Introduction

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This handbook intends to offer a comprehensive and authoritative overview of the human rights implications of emerging technologies in the fields of life sciences and information and communication technologies (ICT). To this end, the volume brings together leading experts whose expertise encompasses several disciplinary domains (law, ethics, technology, basic science, medicine, business etc.) with the purpose of gathering extensive multidisciplinary knowledge about the evolutive transformation of the human rights framework in response to technological innovation.

In particular, the aim of this volume is threefold. First, it aims to provide a comprehensive state-of-the-art report on emerging technologies that are likely to transform the human rights framework in the upcoming decades. Second, this collection of essays aims to raise awareness of the ethically and legally appropriate implementation of these technologies and to identify possible critical issues that arise or might arise in the context of their application. Third, and ultimately, the volume intends to contribute to the development of a robust, inclusive and anticipatory human rights framework that can guide global societies across the ongoing digital transformation. In doing so, special attention is devoted to promoting policies and regulatory frameworks that foster the inalienable rights of individuals and the prevention of potential inappropriate uses or abuses of emerging technologies.

The chapters presented in this volume have been organized into three parts. Part I deals with the human rights implications of emerging technologies in the life sciences, with special focus on biotechnology, neurotechnology and medical robotics. Each contribution analyses one specific biotechnological domain and the associated rights. Part II does the same in the context of information and communication technology (ICT). Finally, Part III aims to integrate the domain-specific analyses contained in Parts I and II into a broader examination of the current and future techno-legal conjuncture.

Chapter 1, authored by Laura Liguori, Oreste Pollicino and Elisa Stefanini, focuses on mHealth, that is, mobile and wireless technologies for the improvement of health outcomes. The contribution highlights that the mass use of these technologies is raising many challenges to national and European legislators, who are now faced with a twofold task: ensuring the safety, security and reliability of the data generated by these products and protecting the privacy of patients and consumers. From the first perspective, such software may sometimes be classified as a medical device, although this classification is not always easy as there may be 'borderline products'. If software is classified as a medical device, then its safety and efficacy are guaranteed by the applicability of relevant regulations, which dictate specific prerequisites, obligations and

responsibilities for manufacturers and distributors. From a data protection perspective, the massive use of these technologies allows the collection of huge amounts of personal data, both sensitive data (e.g., relating to health) and data that are not sensitive per se but can nonetheless contribute to the creation of detailed user profiles. Considering these needs, an integrated approach suggests assessing compliance with data protection regulation as one of the requirements to ensure the safety and security of software as a medical device.

In Chapter 2, Emily Einhorn and Rafael Yuste focus on the specific human rights implications raised by novel neurotechnologies. This set of human rights applied to the neurotechnology domain is increasingly referred to in the ethical-legal literature as well as in international policy under the umbrella term 'neurorights'. The neurorights they propose protect mental privacy, mental freedom and fair access to neuroenhancement. The authors also discuss research and advocacy in the field of neurorights, including the recent proposal for an amendment to the Chilean Constitution and neuroprotection bill. Further, they outline a proposal for the regulation of neurotechnology based on a medical model.

The protection of the human mind, broadly conceived, is also the central theme of Chapter 3, written by Sjors Lightart, Gerben Meynen and Thomas Douglas. This chapters provides an extensive and critical discussion about persuasive technologies and the right to mental integrity. The authors note that medical ethics, medical law and human rights protect us from technological manipulation of our bodies: for instance, through the recognition of a right to bodily integrity. Accordingly, they argue that they might also protect people against technological manipulation of their minds by recognizing a right to mental integrity: that is, a right against interference with the mind. In particular, the chapter describes some of the recent developments in the areas of persuasive and monitoring technologies, and discusses how these technologies are currently used (e.g., in criminal justice and on the Internet). In doing so, the authors survey existing and proposed novel human rights regulations relevant to the right to mental integrity. Moreover, the authors consider how existing law and philosophical scholarship might help to resolve the question of which persuasive and monitoring technologies would infringe the right to mental integrity.

In Chapter 4, Hrefna D. Gunnarsdóttir, Glenn Cohen, Timo Minssen and Sara Gerke discuss the ethical and legal implications of biomedical big data. The authors start from the consideration that the COVID-19 pandemic has highlighted that leveraging medical big data can help to better predict and control outbreaks from the outset. However, they note that there are still challenges to overcome in the twenty-first century to effectively leverage big data for medical and public health purposes while at the same time adequately protecting the privacy of individuals and groups. The metaphor that property is a 'bundle of sticks', each representing a different right, applies to biomedical big data. Understanding biomedical big data in this way raises a number of questions, including, Who has the right to make money off buying and selling data? Are data inalienable? When is biomedical big data sufficiently devoid of identifiers that an individual's rights in relation to the data disappear? How have regimes such as the General Data Protection Regulation (GDPR) in Europe and the Health Insurance Portability and Accountability Act in the United States answered these questions differently? On this basis, the chapter uses examples related to the use of medical big data during the COVID-19 pandemic and discusses the ethical and legal challenges related to the following three issues (1) privacy and data sharing, (2) informed consent and (3) ownership.

In Chapter 5, Judit Sandor discusses the right to have a child in the context of the latest developments in assistive reproductive technologies. According to the author, while no one can

be legitimately deprived of the right to have a child, this claim does not equate to claiming a positive right to have a child. This issue has become more complicated since the first in vitro baby was born in 1978, and since then more and more new reproductive technologies have been developed. Ethical dilemmas arise when in vitro fertilization involves donated gametes, or when the mother-to-be needs a surrogate mother because she does not have a womb. Legal regulation of surrogacy arrangements varies from outright prohibition to acceptance, or is simply silent on their legitimacy. In this varied legal landscape, Sandor discusses the ethical legal framework of requests for access to the latest reproductive services, including those technologies that replace or transplant the human uterus.

In Chapter 6, Robin L. Pierce and Eduard Fosch-Villaronga provide a contextual analysis of medical robotics and the right to healthcare. Their chapter critically discusses the extent to which technology that promises to improve health outcomes should be made available, to whom and on what basis. Given that countries typically have limited resources to foster access to cutting-edge robotic technologies and develop strategies to progressively realize the right to health, the authors investigate whether the right to health, particularly the fundamental obligations specified in this right, can facilitate the implementation of medical robots.

Federico Pizzetti's Chapter 7 focuses on life-sustaining technologies and the right to die, analysing the origins of this right and its intersections with the development of life-sustaining technologies in medicine. His analysis distinguishes between a right to refuse (actual or through a living will) medical support and the recognition of some form of active aid to suicide, considering the main elements of the American, Canadian, European (EU) and Chinese legal frameworks.

Another important application of technology to healthcare is telemedicine, which is addressed in Carlo Botrugno's Chapter 8. The author analyses the risks and benefits of the diffusion of telemedicine in daily practice. Although it was initially conceived as a means of overcoming geographic barriers and addressing emergency situations, the spread of telemedicine into everyday practice is reshaping the most intimate features of medical practice and shifting organizational models in healthcare. Proponents of telemedicine argue that it will reshape the accessibility of healthcare, improving service quality and optimizing costs. However, the use of telemedicine raises several ethical, legal and social issues, an overview of which is given in this chapter. The chapter also provides concluding thoughts on the role of telemedicine in COVID-19 emergency care management.

Part I concludes with a contribution by Belinda Bennett and Bernadette Richards (Chapter 9) that focuses on reproductive technologies and reproductive rights from a legal and ethical perspective. The chapter begins by examining the evolving nature of reproductive rights, situating these rights within broader debates about health and human rights. The chapter also considers the role of developments in assisted reproductive technology in shaping debates about rights. In analysing the evolution of rights in the context of assisted reproduction, the chapter explores the role of ethics within regulatory debates about assisted reproduction, the issue of access to assisted reproduction and the globalization of healthcare, including health tourism, and its relevance to assisted reproduction. The analysis of each of these areas also includes considerations of the putative role of the law in defining reproductive rights.

Part II deals with the interaction between human rights and information and communication technologies (ICTs). This section opens with Chapter 10 by Oreste Pollicino on the right to internet access from a comparative constitutional perspective. The author focuses on the question of whether the right to internet access can be considered a human right (or a

fundamental right) that enjoys semantic, conceptual and constitutional autonomy. In other words, the main issues at stake concern whether internet access is an autonomous right or only a precondition for enjoying other rights (freedom of expression, among others) and why classification as an autonomous or derivative right matters. In addition, the author reflects on whether the proliferation and flourishing of rights and covenants, which are subject to multilevel protection at the constitutional, EU and ECHR levels along with the growing number of ad hoc Internet Bills of rights, is generally achieving the result of increased protection of the rights in question. The author concludes his chapter by addressing the question of whether the increase in the number of rights may, paradoxically, amplify the risk of constitutional collisions, thus ultimately leading to a decrease in the protection of those rights.

In Chapter 11, Clare Garvie discusses the issue of face recognition and the right to remain anonymous. Freedom of expression and association are both fundamental human rights and necessary for the promotion and protection of other rights. In many contexts, anonymity is essential to the realization of these rights, providing citizens with the ability to speak without fear of retribution. However, while there is a growing recognition of the importance that anonymity plays in enabling free expression and association in the online world, debates about the right to remain anonymous in the physical world have lagged. The widespread application of facial recognition technology by governments around the world poses a threat to anonymity in public spaces by enabling remote and covert identification. This chapter examines existing international and domestic legal frameworks that can be mobilized to prevent the erosion of anonymity in public. It then offers considerations for rebalancing the right to anonymity against public safety interests in identification in light of facial recognition and other biometric surveillance technologies.

Marc Rotenberg addresses in Chapter 12 the interplay between artificial intelligence (AI) and the right to algorithmic transparency. The author considers this right the most urgent goal for AI regulation, as it will become a critical indicator of the health of democratic societies in the years to come. Algorithmic transparency is the foundation of machine accountability and the cornerstone of policy frameworks that regulate the use of AI techniques. The goal of algorithmic transparency is to ensure accuracy and fairness in decisions that affect individuals. This is particularly important in the criminal justice system, as opaque determinations are necessarily at odds with principles of fairness and due process. AI techniques can replicate biases and, depending on the types of AI techniques and their degree of mechanistic opacity, such biases can be difficult to detect and control. However, the principle of algorithmic transparency remains important in a wide range of areas. Credit determinations, employment evaluations, educational tracking, as well as government benefit decisions, border crossings, communications surveillance and even inspections at sports stadiums increasingly rely on black box techniques that produce results that are unexplained, opaque and often unfair. Even the organizations that rely on these methods often do not fully understand their impact or weaknesses. The author reviews recent developments in algorithmic transparency, examines key policy frameworks, highlights related cases in the United States, notes related transparency provisions in data protection law and proposes further steps.

In Chapter 13, Lee A. Bygrave focuses on a popular approach to AI, namely machine learning, and reflects on its implications for cognitive sovereignty and data protection rights (especially as they relate to automated decisions). Human behaviour is increasingly governed by automated decision making systems based on machine learning (ML) and big data. While these systems promise a number of benefits, they also raise a number of challenges, not least to our ability as

humans to understand their logic and ramifications. This chapter traces the basic mechanics of such systems, the concerns they raise and the degree to which these concerns can be addressed by data protection law, particularly those provisions of the EU General Data Protection Regulation that specifically address automated decision making. Drawing on the work of Ulrich Beck, the chapter employs the notion of 'cognitive sovereignty' to provide a general conceptual framing of the topic. Cognitive sovereignty essentially denotes our moral and legal interest in being able to understand our surroundings and ourselves. By focusing on this interest, the chapter fills a blind spot in scholarship and policy discourse on ML-enhanced decision making systems and is vital to grounding calls for greater explainability of machine processes.

Peggy Valcke and Simon Verschaeve discuss in Chapter 14 the right to be forgotten, with reference to search engines and press archives. Indeed, since the CJEU's May 2014 ruling in the Google Spain case (also known as the Costeja case), the 'right to be forgotten' on the Internet has been the subject of heated debate in Europe and beyond. The term was coined by Viktor Mayer-Schönberger in his seminal 2009 book *Delete: The Virtue of Forgetting in the Digital Age* and was taken up by the European Commission in its 2012 draft General Data Protection Regulation (the GDPR also refers to it in the title of Article 17 and in several recitals). The chapter begins by noting that two key disseminators of information in the digital age have been subjected to new responsibilities under the umbrella of the 'right to be forgotten'. The desire of some individuals to change and exercise control over their online image has led them to turn to the media that made their personal information initially available online, or to the search engines that subsequently brought it to the general public, or both. However, these paths differ significantly from one another. This chapter analyses the extent to which the application of the 'right to be forgotten' – as applied in the EU – differs between these two types of actors. First, it takes stock of the right to de-link that sparked the CJEU's landmark ruling in Google Spain and discusses subsequent CJEU cases. Next, it lays out the broader right to deletion in the thorny context of the press and its archives. Since balancing is a key element, a key role is reserved for the jurisprudence of the European Court of Human Rights. The author concludes that EU data protection law does not allow for a general assessment of which route is best suited for the purpose and provides recommendations that should guide individuals when seeking the state of being forgotten.

In Chapter 15, Ronny Bogani and Burkhard Schafer discuss the relationship between artificial intelligence and children's rights. The authors propose using artificial intelligence to rethink the place of the child in society. Advances in digital technology and applied statistical analysis offer an opportunity to remove the widely held view of the child either as a potential victim to be protected at all costs, even if it comes at the expense of full participation, or as an inferior rights holder without genuine agency. In the current position, the child's power is derived from parents or legal guardians. This currently accepted derivative power structure limits the child's autonomy to exercise power independently of the parent. This 'power borrowing' structure may have been successful in the past. However, technological advances and the modern child's dependence on digital resources call for a re-examination of this parent-based derivative power structure. This chapter addresses the transformative effects of the digital revolution on children's rights and discusses the compatibility and applicability of AI and its potential impact on children's rights, as well as the revolutionary analytical and predictive capabilities of machine learning (ML) and AI in this context. At the end of this chapter, and in line with this conceptual framework, a brief report by Bobby Soobrayan and Sarah Fuller (UNICEF) informs the reader about UNICEF's ECARO programme, the main purpose of which is to leverage digital

technology and e-learning to support continuity of learning for children and promote the right to education globally.

In Chapter 16, James Scheibner, Anna Jobin and Effy Vayena focus on Internet of Things devices, citizen science research and the right to science from an ethical and legal perspective. They note that although lay participation has long been a feature of scientific research, the last few decades have seen an explosion in the number of citizen science projects. At the same time, the number of low-cost networked devices, known collectively as Internet of Things (IoT) devices, has proliferated. In concert, these two trends have seen a paradigm shift in scientific practice, with citizen scientists able to collect large amounts of scientific data with relative ease. However, there is limited guidance on how researchers should resolve the ethical and legal issues they encounter during their research. Furthermore, the increased use of Internet of Things devices in citizen science has coincided with a reconsideration of the right to science under international law. In this chapter, the authors first describe the origins and boundaries of the right to science, as well as its relevance to citizen science. Then they use the results of a scoping review to examine three main ethical and legal issues for the use of Internet of Things devices in citizen science. These ethical issues are data protection and privacy, data quality and intellectual property rights. Finally, they explain how the right to science can help inform citizen science research conducted with Internet of Things devices and address ethical issues.

Part II is concluded by Sofia Ranchordás' (Chapter 17) reflections on digital exclusion beyond Internet access. Digital government has enabled the automation of many public services and improved the efficiency and openness of public administration. However, for senior citizens, undeserved communities and individuals with low literacy and limited digital skills, the shift to government portals, online payments and smartphone apps remains significantly limited and does not facilitate interactions with public authorities. The author argues that digital inequality diminishes vulnerable citizens' rights twice: first, their ethnicity and socioeconomic status may be conducive to a 'negative' ranking or score (e.g., higher risk of welfare fraud); and second, they are also excluded because they lack adequate access to technology, are not well informed and lack the time and skills to interact with digital government. This chapter explores one of the paradoxes of the digital society: connected citizens in developed countries are also affected by the digital divide and are increasingly excluded from the widespread digitization of public services. Drawing on an interdisciplinary literature review, this chapter contributes to the legal literature with an account of the underlying causes of digital exclusion and a discussion of its most relevant legal implications through the lens of fundamental rights (e.g., due process, equal treatment) and principles of good administration.

Finally, the third and last part of this volume aims to integrate the specific analyses contained in the previous parts into a broader philosophical, legal and socio-political framework on the relationship between humans and technology. Further, it attempts to explore a convergence between human rights discourses within, respectively, the life sciences and information technology. A contribution by Marta Bertolaso and Alfredo Marcos (Chapter 18) offers a philosophical overview on the technological changes and rights evolution in the bio-digital era. Starting from the consideration that human beings are inherently technical beings and their lives cannot be accomplished without technology, the authors comment that, at the end of modernity, the symbiosis between science and technology has become so tight that we can now legitimately speak of *technoscience*, that is, an epistemic system that *gives us more power and responsibility* than simple traditional techniques, as in the case of the new biotechnologies. In their chapter, the authors offer a critical reflection on the two major anthropotechnical proposals, that is, the

bio-project and the *info-project*, and present arguments and criteria crucial to human rights development and their relevance for an adequate technological humanism. In addition, they carry out a philosophical analysis of the importance of responsibility for safeguarding the duties towards future generations and a non-dualistic anthropology. They also highlight the relevance of societal responsibility, care and solidarity in making the impossible detachment of human beings from technology an opportunity to develop a fruitful debate on human rights based on a deeper understanding of human beings' relational nature.

Chapter 19 by Roberto Andorno draws attention to the key role that the notion of human dignity is called to play in the context of life sciences technologies. The chapter begins by objecting to the common view according to which technology is in itself always a morally neutral tool. Then, it presents respect for human dignity as the principle that provides the overarching ethical guidance for a responsible use of emerging technologies. The chapter points out the central role played by this principle over the past few decades in the international legal instruments dealing with biomedical technologies, in particular from UNESCO and the Council of Europe. At the same time, the chapter attempts to respond to the criticism that dignity is a merely rhetorical or political notion without any substantial content. Then, the author makes a distinction between the classic, primary meaning of dignity, which refers to the intrinsic worth of every individual, and a secondary or derived meaning, which relates to the value we attach to the integrity of humankind as a whole, including future generations. The strong emphasis on dignity that characterizes recent international biolegal instruments shows well that this notion is invoked to articulate a disquiet about biotechnological developments that may impact not only on individuals but on our understanding of what it means to be *human*. The chapter ends with the claim that dignity has a crucial role to play in preserving freedoms that were always taken for granted, but which are today at stake in our technology driven societies. The chapter illustrates this claim by presenting some of the serious challenges to freedom posed by neurotechnologies and germline gene editing tools, and by arguing that it is urgent to adopt appropriate policy measures in these new areas.

This final part concludes with Chapter 20 by Jan Christoph Bublitz, Jennifer Chandler and Marcello Ienca, which reflects on the philosophical, ethical, legal and anthropological implications of human–machine interaction, with special focus on the direct interaction between human cognition and AI. In this chapter, the authors sketch out a preliminary account of the normative questions raised by an emerging form of human–machine interaction that they call the 'hybrid mind'. This interaction is characterized by a direct coupling of the human cognitive system with an artificial cognitive system, so that cognitive processes of the two systems are functionally integrated through bi-directional interactions and mutually adapt to each other. Their inquiry is provoked by the development of novel technologies such as closed-loop neural interfaces that can establish a direct communication pathway between the human brain and an external computing device. This communication pathway is typically mediated and facilitated by artificially intelligent components such as machine learning algorithms. The hybrid mind thus emerges as a form of functional symbiosis between the biological brain-mind system of humans and the hard- and software of computing technologies. The authors posit that this development represents only the latest step in the evolution of human beings and their technologies, a process that has necessitated a parallel evolution in our moral concepts and practices over time. The authors discuss several normative and philosophical questions raised by these technological advances. In particular, they reflect on the boundaries of the body, the mind and the human person; responsibility for action; as well as on whether the integration and

inseparable blending of cognitive systems in hybrid minds may have the effect that artificial intelligence may become part of the person, or might be regarded as such, by the law.

At the end of the volume, an epilogue (Chapter 21) entitled 'Technology, Human Rights and the Future of the Human', authored by Marcello Ienca, reviews the main themes emerging from this collection of articles and opens a discussion on the evolution of human rights in light of technological progress.