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Book Review

Book Review Editor

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ETHICS, COMPUTING AND GENOMICS
Herman Tavani (Ed)
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Computational genomics is a growing field that encompasses computer science/information technology, and bioethics/biotechnology. Computational genomics places itself on the juncture between information technology and new genetics. It creates a new field of unaddressed ethical and philosophical questions.

Ethics, Computing and Genomics brings together in one volume a collection of distinguished papers, by a number of highly-esteemed scholars coming from a range of diverse disciplines, namely lawyers, ethicists and bioethicists, physicians, philosophers and information experts. We have seen in the past decade a number of books on biomedical ethics and on computer ethics; however, this book, edited by an American scholar whose work is known to many in the information ethics community, is the first to cover the cluster of ethical issues, which arise because of the role that computers play in genetic/genomic research. The book covers a vast area of scientific research, and it provides some theoretical foundations for analysing the ethical questions posed. It also includes discussions of very special topics, such as environmental genomics, bioinformatics and the open-source movement, and nanotechnology.

Tavani explains clearly why these ethical questions should be explored. Ethical issues affecting computational genomics deserve special attention for two reasons. The first is that computational techniques and methods used in genomic research introduce ethical concerns that are not easy to anticipate, and that may be difficult to articulate and analyse as ethical issues. Secondly, these ethical concerns are significant because they can result in serious harm, including discrimination and stigmatisation, both to individuals and to groups.

The book contains eighteen chapters that are organized into five main sections. In Section I, Tavani opens with a 'map' sketching the boundaries of the issues examined in this scientific endeavor. The reader is introduced to some key distinctions that differentiate four areas of inquiry: computational genomics, bioinformatics, computational biology and genome informatics. (A very useful figure that illustrates these distinctions is included on p.10). The book contains an introduction and four sections: Moral, Legal, Policy and (Scientific) Research Perspectives; Personal Privacy and Informed Consent; Intellectual Property Rights and Genetic/Genomic Information; and Challenges for the Future of Computational Genomics. Each chapter includes original and republished papers written by the most influential scholars from both sides of Atlantic in computer science, bioethics, genethics, and ethics of research.

In the introduction, "Mapping the conceptual terrain", Herman Tavani aims to introduce the reader to ethical issues that are examined in greater detail in subsequent chapters of the book, and to present arguments for the view that ethical issues affecting computational genomics deserve special consideration. The introduction begins with a brief examination of some conceptual and practical connections that link the fields of computer science and genetics. It then defines computational

genomics as a field of inquiry differentiating it from three distinct but related fields such as bioinformatics, computational biology and genome informatics. Next, it identifies and briefly examines a cluster of ethical issues affecting computational genomics such as the ownership of personal genetic data. It concludes that some ethical issues affecting computational genomics are not as easily recognizable as others as it is still mostly "uncharted" and awaits sustained discussion, rigorous analysis and clear identification of issues.

The final part of this chapter deals with the problem of whether ethical issues in computational genomics deserve special normative consideration. Tavani, after dismissing the popular argument based on genetic exceptionalism, proposes an alternative reason as to why personal genetic data deserves special consideration from a normative point of view. Tavani concludes, quite originally, that we can decouple the claim that personal genetic data deserves special consideration from any claim that this data itself must also be distinctive: 'A different rationale based on the kinds of unanticipated outcomes made possible by the computational techniques used in genomic research can be given to show why the use of personal genetic data warrants special normative consideration'. These unanticipated outcomes will lead to policy vacuums/gaps. Therefore, Tavani's thesis can be placed at the level of public policy discussions rather than at the level of practical ethics.

Section II of the book contains four chapters, each providing a distinct framework or methodological perspective (i.e., moral, legal, policy, or scientific research) for analyzing specific controversies that are examined in detail in the chapters included in Sections III–V of this book. Bernard Gert, in the first essay of Section II (entitled 'Moral Theory and the Human Genome Project') lays down the necessary foundations of an account of morality, required in any attempt to resolve moral problems arising because of the Human Genome Project (HGP). He argues that standard ethical theories, including utilitarianism and deontological theories, are both artificial and simplistic and thus are inadequate models for analysing ethical questions such as those in the HGP. As an alternative he proposes that our system of ordinary moral rules, which Gert calls "common morality", should be used. (Marturano has previously argued that this thesis has certain limitations – such as collapsing the very important theoretical difference between normative and descriptive ethics and reducing ethics to a series of informal, intuitive prescriptions whose presuppositions are difficult to ground.)

In the next chapter of Section II, entitled 'Lex genetica: the law and ethics of programming biological code,' Dan Burk presents some very original ideas. Lex informatica, Joel Reidenberg's eloquent phrase describing code which has the effect of laws, is well known. Burk takes the idea a step further: he proves that, just as software owners use sophisticated software systems to prevent user behavior they do not want; recent advances in genetic design allow similar control by having 'terms of usage' of a seed (terms which would have been contractual), embedded in genetic code. This does not necessarily apply only to seeds, or indeed, genetically engineered animals, such as the well known 'oncomouse'. Such a development substitutes private technological rules for the public statutory rules developed by Congress-producers employing such technology become private legislatures. Because of these concerns, Burk believes that we are presented with new conceptual problems that require a more comprehensive evaluation of the interplay between law and "technologically embedded values". Lex genetica simply cannot be left entirely at the hands of those who demand such behavioral constraints, and disclosure of these constraints acquires a quite different function in these cases. Interestingly Burk also addresses some of the broader questions involving what he describes as "long standing discussions about contract laws" and their effective application to technological restraint.

In Chapter 4, Ruth Chadwick and Antonio Marturano examine some public policy implications of genomic research, which they argue have increasing relevance to policy issues. The authors begin by asking whether genomics should be considered a global public good and thus be viewed as something that is "globally relevant". Because numerous genetic databanks have been formed around the world and because they have been the centre of grave ethical concerns, the argument that a genetic databank is a global public good (or not) is central to current discussions. But does a genetic databank contain knowledge or just information? For Chadwick and Marturano, information in the form of raw sequence data, such as those contained in the databanks, may be a good but it is not the same kind of good as knowledge. They find the argument that 'just because genomic databases contain genomic information they are a global public good' simplistic, explaining that '...Not only is it the case that most people would be unable to understand the information therein, but the concept of 'information' itself may be one that does not include meaningfulness'. But is it true that, whether something is a global public good, depends upon how many people can understand it or 'read' it? Perhaps it is; perhaps the meaningfulness, or not, of information here, determines its status as a good. Chadwick and Marturano also pose another problem with the databank-public good equation: knowledge is not always 'good' as people may invoke their 'right not to know' their genetic makeup. Therefore, the 'good' becomes a relative concept. Access to genomic information may be good for a particular person and not at all desirable for another. Whether this

as an argument may refute the value of a databank for science, remains perhaps an open question. However, the discussion here is fascinating.

Section II closes with an essay by Christiani, Sharp, Collman and Suk, 'Applying Genetic Technologies in Environmental Health Research: challenges and opportunities'. The authors describe in detail aspects of the Human Genome Project with respect to environmental health research. Using lung cancer as an example, they portray the gene-environment interaction so that the reader may understand in practice what it means to apply genetic analysis successfully in environmental health research (e.g. how can genetic analysis help prevent cancer?). The authors do not underplay the possible negative effects of genomic research, as they explain how it presents diverse, ethical and social challenges. They move a step further from the well known problems of protecting individual privacy and avoiding individual genetic discrimination, highlighting how genetic research allows for a tendency to pathologize certain genotypic differences on the basis of perception of disease risk. This pathologicization may not refer only to individuals; whole ethnic groups may be considered 'defective', even if key environmental triggers are required for the development of the disease in question. History offers us evidence that in parallel cases already disadvantaged groups will probably suffer the consequences of such pathologicization. The essay ends with the recommendation that environmental health scientists become actively involved in policy debates regarding the implications of research in environmental genomics.

Section III of the book addresses issues of Personal Privacy and Informed Consent in two subsections; one concerns the concept of privacy in computational genomics and the other focuses on the use of data mining and non-consensual secondary uses of personal information. The concept of privacy has a long history that has been regenerated by the challenges posed by Information Technologies (IT). Possibly no ethical issue associated with the field of IT or with genetics research, has been more controversial than privacy. Different models of privacy have been suggested; in particular, two theories associated to informational privacy have received special attention recently: the "control theory" and the "restricted access theory". In Chapter 6, James Moor applies his own control/restricted access theory to controversies involving the collection and transfer of personal genetic data. He argues that on the one hand computers can help protect privacy by restricting access to genetic information in sophisticated ways. On the other hand, however, Moor is concerned that computers can increasingly collect, analyse and disseminate abundant amounts of genetic information which, when combined with cheaper processing, will make genetic information gathering much easier.

Judith DeCew, in the following essay, also analyses privacy from the standpoint of a philosopher. She argues that the value of privacy is that it 'acts as a shield to protect us in various ways...its value lies in the freedom and independence it provides for us, nurturing our creativity and allowing us to become better people'. She then presents three public policy approaches to the problem of privacy protection (governmental guidelines, corporate self-regulation and a process that she calls 'dynamic negotiation'). Dynamic negotiation means that the patient has access to their records as a rule, not as an exception, and that discussion between patients and parties asking for access to their data occurs (this is 'dynamic negotiation' – a meaningful dialogue). DeCew realizes the disadvantages of dynamic negotiation, but her approach, ensuring that people are educated, consulted and allowed to give consent though this process, is laudable. At the very least, this approach signals that DeCew is fully aware that informed consent is (or should be) a democratic process and not a second of signing – while in need of treatment – an incomprehensible piece of small print. She emphasises the importance of privacy protection with regard to sensitive medical and genetic information, which she claims should be a legislative priority whilst at the same time encouraging patient care, public health, and scientific research.

The section devoted to the use of data mining in genetics consists of two chapters. In Chapter 8, 'IT implications of the Health Insurance Portability and Accountability Act', Baumer, Earp and Payton point out that medical records are increasingly being stored in computer databases. On the one hand, the authors note that this practice allows for a greater efficiency in providing treatment and in processing of clinical and financial services. The authors note that digitalisation of medical and genetic records has diminished patient privacy and has increased the potential for misuse. This is especially true in the case of non-consensual secondary uses of personally identifiable records, which requires an establishment of security measures by those organisations that store and use medical data. They proceed with the standards for privacy of individually identifiable health information, as a proposed rule by the Department of Health and Human Purposes, in combination to HIPAA. The results of a recent survey by Earp and Payton on the views of healthcare workers about privacy of medical records offers us a view from another angle on this crucial matter. A useful table illustrating their answers to a number of related questions is also included.

In Chapters 9 and 10, the problem of non-consensual secondary uses of medical and genetic records is linked to the problem of using data mining in two different contexts: epidemiological and environmental genomic research. The outcomes of these chapters are a consensus

on the risk of data mining to create discrimination. In Chapter 9, Custers describes the main principles of the European Privacy Directive 95/46/EC (the data collection limitation principle, the data quality principle, the purpose specification principle, the use limitation principle etc.). The special problem of group profiling through data mining is then analyzed, along with the separate question of the effects of using group profiles. Patterns revealed from data-mining technology may result in the construction of both individual and group profiles, but data in group profiles is not protected by privacy law. The same data may also not be reliable and these concerns are originally and thoughtfully raised in this essay.

In Chapter 10 Tavani focuses on informed consent. He claims that the same technology of data mining that on the one hand has assisted researchers in identifying "disease genes" common in specific populations also threatens the principle of informed consent (in the sense in which that notion has traditionally been used in epidemiological studies). Tavani describes the problem of opacity: when an individual has consented to give DNA samples for use in one context, does it follow that they have consented to the same use in another context? Perhaps, as Tavani suggests, it is true that in genomic studies the kind of conditions for what we understand as a valid informed consent (for example, to surgery) is impossible – or at least extremely difficult. Thus we are posed with a significant challenge for the possibility of "valid informed" consent procedures needed for research subjects. Tavani recommends a collaboration between various stakeholders so that a more robust consent policy is framed, taking into account group-related risks to research subjects.

Section IV of the book turns to the controversial question of intellectual property rights involving genetic/genomics information. It analyses the debate about genetic IPR from two different points of view: 1. issues affecting ownership of personal genetic information that resides in computer databases, and 2. issues involving the patenting of non-personal genetic data (such as DNA sequences, genes and entire genomes). The opening chapter by Adam Moore provides an overview of two different kinds of arguments used by proponents of IPR: the natural rights theory viz. utilitarian/incentives based property theory. Moore claims that data are kinds of "intangible" or "virtual" objects. Therefore, the author argues that for this reason the "Lockean model" of property is better than the utilitarian one, as the latter justifies the ownership of intangible objects on the basis on economic incentives. He uses the natural rights theory to show how ownership rights can be justified in the case of "virtual" objects such as medical information.

Richard Spinello, in the next essay, focuses on property-rights controversies in genetic information. Spinello rejects the view advanced by some privacy theorists that granting property rights to personal information is necessary to protect their privacy. The risk of harm by an inappropriate release of an individual's genetic information may well exist, but Spinello argues that granting a property right to individuals is not the correct answer. It is wrong, he believes, because ownership rights will cause inefficiencies and 'disutility' of genetic discoveries and that scientific research will also be threatened. However, he does not support the view that individuals should have no rights at all with respect of their data – instead, he believes that a compromise position would be the best solution. This compromise should take into account the individual's right to access their data and also the investment incentives that the system should offer, so that scientific research remains possible. Transaction costs should not be so high so as to preclude research (and it is reasonable to assume that propertization of genetic information will increase them). It is therefore preferable to resort to informed consent and confidentiality as a legal prerequisite, because they involve lower transaction costs for the researchers. Spinello reminds us that the European Privacy Directive offers an adequate safeguard of privacy without resorting to property, and that property rights to genetic information will lead to the well-known tragedy of the anti-commons. This does not mean, however, that individuals should not have property rights to their data, and that the private research companies (like deCODE) should. On the contrary, Spinello argues for a liberal access policy in favor of scientists who engage in research and need the information. Although Spinello does not provide a specific proposal on how this middle ground can be achieved, his chapter includes a clear and detailed analysis of important issues that need to be resolved with respect to ownership rights involving personal genetic data.

Chapters 13-15 deal with problems concerning patents of DNA sequences, genes, and entire genomes. In Chapter 13, Marturano in examining some analogies between molecular geneticists and computer hackers claims that the "Shotgun Method" can be viewed as a kind of "computer hacker" technique. This is an idea which proposes that molecular biologists may be seen as hackers in the sense of people 'who solve problems and build things and believe in freedom and voluntary mutual help'. He argues for the adoption of the open source software philosophy in the genetics field. In this context 'Open source' means that a gift economy-status among peers will be achieved by giving away things that are useful to the community. The most appealing feature of the open source philosophy is the fact that it is possible to create a research network based on the model that the source code can be given away and other researchers can fix and improve the software. The same effect could be achieved in the field of genetics research if access to data

was open to scientists as well. Thus Marturano argues that OSM provides an answer to regulating genetic information that would lead to a "fairer distribution of research opportunities around the globe". That would shift the debate away from patenting and toward copyright protection for genetic data.

In Chapter 14 Burk continues the discussion on the "Open Source" theme. Burk agrees with Marturano on the similarities between Hacker ethics and the Open Source Movement regarding the free flow of information. 'There is a very striking sort of parallel' he notes, 'when you think about the tenets of this open source movement that is committed to the free flow of information, and the tenets of the scientific research community'. Burk compares the norms in the digital rights literature of physical layer, logical layer and content layer (easy to detect in the telephone network, for example) and the similar features in the bioinformatics realm (hardware level, logical level, content). He concludes, similarly to Marturano, that there is fruitful 'cross-fertilization' potential between bioinformatics and the open source movement in software. He also notes, however, that the viability of a copyleft scheme depends on the threat of lawsuits involving copyright violations.

James Boyle closes Section IV with an essay titled 'Enclosing the Genome: What the Squabbles over Genetic Patents Could Teach us'. He invites us to consider some general points that can be learned from the "squabbles over patents" involving genomic data. The author examines a range of arguments about what it means to "own a gene" to show how this debate has revealed both the "selective focus" and the "selective blindness" of arguments made in the property debate involving genomic patents. According to Boyle, rather than trying to solve the problems introduced by the patenting of genes and genomes, including solutions that might involve the kinds of licensing schemes that Burk describes in the previous chapter, Boyle elects to discuss the debate over gene patents in terms of what he calls a "rhetorical case study". Boyle quite convincingly concludes that our common genome should not be turned into private property because it "belongs to everyone" and thus is the "common heritage of humankind".

The final section of the book, Section V, includes three chapters that speculate about the future of computational genomics. In the first essay, Collins, Green, Guttmacher and Guyer offer us a vision of the future of genomic research: what will genomics bring to biology, to health, to society (as three separate classes, which are seen as 'three floors of a building, firmly resting on the foundation of the Human Genome Project')? The authors then list and present in detail the 'bold ambitious research targets', the great challenges to be faced. For example one of these challenges, in relation to biology, is to comprehensibly identify the structural and functional components encoded in the human genome; another, in relation to health, is to develop robust strategies for identifying the genetic contributions to disease and drug response; another, in relation to society is to understand the relationships between genomics, race and ethnicity and the consequences of uncovering these relationships. Areas of high interest for the National Human Genome Research Institute to focus on include large-scale production of genomic data sets, technology development, use of genomic information to improve health care and policy development. The authors' 'creative dreaming' (and what is the use of a scientist who does not dream?) includes 'the ability to determine a genotype at very low cost...', the ability to sequence a human genome for less than a $1.000, the ability to monitor the state of all proteins in a single cell in a single experiment. The vision the authors offer us is indeed exhilarating, as they admit the preparation of their vision was itself. This essay, in a way, is the foundation of the entire book, as the vision gives us the very reason to explore genomics.

The next essay, by Kenneth Goodman, also deals with the future, i.e., with challenges at the frontier rising from bioinformatics. Goodman describes these challenges as 'the greatest intellectual and practical challenges in the history of science'. Goodman analyses the main ethical and social issues raised by clinical bioinformatics, namely accuracy and error, appropriate uses and users of digitized genetic information and privacy and confidentiality. According to the author, there are no clear standards to guide health professionals with respect to the diverse kinds of ethical questions posed by clinical informatics; indeed, health professionals are guided either to a set of principles commonly found in organisational guidelines or to what Goodman calls "best practice standards". But he believes that these are inadequate for either one or both of the following reasons: they tend to be too loose or overly simplistic so that they cannot adequately guide behaviour or, conversely, they are so specific or detailed that they lack the flexibility useful in practice, and in particular in unexpected cases.

John Weckert, in the book's concluding essay, focuses on controversies in scientific research involving nanotechnology. Nanotechnology refers to the projected ability to construct items at the nano level from the 'bottom up,' using techniques and tools being developed today to make complete, highly advanced products; it is a branch of engineering. Nanotechnology and genomics research will pose, at their intersection, important questions about nano-level research and development. Although Weckert is not considering any specific implication of nanotechnology research for genomics, he considers some overall benefits and harms that might develop from continued nanotechnology research in general, and he asks what our default presumption should be about this research continuing. Weckert shows that

there are cases in which it could be justified to halt certain types of research. He also does not rule out the possibility that research into nanotechnology and quantum computing may harm the human spirit or reduce the value in human life. It would be prudent, he concludes, to establish an ethical framework to guide research – similar to the ELSI standards.

Ethics, Computing and Genomics is a book that can serve as a continuous reference to the reader. The organization of sections and selection of essays included in each of the five main sections is excellent. The book approaches a diverse set of problems from a realistic and pragmatic point of view, while also equipping the reader with the necessary theoretical and philosophical foundations to deal with the challenges posed. The book does not include any special scientific terms or terminology (that are undefined) or any unnecessary jargon. This is helpful to readers who lack a scientific background in genetics and genomics research. Tavani has incorporated a useful short introduction to every section (apart from his general introduction) and has added a list of questions at the end of the introduction to each section to help readers key in on important points raised by the contributing authors in their respective essays. The only shortcoming noted in this book is in the American oriented legal discussion. There is little reference to European legislation which takes a different approach to, for instance, the field of privacy or genetic data regulation. That is, European regulations emphasise respect for the right of individuals, rather than the more market-oriented approach of the US.

That said, Tavani's book is a leading publication that not only gives the most recent developments of computing, ethics and genomics, but is also way ahead of its time in that it also describes the challenges for the future. Indeed, it is worth noting that it is being republished, having sold out in its first year.

Reviewed by Maria Canellopoulou-Bottis, ALD, Ionian University, Corfu, Greece and Antonio Marturano, Centre for Leadership Studies, University of Exeter, UK.[1]

NOTES

1. This review is a compilation of two separate reviews sent in by these authors. As both reviewers had made substantial summaries of the chapters, and because of the novelty of the topic, it was decided to incorporate both. This final version has been compiled and edited by Penny Duquenoy, and approved by both authors.