HEALTH AND HUMAN RIGHTS IN EUROPE
Increasingly, scholars from various disciplines are addressing the interfaces between health and human rights. As a legal scholar interested in this area, I started to teach a course entitled 'Health and Human Rights' at the University of Aberdeen School of Law in 2006. Finding this an important and developing area of law, I tried to identify its legal contours and its most important topics.

While I decided that there was an urgent need for a book, I struggled to cover all the areas of this broad and developing field. I am therefore utterly grateful to co-editors Mette Hartlev, Aart Hendriks and Janne Rothmar Herrmann for their excellent input and collaboration in this project. Many thanks also go the other authors for their valuable contributions and for their confidence in this project. Without them we would never have been able to cover so many perspectives of this new field and to demonstrate such knowledge and insight.

Altogether, the book is the result of much interaction and debate between the editors and authors of the book, scholars who together cover the wide areas of health law and human rights law from four different countries in Northern Europe. The aim of our project has been to write a truly coherent and comprehensive work with a number of interconnected chapters. These chapters roughly cover the scope of the area of health and human rights in Europe.

A few people have helped us at different stages in the writing and/or editorial process, including Sofia Gruskin and Daniel Tarantola, Herman Nys, Catherine Jacqueson, Dabney Evans, Maria Green, Simone Wijte, Tom Scheirs (Intersentia Publishing), and Fiona McGrath (for editing). Thanks also go to the School of Law of the University of Aberdeen, for extending my affiliation, and to the Faculty of Law of the University of Copenhagen, for enabling us to 'test' several chapters of the book by teaching a course entitled 'Health and Human Rights' in 2011. Lastly, I am grateful to the Research Department of the Danish Institute for Human Rights for granting me a temporary visiting research position, which enabled me to set the stage for this book.

Brigit Toebes, Managing Editor
Groningen, January 2012
## CONTENTS

Preface and Acknowledgements ................................................. v  
About the Editors and Contributors ........................................ xv  
List of Abbreviations .............................................................. xvii  

Introduction: Health and Human Rights in Europe  
  Brigit Toebes ................................................................. 1  

1. Rationale and aim of this book ........................................... 1  
2. Historical introduction to ‘health and human rights’ .................. 3  
  2.1. Introduction ........................................................... 3  
  2.2. The human rights movement  ....................................... 3  
  2.3. Medical law, health law, medical and bioethics, and patients’ rights 5  
  2.4. The public health movement ....................................... 7  
3. Theoretical approach ....................................................... 9  
  3.1. Main theoretical questions underpinning this research .......... 9  
  3.2. Conceptual grounding of human rights law ........................ 10  
  3.3. Conceptual grounding and analysis of economic, social and cultural rights ................................................................. 12  
  3.4. Identification of main concepts and principles underpinning this study ................................................................. 13  
4. Method and chapter outline ................................................ 16  

PART I.  
HEALTH AND HUMAN RIGHTS: THE EUROPEAN INSTITUTIONS  

Chapter 1. The Council of Europe and Health and Human Rights  
  Aart Hendriks ................................................................. 23  

1. Introduction ................................................................. 23  
2. European Convention on Human Rights ............................... 24  
  2.1. European Convention on Human Rights .......................... 24  
  2.2. Rights and case-law .................................................. 26  
    2.2.1. General .......................................................... 27  
    2.2.2. Health and human rights topics .............................. 30  
      a. Right to health ................................................... 30  
      b. Right to life (Article 2) ....................................... 31
Contents

c. Right to care (Article 3) ........................................ 34
d. Patients’ rights (Article 8) .................................. 36
2.3. Conclusions .................................................. 43
3. European Social Charter ....................................... 44
4. European Convention for the Prevention of Torture .......... 47
5. Convention on Human Rights and Biomedicine ............. 48
6. Conclusions ...................................................... 50

Chapter 2. The European Union and Health and Human Rights
Janne Rothmar Herrmann and Brigit Toebes .................... 51
1. Introduction ...................................................... 51
1.1. The aim of this chapter .................................... 51
1.2. The EU, its institutions and functioning .................. 52
2. EU, health and human rights ................................ 53
3. Specific responsibilities for health in the EU ................. 57
3.1. Focus on human health in the new TFEU .................. 57
3.2. EU engagement with public health ....................... 60
4. Free movement & health ...................................... 63
4.1. Introduction .................................................. 63
4.2. Free movement of services: cross-border healthcare services .... 63
4.2.1. The legal framework ..................................... 63
4.2.2. Cross-border healthcare and issues of morality ......... 66
4.2.3. Evaluation ................................................ 68
4.3. Free movement of persons: healthcare professionals .... 69
4.4. Free movement of goods: pharmaceuticals ............... 72
4.5. Free movement of goods: blood (safety) .................. 75
4.6. Free movement of goods: cells and tissues (safety, standards and quality) ........................................ 76
4.7. Data protection .............................................. 77
5. Conclusions ...................................................... 78

PART II.
HEALTH AND HUMAN RIGHTS: AN EXPLORATION OF THE FIELD

Chapter 3. The Right to Health and Other Health-Related Rights
Brigit Toebes ...................................................... 83
1. Introduction ...................................................... 83
2.1. The right to health ........................................... 86
2.1.1. Introduction .............................................. 86
2.1.2. The right to health at the UN level ................. 87
2.1.3. The right to health at the European level .......... 89
2.1.4. Constitutional provisions ............................... 91
2.1.5. The scope of the right to health ............................................. 92
2.1.6. Elements of the right to health .............................................. 93
2.1.7. Guiding principles for the right to health ............................ 94
2.1.8. Vulnerable groups ............................................................... 96
2.1.9. Legal obligations ............................................................... 97
   a. Respect, protect, fulfil ......................................................... 97
   b. International obligations ..................................................... 99
   c. Core obligations ............................................................... 99
2.1.10. The right to health: responsible actors .............................. 100
2.1.11. The right to health and public health .................................. 101
2.1.12. Justiciability of the right to health ..................................... 102

3. Other health-related rights. ....................................................... 103
   3.1. Introduction ................................................................. 103
   3.2. The right to life ............................................................. 104
   3.3. The right to liberty and security of the person ...................... 106
   3.4. The right to privacy and family life ................................... 107
   3.5. Freedom of expression and the right to information ............. 107
   3.6. The right to marry and found a family ............................... 108
   3.7. The rights to benefit from scientific progress ..................... 109
   3.8. Economic, social and cultural rights, and the protection of health ......................................................... 109

4. Conclusions .............................................................................. 110

Chapter 4. Patients’ Rights
Mette Hartlev .................................................................................. 111

1. Introduction .............................................................................. 111
2. Definition and development of patients’ rights .......................... 112
   2.1. Concept of patients’ rights .................................................. 112
   2.2. Development of patients’ rights .......................................... 114
3. Patients’ rights in international law: general principles and legal instruments ......................................................... 117
   3.1. Legal instruments ............................................................. 117
   3.2. General legal principles ..................................................... 119
4. Right to self-determination ....................................................... 122
   4.1. Autonomy, self-determination and consent ......................... 122
   4.2. Patients’ right to self-determination in human rights and patients’ rights law ......................................................... 123
   4.3. Restriction on right to self-determination in patients’ rights law ......................................................... 125
5. Patients’ right to information .................................................... 130
   5.1. Patients’ interest in information ......................................... 130
   5.2. Right to information in medical decision-making ................ 130
   5.3. Right not to know ............................................................. 132
Chapter 5. Reproductive Health
Janne Rothmar Herrmann .......................... 145

1. Introduction ..................................................... 145

2. Women’s reproductive health and human rights ......................... 146
   2.1. Introduction ................................................. 146
   2.2. Reproductive autonomy ................................. 147
   2.3. Right to respect for privacy and family life ............... 149
   2.4. The prohibition of discrimination ....................... 149

3. Family planning ............................................... 149
   3.1. Abortion ..................................................... 150
      3.1.1. The UN Conventions .................................. 150
      3.1.2. The European Convention on Human Rights ......... 152
            a. The balancing of interests between woman and foetus ... 152
            b. The balancing of interests between woman and state ... 155
            c. The balancing of interests between woman and man .... 158
   3.2. Contraception .............................................. 160

4. Procreative healthcare services .................................. 161
   4.1. Fertility treatment ....................................... 162
      4.1.1. A privacy issue? ...................................... 162
      4.1.2. Access to treatment? ................................. 164
   4.2. Embryo and foetus selection ................................ 169

5. Pregnancy, health and autonomy .................................. 174
   5.1. Maternal and foetal health ............................... 174
   5.2. Forced treatment of pregnant women ...................... 175

6. Concluding remarks ............................................ 176

Chapter 6. Euthanasia and Physician-Assisted Suicide from a Human Rights Perspective
Jozef Dorscheidt ............................................. 177

1. Introduction ..................................................... 177

2. Terminology ..................................................... 178
4. Health inequalities affecting children ................................................. 231
5. State obligations to provide equitable access to healthcare for children ... 232
   5.1. The Biomedicine Convention .................................................. 232
   5.2. The Charter of Fundamental Rights of the European Union .......... 234
   5.3. Special focus on children and accessibility of healthcare services and information ............................................................. 235
6. Health protection and promotion.................................................... 238
   6.1. The European Social Charter (ESC) ......................................... 238
       6.1.1. Overview ......................................................................... 238
       6.1.2. General provisions ............................................................ 239
       6.1.3. Child-specific provisions .................................................... 241
   6.2. EU regulation ........................................................................... 242
       6.2.1. The Charter of Fundamental Rights .................................. 242
       6.2.2. The Treaty on the Functioning of the European Union .... 243
7. Implementation of the right to health for children: challenges and strategies ............................................................................. 244
8. Conclusion: human rights not a matter of choice but of legal requirement ..................................................................................... 246

Chapter 9. The Rights of Persons with Disabilities in the Context of Healthcare
   Oddný Mjöll Arnardóttir ................................................................. 249
1. Introduction .................................................................................... 249
2. Disability and health ..................................................................... 250
3. Non-discrimination and accessibility ............................................. 253
4. Mental disability and autonomy ...................................................... 257
   4.1. Placement in institutions ............................................................ 258
   4.2. Treatment .................................................................................. 263
       4.2.1. General principles .............................................................. 263
       4.2.2. Compulsory medical treatment ............................................ 265
       4.2.3. The protection of persons not able to consent .................... 268
5. Concluding remarks ...................................................................... 271

Chapter 10. The Right to Health Protection for the Elderly: Key Elements and State Obligations
   Henriette Sinding Aasen ................................................................. 273
1. Introduction .................................................................................... 273
2. Legal sources and starting points ................................................... 276
3. Other important instruments ........................................................... 277
4. Health concerns and ‘ageism’ .......................................................... 279
5. Maltreatment and serious neglect: application of Article 3 ECHR .... 281
6. Right to health protection for older persons: State obligations 283
  6.1. Overview 283
  6.2. The Biomedicine Convention and equitable access to appropriate healthcare 283
      6.2.1. Starting points 283
      6.2.2. ‘Equitable access’ 284
      6.2.3. ‘Appropriate healthcare’ 288
      6.2.4. Respect, protect, fulfil: recommendations for actions 290
  6.3. The European Social Charter and health protection for the elderly 292
      6.3.1. General provisions: Article 11 292
      6.3.2. General provision: Article 13 293
      6.3.3. General provisions: Articles 14, 30 and 31 295
      6.3.4. Provisions directed towards older persons 295
  6.4. The EU Charter of Fundamental Rights and the right to health protection 297
  7. Final remarks 298

PART IV.
CONCLUSIONS, CHALLENGES AND RECOMMENDATIONS

Conclusions
Brigit Toebes 303
ABOUT THE EDITORS 
AND CONTRIBUTORS

Oddný Mjöll Arnardóttir (PhD) is a Professor in human rights law at Reykjavik University, Iceland. Her main research interests are human rights jurisprudence, non-discrimination law, disability rights and health law. Her publications include Equality and Non-Discrimination under the European Convention on Human Rights (Martinus Nijhoff 2003), The UN Convention on the Rights of Persons with Disabilities – European and Scandinavian Perspectives (ed., with Gerard Quinn and Martinus Nijhoff 2009), and numerous edited book chapters and articles. She currently holds the post of President of the Board of the Icelandic Human Rights Centre.

Jozef Dorscheidt (PhD) is a senior lecturer in health law, Faculty of Law, University of Groningen, the Netherlands, and board member of the Groningen Centre for Children’s Rights in Health Care. Furthermore, he is an alternate judge at the District Court in Groningen, and alternate legal member of the Dutch Central Commission on Research involving Human Subjects. His research interests involve the legal position of the child in healthcare, health law matters at the beginning and the end of life, and the regulation of medical research on humans.

Mette Hartlev (PhD and LL.D) is a Professor in health law at the University of Copenhagen, Denmark. Her main research interests are health law and patients’ rights, with a special focus on right to health in EU law and international law. She has also researched and published in the field of biolaw and bioethics and law, science and technology studies. She has participated in a number of EU-funded cross-disciplinary research projects, and is a member of the editorial board of European Journal of Health Law.

Aart Hendriks (PhD) is a Professor in health law at Leiden University/Leiden University Medical Centre (LUMC); a health law advisor to the Royal Dutch Medical Association (KNMG); a substitute judge at the District Court of Rotterdam; a Member of the Group of specialists on predictivity, genetic testing and insurance of the Council of Europe; a board member of various national and international non-governmental organisations (NGOs) working in the field of health, disability and human rights law; and an editor of several academic
journals. He obtained his Ph.D. from the University of Amsterdam (UvA) on a dissertation concerning the right of persons with disabilities to equal access in the employment market, and has written extensively on such issues as human rights, health law, minority rights and patients' rights.

Janne Rothmar Herrmann (PhD) is an Associate Professor in biolaw at the Faculty of Law of Copenhagen University. Her research interests include biolaw & bioethics, reproductive rights, conscientious objections, beginning and ending of life, and privacy & technology. She is a Member of the Nordic Committee on Bioethics by appointment by the Nordic Council of Ministers, and is currently an elected Member of the Board of Directors of the European Association of Health Law.

Henriette Sinding Aasen (dr. juris) is professor at the Faculty of Law at the University of Bergen, Norway. She is currently the coordinator of the University of Bergen’s research programme on the Rule of Law and Democracy. Her current research activities are in the area of health and human rights, vulnerable groups (children, immigrants, women), constitution and welfare state. She has participated in several national law commissions in the area of health, human rights and biomedical research, and is currently leading three interdisciplinary research projects funded by the Norwegian Research Council (Juridification and social citizenship; Constitution, welfare state and citizenship; Health promotion, dignity and human rights: the improvement of maternal health in Tanzania).

Karien Stronks (PhD) is professor of social medicine at the Academic Medical Center (AMC) /University of Amsterdam (UvA), and head of the department of Public Health of the AMC. Her main research interests are inequalities in health caused by socioeconomic status, as well as ethnic background, and the effectiveness of interventions and policies tackle these inequalities.

Brigit Toebes (PhD) is a lecturer in international law at the Faculty of Law of the University of Groningen. She previously worked as a lecturer at the University of Aberdeen School of Law, after which she was based as an external lecturer and consultant in Copenhagen. Her PhD research, which she conducted at Utrecht University, involved the definition of health as a human right (Intersentia 1999). Her research interests are public international law, human rights law, economic, social and cultural rights and the definition of health as a right, health law, and medical ethics. She is a Board Member of the International Federation of Health and Human Rights Organisations (IFHHRO).
LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Biomedicine Convention’</td>
<td>Convention on Human Rights and Biomedicine (CoE)</td>
</tr>
<tr>
<td>CAT</td>
<td>Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (UN, 1984)</td>
</tr>
<tr>
<td>CEDAW</td>
<td>Convention on the Elimination of All forms of Discrimination Against Women (UN, 1979)</td>
</tr>
<tr>
<td>CIE</td>
<td>Committee of Independent Experts (ESC, CoE)</td>
</tr>
<tr>
<td>CoE</td>
<td>Council of Europe</td>
</tr>
<tr>
<td>CPT</td>
<td>European Convention for the Prevention of Torture (CoE, 1987)</td>
</tr>
<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities (UN, 2006)</td>
</tr>
<tr>
<td>CSDH</td>
<td>Committee on the Social Determinants of Health (WHO)</td>
</tr>
<tr>
<td>EC Treaty</td>
<td>Treaty establishing the European Community (EU, 1993)</td>
</tr>
<tr>
<td>ECFR</td>
<td>Charter of Fundamental Rights of the European Union (EU, 2000)</td>
</tr>
<tr>
<td>ECtHR</td>
<td>Convention for the Protection of Human Rights and Fundamental Freedoms (CoE, 1950)</td>
</tr>
<tr>
<td>ECJ</td>
<td>European Court of Justice</td>
</tr>
<tr>
<td>EComHR</td>
<td>European Commission of Human Rights</td>
</tr>
<tr>
<td>ECSR</td>
<td>European Committee of Social Rights (ESC, CoE)</td>
</tr>
<tr>
<td>ECtHR</td>
<td>European Court of Human Rights (CoE)</td>
</tr>
<tr>
<td>ESC</td>
<td>European Social Charter (CoE, 1961)</td>
</tr>
<tr>
<td>EU</td>
<td>European Union</td>
</tr>
<tr>
<td>GC</td>
<td>Grand Chamber (of the ECtHR)</td>
</tr>
<tr>
<td>GC 14</td>
<td>General Comment 14 to the ICESCR (on the right to health) (UN, 2000)</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>ICCPR</td>
<td>International Convention on Civil and Political Rights (UN, 1966)</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>ICERD</td>
<td>International Convention on the Elimination of All Forms of Racial Discrimination (UN, 1965)</td>
</tr>
<tr>
<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights (UN, 1966)</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ILO</td>
<td>International Labour Organization</td>
</tr>
<tr>
<td>MIPAA</td>
<td>Madrid Political Declaration and International Plan of Action on Ageing (UN)</td>
</tr>
<tr>
<td>MWC</td>
<td>International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (UN, 1990)</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Co-Operation and Development</td>
</tr>
<tr>
<td>‘Oviedo Convention’</td>
<td>Convention on Human Rights and Biomedicine (CoE)</td>
</tr>
<tr>
<td>PAS</td>
<td>Physician assisted suicide</td>
</tr>
<tr>
<td>(Revised) ESC</td>
<td>(Revised) European Social Charter (CoE, 1996)</td>
</tr>
<tr>
<td>TEU</td>
<td>Treaty of the European Union (EU, 1992)</td>
</tr>
<tr>
<td>TFEU</td>
<td>Treaty on the Functioning of the European Union (EU, 2007)</td>
</tr>
<tr>
<td>UDHR</td>
<td>Universal Declaration of Human Rights (UN, 1948)</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNECE</td>
<td>UN Economic Commission of Europe</td>
</tr>
<tr>
<td>UNESCO</td>
<td>UN Educational, Scientific and Cultural Organisation</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WMA</td>
<td>World Medical Association</td>
</tr>
</tbody>
</table>