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Nicola Lucchi

# The Impact of Science and Technology on the Rights of the Individual

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# Foreword

Advances in information technology and biosciences have undoubtedly provided for a better information infrastructure and quality of life for many people, but at the same time they brought with them a number of new challenging regulatory issues. The legal response to these developments has been a subject of global controversies and litigations in numerous courts and still remains an unresolved issue. In addition, a relatively new phenomenon is occurring in the field of scientific and technology regulation: constitutional provisions in general and fundamental rights in particular are increasingly considered by courts as a measurement for determining potential threats and impacts deriving from scientific and technology issues. This increasing trend is quite evident not only from the growing scholarly works highlighting the human rights dimension on techno-scientific aspects but also from a relevant and expanding number of international documents "laying down principles to guide and regulate technological development that are openly based upon human rights norms".[1]

This book investigates the conflict between technology, scientific advances and fundamental rights principles proposing alternative strategies and best practices for accessing and using informational assets.

Based on these premises, the manuscript aims to offer a critical and comparative analysis of the impact of science and technology on the rights of the individuals considering alternative regulatory regimes for digital and information goods. This is an increasingly complex area of regulation with a specifically global dimension and involving problems which cannot be resolved at the level of individual states. In this

[1] See Roger Brownsword and Morag Goodwin, Law and Technologies of the Twenty-First Century 226 (2012). Among these relevant documents, see e.g. some recent reports issued by different Special Rapporteurs appointed by the United Nations Human Rights Council. See United Nations General Assembly, Human Rights Council, Report of the Special Rapporteur in the Field of Cultural Rights: The Right to Enjoy the Benefits of Scientific Progress and its Applications, Farida Shaheed, U.N. Doc. UA/HRC/20/26 (14 May 2012); United Nations General Assembly, Human Rights Council, Commission on Human Rights, Report by the Special Rapporteur on the Promotion and Protection of the Right to Freedom of Opinion and Expression, Frank La Rue, U.N. Doc. A/HRC/17/27 (16 May 2011).

context, the book aspires to identify and design a map of the changing nature of law and rights in the face of emerging issues in science and technology, discerning when rights are under stress and when they must be reasserted.[2] To achieve this goal, it covers a wide variety of issues – both theoretical and practical – exploring emerging controversies at the crossroads of law, science and technology ranging from patent implications in the area of personalized or precision medicine, to copyright and free speech issues arising on the Internet, to legal and ethical concerns surrounding new discoveries in the biosciences. In this scenario, the main objective of the book is to seek a better understanding of the role of law in the global regulation of innovative technologies. The overall approach will be to seek provocative parallels and analogies between the regulative rules of technologies for the biological and communicative fields: the so-called "meta-technologies of information".[3] This objective will be achieved through a case-based analysis on the global strategies for accessing and using essential public knowledge assets in the knowledge-based society and in the life sciences in general. Drawing upon comparative and case study material, the research also analyses the functional relationship between modern communication technologies, legislative reforms in the area of digital communications, biomedical innovations and their implications on individual rights and democratic principles. These are serious and sensitive issues which can have challenging consequences on global public health, biomedical ethics, freedom of speech, media freedom and media pluralism.

In addressing these thought-provoking questions, the book investigates ethical, legal and security aspects resulting from emerging technologies and regulatory policies. The law's intersection with science and technology is – in fact – representative of many challenging problems that are part of the EU legal order: tension between "rights" and "regulations" on the one hand, and between national heterogeneity and European harmonization on the other hand. These are two fruitful paths of investigation that make the manuscript an interesting contribution to a number of crucial legal and theoretical aspects within a range of different regulatory spheres: global, European and national. The manuscript looks at these issues in the context of European and North American jurisdictions.

The book is based on research projects undertaken over the past three years and conducted under the sponsorship of various research institutions.

Jönköping Nicola Lucchi
April 2016

[2] See Sheila Jasanoff, Rewriting Life, Reframing Rights, in Reframing Rights: Bioconstitutionalism and the Genetic Age 1, 9 (Sheila Jasanoff ed., 2011).

[3] See Biotechnology and Communication: The Meta-technologies of Information 3, (Sandra Braman ed., 2004).

# Preface

The rapid pace of scientific discoveries and the development of new technologies are creating new legal dilemmas intensifying calls for legislative solutions. At the centre of these dilemmas, there is often a tension between respecting the rights of the individual and the rights of the community. The impact of these innovations can also influence human behaviours, legal constraints and cultural values. At the same time, technological and scientific developments have also drawn attention to the necessity for new rights to be acknowledged or even old ones reinterpreted.

The question of the "new rights" has become a perennial theme. It is the result of a taxonomic trend that goes a long way back. This question has produced several classifications of "rights" ranging from those that distinguish between "negative" freedom and "positive" rights to those supporting the opposition between liberal rights and social rights or between rights with or without a cost, or even the periodization of the different "generations" of rights. Apparently, the emergence of new rights claims belongs to the last of these generations. This phenomenon greatly increased with the development of new technologies, especially in the area of biotech innovations and telecommunications. These technologies – in fact – interact with law, generating discussions for new rights claims or conflicts with existing rights.

In considering this vexed question, classifications and distinctions should be used to better understand the characteristics of the objects to which new and existing rights can be applied. But the different classifications of rights seem to operate in the opposite direction: in fact these classifications do not make clear, but often misrepresent the reality of rights, placing them in frameworks shaped by ideological sclerosis.

As noted by Forsthoff,[1] the rule of law does not arise from the liberal demand to protect the rights of individuals from the aggression of the public authorities, but it stems primarily from the need for individuals to find protection in the public power by the dominance of private individuals who hold economic and social power. *Homo homini lupus* is the Hobbesian condition from which the law of the state must take individuals to safety: this is also the reason why Thomas Hobbes is considered

[1] Ernst Forsthof, Der Staat der Industriegesellschaft (1971).

the "true father of the liberal constitutional state".[2] It is not surprising that the civil and the other national codifications anticipate the constitutionalization of the public institutions: the first request made to the enlightened sovereign by those who fear the predominant power of the stronger, was the legal regulation of the relationships between private parties.

If we look at the current challenge hinged on the recognition of new rights, the problem of the distinction between rights with a cost and rights that cost nothing has been successfully demystified by Holmes and Sunstein,[3] which have highlighted their deeply ideological nature. Holmes and Sunstein's main criticism concerning this distinction is that both these types of rights involve some degree of expenditure by the government. Therefore, all legal rights have costs (both economic and non-economic). Consequently, one of the key problems in deciding what rights individuals should have, is to consider whether they are worth those costs. Under such conditions, the claim of a new right involves considering whether a limitation of other conflicting right or interest is an equitable and reasonable solution.

The theme of the recognition of new rights is currently mostly related to the tangled jungle of "claims" that are being made in the areas of biological and life science, healthcare and information technology. Consider – for example – the categories of rights related to the sphere of biolaw, specifically all those rights claims related to the so-called life sciences or the care of the health of the human being. Along these lines, there is much talk over the reproductive health right, the right to a particular kind of treatment, the right to die with dignity, the right to refuse medical treatment, the right to have a healthy child, the prenatal eugenic right, the rights of the embryo and of the right to abortion, etc. Around the undefined concept of human dignity – often framed under the category of human rights – any kind of "right" generally associated with the phenomenon of globalization and multiculturalism can take shape. In the same way, there is an extensive catalog of "rights" claimable in relation to the development of the Internet and the digital communication technologies: it is here suffice to mention the right to access to knowledge, the right to communicate and the right to access the Internet.

In this context, it is hard to say to what extent the new phenomena that occur in social relationships or in the world of technology can really change the structure of the old rights, or whether they are simply a new perspective in which to view them. However, there is a trend that I see growing in the scientific literature on the issue of "new rights": it is a sort of parthenogenesis of new disciplines, namely the multiplication of new fields and subjects of specific study related to "new rights" and the technologies connected to them. At the same time, the need clearly emerges to study these issues entering the gray area between legal, and scientific or technological knowledge. In addition, the study on "new rights" often requires extensive encounter with scientific data, technological standards, and medical protocols, etc. All these aspects move the attention to factors and information that are not associated with some specific national domains but rather encourage the expansion of this type

[2] Carl Schmitt, The Leviathan in the State Theory of Thomas Hobbes: Meaning and Failure of a Political Symbol 71 (Schwab and Hilfstein trans., 1996).

[3] See Stephen Holmes & Cass R. Sunstein, The Cost of Rights: Why Liberty Depends on Taxes (1999).

of investigation to a cross-border dimension, rather than comparative. The resolution of these issues is increasingly losing relations to the laws of individual states while their treatment is becoming more connected to legislative or jurisprudential answers capable of circulating across different borders.

In this fragmented and complex environment, this book tries to highlight the connections between these various points indicating some of the most recent trends in science and technology policy and their interconnection with individual rights exploring controversies surrounding the creation of new rights claims.

Working with rights is a tricky business. The problem is that the recognition of new rights is a zero-sum game, because every progress in the acknowledgment of a new right often implies a step back of another right. For example, it may happen that to pay the price is the right of another individual (the right to fence off my land produces the limitation of the right of movement of other individuals) or a general interest (the right to carry arms reduces the safety of the community). In addition, in the human rights area admitting a new fundamental right would create downside risks connected to an over-extension of human rights protection. The paradox at the center of the human rights discourse is that the uncontrolled proliferation "of new rights would be much more likely to contribute to a serious devaluation of the human rights currency than to enrich significantly the overall coverage provided by existing rights".[4] In other words, an excessive and uncontrolled proliferation of new rights claims can lead to the erosion of their importance and credibility as well as of the effectiveness of their protection and enforcement.

Any limitation to the enjoyment of a right is justified only on the basis of the need to safeguard rights of other individuals or collective interests. The method of balancing different conflicting values is part of the intrinsic nature of rights, at least in a pluralist constitutional order in which there are no absolute rights or "non-negotiable values". The balancing exercise includes the assessment of the reasonableness of the limits and of the proportionality between the compression of a right and the advantage secured to a competing right or interest. This is increasingly recognized as a constitutional dilemma, and courts and legislatures are more and more called upon to consider these questions.

When we look at a limitation of a right – without considering the category to which it belongs – the questions are always the same: Is this limitation reasonable? What is the competing interest? Is the competing interest appreciable? Is the competing interest proportionate to the sacrifice required? These are the questions we should ask whenever a claim for a new right is made. The merit of this book is to go hunting for these conflicting interests and competing values, making interesting discoveries and finding interesting patterns.

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[4] See Philip Alston, Conjuring Up New Human Rights: A Proposal for Quality Control, 78 American Journal of International Law 607, 614 (1984).

# Acknowledgements

This work constitutes the final, comprehensive and exhaustive outcome of previous studies essentially based on a project entitled "The Global Governance of Access to Knowledge: An Interdisciplinary and Comparative Research" undertaken and conducted under the sponsorship of a EU Marie Curie Post-doctoral Fellowship at the Université catholique de Louvain (Belgium) funded by the Marie Curie Actions of the European Commission. The work performed during the fellowship was an opportunity to explore and evaluate the concrete and potential consequences of bio and digital technologies on the global intellectual property regime and the tensions between exclusive private rights, individual legal rights and essential public knowledge assets. The research was then further developed and implemented at Jönköping University International Business School (Sweden) where I am currently tenured as an associate professor in law.

Writing this book helped me to put together two topics about which I am passionate, working on emerging scientific and technological developments and their associated regulatory implications. It also allowed me to revisit, implement, combine and refine ideas described in some of my earlier works. In order to complement this objective, the investigation seeks not only to develop the analytical and theoretical apparatus further, but also to review the current research frontline and stimulate cross-disciplinary approaches. On this terrain, the book extensively discusses cross-cutting research conducted and published by a broad range of scholars and civil rights activists, who pursue diverse methodologies. Extensive citations supplement this controversial debate within the body of research that focuses on these issues. This means that some sections of this book are heavily footnoted. My intention is for this book to assist readers by also providing a compilation and reference resources.

A number of the ideas and arguments in this book were first presented, discussed and tested out in the following public research seminars and conferences: Biotech Innovations & Individual's Rights Conference, University of Ferrara, Ferrara (20–21 January 2011, Italy); the conference on the "Impact of Biotechnological Innovations on Human Society", University of Trento, Trento (17 and 18 May 2012, Italy); the 5th International Conference on Information law and ethics, Ionian

University, Corfu (29–30 June 2012, Greece); the research seminar held at Jonkoping International Business School, Jonkoping (19 June 2012, Sweden); the 1st Global Thematic IASC Conference on the Knowledge Commons, Université catholique de Louvain, Louvain-la-Neuve (12–14th September 2012, Belgium); the Intellectual Property and Human Rights Conference and Roundtable Discussion, American University Washington College of Law, Washington DC (21–22 February, 2013, USA); the Italian-Spanish conference on constitutional law on "The new guiding principles for protection of individual rights", University of Bologna – Real Colegio de España en Bologna, Bologna (3–4 May 2012, Italy); the Workshop on Biodiversity governance and social innovations: taking the legal, governance and epistemological agenda forward- 7th to 9th of October 2013 – Université catholique de Louvain, Collège Thomas More, Louvain-la-Neuve (Belgium); the 22th Biennial Conference of the Italian Association of Comparative Law University of Salerno, Salerno, May 30–June 1, 2013 (Italy); the conference on Pluralism in the Age of Internet – European University Institute – Florence School of Regulation, Florence (8 November 2013 – Italy); XXI International Conference in Law and the Human Genome, May 14, 2014 – Universidad de Deusto & Universidad del País Vasco, Bilbao (May 14, 2014, Spain); IXth AIDC-IACL World Congress on "Constitutional Challenges: Global and Local", Oslo (16–20 June 2014 – Norway); Sixth Annual Conference on Innovation and Communications Law – University of Leeds, Leeds (2–3 July 2014 – England); 2nd Thematic Conference on Knowledge Commons: Governing Pooled Knowledge Resources, NYU School of Law, New York (5–7 September, 2014, USA).

I have benefited greatly from the comments of participants at all these meetings. They are too numerous to mention here, but without their helpful criticism and valuable insights this work would not have been completed in such an inspiring way.

So many people have helped, guided and inspired me during this research study. First of all, for his invaluable and constructive guidance on my Marie Curie project and his generous support of my work, I am most grateful to Tom Dedeurwaerdere. I have learned much from him and I am really indebted for his fruitful collaboration, valuable advice and inspiration to my research activity. I am also grateful for his trust and constant encouragement. Tom and all my former colleagues at the Université catholique de Louvain have been wonderfully supportive of my work. I am then especially grateful to all the friends and colleagues that read, criticized, discussed or suggested improvements to parts and topics of the manuscript during the long course of its composition: Fulya Batur, Marco Bassini, Filippo Benelli, Iñigo de Miguel Beriain, Roberto Bin, Enrico Bonadio, Carlos María Romeo Casabona, Ricardo Chueca, Brendan Coolsaet, Tom Dedeurwaerdere, Carla Faralli, Mathieu Guillermin, Guido Margutti, Giuseppe Mazziotti, Sylvie Nérisson, Mart Ots, Simone Penasa, Oreste Pollicino, Monroe Price, Arul George Scaria, Silvia Schiavo, Carol-Ann Soames, Paolo Sommaggio, Lars-Göran Sund, Stefan Verhulst, Paolo Veronesi and Eric Welch.

For suggestions on how improve some sections of the manuscript, I am finally grateful to the comments provided by the Springer anonymous referees on the

penultimate draft of this book that enabled me to make many valuable final edits and improvements to the manuscript.

This book would not have been possible without the active and generous support of my current home institution – Jonkoping University International Business School – and the wonderful people with whom I have now the privilege of working.

I express my gratitude to all these people, but all errors and omissions remain my own.

# Contents

# List of Abbreviations

| | |
|---|---|
| ACLU | American Civil Liberties Union |
| ACTA | Anti-Counterfeiting Trade Agreement |
| CDA | Communications Decency Act |
| CJEU | Court of Justice of the European Union |
| DNA | Deoxy-ribo-Nucleic Acid |
| ECHR | European Court of Human Rights |
| EFPIA | European Federation of Pharmaceutical Industries and Associations |
| EPO | European Patent Office |
| EUCFR | European Union Charter of Fundamental Rights |
| EST | Expressed Sequence Tag |
| GR | Genetic Resource |
| HADOPI | Haute Autorité pour la Diffusion des Oeuvres et la Protection des Droits sur l'Internet |
| IP | Intellectual Property |
| IPR | Intellectual Property Right |
| ISP | Internet Service Provider |
| JPO | Japan Patent Office |
| OECD | Organization for Economic Cooperation and Developement |
| RNA | Ribo-Nucleic Acid |
| USC | United States Code |
| USPO | United States Patent Office |
| WIPO | World Intellectual Porperty Organization |
| WTO | World Trade Organization |

# Journal Title Abbreviations

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|---|---|
| Alb. L.J. | Albany Law Journal of Science & Technology |
| Alb. L. Rev. | Albany Law Review |
| Am. J. Comp. L. | American Journal of Comparative Law |
| Am J. Int'l L. | American Journal of International Law |
| Am. U. L. Rev. | American University Law Review |
| Ann. Surv. Int'l & Comp. L. | Annual Survey of International & Comparative Law |
| Berkeley J. Int'l L. | Berkeley Journal of International Law |
| Berkeley Tech. L. J. | Berkeley Technology Law Journal |
| B.C. Int'l & Comp. L. Rev. | Boston College International and Comparative Law Review |
| B.C. J.L. & Soc. Just. | Boston College Journal of Law and Social Justice |
| Brook. L. Rev. | Brooklyn Law Review |
| Brook. J. Int'l L. | Brooklyn Journal of International Law |
| Buffalo L. Rev. | Buffalo Law Review |
| B.U. J. Sci. & Tech. L. | Boston University Journal of Science & Technology Law |
| B.U. L. Rev. | Boston University Law Review |
| Cal. L. Rev. | California Law Review |
| Cardozo Arts & Ent. L.J. | Cardozo Arts & Entertainment Law Journal |
| Cardozo J. Int'l & Comp. L | Cardozo Journal of International & Comparative Law |
| Cardozo L. Rev. | Cardozo Law Review |
| Case W. Res. | Case Western Reserve Law Review |
| Chi.-Kent J. Int'l & Comp. L. | Chicago-Kent Journal of International and Comparative Law |
| Chi.-Kent L. Rev. | Chicago-Kent Law Review |
| Civ. Rts. L.J. | Civil Rights Law Journal |