CAMBRIDGE Law, Medicine and Ethics

Genes and Insurance

Ethical, Legal and Economic Issues

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Genes and Insurance
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The results are examined here of two key social developments in recent years: the partial dismantling of the welfare state and the progress of genetics. Genetic insights are becoming increasingly valuable for risk assessment, and insurers would like to use these insights to help determine premiums. Combined with the fact that social welfare is being curtailed, this could potentially create an uninsured high-risk population. Along with considerations of autonomy and privacy, this forms the basis for an ethical critique of insurers' access to information. There has often been regulation of such information, but the authors argue that because of adverse selection regulation will not solve these problems and may jeopardise the survival of private personal insurance. Instead, we should look towards the resurrection of social insurance, a key component of the welfare state. This book will interest academic researchers and professionals involved with genetics and insurance.

MARCUS RADETZKI is Research Fellow in Private Law in the Faculty of Law, Stockholm University, and Assistant Professor in Private Law in the Department of Law, Örebro University. His recent publications include 'Limitation of Third Party Nuclear Liability: Causes, Implications and Future Possibilities' (*Nuclear Law Bulletin*, 1999) and 'Cause and Damage – Interpretation of Liability-Activating Terms in Property Insurance' (*Scandinavian Studies in Law*, 2000).

MARIAN RADETZKI is Professor in the Department of Economics, Luleå University of Technology, and a Senior Research Fellow at Studieförbundet Näringsliv och Samhälle (Centre for Business and Policy Studies), a Stockholm think tank. His recent publications include *Fashions in the Treatment of Package Waste: An Economic Analysis of the Swedish Producer Responsibility Legislation* (2000) and *The Green Myth: Economic Growth and the Quality of the Environment* (2001).

NIKLAS JUTH is a Lecturer in the Institute of Philosophy, Göteborg University. His publications include 'När är idrotten jämställd?' ('When Shall We Have Equity in Sports?', *Filosofisk tidskrift*, 2000) and 'Insurance Companies' Access to Genetic Information: Why Regulation Alone Is Not Enough' (*Monash Bioethics Review*, 2003).

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This is a series of books focusing on medical law, but including titles in which both legal and ethical policy issues are discussed. The series is intended to respond to the growing importance of medical law not only in universities and in legal and medical practice, but in public and political affairs. It aims to reflect the fact that many major policy issues over the last few years have had a strong medical law dimension (organ retention, embryonic stem cell research, safety issues etc.). The emphasis is therefore on issues of public concern or practical significance rather than merely on the theoretical dimensions of the subject.

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Preface

The ideas contained in this book matured gradually over a period of some two years at the end of the 1990s in discussions between Marcus Radetzki and Marian Radetzki. A minor grant from the Trygg Hansa Research Foundation early in 2000 made it possible to start work in a small way. The result was a paper in Swedish, 'Genetic Knowledge and Insurance', by Marcus Radetzki, published in *Nordisk Försäkringstidskrift (Scandinavian Insurance Quarterly)* in 2001. The paper provides an overview of the subject area, and constituted a starting point for the present work. At a later stage during preparations, Niklas Juth was associated with the team, with the special task of covering the ethical aspects arising from the issues under investigation.

Work on the book was undertaken during the period September 2001–September 2002, with Studieförbundet Näringsliv och Samhälle (SNS – a Swedish think tank) as an administrative base, and a Swedish edition was published by SNS during 2002.

The manuscript is the result of close collaboration between the authors, but the work has been divided according to the authors' areas of competence. Chapters 1 and 8 have been jointly written by Marcus Radetzki and Marian Radetzki. Niklas Juth carried the main responsibility for chapters 2 and 7 and Marcus Radetzki for chapters 3 and 6, while Marian Radetzki wrote chapters 4 and 5.

While the responsibility for remaining weaknesses and errors rests entirely with the authors, we wish to acknowledge and thank for their valuable and highly constructive comments on earlier versions of the manuscript Göran Flood (insurance specialist), Christian Munthe (philosopher) and Jan Wahlström (geneticist), and three anonymous referees appointed by Cambridge University Press. Teresa Bjelkhagen and Timothy Chamberlain have provided valuable help in making sense of the English language, not our mother tongue. Generous grants from ELSA, the Swedish research programme, from Sven and Dagmar Salén's Research Foundation and from Swedish Ethics in Health Care have been crucial prerequisites for the work. We express our sincere thanks and hope that the results of our effort are up to our benefactors' expectations.

MARCUS RADETZKI, MARIAN RADETZKI and NIKLAS JUTH
Stockholm, December 2002

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1 Introduction

This book is about the confluence of two developments which assumed significance during the 1990s in most rich market economies on both sides of the Atlantic. Unexpected consequences followed the combination of the two tendencies, and they led to a set of political decisions which, on closer scrutiny, appear to be neither well founded nor sustainable.

The first development is the remarkable progress made in genetics during the 1990s and the promise of even greater potential gains in the not-too-distant future. In the 1990s it became possible to identify the relationship between defective genes and a set of serious illnesses. This insight strengthened the incentives to develop genetic testing which could potentially anticipate many more illnesses, as well as therapies to reduce the risk of the illnesseses breaking out or to provide remedies once they have done so. The number of illnesses that can be prognosticated or diagnosed with the help of genetics is steadily growing. In consequence, genetic insights become increasingly more valuable as instruments for assessing the risk of illness as well as longevity. In a somewhat longer time perspective, there are clear possibilities for the use of genetics to reduce the outbreak of illnesses with genetic origin, and to limit the risk of such illnesses. In an even longer perspective, this new branch of science appears to offer the potential to manipulate genes not only to avoid illness but to improve individual characteristics and qualities in various respects. In the very long run, genetic knowledge is thought to have the potential for creating a new species, a 'superhuman', but such speculation is currently part of science fiction rather than science.

The second development is a contemporaneous transformation of the social insurance systems that were built up during the first half of the twentieth century, and consolidated in its third quarter, in the welfare states around the north Atlantic. The evolution of social insurance has taken somewhat different paths in the countries under review (see chapter 4), but several key features have been common everywhere. Thus, the systems have all been motivated by solidarity, and characterized by strong collective and mandatory elements; public involvement has been complete in many cases and predominant in others, while the profit motive has been completely absent or strongly subdued. Social insurance has covered many aspects of life, but our interest is limited to those whose goals have been to insure against the cost of treatment in the event of illness, and against loss of income due to illness or premature death, or during old age. In the 1990s the systems of social insurance were subjected to a partial dismantling. The main reasons for this development are (i) the fast expansion of public financial obligations; (ii) a desire to make the provision of insurance services more efficient; and (iii) a wish to expand the freedom of choice of those insured, and so to facilitate the satisfaction of each individual's particular needs. The reforms of the 1990s have comprised (i) the partial individualisation and commercialisation of the public arrangements; (ii) a lesser generosity towards those insured; and (iii) an active encouragement to seek private supplements to the remaining public arrangements. The supply of private personal insurance by profit-making insurance companies operating in competitive markets has been strongly stimulated by these reforms.

The confluence of the two developments has created a set of new opportunities but also a number of fears. There was no need for individual risk assessments in the collective and mandatory social insurance systems. In contrast, the commercial insurance companies that have taken over in part from these systems desire, as far as possible, to adjust the premiums that they charge to their customers, and to place restraints on the extent of the service that they provide (in the case of health insurance), or to exclude the cover of certain causes of premature death, in accordance with the risk represented by each individual engagement. The emerging genetic technology provides a powerful instrument for individual risk assessments for the health, premature death and pension policies underwritten by private insurers. Access to such risk information will facilitate more precise actuarial premium assessments, and so make the insurance business more efficient. Uncertainty remains regarding the extent to which genetic science will be able to play such a role in risk assessment (chapter 2). To some extent it does so already, and therefore insurance companies feel a need to take genetic insights into account, just as they must seek and obtain all other information of relevance for assessing risk.

Simultaneously, the freedom of insurance companies to employ genetic insights in risk assessment is being increasingly questioned on ethical grounds. With reference to the individual's right to autonomy and privacy, it is claimed that he should be free to remain ignorant about possible defects in his genetic make-up and under no circumstances be coerced into handing over such intimate information to others. At a time when social insurance systems are being partially dismantled, arguments of solidarity and equality have also been a starting point for criticising the use of genetic information for the purpose of insurance. Genetic insights make it possible to widen the range of premiums charged for private personal insurance, and/or to vary the extent of cover for the treatment of an illness. The actuarial justice of each insured paying for the risk he represents, no more and no less, has been criticised and juxtaposed against the injustice that follows from a discriminatory situation where some are forced to pay more, or to accept a less comprehensive cover, because of a genetic make-up that is not of their own choice. Such a concept of injustice has been at the forefront of many public debates.

The criticism directed towards what has been perceived as injustice has resulted in restrictive regulation of insurance companies' access to genetic information. Clearly, the insurance industry in all countries is subject to a variety of regulatory regimes, but in what follows, attention is entirely focused on the regulation related to the access to and use of genetic information. In some countries, Austria, Belgium, Norway and Denmark among them (but also in a few states in the United States), regulation has been given the form of legislation. In other countries, for example the Netherlands, Sweden and the United Kingdom, regulation is in the form of an agreement between the government and insurers' associations, in which the insurance companies commit themselves not to use genetic information other than under particular specified circumstances. Since the problems related to genetic information and personal insurance are new and their practical importance is growing, it is our belief that regulation restricting insurance companies' access to genetic insights will be introduced in an increasing number of countries.

As noted, regulation can take the form of either legislation or a voluntary agreement. In chapter 3, where existing regulatory arrangements are described and analysed, we discuss this distinction in some detail. In the rest of the book, however, we find little reason to distinguish between the two forms. One could of course claim that agreements are less stable, since they can be cancelled when one of the parties so desires. However, since cancellation by the insurance industry can immediately be countered by legislation, the practical implications of the difference between the two regulatory forms appear to us to be insignificant.

The content of regulation, in contrast, requires a rough categorisation into two fundamental types. The first, called *partial regulation* in what follows, prevents insurance companies from requiring their clients to undertake genetic testing as a precondition for a policy, but allows them to demand access to information in already existing tests. The second, *total regulation*, prohibits the latter as well. Some countries that have so far introduced restrictions in this area have chosen total regulation. In other countries a mixture of the two is applied. Thus the insurance companies are prohibited from requiring new tests. Access to results from existing tests, however, is permitted when the insured amount exceeds a pre-specified amount.

The political decisions partially to dismantle existing social insurance systems may well have had strong and well-founded motivations. However, a consequence is that private personal insurance has in many cases become a basic good of overriding significance for social welfare. This is the background against which the proliferating restrictions against the insurance industry's use of genetic insights should be seen. Fundamental welfare goals must not be compromised through increased differentiation of insurance premiums, which could make insurance unaffordable for exposed groups, or through genetically motivated restrictions of cover that leave them unprotected altogether. Regulation can be seen in this light as an appropriate action, certainly in the short and medium run. However, it seems to us that the political decision-makers have not sufficiently considered the long-run consequences of the restrictions that they have introduced.

Private insurance companies play an important role in market-oriented economies. *Asymmetric information* and *adverse selection* are two related problems that always threaten to undermine the activities of profit-making insurance businesses that operate in competitive markets (Akerlof, 1970, pp. 480 ff.), and firms must always act to minimise both. The insurance companies have strong incentives to obtain information about their clients, and to charge a premium in each case that corresponds to the risk of that case. The insurers who fail in this task will make losses on policies that represent a high risk. At the same time there is a likelihood that clients representing low risks who are charged premiums in excess of this risk, will gradually switch to competing insurance companies prepared to offer them a lower, actuarially determined premium. Continuous analysis of risks and the adjustment of premiums or extent of cover to the cost represented by each risk are therefore preconditions for the long-term health of the private insurance company.

Genetic insights constitute an instrument for risk analysis in personal insurance. At the beginning of the twenty-first century the potential of genetics in this regard is not overwhelming, but it is growing rapidly. Prohibition of the use of genetic insights for insurance risk analysis might well contribute towards greater equality, but at the cost of lowered efficiency in the insurance business. The precise reasons why private insurance firms operating in competitive markets should assume the burden of equality promotion in this regard, and why *genetic* information should be banned as a premium differentiating tool, are neither self-evident nor clear.

The consequences of restricting regulation will be particularly serious for insurance companies when some of their competitors can avoid the restrictions through their location. Adverse selection will become an increasingly serious problem to the domestic insurance industry, as rising numbers of clients representing below-average risk move their business to insurance companies located offshore, which are not subject to regulation. Ultimately, regulation may impose a survival threat to the domestic insurance industry and by implication to the domestic supply of personal insurance. Regulation loses all justification if the ultimate outcome is the breakdown of the domestic insurance market.

From a legal perspective it is clear that existing restrictions on the use of genetic information for the purpose of insurance constitute part of a wider set of regulations to prevent discrimination in the private sector. Our analyses reveal that existing prohibitions of such discrimination are not based on uniform legal criteria in the countries under review. It would appear that rules against discrimination have been introduced from time to time independent of each other, and each time as a result of political fashion. Thus the existing restrictions against genetic discrimination in the field of insurance are not based on any uniform and consistent system of rules regarding discrimination in the private sector, because no such system is in existence. Since regulation to prevent genetic discrimination in the field of insurance has been set up without the application of any general and uniform legal principles, we conclude that it can also be abolished without reference to such principles.

We should also add that the ethical foundations of the regulation under scrutiny are far from clear-cut. Some ethical arguments provide an unambiguous support for the existing restrictions. But, as will be clear from our investigations, several other ethical considerations point in the opposite direction.

Fascinating combinations of genetic insights and insurers' interests can be envisaged in the longer run, to prevent illnesses or ameliorate their course by indicating early prophylactic interventions, so as to improve the life of the insured, and reduce the cost to the insurer. In the absence of regulation insurance companies will have strong incentives to contribute to the developments in genetics, so as to reduce the cost of genetic risks. Such developments are likely to be delayed, or could fail to materialise altogether, as a consequence of the regulations under review.

In sum, then, these observations lead us to the conclusion that the restrictions on insurance companies' use of genetic information are not sustainable and will be repealed. Important aspects of welfare will be hurt in consequence. In the last part of the book we discuss how the rich welfare states on both sides of the north Atlantic could act to resolve economic issues and at the same time protect the genetically exposed population groups from suffering.

The book is divided into four parts. Part I provides the main starting points for the analyses that follow. Chapter 2 is intended for the novice in the field of genetic science. We introduce basic genetic terms, and discuss how genetic science has evolved and its significance for the insurance industry. We also outline the likely role that this science may play in the future, especially as an instrument to assess risk. In chapter 3 we present the regulation that restrains the insurance industry's access to genetic information. We also review its motivations and implications for the insurance industry and its clients.

Part II deals with the social, economic and legal aspects of genetic knowledge and personal insurance. Chapter 4 provides a brief history of social insurance, from its emergence early in the twentieth century to its maturing after the Second World War, the emerging problems during the 1970s and 1980s, and the partial dismantling of the obligatory, collective arrangements in the 1990s. An important reason to doubt the sustainability of the regulation that restricts insurance companies' access to genetic information is explored in chapter 5. As the world economy becomes increasingly integrated, we expect a greatly expanded international trade in personal insurance. Since absence of regulation in this regard provides a clear-cut competitive edge, we anticipate a rising propensity to relocate insurance activities to countries where such restrictions do not apply. Insurance companies subject to regulation will then increasingly suffer from adverse selection, and in consequence gradually lose their share of the market. It is clear that such developments raise the likelihood of deregulation, and an ensuing freer access to genetic information for all insurance endeavours. We note, however, that some regulation is maintained even when its stated objectives are not achieved. One important reason why this is so is that it forms part of a broader regulatory system, and there is an unwillingness to break that system. In consequence, chapter 6 explores whether the regulation of the insurance industry's access to genetic information is in fact a coherent part of a broader, uniform regulatory system. The system that we investigate in this context relates to the legislation concerning discrimination in general in the private sector.

Part III treats the ethical issues arising from insurance companies' access to genetic information thus, chapter 7 discusses whether consequentialist arguments, reasons related to the individual's autonomy and privacy or outright justice can be seen to provide support for regulation. The most important consideration appears to be that personal insurance has developed into a basic good, of great importance for welfare. Consequently, the inability of groups with genetic deficiencies to obtain insurance because premiums become prohibitively expensive or because insurance companies refuse to offer insurance at any price, cannot be regarded as acceptable on ethical grounds.

Part IV summarises and develops further the analytical results of earlier parts. In chapter 8 we demonstrate that politicians have apparently not thought through the combined consequences of their decisions regarding the partial dismantling of social insurance, on the one hand, and restrictions against the use of genetic insights in personal insurance, on the other. Our most important conclusion is that the existing total regulation of the use of genetic information in the field of insurance should be abrogated. Such an action will undoubtedly arouse a variety of economic as well as social and ethical problems. The chapter discusses how to come to grips with these problems.

A few clarifications are needed before we conclude this introductory chapter. Our concept *personal insurance* comprises three different forms of insurance, namely (i) insurance against income loss and for the cost of treatment in the event of illness; (ii) insurance against income loss due to the premature death of a household's income earner; and (iii) insurance to provide income during old age. Our analysis is limited geographically to the fifteen member countries of the European Union, along with Norway and Switzerland, and to the United States and Canada on the other side of the Atlantic. As mentioned, we differentiate between two types of regulation of insurance companies' access to genetic information: *partial regulation* forbids insurance companies to demand that new tests be undertaken as a precondition for insurance, but allows them to demand information from tests that already exist; *total regulation* forbids the latter as well. Two concepts that are frequently used in the following chapters are *asymmetric information*, a circumstance where the insured knows more about the insured risk than the insurance company, and *adverse selection*, defined as a situation where the insured group comprises a declining number of low risks and a mounting number of high ones. We distinguish between the degree of risk represented by individuals. *Low risks* comprise insured individuals whose risk is lower than the average in the insured group, *high risks* are the insured individuals whose risks are higher than the same average. There is no other connotation in the concepts 'low' and 'high' in this context.

Part I

Starting points