



TECHNOLOGY AND ETHICS

**The human being through the lens of advances in genetics,
biotechnology, and artificial intelligence**

Scientific cycle 2020-2023

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Technology and ethics

The human being through the lens of advances in genetics, biotechnology, and artificial intelligence

Technology is a fundamental feature of humanity. Its impact on our lives at the beginning of the 21st century seems greater than ever. Our entry into the digital age has brought rapid and profound changes and breakthroughs on many levels in our individual and collective lives. At the same time, major advances have been made over the past 30 years in the areas of biotechnology and the life sciences, including, for example, genetically modified organisms, cloning, artificial organs, assisted reproductive technology, and technologies for sequencing and editing the human genome. These developments bring new social challenges and confront us with ethical dilemmas. Technologies such as human genome editing, for example, have the potential to cure serious diseases or save lives, but could also lead to new forms of social inequality and may have unforeseen negative consequences for humanity in the long term. How can inventions such as these be managed to enable us to take advantage of the benefits they can bring while mitigating their risks? As technological advances seem to continually push back the boundaries of the possible, this type of question has become increasingly important in today's societies.

Aware of the major issues raised by contemporary technologies, the Pierre Elliott Trudeau Foundation will focus on the theme of "Technology and ethics" in its cycle of leadership programs beginning in 2020-2021. While these programs aim to train our Scholars to become engaged leaders in their communities and around the world, it is essential that these emerging leaders understand the ethical issues that are raised by contemporary technologies and that they are equipped to face the challenges these technologies pose. Our 2020 Scholars, Fellows, and Mentors will particularly focus on developments in biotechnology and on the incorporation of artificial intelligence into health care. How is humanity shaped by advances in these areas, and, in turn, how can we shape them on the basis of ethical principles? This is the core question that will direct our scientific cycle, including our *Institutes for Engaged Leadership* in 2020-2021.

This paper focuses on three areas of technological application that will be examined in light of the issues referred to above: genetic testing, human genome editing, and the incorporation of artificial intelligence into health care.

1. Towards a "geneticization" of society?

Since the completion of the Human Genome Project in 2003, which has given us an understanding of the human genome pattern, genome sequencing technologies have become more efficient and less expensive.¹ It has therefore become easier to explore an individual's genome and to identify genes or sequences responsible for certain diseases.² In recent years, researchers have also become interested in the complex relationships between human genes and the environment. They have focused on genes that may increase the *predisposition* to certain diseases as well as looking at environmental and behavioral conditions that could prevent such predispositions from being expressed.³

In the wake of these scientific and technological developments, Western societies have witnessed the development of a market for genetic tests, including over-the-counter tests. More than 30,000 genetic

tests are currently available.⁴ For a few hundred dollars, private companies offer tests that can paint a picture of the risks of developing certain diseases and inform consumers about their heredity. Some companies go beyond heredity and predisposition to disease, offering to interpret the various potential capabilities (such as athletic abilities) of a person based on their genetic analysis. For some analysts, such as Timothy Caulfield, a 2013 Fellow of the Pierre Elliott Trudeau Foundation, these developments reflect the “massive emphasis” placed on genetics by society over the last twenty years.⁵

Other researchers echo this sentiment, criticizing the current trend towards “geneticization,” or the tendency to focus on the genetic determinants of our health or identity as individuals, to the detriment of social, economic, and environmental factors that affect the human condition.⁶ Professor Kim Tallbear, a 2018 Fellow of the Pierre Elliott Trudeau Foundation, expressed a similar perspective in her critical analysis of the concept of “indigenous DNA” that is used in the study of the genetics of human populations and in the genetic ancestry testing industry.⁷ Going against a biological conception of indigenous identity and the idea that it can be “proven” by a genetic test, she has demonstrated that the composition of this identity is much more complex and involves social factors.

Moreover, one of the major ethical issues raised by genetic testing – and the collection of genetic information in general⁸ – is the confidentiality of the information gathered. According to the Genetic Discrimination Observatory, “The quality and scope of privacy policies and security features of private DTC-GT [Direct-to-consumer genetic testing] companies’ genetic databases are highly variable and consumers are not always informed of applicable limitations.”⁹ It can prove very difficult to maintain a minimum level of control over your data and the way it will be used.¹⁰ And when personal genetic data is shared with third parties, such as insurance companies or employers, these third parties may treat the individual concerned differently on the basis of their genetic characteristics. The typical scenario of this nature relates to the possibility of an insurer using an individual's genetic profile to calculate their insurability.¹¹ How and to what extent can we mitigate the risks of genetic discrimination, namely the “denial of rights, privileges, or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests”?¹² Are the existing regulations sufficient?

In Canada, the Act to Prohibit and Prevent Genetic Discrimination came into force in May 2017. This law prohibits obliging a person to undergo genetic testing or to report results of testing as a prerequisite for the provision of goods and services. It also amends the Canadian Human Rights Act to prohibit discrimination based on a person’s genetic characteristics. In December 2018, however, the Court of Appeal of Quebec ruled that the law was invalid because it did not fall within federal jurisdiction.¹³ The Canadian Coalition for Genetic Fairness has lodged an appeal against this decision to the Supreme Court, which will decide the case in the coming months.

Recent developments in prenatal genetic testing have also raised important questions. Since 2011, a new non-invasive prenatal test (NIPT) to screen for Down syndrome has been offered to pregnant women during the first trimester of pregnancy. Consisting of a simple maternal blood test, this is a more reliable technique that is safer for the fetus, and can be used earlier in pregnancy than the method previously used for this type of genetic screening. Some experts believe that these features, combined with the commercial interests backing the routinization of the NIPT, may put more pressure on women, who are left with the moral burden of deciding whether or not to accept the test, but are not always properly informed about this decision by medical staff.¹⁴ Moreover, the number of conditions that can be detected by the NIPT is continually increasing, so that the test should soon be capable of offering a wide

range of genetic information about the fetus. It is important to consider whether the ability to obtain an increased amount of genetic information about a fetus is a positive development, from both individual and societal perspectives. To what extent should we protect the right of pregnant women to choose not to be informed of the likelihood that their fetus has atypical genetic conditions? At the societal level, is it not possible that prenatal genetic screening encourages eugenics?

For some analysts, genetic tests, along with the “genetic understanding of health” that they shape, reflect our society's focus on individual responsibility and productivity. In the words of Roxanne Mykitiuk, “with genetic tests marketed as a kind of health-risk kit, individuals are being called upon to undertake self-surveillance in the name of reducing the burden of disease on themselves and on society as a whole,” and in doing so to maintain a “disciplined order of productive citizens.”¹⁵

2. Using genetic engineering to manipulate living organisms

Genome sequencing technologies and the development of knowledge in the field allowed scientists as early as the 1970s to begin to undertake genetic manipulation by moving DNA molecules from one living organism to another.¹⁶ This laid the foundations of the modern biotechnology industry. Research within this industry has gradually led to the development, in the 1980s, 1990s, and 2000s, of genetically modified organisms (GMOs) in plants and a number of animal species (such as salmon) with the intention of improving their characteristics and advantages in terms of production, marketing, and human consumption.

More recently, in 2012, the invention of a new genome editing tool called CRISPR-Cas9¹⁷ marked a major and even revolutionary advance in biotechnology and biomedicine. The CRISPR-Cas9 molecular complex makes genome editing much more accurate, faster, and less expensive than previous genome editing techniques, so that DNA modification has become easier than ever before.¹⁸ Use of the CRISPR-Cas9 “molecular scissors” has therefore quickly become popular among scientists in various fields of research related to the biological sciences and medicine, but not without raising a host of ethical, social, and political issues.

Shaping nature by means of gene drive engineering?

Among scientists seeking to develop applications based on the CRISPR-Cas9 genome editing tool, some have recently been testing a technique known as “gene drives,” aimed at increasing control of species that pose a threat to humans. This technique involves the introduction of hereditary gene mutations into a species; the mutation is designed to propagate within the species more efficiently than is the norm.¹⁹ Gene drive techniques could be used to eradicate or reduce insect populations that carry diseases (such as malaria, Lyme disease, or Zika virus), to control invasive species (such as rats), and to eliminate pesticide resistance in pest populations.²⁰

Scientists are working with Target Malaria, an international non-profit research consortium, to find ways to use gene drive techniques to fight malaria in Africa.²¹ Internationally, the eradication of malaria-transmitting mosquitoes could save a million lives annually.²² The technology is not yet ready to be used in this way, but in three years or so, once tests have been carried out safely in the wild, it could be at implementation stage (so far tests have only been conducted in laboratory conditions).

Gene drive technology clearly has its risks. The elimination of a species from the food chain could have unforeseen consequences within ecosystems. The parasites or viruses that we are trying to eliminate

may actually become more virulent and use other species as carriers. Some bioethicists believe that, “This technology has the potential to be immensely powerful and to change the course of things that we may not be able to predict.”²³ Others are concerned there is a risk that gene drive engineering could be used to make weapons by designing mosquitoes that can inject toxins.²⁴

In view of the significant risks of gene drive engineering, are we misguided in attempting to develop this technology? Or should we accept that the potential benefits – especially the possibility of saving the lives of millions of people – outweigh the risks and justify this intensification of the human impact on the environment? In addition to these fundamental ethical issues, the implementation of gene drive engineering could pose future complications in terms of governance: Who should have the authority to make decisions on the use of gene drive, who should be part of the decision-making process, and who will regulate the use of this technology? We should not overlook the fact that one country's decision to use gene drive engineering could have consequences for neighboring countries, since the species modified using this technique are mobile across borders.²⁵ UN Member States have therefore begun to hold discussions during a series of meetings on biodiversity to consider measures to be taken concerning gene drive engineering and, in 2016, rejected the proposal of a moratorium.²⁶

Is human genome editing acceptable?

The advent of CRISPR-Cas9 technology particularly raises hopes regarding its therapeutic potential in humans. Since it allows precision manipulation of individual genes, this technology could prevent, slow down, or cure diseases with a genetic basis, including cancer and diseases such as cystic fibrosis, asthma, or diabetes.²⁷ “Somatic” gene therapies, that is, those targeting the non-reproductive cells, are under development in laboratories around the world and clinical trials are also underway. According to experts, however, a number of technical obstacles make this type of gene therapy not yet ready for safe use in patients.²⁸ One such complication is that, given our current levels of understanding, the modification of a gene to cure a disease could in fact trigger another disease, since a number of genes have more than one function.²⁹

As well as its use in somatic therapies, CRISPR-Cas9 can be used to modify the DNA of germ cells, or reproductive cells. In contrast to somatic modifications, the editing of germ cells, whether of spermatozoa, ova, or embryos, entails the transmissibility of genetic modifications to human offspring. Genome editing of the germline has become particularly controversial in recent years because these manipulations have the potential to affect the genetic makeup of humanity and because of the lack of knowledge of possible risks for future generations. However, both somatic and germline therapies have the potential to be used for the treatment and prevention of disease as well as for the enhancement of non-pathological traits, such as physical appearance, athletic ability, or cognitive ability.³⁰

Some bodies, such as the US National Academy of Sciences, make a clear distinction between the use of genetic modification for therapeutic purposes as opposed to using it for enhancement, recommending greater caution (as well as displaying greater concern) about the use of the technologies for reasons of enhancement.³¹ Nevertheless, this approach raises a fundamental question: Where do we draw the line between the two types of use? For some, including Professor Sheila Jasanoff, who specializes in science and technology, the distinction between the treatment of disease and genetically engineered enhancement is problematic. “But how do we know what illness is?” Jasanoff asks, emphasizing that, “Over human history, we’ve tried to cure conditions that you and I today would say are not sickness.”³² With this perspective in mind, we should be ready to consider the risk that these new possibilities of

modifying the human genome, even for purposes considered to be “therapeutic,” may eventually place individuals under social pressure to conform to certain genetic norms, while encouraging inequality and discrimination against people whose characteristics do not meet these norms. Does this scenario not begin to resemble eugenics?

The issue of access to genetic modification technologies also raises questions relating to social justice. Once the technology is ready to be used clinically (currently it is essentially only employed in research contexts), it may be the case that, like other technologies, it will only be accessible to the richest, thereby aggravating social inequalities and marginalization.

How should human genome editing be regulated in Canada and worldwide?

The controversy surrounding genome editing of germ cells was heightened by the revelation in 2015, and more recently in November 2018, of scientific studies in China, where researchers made genetic modifications to human embryos.³³ While the 2015 studies were conducted on non-viable embryos, the 2018 study went further, with the researcher using viable embryos that he later implanted in women, one of whom gave birth to twins.³⁴ The genome of these “CRISPR babies,” as they have been called, was modified to immunize them against the HIV virus. The news of this genetic manipulation, which was conducted with a view to prevention despite a lack of knowledge about the long-term effects of this intervention, has provoked global outrage, including within the scientific community, which considered that the researcher in question had demonstrated a serious breach of ethics by overstepping global scientific standards for the responsible use of genome editing.³⁵

How can we avoid irresponsible use of human genome editing at a global level? Since the 1990s, and increasingly since 2015, many national and international bodies have formulated guidelines for human genome editing.³⁶ Most of these support germline editing for purposes of research and the advancement of knowledge but prohibit it for reproductive purposes in a clinical context.³⁷ This approach seems to have the approval of a number of scientists.³⁸ Nevertheless, in the light of the Chinese “CRISPR babies,” we may need to consider the case for better regulation of human genome editing on national and international levels. Is it possible to harmonize national frameworks for legislation and standards in an attempt to avoid a form of social dumping in genetic engineering?

In Canada, there are no specific regulations or guidelines for somatic editing of the human genome for therapeutic purposes, but germline editing is prohibited under criminal law by the Assisted Human Reproduction Act (2004).³⁹ Many experts believe that Canada's human genetic engineering regulations are inadequate and should be reviewed and potentially revised to take into account the technological advances of recent years and the ethical, legal, and social implications of these technologies.⁴⁰ Another question for consideration is the role of the public in discussions and reflection on these issues. How can we encourage informed and democratic public debate on human genome editing and its possible applications in the field of medicine?

3. The application of artificial intelligence in health care: A dehumanization of care?

Progress in the field of artificial intelligence (AI) has gathered speed over the past decade. The term AI refers to the range of technologies that draw on large sets of numerical data in order to simulate certain

functions of human intelligence, such as learning, reasoning, and interaction.⁴¹ Machine learning underpins most existing AI applications.

In the coming years, AI will increasingly play a key role in the areas of human health and biotechnology.⁴² Research in biotechnology (and especially the discovery of new drugs)⁴³ is also increasingly dependent on AI technologies to process and explore big data stored in databases.⁴⁴ Moreover, major technology companies such as Google, Microsoft, and IBM are investing in the development of AI for health care and medical research.

There are many opportunities for AI in the healthcare industry, including medical research, the detection of disease, the management of chronic disease, and the delivery of health services.⁴⁵ Similarly, the use of AI to detect diseases such as breast and skin cancer has recently shown promising results, suggesting that these diseases may soon be diagnosed more quickly and more accurately than is currently possible.⁴⁶ AI could also assist in medical decisions about the treatment of various conditions through the use of tools to analyse clinical data and data generated by scientific research.⁴⁷ There are in fact already several tools that use AI to provide personalized home health assessments and advice.

Although they have the potential to offer significant benefits, the various applications of AI in the health sector raise a host of ethical and social issues. We cannot underestimate the importance of the reliability and security of AI applications when they are used to make complex judgments in scenarios that require an understanding of the context and the ability to apply tacit knowledge. Medical applications of AI could make mistakes and, since the health or even the life of human beings is at stake, such errors could have serious consequences. Similarly, the question arises as to who can ultimately be held responsible for decisions made by AI, and how a person who suffers as a result of those decisions should be compensated.

The lack of transparency of AI systems is problematic; the decision-making process followed by an algorithm to arrive at a given conclusion is often quite opaque, even to the designers of the algorithm.⁴⁸ This black box phenomenon makes it difficult for humans to verify whether the result or the information produced by an algorithm is reliable. It also limits the ability of health professionals to explain to their patients why, for example, a particular treatment should be undertaken, thereby restricting the right of patients to make free and informed decisions about their health.

The use of AI in the health sector also poses significant risks to the protection of patient privacy. For an algorithm to be able to produce medical predictions about an individual, access to personal data is needed and in this context it is not possible to anonymize the data (i.e., to break the link between data and individuals).⁴⁹ While it is possible to obtain an individual's consent to use his or her personal data for a specific purpose at the time of collection, it is important to understand that, in the era of AI and big data, there are strong incentives to reuse data originally collected for a one reason for other ends, and to relate it to data from other sources in order to generate information that can be used for a variety of purposes.⁵⁰ This context makes it difficult for an individual to fully understand and control how their data will be used once collected.

With regard to the protection of privacy, concerns center on access by commercial companies to the health data of individuals (and the use of this data to better target the commercial promotion of their products). A recent case illustrates how, when AI is used in a medical context, personal data may end up in the hands of companies without the consent of the individuals concerned. As part of a partnership

working on a trial of an AI application for medical purposes, a London hospital transferred the personal data of 1.6 million patients to a company called DeepMind. In 2017, this transfer of data was deemed illegal by the UK authority responsible for enforcing data protection legislation.⁵¹ Moreover, there is the risk that individuals' sensitive health-related data could be illegally accessed and altered by hackers attacking AI systems.

Another major ethical issue in AI applications in the health sector (as in other areas) is that these technologies reproduce any bias in the source data that they are using. There is a commonly held view that the data used to train AI systems often do not represent the diversity of the population.⁵² The individual biases of AI developers, who do not necessarily represent a diverse social profile, can be integrated into the algorithms themselves.⁵³ Attention has also been drawn to the risk that AI may discriminate insidiously – in ways that may be difficult to detect – in terms of gender, ethnicity, disability, or age. One study has shown, for example, that the validity of medical predictions made by algorithms may vary depending on race, gender, or socio-economic status.⁵⁴ For these reasons, the healthcare benefits of AI technologies may not be equally accessible to all (in terms of the validity of therapeutic or diagnostic recommendations, fair access to healthcare resources, or impartial treatment by healthcare professionals).

In an attempt to deal with such ethical issues, some stakeholders from the AI community, along with representatives from the healthcare sector and others, have started to take action by formulating guidelines for the ethical development of AI.⁵⁵ The Montreal Declaration for a Responsible Development of Artificial Intelligence is an important initiative in this respect, positioning Canada as a leader in AI ethics. In the field of healthcare alone, however, much remains to be done to promote regulation and the development of mechanisms to oversee AI, in order to reduce the risk of harm to individuals and society in general.

Conclusion

This document has drawn attention to the potential benefits of some biotechnologies and artificial intelligence – such as the possibility of detecting diseases earlier or curing them more easily – but has also illustrated the risks as well as the ethical and social issues posed. One of the most significant and pervasive issues is the risk that these new technologies will give rise to new forms of discrimination, inequality, and violations of human dignity, such as discrimination on the basis of genetic characteristics or unequal access to genetic enhancements. Other potential adverse effects include irreparable damage to the environment and to human health and the human genome.

From a more philosophical perspective, the new possibilities that are opened up by contemporary technologies compel us to reflect on the future of humanity: is it true, as Francis Fukuyama has argued in the context of the “biotechnology revolution,” that we are heading towards a “posthuman future” where human nature is fundamentally changed?⁵⁶ How much have or will the new technologies alter humanity? Since biotechnology and artificial intelligence seem set to take an ever greater place in our lives, these questions and their corollary – how can we manage these technologies in ways that preserve human dignity and the values that are dear to us? – are of paramount importance for innovative thinkers and the engaged leaders of the 21st century. This is why the Pierre Elliott Trudeau Foundation will invite our

2020 Scholars to reflect on these issues, alongside our Fellows and Mentors, as part of the leadership training activities that they will be taking part in from the fall of 2020.

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⁵⁴ Rigby, M. J., 2019, *ibid.*

⁵⁵ The Montreal Declaration for a Responsible Development of Artificial Intelligence, 2018, <https://www.declarationmontreal-iaresponsable.com/>; “University of Toronto's leading bioethics centre to design ethical artificial intelligence for health,” March 2019, Dalla Lana School of Public Health, University of Toronto, <http://www.dlsph.utoronto.ca/2019/03/u-of-ts-leading-bioethics-centre-to-design-ethical-artificial-intelligence-for-health/>.

⁵⁶ Fukuyama, F., 2002, *Our Posthuman Future: Consequences of the Biotechnology Revolution*, Farrar Straus & Giroux.