J.H. Gerards, A.W. Heringa & H.L. Janssen

Genetic Discrimination and Genetic Privacy in a Comparative Perspective

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C. H. van Rhee

Genetic Discrimination And Genetic Privacy In A Comparative Perspective Ius Commune Europaeum: Genetic Discrimination and Genetic Privacy in a Comparative Perspective Janneke H. Gerards, A. W.

Heringa, Heleen L. Janssen, 2005 During the last decades a better understanding of the influence of genetic factors on the onset of illness and disease has evolved Unfortunately however the information revealed by genetic tests is not always accurate and reliable and its probabilistic value is often limited Throughout the world the possibility of genetic testing and the availability of individual genetic information have therefore caused increasing social concern especially since many actors outside the medical profession such as health and life insurance companies and employers have shown a growing interest in individual genetic information. In many states as well as on the international level there is an ongoing debate about the balance that should be struck between the protection of the individual against misuse of genetic information and the interests of social actors and genetic research institutes and about the policy options that are at hand to reduce the risks that are created by the availability of genetic information This book offers some clarity as to the choices that have been made in various legal systems both national and international with respect to the regulation of genetic information On the basis of an elaborate analysis of relevant legislation policy approaches and case law in the United States the various European states and on the international level the book aims to provide insight in the issues that must be deemed relevant in considering and Judicial Lawmaking and Administrative eventually introducing regulative measures with respect to genetic information Law, 2005 The book before carries a broad title In the Dutch literature the terms lawfinding and lawmaking are often used interchangeably From a legal point of view however it makes guite a difference to the position of the court whether lawfinding or lawmaking is meant Why write a book about lawmaking by the courts just in the area of administrative law In administrative law the administration is positioned between the legislature and the judiciary The courts review decisions taken by the administration in implementing the law however where the administration has often been granted a degree of discretion the courts access the lawfulness of the decision The relation administration judiciary raises so many specific questions that it justifies a book on judicial lawmaking in administrative matters The authors are all members of the research program Public Law of the Ius Commune School European Journal of Social Security ,2004 **European Traditions** in Civil Procedure C. H. van Rhee, 2005 European co operation has resulted in many new and challenging opportunities for legal scholars who since the so called codification period have become used to operating in a purely national context This applies also to scholars in the field of civil procedure who for a considerable period of time have resisted leaving the purely national domain These scholars have devoted a great deal of attention to the guestion whether or not harmonisation of civil procedural law is a feasible option and if so in what manner harmonisation should be achieved The contributors to this book seek to further the harmonisation debate by exploring some of the main trends in the development of civil procedural law during the last two centuries in several European countries Germany Austria Switzerland France England and Wales The

Netherlands and Belgium Two of the central issues that are addressed by the contributors are the extent to which the various procedural models have influenced each other and the extent to which common traditions in civil procedural law may be distinguished in Europe Each general chapter in this book is supplemented by three chapters devoted to specific procedural topics Conciliation Party Interrogation as Evidence and the Role of the Judge In addition extensive bibliographical references are included **Current Publications in Legal and Related Fields**, 2006 Gehuwd of niet--maakt het iets uit?, 2005

Towards a Unified System of Land Burdens? Bram Akkermans, 2006 Various legal systems were discussed Austria Belgium England France Germany the Netherlands Scotland and the United States The leading theme was whether civil law systems can learn from the Anglo American experience Particularly the American Law Institute's Restatement Third of Property Servitudes offers an interesting model for unification Genetic Discrimination Gerard Ouinn, Aisling de Paor, Peter Blanck, 2014-11-20 As genetic technologies advance genetic testing may well offer the prospect of detecting the onset of future disabilities Some research also forwards that certain behavioural profiles may have a strong genetic basis such as the determination to succeed or the propensity for risk taking As this technology becomes more prevalent there is a danger that genetic information may be misused by third parties and that particular genetic profiles may be discriminated against by employers by providers of social goods and services such as insurance companies and even by educational facilities This book explores the different forms and potential uses of genetic testing Drawing together leading experts in disability law bioethics health law and a range of related fields it highlights the ethical and legal challenges arising as a result of emerging and rapidly advancing genetic science On examining transatlantic perspectives on the matter chapters in the book ask whether the US Genetic Information Nondiscrimination Act GINA is proving to be an effective tool in addressing the issue of genetic discrimination and alleviating fears of discrimination The book also reviews what insights may be gained from GINA within employment and health insurance contexts and asks how the UN Convention on the Rights of Persons with Disabilities CRPD may impact similar debates within the European Union The book focuses particularly on the legislative and policy framework in the European Union with an emphasis on the gaps in protection and the scope for specific legislative action in this area This book will be of great interest to scholars and students of discrimination law bioethics and disability law and will be of considerable use to legal practitioners medical practitioners and policy makers in this area Genetic Testing and the Governance of Risk in the Contemporary Economy Lara Khoury, Adelle Blackett, Lukas Vanhonnaeker, 2020-10-01 This book addresses emerging questions concerning who should bear responsibility for shouldering risk as well as the viability of existing and experimental governance mechanisms in connection with new technologies Scholars from 14 jurisdictions unite their efforts in this edited collection to provide a comparative analysis of how various legal systems are tackling the challenges produced by the legal aspects of genetic testing in insurance and employment They cover the diverse set of norms that surround this issue and share insights into relevant international regional and national incursions into the field By doing

so the authors offer a basis for comparative reflection including on whether transnational standard setting might be useful or necessary for the legal aspects of genetic testing as they relate to the insurance and employment contexts. The respective texts cover a broad range of topics including the prevalence of genetic testing in the contexts of insurance and employment and policy factors that might affect this prevalence such as the design of national health or social insurance systems of private insurance schemes or the availability of low cost direct to consumer genetic testing Further the field of genetics is gaining in importance at the international and regional levels Relevant concepts mainly genetic tests and genetic data information have been internationally defined and these definitions have influenced definitions adopted nationally International law also recognizes a special status for human genetic data The authors therefore also consider these definitions and the recognition of the special status of human genetic data within regional and national legal orders They investigate the range of norms that specifically address the use of genetic testing in employment and insurance encompassing international sources including human rights norms that may be binding or non binding as well national statutory regulatory and soft law mechanisms Accordingly some of the texts examine general frameworks relevant to genetic testing in each country including those that stem from general anti discrimination rules and norms protecting rights to autonomy self determination confidentiality and privacy In closing the authors provide an overview of the efficiency of their respective legal regimes approaches specific and generalist to genetic testing or disclosure of genetic information in the employment or insurance contexts including the effect of lack of legal guidance In this regard some of the authors highlight the need for transnational action in the field and make recommendation for future legal developments An Evaluation Of The Ethical And Legal Landscape Terry Sheung-hung Kaan, Calvin Wai-loon Ho, 2013-07-04 Privacy is an unwieldy concept that has eluded an essentialised definition despite its centrality and importance in the body of bioethics The compilation presented in this volume represents continuing discussions on the theme of privacy in the context of genetic information It is intended to present a wide range of expert opinion in which the notion of privacy is examined from many perspectives in different contexts and imperatives and in different societies with the hope of advancing an understanding of privacy through the examination and critique of some of its evolving component concepts such as notions of what constitute the personal the context of privacy the significance and impact of the relational interests of others who may share the same genetic inheritance and mechanisms for the protection of privacy as well as of their limitations among others More specifically the discussions in this volume encourages us to think broadly about privacy as encompassing values that are entailed in the sociality of context and of relations and also as freedom from illegitimate and excessive surveillance A long standing question that continues to challenge us is whether genetic information should be regarded as exceptional as it is often perceived A conclusion that could be derived from this volume is that while genetic information may be significant it is not exceptionally so The work presented in this volume underlines the continuing and growing relevance of notions of privacy

to genomic science and the need to take ownership of a genetic privacy for the future through broad rigorous and open discussion Contributors Alastair V Campbell Benjamin Capps Jacqueline JL Chin Oi Lian Kon Kenji Matsui Thomas H Murray Nazirudin Mohd Nasir Dianne Nicol Anh Tuan Nuyen Onora O Neill Margaret Otlowski Yvette van der Eijk Chunshui Wang **Genetic Data and the Law** Mark Taylor, 2012-03-08 Research using genetic data raises various concerns Ross S White relating to privacy protection Many of these concerns can also apply to research that uses other personal data but not with the same implications for failure The norms of exclusivity associated with a private life go beyond the current legal concept of personal data to include genetic data that relates to multiple identifiable individuals simultaneously and anonymous data that could be associated with any number of individuals in different but reasonably foreseeable contexts It is the possibilities and implications of association that are significant and these possibilities can only be assessed if one considers the interpretive potential of data They are missed if one fixates upon its interpretive pedigree or misunderstands the meaning and significance of identification This book demonstrates how the public interest in research using genetic data might be reconciled with the public interest in proper privacy protection Genetics, Disability and the Law Aisling de Paor, 2017-09-21 With genetic technologies advancing rapidly Aisling de Paor examines the urgent need for an EU level framework to regulate genetic information Comparative Perspectives Anya E.R. Prince, 2019 Fear of genetic discrimination has led individuals worldwide to avoid medically recommended genetic testing and participation in genomics research causing potential health effects as research and clinical care are stymied In response many countries have adopted policies that regulate how insurers such as life disability or critical illness insurers can underwrite using genetic test results This article presents a comparison of policies in the United Kingdom Canada and Australia through analysis of interviews with 59 key stakeholders representing insurance government advocacy academia and genetics While the ultimate policy of each country is different the policy motivations and issues raised share commonalities across the countries particularly around themes of fairness usefulness of genetic information and the determination of actuarial fairness Human Dna: Law and Policy Bartha Maria Knoppers, Claude M LaBerge, Marie Hirtle, 1997-07 Human DNA Law and Policy provides the first international debate on a topic of universal concern No book has brought together such a diverse range of multidisciplinary ethical and legal expertise on the highly controversial issues surrounding the use storage exchange and sale of the very stuff of which we are made human genetic material Testing of human genetic material involves a variety of samples pathological samples newborn screening samples samples leftover after testing and research samples shared around the world This places consent issues on an individual familial and societal level The comparative and international perspectives presented reveal the transnational nature of genetic studies This book focuses on the issues of DNA sampling and testing consent and confidentiality banking policies genetic epidemiology and diversity Since financial and technological pressures are inextricably linked to human genetics research commercialization and patents are also examined Academic researchers

policy makers and industry will benefit from the learned papers and reports of the discussion which is rich in diversity of opinion controversial in the diversity of policy and approaches presented anchored on scientific facts and yet sensitive to cultural political and economic differences Genetic Privacy Graeme Laurie, 2002-05-16 The phenomenon of the New Genetics raises complex social problems particularly those of privacy This book offers ethical and legal perspectives on the questions of a right to know and not to know genetic information from the standpoint of individuals their relatives employers insurers and the state Graeme Laurie provides a unique definition of privacy including a concept of property rights in the person and argues for stronger legal protection of privacy in the shadow of developments in human genetics He challenges the role and the limits of established principles in medical law and ethics including respect for patient autonomy and confidentiality This book will interest lawyers philosophers and doctors concerned both with genetic information and issues of privacy it will also interest genetic counsellors researchers and policy makers worldwide for its practical stance on dilemmas in modern genetic medicine **Genetic Privacy and Discrimination** Eugene Oscapella, 2012-01-01 Genetic **Discrimination** Leana J. Albertson, 2008 Genetic information can be misused It can be used to discriminate against people in health insurance and employment People known to carry a gene that increases their likelihood of developing cancer for example may get turned down for health insurance Without health insurance it may be impossible for some people to get treatment for a disease that could be fatal This may lead some people to decide against genetic testing for fear of what the results might show and who might find out about them It also could lead some people to decline participation in biomedical research such as studies of gene mutations associated with certain diseases that examine the history of families prone to those maladies. This new book examines some of the hot areas of research in the field **Genetic Privacy and** Non-discrimination UN. Economic and Social Council (2004, substantive sess. : New York), 2004 Genetic Democracy Veikko Launis, Juha Räikkä, 2007-12-20 Genetic Democracy involves an in depth analysis of the ethical social and philosophical issues related to modern genetic research and gene technology The aim of the book is to introduce systematic research on the social and ethical impacts of the use and development of genetically modified organisms GMOs as well as the acquisition use and storage of human genetic information HGI The book contributes to enhancing public discussion and reaching fair and democratic decision making practices in GMO and HGI use and development both on local and global level There are currently few European texts which address the issues involved in a theoretical and systematical manner Genetic Democracy has been written from the viewpoint of social and political philosophy rather than that of traditional bioethics There is a clear need for a throughout and authoritative philosophical and ethical analysis of the issues involved in genetic research and gene technology The book will appeal to philosophers social scientists genetics professionals policy makers academics industrial organisations and human rights organisations as well as university students and legal scholars The book will have a broad appeal across Europe Asia and America since many states are currently considering policy responses to

many of the practices discussed in the books e g human biobanks
The New Genetics: From Research into Health Care Irmgard Nippert, Heidemarie Neitzel, Gerhard Wolff, 1999-07-15 The ultimate goals of human genome research are the treatment cure and eventual prevention of genetic disorders but treatment and cure lag behind the ability to detect disease or increased suceptibility to disease Most genetic services today deliver diagnosis and counseling effective treatment is rare As more genes are identified there is growing pressure to implement new testing programs or broaden existing programs and otherwise increase both the number of available genetic tests and the amount of genetic information The main issues concerned among others are voluntariness of services freedom of choices patient autonomy informed consent confidentiality of genetic information privacy testing of minors social discrimination and stigmatization

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