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Unpacking Ethics: A Survey of Existing Literatures on Bioinformatic Research

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Abstract : The main ethical, legal, and social issues in bioinformatics research concerns who controls the acquisition of a person's Genome and the information it contains; what are the uses of the information; and who decides how the information is used. The ethical and legal challenge is to fairly resolve the ownership, consent, and privacy questions so that individuas, consumers and the public will have confidence that results of bioinformatics sequencing carried out by bioinformaticians will benefit rather than harm them. A key foundational issue is determining who has dispositional rights over an individual's health report. This research work surveys the current state of the art in ethical issues as it affects research in bioinformatics. The purpose of this Research work is to survey available ethical issues in Bioinformatic research. The intention is not to provide an exhaustive list. Rather, the intention is to identify well-established ethical issues that are used as ethical standard in Bioinformatic research.

Keywords – Bioinformatics, Genome, Ethics, Reserach,* Biological Information, *Information Technology, Objective of Ethics, Code of Ethics.

I. Introduction

Recently, the field of bioinformatics has experienced a tremendrous rapid growth. However, as with other young disciplines, it now faces a whole host of critical ethical issues. Successfully addressing these key issues is essential to further progress in the field. This article surveys existing ethical issues as well a triad model developed by [12] to unpack the current ethical issues and future issues in bioinformatics from the perspective of computing professionals. The goal is to create awareness for researchers that intend to research in this area and on the opportunities (for example, career paths) and challenges (for example, privacy) that arise. These issues discussed can be operationalized with future empirical research.

What is Bioinformatics ?

According to [30], the origin of bioinformatics can be traced back to Mendel's discovery of genetic inheritance in 1865. Since 1953, big revolution achievements took place by James Watson and Francis Crick as they determined the structure of DNA [29]. Later in 1960s, the hard work of bioinformatics research started, symbolized by Dayhoff's atlas of protein sequences and the early modeling analysis of protein and RNA structures [28]. After then the term Bioinformatics came to our consciousness and use in around 1990s and was described by the management and analysis of DNA, RNA, and protein sequence data. Later in 2000 a big achievement took place which was the announcement of the initial draft of the Human Genome Sequence. Later after 13 years of research and work from 1990 up to spring 2003, in which the official announcement of the Human Genome Sequence Project took place [30].

In this project around 20,000 – 25,000 of human genes where discovered, so the access to this huge amount of gene data and its information was not an easy task for the biologists and for this it opened the doors for a new era in modern biology with an assistant to new computerized technology or in other words the marriage between Biology and Computer Science to bear a new baby known as Bioinformatics which will played a significant role in gathering, analyzing, classifying and storing genetic data collected from the human project or at biological points in a more efficient or powerful way [30]. According to [30] then a question was raised -

what is the importance of Computers in Biology? The accurate answer of

this question will be resulted out from the following formula: Biology + Computer Science = Bioinformatics. [30]. So there arised another question - WHAT IS BIOINFORMATICS? Bioinformatics has been defined from different perspectives , first from the English Oxford Dictionary, and then from the summary of researchers' definitions [30].

Bioinformatics: (According to the Oxford English Dictionary) (Molecular) bio – informatics: bioinformatics is conceptualizing biology in terms of molecules (in the sense of Physical chemistry) and applying "informatics techniques" (derived from disciplines such as applied math, computer science and statistics) to understand and organize the information associated with these molecules, on a large scale. In short, bioinformatics is a management information system for molecular biology and has many practical applications [30]. So, Bioinformatics can be defined as a new hybrid emerging field of science in which biology, computer science, mathematics, statistics and Information Technology merge and interact together to form a whole new discipline field [30]. It is a science used to manage, analyze, organize, and classify the huge amount of biological data by using well developed algorithms, computational and statistical techniques, designing and construction of software tools and theories to solve different problems arising from biological data and help in generating, storing, accessing and analyzing data and information that are related to molecular biology. [30]

Also, the National Institutes of Health defined "Bioinformatics" as the "research, development, or application of computational tools and approaches for expanding the use of biological, medical, behavioral or health data, including those to acquire, store, organize, archive, analyze, or visualize such data." [31]

The researcher defined Bioinformatics as the intellectual research that combines principles of different fields such as mathematics, physics, computer science and engineering, biology, and behavioral science and deals majorly on the computational management, storage and analysis of biological information (genes, genomes, proteins, cells, ecological systems (with respect to global warming), medical information, robots as well as artificial intelligence.

II. Objectives of Ethic

According to [12] in her paper titled - Ethics: ―Its Importance, Role and Code in Information technology gave the following as objectives of ethics

GROWING GLOBALLY: School administrators have realized that globalization should be integrated in school curriculum. On campus, we are increasingly placing our students in diverse teams that mirror the workplaces they will be entering upon graduation [12]. Off campus, we are giving students the opportunities—if not the mandate—to travel and study globally [12]. The number of researchers are increasing by the minutes. This increament reflect a great potential for growth throughout the world. Hence it is important to maintain standards of excellence, we need to be flexible and fair in our academic requirements and keep overall quality as the overriding priority.[2]

PROMOTING PEACE: While significant cultural differences exist among the schools, it is believed that some principles and standards should be common to all institutions. These include honouring basic human rights and promoting diversity [12]. As the accrediting body, must not lose sight of its responsibility to humanity to do what is right and just. It is, therefore, important that we continue such efforts to raise world levels of humanity while expanding our global footprint in management education.

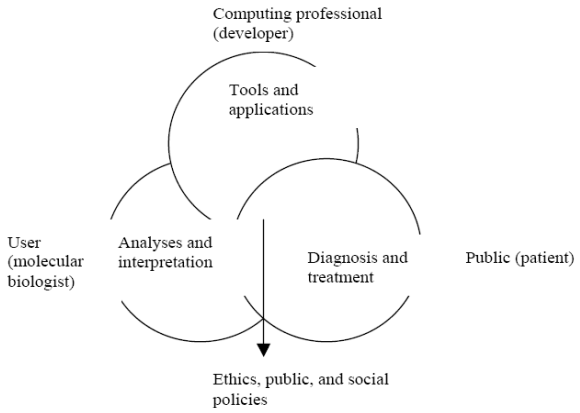
ASSURING LEARNING OUTCOMES: The Assessment and assurance of learning are of great areas of importance to be addressed in the nearest future. Businesses that hire our students expect them to be ready to contribute from day one to the output of the organisations. Both at the undergraduate and graduate levels, most of these companies are making large investments in the training of these personnel (undergraduates & postgraduates). They expect to benefit from a high value-added component when these investments—our students—hit the front door of the organisations. And our alumni, who are aware

that the values of their degrees are in part affected by the quality of the institution going forward. It is then expected that institutions should define their learning goals for their programs and to link their students' learning goals to the mission of their institutions. Our students, government leaders, and taxpayers demand that outcome; our hiring companies expect it as well [12].

EVALUATING RESEARCH: A natural extension of learning assessment is a discussion of the meaning and value of our research [12]. It is, then, very necessary to evaluate research work in other to ascertain its level of possitve/negative effect to organisations and the world at large.

The Triad Model and other ethical issues [17] developed and applied a triad model (fig 1) to discuss current and future issues in bioinformatics research from the perspective of computing professionals. The participants' roles and responsibilities were presented, along with the identification of the challenges and possible solutions as well. He further projected that the model can also be used in the future as newer issues emerge in Bioinformatic research. The main goal of the triad model is to create awareness and debate on the opportunities (for example, career paths) and challenges (for example, privacy) that arise during research in Bioinformatics. According to him these ideas discussed can be operationalized with future empirical research.

Figure 1: The Triad Model



Computing professionals as shown in the Triad Model include developers, programmers, consultants, and vendors. They are concerned with building and testing robust applications and performance as well as integration and management of data deployed to serve multiple purposes simultaneously.

Users – these include molecular biologists and other scientists in the life science department. They are concerned with biological data input and user interfaces, analysis and analytical tools, and interpretation using biological tools.

The public is concerned with the implications of potential medical applications, ethics, privacy, potential misuse of data, and public and social policies.

According to [17] the intersecting area in the venn diagram in Figure 1 shows the overlapping and responsibilities of participants (i.e. professionals and the public) in the application of the triad model. The public should be in a position to decide what can and should be ethical and legal in carrying out research in Bioinformatics. This in a way directly places limits on the type of research the user may perform. Once it has been decided *what* can be done, the relationship between the user and the computing professional comes into play to determine *how* computing technology can assist the user possitively [17].

According to [13], other Public /Ethical issues Computing professionals in bioinformatics need to deal in carrying out research are:

Bioethics—The moral and ethical implications in the application of bioinformatics to genetics.
Intellectual property—The ownership of the human genome is probably the most critical issue. Researchers at the universities where a great deal of bioinformatics research is done should clarify intellectual property issues with the institution.
Responsibility—Who is responsible for the results? Example, when errors cause injury or damage, who will be responsible?
Access—Who should have access to the data and for what use? Should law enforcement, insurance companies, HMOs, and employers have access?

Privacy—How will privacy be protected? Who controls the information? How will conformance to laws like **H**ealth **I**nsurance **P**ortability and **A**ccountability **A**ct (HIPAA) be enforced? (HIPAA

provides national standards to protect the privacy of personal health information.)
Standards—In terms of gene therapy what is normal and what is a disability or disorder.
Technology access—How will the digital divide between those who do and do not have access to expensive technologies be reconciled?
Outsourcing—How will outsourcing affect the field? Given the sensitive nature of research in bioinformatics, what additional legal and intellectual property rights issues will develop?

Also, [18] identified the following issues in bioinformatic research :
Who has the right to access and use our personal genetic data?
Who controls the data?
If medical records are used as a community resource, should they not be available to all research facilities within the community?
Will the medication for a disease discovered through population genetics studies be available to the participants?
Can anybody own pieces of our genome through patents, copyrights, and so on?
Should genetic testing be done, and how scientifically reliable is it?
How will other citizens perceive an individual whose genetic tests reveal a potential disease?
Will the data lead to discrimination?

The triad model can be generalized for the larger field of Health Information Management (HIM), which encompasses all aspects of the healthcare industry, including the flow of information therein; [17]. The participants would include patients, healthcare providers (including physicians, nurses, health maintenance organizations [HMOs], insurance companies, hospitals, pharmacies, and medical testing agencies), and federal programs such as Medicare. The gathering, storage, processing, and dissemination of the disparate and complex medical information generated by the overlapping interaction between these entities will result in the need to address privacy and security issues. The dynamics of the interaction and the resultant outcomes can be studied using the triad model; [17].

III. Conclusion

Ethics is definitely part of every one's life. It is useful in Information Technology for security purpose and it guides us in making sure that illegal work is not carried out in research. To follow code of ethics in each and every field.

The ethical, and legal aspects concerning the use of genetic tests should be reviewed and updated on a periodic bases to keep in step with new developments in scientific progress and the changing face of society with respect to Information Technology in the area of Bioinformatics. The scientific community should play a key role in raising awareness in patients, and society, regarding the correct use of these new technologies (Bioinformatics).

The triad model described provides a framework for discussion in the computing field. Additionally, research constructs/proposals and designs can be developed to examine the relationships, responsibilities, and roles of the participants in the model. The promise of hope from genetic studies in diagnosis and treatment of diseases[17] can be fulfilled by the advances in computing technology and its many facets, as well as by addressing the ethical, public policy, and social issues.

The healthcare workers, providers, recipients, ethicists, sociologists, computing professionals, and scientists will have to fulfill the important role of achieving consensus in Bioinformatics Research. This article provides the ethical issues that are germane in carrying out research in Bioinformatics and this will go a long way to guide new researchers that intend to research in this new Technology.

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