Instead of just having unhealthy people pay extra we chose the strategy of lowering the standard premium in the case of non-smoking. Thus we explicitly suggest to our clients that their lifestyles matter. If they do not smoke they are now rewarded via a reduced standard premium. It is, of course, a positive strategy to first assign a client the smokers rate and so when it turns out he doesn't smoke you can tell him that he qualifies for a reduced premium. In cases of the reverse, when someone claims to be a non-smoker but the codeine test establishes that he is in fact, a smoker, requiring us to inform him that he has to pay a higher premium. The first strategy is more customer-friendly. (Case1, manager G)

Essentially, the new policy reinforces the difference between a healthy and an unhealthy lifestyle.

### **The Voluntary and Involuntary Character of Insurance Risks**

If we take a closer look at the above described processes, we see that ideas on responsibility for health are embedded in insurance practice. If we turn for example back to the genetic



risk cases, insurers seem to attach minor significance to family history data. In fact, they articulated doubts about the use of family history as decisive risk factor:

We cannot afford to give a higher premium merely on the basis of family history. We cannot tell our clients that they'll have to pay more because of their father's heart problems. This is not client-friendly. If someone honestly declares that he is not suffering from anything and our tests confirm that there is nothing wrong with his heart, charging him a higher premium is hard to defend. (Case1, underwriter K)

Charging somebody because of his genes or his family history alone is considered un-delicate or unjustifiable, because having 'bad genes' is something this person cannot help. The same doubt was advanced more fiercely when it involved behavioural disorders among family members. As an underwriter noted in the case of alcoholism:

If we consider whether the mother and father have an alcohol problem? This is even a more delicate matter. You have to realise that when we charge someone a higher rate because his mother was an alcoholic, that leaves a bad impression commercially. After all, can this person be blamed for his mother's alcoholism? So why penalise him for his mother? (Case1, underwriter R)

The involuntary character of genetics, in other words, was thus emphasized. These judgements are closely related to broader public disapproval about the use of genetics in insurance, as crystallised in the Belgian Law (1992). Insurers take these social acceptability considerations into account.

We may succeed in selling a classification policy on age, sex or smoking behaviour. But on genetic issues, that won't hold. . . [ . . . ] So we can not afford us a headline in the newspaper stating that our company differentiates along family history, because the public won't put up with that. (Case2, manager B)

The legal prohibition of genetics in insurance then seems to introduce a kind of fault-based labelling in insurance. As illustrated here, this expresses a withdrawal of responsibility for genetic risks. But from there, we can wonder what this means for responsibility for other predictive, non-genetic risks.

If we take a closer look at our lifestyle risk cases, again societal visions on responsibility for health seem to be embedded. These views were also observed in interviews with managers involved in strategic policy developments:

So I believe insurance companies have a social function in that. We are gearing against societal cowardice. We must protect people against themselves. They need to take care of their health. (Case1, manager S)

Again, such judgements in insurance seem closely related to broader social imageries on individual responsibility for health, as for example expressed in newspapers, governmental legislation or epidemiology. Insurers take these societal visions in consideration in deciding which risk classification factors to use in underwriting. The uptake of the smoker/non-smoker rating in insurance illustrates this. Consider for instance these quotes from managers:

Yes, whether you're rating them [*smokers*] in your standard or not, that's part of a marketing issue. That's a business issue in fact. [ . . . ] But it is society [*stress*] that decides what they want as classification factors, I mean, the consumers. And that was exactly what happened in the US, the consumers [*stress*] wanted these smoker rates, so we started a lot of business with these smoker rates. It didn't happen for example

in Switzerland, because it was not socially accepted, because people there said: ‘Well, smoking is something we live with’. So it was not commercially viable, I mean, in Switzerland the insurers have said: ‘We don’t think that is commercially viable to go down that road.’ But now it has changed there as well I think, because now, all of a sudden, we have these Swiss laws restricting certain areas that you’re not allowed to smoke. And once that happens that will put the pressure on the insurance market as well to allow smokers rates. I mean, then there is a market, all of a sudden. (Reinsurance1, manager G)

You just have a market here that changed. It stirred up a few insurance companies who started thinking there was now a market differential possible between smoker/non-smoker rates. And then within two or three years, companies started to ask questions on their application forms just about people smoking or not. And those companies who hadn’t changed their policy had a lot of smokers coming in, saying ‘where should I get my best deal now?’ And then these companies also changed their policy. The market went very quickly there. [. . .] It’s a dynamic field, you have to explore all the factors that are out there. Like, “What is socially acceptable?” I mean, the social acceptability factor plays a huge role in insurance marketing. (Reinsurance 1, manager L)

The construction of the self-inflicted nature of lifestyle risks also returns in the way underwriters deal with remissions or modifications. It is permitted in specific cases to adapt a premium after a given timeframe. Insurers, however, only do this when it concerns “real diseases,” rather than lifestyle risks, such as obesity:

In the case of poor lifestyle habits we will not issue an adjustment. If one used to have poor lifestyle habits this can no longer be entirely erased. There is always a specific lifestyle that automatically affects one’s future. So this is not an issue. There are only a few serious diseases that may return after a certain period. Of these you can say, okay, as in the case of breast cancer; when it appears the disease has been stable for ten years, we may issue a premium adjustment. So then we re-determine the premium because with breast cancer, that is not a consequence of lifestyle, it is beyond one’s will. In these cases the disease is to blame. Meanwhile, lifestyle habits are dependent on people’s decisions, and so in those cases we do not change our earlier decisions. Because if they used to have poor lifestyle habits, there is no guarantee that they have permanently changed their behaviour. (Case1, medical advisor E)

Overweight people often say: ‘Yes, I weigh too much, but from now on I’m going to do something about it.’ So we get a lot of reactions like these, and questions like: ‘How much am I allowed to weigh so I can get the standard premium?’ This is not how it works of course. You can decide to lose weight but there is no guarantee that your weight will stabilize. (Case2, underwriter O)

The same happens when underwriters are faced with the postponement of a decision. In the case of a pregnancy, for instance, the medical examination is postponed until after birth. For those with high cholesterol, however, postponement is impossible. These patients instantly receive an increase in their premiums:

In the case of high cholesterol we will not postpone our assessment. We go right to a higher rate. With pregnancies we could do the same, but, well, I feel it involves an issue whereby those who are pregnant are being punished for something they have no control over. (Case1, underwriter R)

As the examples demonstrate, a good lifestyle has become decisive in offering cover and at what cost. By using lifestyle risk factors, insurers focus on the applicants' self-control over their risk. Through 'measuring' lifestyle variables it is traced to what degree individuals exercise control over their health. Individual control over health is thus translated as selection criterion for taking out insurance. Through the normative claims that are linked to specific applicants, insurers (co)-contribute to the construction of the *voluntary* character of 'lifestyle' risk liability. The identification of fault serves as the basis for penalisation. Where disease is, however, not a matter of fault, the person is seen as a *victim*.

We increasingly see people who are overweight, with high blood pressure, and diabetes. These are the main risks today. And the heavy smokers of course. . . This is counter-balanced by the cancer cases for instance. They in fact are the real victims. (Case1, underwriter K)

### New Legislations, New Solidarities?

If we compare the insurers' approaches to asymptomatic risks, lifestyle risks are far more pressing than genetic risks.

The applicant's lifestyle is the most important factor. Well, because lifestyle is really about the person himself. He can do something about it, you see. . . . On the contrary, we don't rate people for their family history alone, because these people themselves aren't ill. You won't punish them for something that's in the family while they don't suffer from the disease, do you? Because they can't help it, it's not their fault. You can't punish them for something they possibly, may be, might get in the future, right? (Case2, underwriter M)

Lifestyle is simply more important for us. I think, you can have familiar things but by modifying your lifestyle that risk can be ruled out. It's not because it's in the family, that you will develop it, you see? For you don't lead the same lifestyle as your family for example. (Case1, medical advisor R)

In the first case, the risk pool will not subsidise the applicant; he must bear his own risk. In the latter case, insurance companies are willing to take the risk. According to Petersen and Lupton [36], the moral judgements involved in predictive medicine create on the one hand "at risk people," that is, people with risks which are perceived as completely out of individual control and, on the other hand, "risky selves," or people whose risk derives from their ignorance or lack of self-control. In Belgian insurance practice we observe the same trend: lifestyle *risk takers* are treated differently than genetic risk *carriers*. This may result in a fault-based approach in underwriting. Risks are assessed differently according to whether they are a result of the applicant's own fault or not.

This prompts questions not so much about the emergence of these judgements but what they *imply*. That is, by stressing the difference between lifestyle and genetic risks, we see how distinct moralities are attributed, and, consequently, different (financial) responsibilities are assessed. From the introduction we recall philosophical work arguing that genetic knowledge production is associated with new forms of determinism, a "geneticization" or "genetic exceptionalism." This means there is a tendency to distinguish people along genetic characteristic lines, resulting as well in different levels of responsibility attributed to genetic and non-genetic risks. Where genes are linked to fatalism or lack of control, lifestyle is

associated with individual control or responsibility.<sup>6</sup> The same approach is found in Belgian insurance practices. In this sense the Belgian legal prohibition on using genetic information in insurance can be considered the institutionalisation of “geneticization.” Such reasoning differentiates between a fateful and immutable genetic predisposition, on the one hand, and chance and controllable lifestyle factors, on the other. The outcome is a financial solidarity or collective responsibility for the genetic *risk carriers* and individual financial responsibility for lifestyle *risk takers*.

Implicitly then, insurers express normative claims on responsibility for health. Although both lifestyle and family history can be identified as asymptomatic risks and as predictors for an individual’s future health status, lifestyle has gained ascendancy in the risk calculation process. Both sections of the group share the fact that the illness is not yet developed, and will possibly never do so, but the legal and moral evaluation of these risks in insurance is completely different. Implicitly insurers thus draw on the argument that our biological fate outweighs our social fate, and therefore deserves more solidarity [15]. This underscores again how insurance is a normative technology. Risk selection is neither a purely technical procedure nor simply the application of insurance principles—but much more of a social and normative undertaking [43]. In the selection of risks, insurance expresses normative claims (originating from epidemiology, regulation or public opinion) of who does or who does not *deserve* solidarity and which criteria people have to fulfil to be included as members of the insurance group. On a wider front, such practices reflect how we, as society, consider the criteria for solidarity with the sick.

### The Limits of Genetics-Specific Legislation

This article has given empirical insight into how genetics-specific legislation works out in insurance practice. As we have seen, articles 5 and 95 of the Belgian Insurance Law [48] are formulated to specifically prevent “genetic” discrimination in insurance. By making an exception for genetics the law expresses that genetic information is *different* from non-genetic information. However, the creation of a legal “wall” between genetic and non-genetic information and the attribution of a special statute to genetics prompts the question whether and in what ways this does not create some unforeseen consequences.

For one thing, we questioned whether genetics-specific legislation is effective at all. As we have seen, the legal “wall” intended by the Belgian prohibitive regulation on genetics is not hermetically sealed: some genetic information still filters through in insurance practice. For example, while family history does not have the same relevancy as lifestyle risk information, we have seen how it is still used as confirming information in rating other risk factors of applicants. As such, the law has not resolved all underlying aspects of the issue, partly by not giving clear definitions on “genetic data.” Furthermore, one should question the tenability of such legal boundaries between genetic and non-genetic information. Through its juridical embargo, the law affords disputable, undeserved *certainty* to the predictive character of genetics. In medicine, it is however increasingly acknowledged that the distinction between genetic and non-genetic information is quite artefactual. Alper and Beckwith [1], for example,

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<sup>6</sup> Chang and Christakis [4], for example, argue that the introduction of genetics to the explanatory frameworks of obesity in medical textbooks has resulted in a different morality for obese bodies and a redistribution of responsibilities. By introducing genetics as an explanatory factor for the obese body, these bodies are less and less individually held responsible. The creation and maintenance of the obese body is not more exclusively the responsibility of individuals themselves, but becomes more the responsibility of the medical profession.

indicate how difficult it is to maintain a distinction between genetic and non-genetic factors. According to them, many clinical tests may also provide information on the genetic code. In addition, while genetic tests are commonly defined as information derived from a DNA-analysis, there also exist more indirect forms of genetic testing, like genetic information derived from chromosomes, proteins or via routine urine or blood tests.<sup>7</sup> As this indirect genetic testing becomes more commonplace, genetic and traditional medicine will probably be administered along side it. Thus it might become difficult for physicians or insurers to differentiate genetic from non-genetic information. Consequently, it is important to ask whether an exclusive legal ban on genetic information will be tenable in the future.

A second type of consequences has to do with the introduction of a fault-based approach in underwriting. Again, this approach may stem from a “genetic exceptionalism,” as institutionalised in genetics-specific legislation, thereby inciting reductive social representations that overly determine the role of genetics. A redistribution of responsibilities is the result: while collective responsibility is attributed to genetic *risk carriers*, lifestyle *risk takers* have to bear individual responsibility. In this regard, the call to distinguish genetic discrimination from other types of discrimination and subject it to special legislation has a paradoxical impact. Such legislative efforts reinforce the cultural belief in the exceptional status of genetic factors, something which the legal regulation was supposed to counter in the first place. The law thus promotes a self-fulfilling prophecy [29]. At the same time, the explicit withdrawal of responsibility in the case of genetic risks is the other side of the coin of an increasing ascription of responsibility for all non-genetic factors. The reductionist concept of genetic fatalism inscribed in the Belgian legislation contrasts with the radicalized appeal to personal responsibility and individual accountability towards health and prevention of illness. This may result in inequities between similarly situated individuals. Lifestyle “risk takers” are disproportionately disadvantaged by laws that protect against discrimination based exclusively on genetic risks. In other words, by giving extra protection to one group of risks, other groups are (increasingly) being under-protected. It appears then that these legislations, though intended to solve the particular issue of genetics, may actually bring new issues out into the open. Looking back at the legislation’s enactment, this type of policy solution rather gets the stance of “feel good” legislation (see Rothstein, *in press*). It may have convinced policymakers that they have resolved issues—by repairing the balance in favour of genetic risks, but it has left the “bigger picture” unreturned. With this article, we have demonstrated time has come now to return to first principles: Which risks deserve our legal protection in insurance? Who do we declare our solidarity with?

On a larger front, the above also stimulates reflection on the relationship between genetic technologies and regulations. Although there has been a scientific revolution in genetics and detailed knowledge of the genome is by now available, the *practices* of genetic testing are still in their infancy. In the years ahead major developments are to be expected but their effects remain uncertain. It is to wonder whether our classic policy tools, like legislation, are useful in governing these major technological developments [15]. Will it be possible to ‘close off’ a genetic revolution by means of legislation?

Finally, these insights about the practical effects of genetics-specific legislation hold beyond the field of insurance as well. In Europe, as well as in the rest of the world, policymakers are currently developing genetics-specific legislation in a large number of other domains, as for example in bio-banking, pre-implantation genetic diagnosis and health care.

<sup>7</sup>Examples are the detection of phenylketonuria via blood tests or Tay-Sachs via measurement of mutated proteins.

Genetics-specific legislation in insurance can be viewed as a test case in this regard. Policy-makers should carefully reflect on the here described complications that emerge from this type of policy solution. Are our “classical” legislative governance approaches still tenable to deal with these new technologies? May be in policy world, it is time for a new paradigm.

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