(Bio)Ethics, Science, and Society:
Challenges for BioPolitics

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Editor
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INDEX

(Bio)Ethics, Science and Society: Challenges for BioPolitics

Ethics, Science and Society: Challenges for BioPolitics is an international project of academic research, scientific dissemination, and social and political responsibility, sponsored by the Luso-American Development Foundation. Its main objective is to stress the importance of this triptych-style approach – ethics, science, society – to address some of the current and major challenges facing humanity. The balance we achieve today between these three realities strongly defines our present and will have a decisive impact upon our common future: scientific progress shapes our modern societies which, from an ethical perspective, should always be acknowledged as being the ultimate goal for science and one which, by contributing to a common good, corroborates its ethical dimension.

Therefore, we wanted to highlight some of the most groundbreaking developments in scientific knowledge and technological innovation, also identifying major trends and upcoming advances. We focus first on life sciences and biotechnologies, mostly in genetics, as one of the most innovative fields for more than a half century; and proceed to computer sciences and digital technologies, highlighting the importance of Artificial Intelligence and robotics as today's most important areas of impact.

We also wanted to outline the impact of scientific and technological advances in shaping societies, both at the structural level – drawn by the network of institutions that organize our collective lives – and at the personal level – through the relationships fostered by individuals. Pursuing this path, from science to society, facilitates strengthening citizenship, and guarantees the ethical nature of these advances, so that they acknowledge humankind as the ultimate beneficiary of scientific achievements, whilst fostering a wider participation in the decision-making process.

This requires us to enhance the dialogue between scientists and ethicists, under a mutual recognition that both groups are working towards a common good. It is the outcome of this joint endeavour, and one in which citizen participation should be particularly encouraged, which should determine public policies that truly promote both scientific progress and social development.

The equilibrium reached between ethical concerns, scientific advances and societal well-being could be enshrined in a consensual and minimalist document, with a global reach, to help politicians and law makers in their decisions relating to scientific policies. The opportunity to promote a Declaration on BioPolitics, to elaborate ethical guidelines for the worldwide management of the new powers, largely represented by the advancements in life sciences, was conveyed as a most desirable outcome. Some major considerations are elaborated around this issue, and stand as core concerns to be acknowledged. But it has not been considered advisable to proceed immediately, in a very short period of time and without a wider representation, to the formal proposal of a Declaration of BioPolitics.

This project, *Ethics, Science and Society: Challenges for BioPolitics*, also organized two international Symposia (Ponta Delgada, 2017, and Lisbon, 2018), which presented high level lectures – and these are now available to a wider public audience. They combine the deepening awareness of the impact of scientific and technological advancements in current and future societies, and stress the need for ethics to manage these new powers on behalf of humankind.

Maria do Céu Patrão Neves

On Ethics, Science and Society

MARIA DO CÉU PATRÃO NEVES

Ethics and sciences intersect each other in our societies on a daily basis. However, the nature of their relationship is not unequivocal for many and it can be diversely defined, sometimes following different perspectives and a variety of interests. The media tends to present scientific breakthroughs with their own, often sensationalist headlines and narratives, triggering powerful emotions – fear always being stronger than hope – as a strategy to gain audience ratings, and thus influence public opinion. In this context of self-interest, the involvement of ethics is more often claimed to impose limits, and to stop specific lines of research. Under the same standpoint of ethics as a builder of barriers, some sectors of the scientific community adopt an opposing position. They reject the contribution or even the participation of ethics within the realm of science, encouraging its exclusion by viewing it to be conflicting with the methodology and goals pursued by sciences. Ethicists advocate the opposite attitude, firmly requiring the presence of ethics in sciences. However, sometimes they develop theories which neglect to make any connection with reality, instead adopting the easiest solution, that is to forbid the unknown.

Generally speaking, the current view of ethics limits it to one of a restraining role. But this has not always been the case.

Throughout the history of humankind and up until very recently, ethics and science have been closely related, and even indistinguishable, as was the case during the first period of the relation between ethics and science.

An indistinguishable relation

Indeed, if we go back in history to the very roots of Western scientific knowledge, to Ancient Greece and specifically to Socrates (4th century BC), we realize that the knowledge of truth and good deeds were once viewed as being indistinguishable: one could only perform good actions when having the knowledge of truth; at the same time, those possessing the knowledge of truth could not act otherwise but good. What later became ethics and science were then perceived to be one single reality.

A subordinate relation

It was only during the 3rd century BC, with Aristotle, that a distinction between the nature of action and the nature of knowledge was made, together with the subordination of good to the truth. Aristotle structured and defined two uses of reason: *a theoretical*, applied to the search for knowledge, and *a practical*, applied to guide the actions (human reasoning was said to be differently structured according to the nature of its goals). Nevertheless, for the Philosopher, good actions required the knowledge of truth, and only those who were educated would know how to perform good actions. This second period of the relation between ethics and science was the longest.

An independent relation

Moral intellectualism – the dependence of good actions on the knowledge of truth – prevailed until Kant's moral philosophy, in the 18th century. Kant was the first philosopher to break the subordination of ethics to science. He explained how pure (theoretical) reason and practical reason were different, following a different causality, the logic of necessity and the logic of freedom, respectively (two different ways of reasoning). Kant also stressed that ethics and sciences are independent of each other; both autonomous: everybody, even someone without education, is equally obliged to comply with the morality which is within their heart. All rational beings can evaluate whether or not their particular norms of action, the maxim of their actions, can become a universal law. There are no excuses: all human beings are moral agents; this entails a democratization of morality. This third period of the relation between ethics and science, characterized by their independence, led quickly to a fourth period, which was distinguished by a progressive detachment between both, and to their subsequent separation.

A separate relation

During the 19th century we witnessed a growing distance appearing between sciences and ethics, with convergent factors subsequently widening the gap. One of the most important factors in this distancing process was the shift of the scientific paradigm from a rational deduction to a rational demonstration rooted in experience. In the wake of this evolution, there was also an independent movement of science (as an objective and universal knowledge) from philosophy (as a rational interpretation of reality, of the world), traditionally regarded as the mother of all sciences. The different nature of sciences and ethics drew them apart, and ultimately, led to their separation.

Another very important factor was the loss of the traditional metaphysical grounding of ethics, which assured its universality. Lacking a universal validity, relativisms arise and its credibility falls. Sciences grew stronger, while ethics became weaker, and the distance between both widened.

In this fourth period, the mighty sciences started to view themselves as an absolute value, thus justifying the use of all possible means to progress. They also viewed themselves as their own ultimate end, given a conviction that their growth would always lead on to a greater good. Ethical concerns were then reduced to the self-regulation of scientists who knew no boundaries and would go ever further in the endless pursuit of knowledge, as their own ultimate goal and supreme value.

Regrettably, the events of the Second World War proved them wrong. The outstanding advances of physics and biology (the most revolutionary sciences of the 20th century) also caused great suffering for many people, and included the cataclysmic humanitarian tragedies of the atomic bombing of Hiroshima and Nagasaki, in Japan, and the medical experiments on prisoners by Nazi doctors. Both society as a whole, and scientists themselves, were compelled to recognize that scientific advances do not always lead to human good. Therefore, science could not continue to be viewed as an end in itself; it must be subordinated to humankind, as a means for individual flourishment and social development, and could not continue to be seen as an absolute value in itself.

A collaborative relation

These were the foundations for a new era in the relationship between ethics and sciences, characterized by their mutual efforts to become ever closer and to establish a collaborative working partnership. This fifth period was boosted by the humbling of the scientists, acknowledging that scientific progress was not a private issue of their own creation. They recognized that society had a contribution to make regarding the goals and means of research, which may have a strong impact on wider society. Besides, it is society that makes the most significant financial investments in science. Scientists have also recognized that there is no such thing as pure science, that all scientific knowledge can be applied, and that all scientific theories have a pragmatic strand. It is therefore important that all of the potential consequences of scientific research are considered and predicted (wherever possible).

This most recent period in the ethics and sciences relationship was also important and necessary for humanists (theologians, philosophers and sociologists); they no longer accepted that society could be put to one side when decisions were being made concerning the progress of sciences, and of technological innovations, both of which affect all individuals and society as a whole. Those affected by progress must be given an opportunity to voice their concerns regarding its dynamics. Ethics became the voice of the citizens, the expression of the community's expectations towards science, and also of social consensus as regards the choice of goals and the implementation of the means by which to achieve them.

After the Second World War, scientists and ethicists agreed that self-regulation of science was no longer sufficient. The hetero-regulation of society was also needed, to guarantee that scientific advances should always contribute to the well-being of humanity. This perspective still acts as a basis for the role of ethics in science and society in the present day. However, this role is not obvious and we may consider that it can be systematized into three different levels.

A repressive function

The first role refers to ethics as playing a repressive function. Indeed, it has already been mentioned that ethics is broadly viewed from the perspective of having a restraining influence, as an authority capable of imposing limits to innovation and progress, mainly due to the fear of new things (neophobia) within society; this fear is nurtured by the media and by their own particular vested interests (such as audience ratings and advertising contracts). Ethics, however, should not and cannot really be reduced down to this repressive function which narrows it, and violates the nature of science in relation to progress; it is unworthy of humankind, who has always evolved thanks to such advances in both knowledge and techniques. There are, of course, some 'red lines' for science, just as there also are for other kinds of human activity. These boundaries should be drawn with the consideration that the benefit of the many outweighs the interests of the few (whilst also ensuring that individual rights are always respected). The balance between individual interests and the common good is a constant social interpretation.

A normative function

Ethics has also been playing a normative function, through the growing proposal of guidelines for good practices in scientific research and technological innovation. Indeed, the more that ethical regulations and supervision are valued, the more relevant that this role becomes. It is at this normative level that hetero-regulation, the participation of society in the destiny of science, and the role of ethics as a social influence, becomes stronger. There are, however, some risks associated with normative ethics which ought to be considered if we are to prevent the transformation of ethics into merely an administrative procedure. The first one is a simple extrinsic compliance with ethical rules, as a check list, and regardless of any commitment. The second danger corresponds to the next step in the same approach: to convert ethical guidelines into legal regulations. Behaviours can, then, be changed, into what is good; but the motivations may remain as they were and will then tend to express what they might have done in the absence of a particular ethical rule concerning the particular action intended. Besides, ethics should not simply be narrowed down to a law, just as intrinsic commitment, and good will, cannot be mistaken for external submission, or self-control.

An educational function

This is why a third role of ethics in the world today should also be considered. A major function performed by ethics is educational; raising awareness that we all live together, with others, thus sharing a community, co-existing in the same, unique world. This entails a commitment to seek out common values, to acknowledge the rights and duties of both ourselves and others; to build up principles and norms towards a peaceful and flourishing co-existence. This level of ethical reflection is of paramount importance, raising our capacity for decision making beyond the simple exteriority of the submission to the law. This becomes particularly relevant when there is no established rule for the situation at stake, or when one presents itself as a dilemma – a conflict between two or more obligations which cannot be fulfilled at the same time and among which the agent has, nevertheless, to make a choice, dropping the other options. It is also at this reflection level that norms are formulated and established, and ethical principles are justified and grounded.

Today, there is a growing tendency to recognize the value of ethics in the development of science and technology. The strong investment in the ethics of scientific and technological research has mainly been pursued under the specification of scientific integrity. It should be stressed that scientific integrity unfolds at the level of normative ethics, mostly as a self-regulated code of ethics, and is evolving to become increasingly closer to positive law. It cannot, therefore, be mistaken for ethics itself, although it is an important part of it, and one which has a broader scope, mostly in what concerns its educational function and grounding level.

1.
Science and Technology
shaping the future

Scientific knowledge and technological innovation have been shaping Western societies, the way people live and the way in which societies are organized, for the last few decades, particularly throughout the second half of the 20th century onwards, and to such an extent that the changes could hardly have been anticipated or predicted.

If we are looking back to the past, trying to pinpoint a single event which particularly boosted the current developments in science and technologies, the discovery of the double helix structure of DNA, by Crick and Watson, in 1953, is of paramount importance. The biotechnological revolution that followed the discovery of the double helix instigated an age of amazing new powers for humankind: to produce human life outside the womb, in a lab, combining biological elements – sperm, oocyte, uterus – from different people, at different periods in the time chain – utilising cryopreservation; to replace nonfunctional body parts from a living person with identical functioning body parts from other humans – dead or alive – or with other biological elements produced by animals (xenotransplantation), or in the lab using the technology of bioprinters, or with mechanical devices; to postpone natural death by resuscitating people who are in cardiac arrest, and keeping dying people in the care of life support systems.

In addition, genetics – after mapping the human genome, and with the most recent advances in techniques of gene-editing applied to somatic and also to germline DNA – has gained the knowledge and power to reshape humanity and even to make it evolve or create a new species, whether biologic or cyborg (enhancing the original physical dimensions with mechanical devices).

The second half of the 20th century was, indeed, dominated by life sciences, and these continue to progress today at an ever-increasing rate. Nevertheless, these first decades of the 21st century have also witnessed the rapid advancement of, what is generally known as, emerging sciences and technologies. This label does not always apply exactly to the same scientific fields, although it tends to denote a joint approach to all of them; that is, the view of these fields of interest in their possible convergences. Frequently, the convergence of emerging sciences and technologies refers to NBIC: nano (nanoscience and nanotechnology); bio (biotechnology and biomedicine); info (information technology); and cogno (cognitive science). Among these, info and cogno, computer sciences and digital technologies, have been particularly under the spotlight, being those which are becoming increasingly influential, both in our present and in our future.

The evolution of the most influential sciences and technologies – from life sciences to digital technologies – bring along other significant changes in the research framework; among these we can stress three major developments. Firstly, research that usually developed into a deeper and narrower field of specialization, is now leading to broader and more interactive convergence (a step further beyond interdisciplinary or transdisciplinary). Scientific progress does not need any further reduction into even smaller issues, but rather it requires opening up into ever wider relations.

A second major change is that progress is taking place more at a technological level rather than at a scientific one; is occurring more in the field of innovation than in the field of knowledge; is happening more in the 'doing' than in the 'understanding'. Some analysts consider that the major and most significant scientific laws have now been discovered; thus, it follows on from this perspective that mainly technological innovations will now shape both our present and our future.

A third feature of the current evolution is the shift from a research arena exclusively pursued at the physical and empirical level, to a growing focus towards a digital horizon and big data analytics, with a *dematerialization* process.

Briefly, it is becoming clear that the current research progress relies less on the development of knowledge and more on the invention of new technologies; less in the multiplication of scientific fields and high expertise, and more on the convergence of technologies and high skills (and soft skills); less at the physical level and more at a digital level. It is in these technological dynamics that the future lies.

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Ethics, science & society in the context of the scientific revolution

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Abstract

Within the context of an on-going complex scientific revolution, developed societies are performing, almost in parallel, digital, industrial and biological transformations that are leading to new products, services, labour modes and living styles. Cyber-physical systems, including collaborative robots and other devices, will ensure the majority of human tasks, from industry, to housework or healthcare. Intelligence will be shared with computers capable of learning and evolving. Furthermore, the increased opportunities for genetic modification and tailoring will challenge life expectations and, indeed, the whole concept of life.

From this perspective of increased complexity, active citizenship will demand a broader cognizance. It will also claim the development of robust critical thinking and spirit, under a well-established ethical framework, capable of considering and accommodating the increasingly faster advances in science and technology, and in human knowledge, at large.

In fact, this new era will bring new political debates and options, requiring new ethical concepts, calling for human-machine ethics, and new education systems and transformed academic institutions, to discuss, strengthen and disseminate those concepts.

Keywords: Scientific revolution, digital transformation, cyber-physical systems, human-machine ethics.

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In the centre of a new scientific revolution

After the consolidation of the globalization movement over the last 25 years, due mainly to progress in transportation and communication technologies, the so-called developed societies are undergoing transformations of much higher importance and impact, driven by new scientific knowledge and disruptive technological advances, as well as by the critical need to ensure the sustainability and the future of planet Earth.

It is becoming commonly accepted that humankind is experiencing a new scientific revolution. The last one took place mostly during the 17th century, from the astronomic discoveries of Thyco Brahe and Galileo Galilei, to the physical laws of Sir Isaac Newton, and led to new concepts and interpretations of the universe, with Earth no longer presented as being at the centre of the Solar System [1]. This period is also largely considered to be the era of the rise of modern science, with Sir Francis Bacon as one of its most influential thinkers. The exceptional evolution in knowledge during these times germinated new ideas and resulted in enormous political, religious and social changes, just as those later on were instigated by the French Revolution, and as the advent of the first Industrial Revolution was fostered by the steam engine. The subsequent evolutions in societal organization and values, including in the political systems, labour, urbanization and ethics, are well known today.

The current scientific revolution is broader and progresses faster, being the result of a complex intersection of apparently independent processes, namely:

– the generalised connectivity between people and things is building a new era, where almost everything is digitally connected – *the internet of things* [2];

– the combination of complex and adaptive computational algorithms with large amounts of data (big data) is already allowing the sharing of intelligence between humans and machines, enabling these artificial devices to take autonomous decisions and to undertake a large number of tasks considered, until recently, to be exclusively carried out by people – *artificial intelligence* [3];

– the continuous increases in computation capacity and performance, with the symbolic benchmark of 100 Pflops (1Pflops = 1015 floating-point operations per second) overcome in 2016; several major countries are competing technologically for exascale computing (i.e. with more than 1018 flops) which is considered essential to support the above referred requirements in data management and artificial intelligence, or to enable virtual modelling of almost all the processes and operations associated with human activities and to the natural phenomena of the universe – *high performance computing;*

– the use of virtual images and environments, and their superposition with reality, is becoming more and more prevalent in several settings, such as work, driving, leisure or entertainment, leading to a near future where citizens may not be able to distinguish if what they are seeing, through their connected smart glasses or contact lens, is real or not – *virtual and augmented reality* [4];

– the emergence of new and revolutionary materials, including piezo-electric (that perform an internal electrical charge variation as a result of an applied mechanical load), functionalized (with specific features associated to tailored changes of the surface chemistry), non-linear (in terms of electric, magnetic or optic properties), biodegradable, high performance, or with adaptive and evolutionary capabilities, for example to tune functionalities and performance to a load or service situation – *smart and self-healing materials*;

– the remarkable developments in biotechnology and genetics are opening new concepts of life and effective opportunities to create, manipulate or clone living organisms, including: *synthetic biology*, a biology-engineering interface area capable of building or re-designing artificial living systems; *genomics edition*, in which DNA is inserted, deleted, modified or replaced in the genome of a living organism with spatial specificity, like the promising and relatively low-cost CRISPR (clustered regularly interspaced short palindromic repeats) system; and *personalised genomics* that uses sequencing and analysis of the genome of individuals to open new frontiers for the treatment, with individual specificity, of several genetically inherited diseases;

– the accelerated development of *tissue engineering*, an area of regenerative medicine that combines scaffolds, cells and biologically active molecules to create functional tissues under specific environments, and anticipates the capacity to produce human organs, e.g. heart valves or liver, once bone or skin production is already a reality.

Furthermore, quantum science and technology is also experiencing major developments, in what could be considered the 2nd Quantum Revolution, after the first one occurred in the first half of the 20th century. As quantum mechanics becomes one of the most complete and accurate physics theories, quantum science is spinning out in new emergent technologies and engineering areas, such as computing, communications, materials and sensors, cryptography, metrology, imaging and simulation. These important developments in the understanding of subatomic particles and their interactions are opening new horizons and theories for the scientific community, and for society as a whole to better understand matter and the physical world. An example of this is the counter-intuitive notion of entanglement that posits a ubiquitous randomness capable of manifesting itself simultaneously in more than one place [5].

Towards new products, working modes and living styles

The discoveries and developments previously mentioned are having significant impacts in different social, economic or technological domains, and these are expected to be more significant in the future.

The most visible and increasingly omnipresent of these is the so-called *digital transformation*, resulting from the combined effect of the overall connectivity (also known as 'the internet of things'), artificial intelligence and virtual reality. The digital transformation is accelerating developments in the great majority of activities, including industry, genomics, health and security, as well as in both working standards and living habits. A major positive consequence of this will be the wider and more common use of analytical and evidence-based decision processes, by humans or machines, enabled by data science.

Furthermore, it is setting new paradigms for human-machine interfaces in workplaces, in transportation, or in private lives, where new areas, such as *emotics* (the capacity of a robot to understand human emotions and to act accordingly) [6] or trustful environments are clearly emerging. Flexible displays, digital contact lens, holographic keyboards, haptic technologies or natural voice processing are expected to revolutionize the way in which people interact with digital devices, and these will be among the interfaces of the future.

Collaborative robots, capable of learning from humans and reacting proactively to their movements, will ensure repetitive, heavy duty and hazardous operations in industry, construction, or services, including health and elderly assistance, without losing efficacy and efficiency when compared to human performance.

In industrial settings, the consolidation of the so-called *4th Industrial Revolution* or Industry 4.0, is noticeable and is characterized by: the high levels of automation and flexibility, with the generalized use of robots; overall connectivity within the different operations and different players of the production value chain; intelligent and analytic-based decision processes; the use of sustainable technologies to minimize environmental impact; the use of digital manufacturing or 3D printing technologies, allowing for unprecedented degrees of freedom in the fabrication of very complex parts; and by the increasing use of micro or nanomanufacturing technologies demanded by the miniaturization drive. This revolution is dramatically changing the landscape of industry, where robots will take, or at least share with humans, the majority of industrial tasks.

Products will no longer be simple goods for working, transportation, decorative or leisure purposes. Products will be developed to be more and more connected, providing additional functionalities and services, fostering an economy based in services that perceive user's needs, track users' behaviours and preferences, and try to rapidly adapt to them. Products will incorporate smart materials and will have built-in intelligence, or will be connected to artificial intelligence applications which are able to evolve, both in cyber or physical functions, and to adapt to the environment or to user requirements.

This new generation of products – *cyber-physical products or systems* – are integrations of interacting networks of physical and digital elements (materials, hardware and software) belonging to a common system with an intrinsic connectivity and articulation of products or product-systems. The physical and digital integration, together with a seamless connectivity, will provide adaptive and evolving capabilities to these product-systems.

As an example, it is expected that by 2025 autonomous cars or trucks will be in use in the streets of major cities or on the highways of East Asia, North America and Europe; furthermore, human driven vehicles will be in a minority by the decade of 2030. It is most likely that the concept of owning a car will have vanished and mobility will be considered as a service, with multiple alternatives in terms of quality and customization. The time currently wasted by millions of people in daily driving commuting will be available for alternative and better uses. The nightmare of finding a parking space will end and towns will be able to use those spaces for more interesting applications. The number of vehicles in circulation is expected to reduce by one third, for the same population size, with significant and concomitant benefits in the air quality and passenger safety.

A *Biological Transformation* is also likely to emerge, as a result of a combination of some of the previously mentioned developments and advances in biology and biotechnology, as well as an increased awareness of the need for more sustainable and efficient processes to produce bio products, including crops and meat. It will involve societal and economic changes as profound as those mentioned for the digital transformation or the 4th industrial revolution, and synergistic effects are expected.

In fact, with current agricultural technology and food habits, it will not be possible to feed a world population of more than 10 billion people by 2050 – more than being simply a question of productivity, it would be a dramatic challenge for the sustainability of the planet. Consequently, artificial food will be a reality, enabled by technology and societal demands, or by expected changes in living styles, such as the growing vegan wave or concern regarding the use of animals as protein-producing devices.

Furthermore, the biological transformation is expected to develop new and more sustainable industrial processes, nature inspired, with important applications in pharma, medical devices and non-fossil based fuels or plastics. Different intermediate mechanism may be used, including fungi and algae, as well as sources of protein or energy, such as organic waste or silk.

More than just being economically efficient, these technologies are expected to be inherently sustainable and to bring effective contributions towards an envisaged circular economy and to the fulfilment of the United Nations Sustainable Development Goals (SDG) [7].

However, and in spite of all these potentially positive developments, Earth is becoming smaller and with an unsustainable level of resources for its growing population. In this context, the sidereal space and the deep sea both appear as new worlds to be explored. These new ventures will experience a huge growth in the first half of the 21st century, enabled by new business models and by the development of more effective devices, vessels, rockets, satellites or stations. The drivers are multiple, including: human curiosity; a clear economic need for new raw-materials or energy sources; and the options for more efficient observation or monitoring activities on Earth, targeting the environment, civil protection or military goals. The approaches are vast and can be as different as near space microsatellites, new space missions to the Moon and to Mars, asteroid mining, manufacturing in space, or improved observation of other galaxies [8]. The preservation of ocean health, mining – such as for the materials for batteries – and geothermal energy, are all examples of diversity in deep sea exploration.

Health will also experience major developments, leading, for example, to an extended life expectancy and to human ageing with quality. The scientific revolution and the technological transformation are already strongly affecting medicine and creating new paradigms. Besides key advances in regenerative medicine and in diagnostic devices, the combination of genomics with information technologies will enable a personalised and consequently more precise medical environment, and one which will be preventive and predictive-based, as well as much closer to citizens and patients, enabling them to be more closely monitored and treated on an individual basis. In this context, public or private health systems are expected to experience radical changes over the next few decades, including those involving infrastructure, business models and insurance practices.

The renewed centrality of education and ethics

Times are changing, and universities and educational systems at large are being challenged. More than just better or specific competences, new and disruptive ways of thinking are required to be both taught and learnt. In fact, digital transformation is also impacting school as an institution, including university, in the way in which learning and teaching is designed, performed and evaluated.

The main differentiating features of universities will no longer be their repositories of written or physical knowledge in libraries of books and scientific journals, which are now easily accessed electronically; whilst physical laboratories will be effectively replaced by experiences in virtual and immersive reality, supported by advanced modelling software.

Accordingly, universities have to become houses for knowledge encounters and exchange: encounters, between professors, students, researchers and professionals to disseminate, discuss and build knowledge, share experiences and, ideally, foster wisdom. Certainly, lectures will remain in the centre of the learning process and of the university environment; but interactions between the academic players will be more and more important, namely for the development of individuals who combine a consolidated knowledge in a specific scientific area and key competences, critical for their professional activities, with a comprehensive cultural background, essential for their citizenship. This individual development process will be an increasingly dynamic long-term process, which is also strongly mediated by digital media and tools.

In this rational, comprehensive cultural background should be considered in *sensu lato* with institutional-specific or distinctive components. Nevertheless, and besides the natural centrality to social sciences and humanities, sustainability awareness and critical issues should be at the core of this educational aspect.

In fact, anthropogenic activities are testing to a dangerous extent the sustainability limits of Planet Earth and compromising the future of humankind. Clean industrial processes, low environmental impact materials, effective recycling solutions and sustainable mobility are mandatory for a safe common future. Digital solutions, namely in modelling, monitoring and decision support – including in evaluating individual footprints, and biological-based processes – will be key technologies to overcome these critical challenges.

In the context of increasing overlaps between technology and citizenship, ethics and ethical thinking have to be an intrinsic part of the education process, both in formal teaching and in interactions of the university experience. Decisions based on values and on value creation for society at large have to be at the centre of human behaviour, both at professional and personal levels. As science and technology are accelerating transformations, values will be continuously challenged creating a potential mismatch with relevant regulations and ethical codes that may lag behind reality. So, more than simply being learnt, ethics has to discussed, requiring institutions and individuals to learn, and to practice how to take and to promote those discussions.

Furthermore, universities will also have to promote creativity, with multidisciplinary curricula and projects, as well as by exposure to new contexts, namely in arts and performance.

Within the borders of actual knowledge concepts, creativity will be, perhaps, one of the ultimate differentiate features of humankind and a key element of future societies, both in human development and in competitiveness between countries or organisations.

Fears, expectations and options

As in other periods throughout history, societies and citizens are afraid of what is new; their fears emphasised by the perception that great changes are or will occur in multiple sectors and dimensions. The consequences of some anticipated technological developments – including those regarding robots and the implicit employment implications they will cause, life manipulation and the expected existence of humanoids, artificial intelligence and the capacity of machines to learn and evolve, as well as the lack of privacy associated with big data and powerful monitoring systems – are recognized areas of concern.

However, societies and citizens also have great expectations and are tempted by promises of an extended life without pain and with improved care for the elderly, as well as by the end of repetitive and hard physical work, and by the belief in a future with sustainable living modes.

Furthermore, these emerging times will also bring new ethical challenges, which will be at the centre of new political debates, namely: critical machine/computer decisions as, for example, in autonomous driving; the use of artificial intelligence in weapons; limits for genetic manipulation; individual privacy; and limits to machine self-evolution. In fact, many subjects that started as research and development topics are currently being considered as ethical issues and may be foreseen to be at the core of future political discussions and options.

Human genius and perseverance took science and technology to a level where intelligence, as currently perceived, is now also available within human-made devices. The limits of what those machines will be able and allowed to decide, and to evolve, as well as how it will be assured and controlled, will be a central debate: A debate that is still weak, but one which is already on the world agenda, such as in the way in which different countries allow the storage and use of information and personal data. Increasingly, this will be the political debate, and one which is only fruitful and relevant if it is performed by an informed and knowledgeable society, with wise ethical options.

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Genetics developments: new opportunities, new challenges

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Abstract

Ever since we began creating technology, we have been handed the dual gift of opportunities and the prospect of challenges. The field of genetics is no exception. Genetically speaking, we are living in fascinating times. Not only have we greatly deepened our understanding of genetic mechanisms, we have also started to apply this knowledge to the fast expansion of genetic technologies in a variety of different areas of our lives. As a result of recent scientific and technological developments, reading our individual genome has never been as inexpensive, fast and accessible to so many, as it is today. Moreover, complementing our ability to read our genome, groundbreaking novel technologies now allow us, for the first time, to also modify it with precision. These, and other recent technological advances, will not only revolutionize the way we predict, prevent and treat disease – they will open up an infinite number of significant new opportunities which were previously unimaginable, as well as revealing equally numerous challenges. *As science fiction becomes reality* we are faced with new questions and will be required to take decisions that will concern each of us as individuals, as a society and as a species. Taking the right decisions requires that we are aware of the risks of new genetic applications, but also that we are aware of their potential. As much as we need to anticipate and avoid their non-ethical use, we must ensure that we do not hold back the development of science and promising life-saving technologies.

Keywords: DNA, genome, gene-editing, CRISPR, gene drive, iPS cells, technologies, genetics.

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We have come a long way since the Father of Genetics – George Mendel – from thoroughly studying the traits of pea plants in his abbey's garden in 1856-1863, identified the existence of units responsible for the transmission of traits that are passed on from one generation to the other. This unit, responsible for heredity, was later named *the gene*.

Since then, we have uncovered not only the beauty of the structure of the gene – the famous DNA (deoxyribonucleic acid) double helix, discovered by Watson and Crick (1953) – but have also achieved a significant understanding of how it can simultaneously play two key roles: one critical for the survival of an organism (providing the *instructions to build and maintain* a healthy organism), and the other crucial for the survival of the species (by ensuring that those *instructions* are reliably passed on to future generations).

Genome sequencing: Reading our DNA

Having realized that DNA contained such *instructions* written as a sequence of DNA letters (nucleotides), we could not wait to be able to decode and read it. Driven by scientific curiosity and supported by developing DNA sequencing technology, as a result of a costly and long investment, we were finally able to read (almost) the full DNA sequence – *our genetic code*. The Human Genome Project, which took approximately 15 years and 3 billion dollars to complete (2000), revealed the sequence of most of the human genome, as well as the observation that the human genome consisted of a surprisingly smaller number of genes when compared to initial expectations.

We now know that the human genome contains 19-20,000 genes, a number not only smaller than that initially expected, but also not very different from, and often even smaller than, the number of genes identified in organisms that we consider to be less complex than humans (such as the fruitfly – *Drosophila melanogaster* – with 17,700 genes; the zebrafish – *Dario renio* – with 26,000 genes; and some plants, such as *Arabidopsis* – with 27,000 genes).

We can think of genes in the same way as we might consider words. The finding above –that less complex organisms may actually have a higher number of genes – implied that in the same way as it is not the number of words that define the complexity of a story, it is not the number of genes that exclusively define the complexity of an organism. It is also how we use those *words*, or genes, that can help shape a simpler or a more complex *narrative*, or organism. In other words, it is not only the number of genes, or the genes themselves, but how we combine them that significantly contributes to the complexity of how we function – hinting at the critical role of regulation in gene activation.

We can only fully make sense of a written story, whether a simple or complex one, by understanding the meaning of each of its words. Similarly, making sense of our genome sequence will only be possible through understanding the *meaning* of each gene: the role they play, when and where they are activated (*turned on*) in the organism, and how they can act in a concerted way.

Why, in the context of genetics and disease, is understanding the meaning of genes so important? Knowing how a word is spelled correctly allows us to recognize a misspelling and identify an error. If besides knowing the correct spelling of a word we also know the meaning of that word, we can not only detect an error, when it occurs, but also assess the impact it has in the whole narrative in which the word is a part. Like words, genes can also be misspelled – either as a consequence of errors that can take place during the cell division process, when the full DNA needs to be replicated to be passed on to the daughter cells, or when they are exposed to external agents, such as sun UV radiation – we refer to these '*misspells*' as *genetic variations*.

As a result of innumerable genetic studies, often using genetic model systems like the ones mentioned above (fruitfly, zebrafish, mouse and other organisms), we have made great progress in understanding the *meaning* of many genes. Studying the genes in these organisms has greatly helped us to understand our own, as we, as human species, share with them an incredible number of genes and biological mechanisms. Through such studies we have progressively started having a more comprehensive appreciation of the role that genes play, what specific processes they are involved in, and in what body tissues.

In the same way that we can detect a misspelled word and can appreciate its impact on a narrative, our increasing ability to read our DNA sequence – and detect genetic variations – combined with our equally increasing understanding of the role of genes, can greatly improve our ability to predict the impact of genetic variations in our organism.

A genetic variant can simply lead, or contribute, to a different trait (such as hair colour) or, in some cases, to the development of a disease. This latter type of genetic variant is commonly referred to as genetic *mutation*. However, not all genetic variants lead to a different trait or pathology; some misspellings can be seen as pure *typos* that do not alter the meaning of a word, i.e. they do not have a *phenotypic effect*. Though we often refer to *the human genome*, because human beings share most of their DNA sequence (99.9%), there is a small proportion of our genome that makes us unique (with the exception of twins, who share the same DNA sequence). Each of us carries a unique set of genetic variants that makes us different in the way that we look, the way that we act, how we think, how we feel, and can also greatly influence whether we tend to develop a certain pathology or not.

It should be noted that *errors* in between genes – the spacing DNA regions that have been increasingly recognized as playing a role in how and when the genes themselves are activated –can also have an impact on the organism, similar to the way in which punctuation can impact a narrative.

As we expand our knowledge on the links between genetic variants and disease, or susceptibility to developing a disease, individual genome sequencing becomes more and more meaningful. The comprehensive reading (*spellchecking*) of our individual genome allows us to molecularly predict or diagnose certain diseases. Although initially unaffordable for any individual to have their genome sequenced, in just a few years we have seen the cost of genome sequencing decrease from 3 billion dollars to approximately 700 dollars – and possibly down to 100 dollars within the next two years. Not only has genome sequencing steeply decreased in cost, this process, which initially took 13 years to conclude, can now be performed in approximately 24 hours. With the exponential advance of technology, having our genome sequenced has become as accessible as getting a smart phone. Having one's full genome sequenced will become as common as having a blood test done. Consequently, with more and more individuals having their genome sequenced, we gradually move towards a more personalized medical approach. Detection of the presence of certain genetic variants in an individual's genome can certainly have multiple applications.

The identification of a specific genetic mutation can be used, for example, to predict the future development of a disease, or to provide insights into the susceptibility of developing a disease. Should the predicted disease be preventable or treatable, this information can be invaluable when gathered in a timely manner. In addition to improving disease prediction and prevention, the detection of a specific mutation can also support the diagnosis of certain ongoing disease or enable its sub-classification (such as cancer sub-types), which in turn can lead to a more targeted and adequate treatment. In fact, as genome sequencing technologies become more accessible and we accumulate larger genetic sets of data, clinical pharmacological studies will progressively start to take into account genetic variability and assess how it can influence response to a specific pharmaceutical drug, not only in terms of efficacy, but also regarding the development of possible adverse events. This expanding new field – pharmacogenetics – is definitely contributing to the prospect of a more personalized approach in disease treatment.

Genome editing: Fixing our DNA

Information on an individual's DNA sequence has become even more powerful with the recent development (2013) of a groundbreaking technology: CRISPR (*clustered regularly interspaced short palindromic repeats).* Curiously, this technology was inspired by a naturally occurring defense mechanism used by ancient archae microorganisms for their own protection against their greatest enemies – viruses. This new tool can be compared to *molecular scissors* capable of cutting DNA with precision. To target a specific DNA sequence, the molecular scissors are guided by a small *GPS unit* that indicates where in the DNA the scissors should cut. In essence, this technology consists of the combination of a protein capable of cutting DNA – the endonuclease enzyme *CRISPR-associated* (Cas) protein – the molecular scissors – and an RNA (ribonucleic acid) molecule – the *guide* RNA – that acts like a programmable GPS unit.

With the development of this tool, today, we can not only *read* our DNA and understand its *meaning*, but also *edit* it at our own will, and correct any *errors* we find in our genome. The fact that CRISPR is such an inexpensive, easy-to-use, accessible-to-all, genome editing tool explains why it has been so readily adopted by so many researchers worldwide and how it opens up an infinite number of new opportunities. This tool can be especially relevant to potentially cure or prevent diseases caused by a clear genetic mutation. This is the case for Duchenne muscular dystrophy (DMD). This disease affects mainly males (1/5000 boys) and is caused by a genetic mutation in a gene that codes for Dystrophin, a protein essential for muscles to function properly. As a consequence of this genetic mutation, the resulting Dystrophin protein is either absent in the muscle or present in very low quantities, leading to progressive weakness and loss of skeletal and heart muscles, and, eventually, death at a young age. Despite the seriousness of this disease, there is still no cure available. However, recent research studies have shown that muscle cells of beagle dogs with this disease could be repaired through DNA editing using the CRISPR technology. This new development brings high hopes for a possible cure, not only for Duchenne muscular dystrophy, but also for other diseases that are also caused by genetic mutations.

Gene drive: Disseminating genetic modifications in the wild

Besides the promise of bringing a cure to currently untreatable diseases, CRISPR has led to the development of an equally significant tool – the *gene drive*. For a long time, we have been trying to modify genes in species around us, as a way to either improve them, for our own benefit, or to minimize their nocuous effects. Any genetic variant we try to disseminate, however, will always have to compete with its wild counterpart for transmission to future generations. With time, a modified genetic variant we may want to disseminate in the wild, will either disappear or persist at very low frequency, especially if it does not confer competitive advantages to that species. Gene drive promises to be a *game changer*, by *tricking* nature and *hacking* the genetic transmission system. This novel approach is based on ensuring that any genetic variant we artificially introduce into the wild will be transmitted to the following generation. This seemingly subtle trick can have very significant implications. For example, it has long been debated whether, as a way to fight malaria, we should spread genetic variants in the wild that would render male mosquito progeny sterile, and therefore reducing, or even extinguishing the mosquito population – the main vector of transmission for this serious disease. With this new genetic tool, we now have, for the first time, the possibility of spreading widely in the wild any genetic variant of choice in a more, or even completely, permanent way. This technology is currently seen by many as potentially useful to control not only malaria, but also other vector-borne diseases, eliminate invasive rodent species from certain islands, or increase susceptibility of weeds to herbicides.

iPS cells: Making egg cells from skin cells?

The expanding understanding of genomes and gene regulation – i.e. when, where and how certain genes are activated or deactivated in different cell types and tissues – has also led to another promising advance*: induced Pluripotent Stem* cells (iPS cells).

Our body has 210 different types of cells, each with a specific role – comparable to a house with multiple utensils, such as cups and plates, where each serves a specific purpose. Utensils in a house can vary in durability; those that eventually break are replaced to ensure that the house continues to function successfully. Similarly, the 210 different types of cells in our bodies also have variable specific life spans (ranging from a few days, to many years, or a life time). When cells naturally reach the end of their life, they need to be replaced with new cells. For this purpose, the body keeps reserves of stem cells capable of giving rise to cells of a specific cell type, more differentiated, or specialized, with a specific role. These reserves can be seen as *clay reserves* ready to be used and molded into any missing utensil – such as a cup, or plate. The conversion of less differentiated stem cells (the clay) into differentiated cells with a specific function (utensils) relies on the activation, or deactivation, of some genes in our genome; i.e. the generation of cells of each specific type relies on which genes are specifically being turned on or off. Our understanding of this *differentiation* process has enabled us to reproduce it in a laboratory setting. We have learned to generate multiple types of cells, with specific functions, from stem cells. Provided we have access to stem cells, this can be invaluable for cell replacement therapies. However, having access to stem cells, such as embryonic stem cells, which have the capability of becoming any cell, is not always possible, and has, in addition, been a controversial matter. Since embryonic stem cells are derived from embryos obtained from in vitro fertilization centers, even though these are donated for research purposes with informed donor consent, the use of these types of cells has been ethically and politically controversial, as it involves the destruction of embryos. A second challenge in cell replacement therapy, which has relied on transplantation of cells from a donor, is the rejection reaction that can occur in the patient's body as it recognizes those cells as being foreign.

Recent revolutionary advances have allowed us to overcome these obstacles by enabling us to use any type of specialized, differentiated cells, with a specific well-defined morphology and function – such as skin cells – and to reprogram them to *go back in time* to generate less specialized cells with the capability of them then becoming any specific cell type. In other words, this newly developed process can be compared to converting a certain type of *utensil* with a specific shape and function, such as a cup, back into *clay*. This *clay* can, in turn, be used to generate any other kind of *utensil*, such as a plate – i.e. this groundbreaking technology allows us to *convert a finished cup into a plate*. Because the less differentiated cells obtained through this process have stem cell-like properties and can be generated (induced) in a laboratory, they were called *induced Pluripotent Stem* cells, or iPS cells.

Such a technology can have innumerable applications in the biomedical field. In the context of replacement cell therapy, a patient's own skin cells can be used to generate cells of a different type that need to be replaced. This tool can be used, for example, to generate pancreatic insulin-producing cells using a diabetes patient's own skin cells, ensuring there is no rejection of the newly generated cells that are transplanted into the patient. Another exciting application is the possibility of producing cells specific to a certain organ or tissue, and to generate chambers of cells – *organs-on-a-chip* – that mimic that individual's organs. Such *organs* can be used to assess the individual's response to a specific pharmacological drug. Multiple *organs-on-chip* can be combined into one single chip, where the organ chambers are interconnected, therefore reproducing a human's organ system – the *human-on-a-chip* – ideal to study the effect of a medical drug not only in one specific organ, but in the overall system. This personalized tool expands the field of pharmacogenetics even further, as the individual's organ system, with genetic variants specific to that individual, can be correlated with response or susceptibility to a certain medical drug. Fundamentally, we can now envision testing a pharmaceutical drug, or array of drugs, on a patient's *human-on-a-chip* to assess the efficacy and safety of that drug in that specific individual. It is anticipated that the combination of iPS cell technology with 3D bioprinting (printing structures, such as organ-like structures, with cells) will open up the possibility of producing organs with one's own cells. Such 3D printed organs could eventually be used for transplantation, to help overcome the current challenge of organ shortage, as well as tissue rejection. Combining the iPS cell technology with the CRISPR gene-editing tool also holds the potential for new cell replacement treatments, where skin cells of a patient carrying a harmful genetic mutation can be used to produce iPS cells whose genetic mutation can be corrected and then used to derive mutation-free cells of any cell type.

This is definitely an exciting time for genetics-based technologies. We are now not only able to easily *read* DNA and increasingly understand its *meaning*, we can also *erase it and correct* it – allowing us to prevent a disease, permanently change the genes of wild species around us, or even *write* new DNA from scratch, to build new organisms. Although still in its infancy, a new field – synthetic biology (the redesign of natural biological systems or the design of novel artificial biological functions, organisms or devices) – is emerging. Based on knowledge that we have gathered on genomes and circuit systems of multiple species, inspired by nature, we have started to *write* new sequences of DNA from scratch and design new organisms that *make* new things, such as producing biofuels, generating components of pharmaceutical drugs or which can be used as an infection diagnostic tool.

New technologies: New opportunities, new challenges and new responsibilities

Used either individually or combined, recent technological advances open up an infinite number of significant new opportunities, but also equally numerous challenges and questions.

Getting to know the sequence of our own DNA has never been cheaper, more accessible or faster. As the number of individuals who will have their genome sequenced exponentially grows, holding promise for more advanced treatments and the expansion of personalized medicine, the number of inherent challenging questions that we need to prepare for also increases.

– Imagine that the DNA sequencing of your DNA unexpectedly reveals the presence of a genetic mutation linked to an as-yet unpreventable disease: Would you want to know? Should you have the right not to know?
– Who should have access to our DNA sequence?
– Will we be at risk of being genetically discriminated against? How can we ensure that employers and insurance companies do not have access to our genetic information?

Given how easily accessible, fast and inexpensive the CRISPR technology is, it has been rapidly adopted worldwide in different settings, from industry to academic research. Gene-editing is bringing previously unimaginable new hope of cures for some genetic diseases. Initial studies that make use of CRISPR-based genome editing tools to correct harmful genetic mutations in somatic cells (i.e. cells that will not be inherited by future generations) of animal model organisms suggest that this approach may indeed be generally successful in curing genetic diseases in humans (such as Duchenne muscular dystrophy, as mentioned above). However, though initially thought of as extremely precise, i.e. accurate in what DNA fragment is exactly edited during this process, some studies have also suggested otherwise: that current CRISPR tools may lead to undesired off-target effects, elsewhere in the genome. The risk of causing undesired side mutations is even more problematic when editing germline cells (gametes that can be passed on to offspring). Under such circumstances, any genetic modification, desired and not, will be passed on to future generations – as opposed to gene-editing of somatic cells, where genetic changes remain confined to the individual and are not passed on to the respective progeny. For this reason, the application of gene-editing tools has been, in many countries, restricted to non-human organisms or to human embryos that are only used exclusively for research purposes and are not meant to be implanted. Worried that we lack sufficient evidence on the safety of current CRISPR-based gene-editing tools, in the light of a recent report of a possible claim that the first gene-edited babies have been created in China, many scientists worldwide, including CRISPR pioneer Feng Zhang (MIT), have called for a moratorium on implantation of edited embryos until the risks of heritable genome editing can be accurately evaluated and safety fully ensured. Though some scientists believe that such a moratorium may hinder the advancement of science, it is, in general, agreed upon that it is too early to carry out pregnancies of edited human embryos, as DNA editing can cause mutations that could result in new health problems that would be transmitted to future generations. The major research funding agency in the United States – NIH (National Institutes of Health) – a major research driver, has also stated their support in favour of an international moratorium on the clinical application of germline editing until it can be done *with the utmost respect for human life*. Despite some general consensus among the scientific community against implanting genome edited embryos, interestingly, a recent public survey carried out in the United States with 1,067 adults, has shown that most participants favour the use of gene-editing: i) to prevent an incurable or fatal disease, or a non-fatal condition, that a child would inherit, or ii) to reduce the risk of diseases that might develop later in life. Most of the survey participants, however, oppose using this technology to alter capabilities or physical features.

As gene-editing technology is advancing at such a fast pace and becoming so widely accessible and adopted, it is critical that we are prepared to answer key questions related to its application:

– How can we ensure that gene-editing tools will only be applied to babies once the tools have been proven to be safe enough without causing undesired secondary edits?
– In times when anyone's basement or apartment is becoming the new George Mendel's garden and gene-editing is taking place in non-institutional settings, will there be a place for regulation?
– Do we have the right to permanently edit a baby's DNA?
– Will there be equal access to gene-editing treatments or interventions?
– How will we deal with GMO vs. non-GMO humans?

Whereas it is known that a capability trait such as intelligence will be hard to gene-edit any time soon, given its complexity and the fact that many gene variants are known to be linked to this trait, many say that it may be merely just a question of time until it actually becomes a possibility. Contrary to the perspective of using gene-editing to improve medical conditions, gene-editing of capabilities or physical features is viewed with resistance and possibly fear, though also with curiosity:

– Where will we draw the line between medical applications and attempts to create genetically enhanced individuals? How do we define disease? When will gene-editing be justifiable?

The iPS cell technology has brought us a multitude of applications that can push the advancement of medicine and pharmacology even further. Recent experiments have already demonstrated that mouse eggs generated from mouse skin cells could be successfully fertilized and give rise to mouse pups. These results, together with the finding that we can create eggs from human skin cells, suggest that – sooner than we think – we will need to start addressing questions such as:

– Who should be allowed to use their skin cells to produce eggs? Should a young child be allowed to become a mother/father?

With technologies like gene drive, we now have the possibility of spreading genetically modified organisms in the wild in a permanent way, taking over wild populations. A major potential application under discussion is the spreading of genetically modified mosquitos that once released into the wild, will mate with their female counterparts to give rise to sterile male progeny and eventually completely extinguish the mosquito species. Though this approach could significantly contribute to a decrease in malaria transmission, it also raises challenging questions, such as:

– Do we know enough about the niche position that mosquitos occupy in our ecosystem and what the consequences of eliminating this species would be?
– Do we have the right to destroy a species, while we are investing so many resources in saving and recovering others?

As new revolutionary technologies emerge and rapidly become more accessible and widespread, biosafety and bioethics need to be continuously reassessed to ensure that new tools are used for the common good. While it is critical that we are prepared to answer all of the challenging new questions that these advancements imply, it is equally important to ensure that we will be able to do so without castrating development of technologies which, when used properly, hold great promise for a healthier future. As important as questioning our *right* to apply new developing technologies, we should, simultaneously, not forget our *responsibility* as keepers of tools that can save lives.

– Do we have the **right** to extinguish mosquitos? Or do we have the **responsibility** of saving children from dying of malaria?
– Do we have the **right** to change a child's DNA, or the **responsibility** of preventing a fatal disease from developing?
– Do we have the **right?** Don't we have the **responsibility**?
– *If I have the technology to save a life and I don't do it, is it ethical*?

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A door is open?
Genome editing, algorithms and the wish to control

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Abstract

The new developments in genetics, applied in parallel with those of equal magnitude in big data and artificial intelligence, give cause to imagine a terrible scenario for future societies, jeopardizing the achievements in ethics and in human rights of the past 70 years.
Keywords: Genome editing, germline intervention, social credit system, future aspects, ethics.

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What are the most urgent bioethical issues at the end of 2018 and what are our future perspectives?

We are currently witnessing a number of scientific developments which may provide benefits if cautiously used, but which might also present a danger to mankind. Genome editing, with its new tool of CRISPR-Cas9, has made genetic interventions easy and cheap. It can be used in the lab achieving results which would once have been impossible, or only possible with a much higher level of effort and cost. The scientific community has welcomed this new tool for many procedures taking place in the lab, but warns against interventions in the human germline. We have a very heterogeneous system globally regulating interventions in the human germline. Some countries do operate legal prohibition. In Austria, for example, the Genetic Act prohibits such interventions. In other countries, prohibition follows established guidelines. But there are also countries where no regulation exists.

We have certain moral responsibilities to future generations. There is a common heritage belonging to all humanity. Any germline genetic intervention is a potential danger to future generations, as it creates unforeseeable risks, both for the children of future generations and also for society as a whole.[2]

When the world first received the news of the gene-editing experiment on human embryos, resulting in the birth of the first gene-edited twin girls in China, the scientific community was shocked.[3] The germline of these two girls had been altered in vitro, so that certain traits were changed. Hardly a newspaper or other media outlet failed to report the news, quoting scientists, interviewing ethicists or referring to politicians expressing their sincere and utter condemnation of these experiments. There were two major issues:

1. The violation of a global consensus regarding research, and the existing taboo in the field of research, by implanting a germline-edited viable human embryo into a woman to create a pregnancy.
2. The germline intervention itself, with its unforeseeable risks, both for the respective children and for society as a whole.

News such as the gene-editing experiment on human embryos, which was presented after the birth of the twin girls, has grossly violated the line between research and practice, and in doing so, has raised many more questions:

– How has it been possible to find an accomplice/collaborator in the gynecology and obstetrics field to undertake an unauthorized experiment?
– How has it been possible to intervene via reproductive medicine?

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2 UNESCO Universal Declaration on Bioethics and Human Rights,, Art.16, https://unesdoc.unesco.org/ark:/48223/pf0000146180

3 Genome-edited baby claim provokes international outcry, Nature **563**, 607-608 (2018)

– What kind of information did the parents of the twin girls receive from the scientists?
– What was the involvement of the gynecologist?
– Did the parents – or could they even – consent after adequate information had been provided?
– Who financed these interventions?
– Is the information that the public has received, complete and accurate?

The scientist He Jiankui presented the news, stating that he is responsible for this gene-editing experiment. The Southern University of Science and Technology in Shenzhen, where He Jiankui was affiliated, terminated his contract in January 2019 on the grounds of "deliberately evading oversight in pursuit of fame and fortune". Needless to say, it seems that personal vanity and international approval may have indeed been reasons for He Jiankui's actions.

Human enhancement

This experiment has shaken the scientific community, because it has violated an existing consensus that research has to be conducted according to legal and ethical guidelines; it has to be transparent and also in line with the relevant institutional and national regulations. Although the information presented to the public was ambiguous, it seems that the experiments were conducted without any ethical review or approval, and that there was no institutional support nor authorization or any permission from any authorities. Financing sources were not transparent.

The experiment was not conducted in an effort to heal the embryos or to protect future children from a severe life-threatening disease. The reason for this intervention was clearly human enhancement:[4] to inactivate the CCR5 gene in human embryos to make the newborns immune to AIDS virus infection! Obviously, we know that there are simpler and safer treatments to avoid HIV infection, but we do not know if gene-editing may be helpful.

CRISPR gene-editing technology is new – the first publications referencing this specific technique date from around 2012; the process is extremely useful in the lab for biomedical research; it is cheap and easy to use.[5] It is currently used in laboratories, for basic biomedical research, and it has great potential for the treatment of genetic diseases,

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4 Clarke, Steve, et al., eds. *The ethics of human enhancement: understanding the debate*. Oxford University Press, 2016.

5 Doudna, Jennifer A., and Emmanuelle Charpentier. "The new frontier of genome engineering with CRISPR-Cas9." *Science* 346.6213 (2014): 1258096.

but it should not be prematurely applied to human beings. One of the reasons for such reticence and reluctance is that we do not yet know the consequences of such techniques and the nature of the side effects which might occur. We are unaware of what dangers may exist when the technique is applied to human beings. Current uses in the lab concern the genetic screening of cells with regard to potential drug targets in cell lines. It can also be used for genome editing in model organisms where the respective national laws permit animal research.

There have been ample discussions among experts about the future of CRISPR. Where should one draw the line? When might an intervention into the germline occur? The common opinion is that a germline intervention, albeit currently forbidden by law, or by professional guidelines in many parts of the world, would become negotiable for the most severe of diseases, and concern rare diseases with no potential alternative treatments. We speak of diseases such as sickle cell anemia, Tay-Sachs disease or Huntington's chorea. No one imagined that 'enhancement' would be the first established reason for germline intervention. Enhancement means, in a bioethical sense, the improvement or 'upgrading' of physical or psychological abilities in human beings. There is common consensus within the scientific community that editing the human germline is currently an unacceptable process.

The intention of the researcher was to improve the traits of the embryos. This is a use which leads us towards eugenics. We have to ask where to draw the line? If we deem it acceptable to alter the germline just to improve traits, where will we stop?

A terrible scenario

The world is constantly on the move, societies develop. But many ideas, which we may have considered to be ideas of the past, are obviously coming back into circulation, and in a new, modern and more 'perfect' way. Nazi Germany had a sterilization law, which was directed at eliminating genetic defects from the entire German gene pool. The people targeted by the German law were those individuals with disabilities, mainly in mental hospitals and other institutions. Forced sterilization was followed by systematic killing – euthanasia – of people with mental and physical disabilities.

States are obviously abandoning their goal – dating from the era of enlightenment – of protecting their citizens and seeking to defend their welfare and that of the common good. An example is China's 'Social Credit System', which was introduced in 2014. The Social Credit System was developed by the Chinese Government, and aims to assess and rank the citizens according to their behaviour.[6] For the citizens who 'behave

[6] https://www.sciencealert.com/china-s-dystopian-social-credit-system-science-fiction-black-mirror-mass-surveillance-digital-dictatorship

well' there are incentives in fields such as housing, travel, job promotion and social activities. For the ones who score lower, the access to a better life can be denied. It seems to come from a dystopian future created by science fiction writers. But it is no fantasy or virtual reality. It is the brainchild of a society which wants to monitor and control everybody and everything, even beyond national borders. It is a system where the state dictates the morality of the citizen.

The Social Credit System is not a completely state-driven system. It is a combination of state and the private sector, with private companies collecting data which is incorporated by the state, thus creating a thorough picture of each individual, which leads on to the states own ranking system. Every citizen has his own account with a certain number of points.

Persons who are 'good citizens' collect the additional points. Misbehaviour (who decides?) leads to a loss of points and to the individual being blacklisted.

Where does such a system lead? It can only lead to a further division within society, creating new classes of people depending on their social credit. Such a system is the basis for an even higher fragmentation of an existing society, where the boundaries between rich and poor, educated and unlearned, wanted by the state and objected, are intensifying.

Where are our human values? Values such as the respect for autonomy, the respect for our private lives? The provision of benefits, the avoidance of harm, and the significance of solidarity, as well as the observance of a global justice?

A call on science fiction

Let us imagine a scenario where genome editing would be combined with a Social Credit System within an authoritarian state!

Let us imagine that such a Social Credit System would be deemed even more efficient in creating the 'citizen of the future' if it were combined with genome editing to achieve the development of a targeted, personalized citizen. This would be a return to a new eugenics, indeed leading to so-called 'Designer-Babies', a selection of children who would have the traits that the state had decided were suitable for their future citizens.

Genome-edited new citizens, who would never ask questions, but would be ready to form a willing workforce. Or be ideal soldiers, supporting a cruel war to conquer foreign territories, or fight against a suppressed minority population. When bioethicist Jonathan Moreno imagined such a possibility some years ago, mentioning the film 'The Boys from Brazil', it seemed a bold imagination![7] 'The Boys from Brazil' is a science

7 Bosley, Katrine S., et al. "CRISPR germline engineering—the community speaks." *Nature biotechnology* 33.5 (2015): 478.

fiction movie depicting a cloning experiment designed to create a race of murderous individuals.

What we take for science fiction today might be reality tomorrow!

Conclusion

There are currently two revolutions which are happening in parallel: the incredible and fast developments in the fields of big data and artificial intelligence, and the development of genetic technology with its goal to design positive perceived traits of children who are as yet unborn.

What can we do? We will not be able to stop developments which also have positive features to them, such as healing and helping. But we can do our utmost to act reasonably and to handle such new technologies with care. Scientists are asking for a moratorium on heritable genome editing.[8] Human genome editing should not be applied until it is safe and effective for human beings. There needs to be a consensus among society as a whole, among the worldwide community of scientists, with scientific journals, funders and scientific institutions, as well as within the life sciences industry. Genome editing is a revolution with the potential of healing many deadly diseases, but it needs to be applied in a reasonable and ethical way. We have to fight to hinder the developments of systems where the transhumanism – a perception which sees the human species as being only in an early stage of development on the way to a better and improved human organism – and a total digitalization of surveillance and genome editing, shape the future of mankind.

[8] Lander, Eric, et al. Adopt a moratorium on heritable genome editing. Nature 567 (2019):

Artificial Intelligence: Challenges and Ethical Issues

ARLINDO OLIVEIRA[1]

Abstract

The development of Artificial Intelligence (AI) technology raises a number of ethical challenges that should be addressed before they become even more urgent. Among these challenges are the loss of privacy and freedom imposed by AI driven business analytics; the possible loss of trust in the information available on the Internet; the social and economic challenges induced by AI systems; the more complex, long-term issues related to the legal status of AI systems and robots; and the possibility of existential risks for humanity caused by the rise of Artificial General Intelligence.
Keywords: Artificial Intelligence, data science, privacy, legal status of robots, income re-distribution

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Introduction

The field of Artificial Intelligence (AI) aims at the development of technologies that will enable computers to exhibit intelligent behaviour, possibly indistinguishable from the behaviour of human beings (Turing, 1950). Although long-standing questions on what 'intelligent behaviour' means remain unanswered, there is little doubt that in the next few decades, many tasks that would require a certain level of intelligence if performed by humans, will instead be performed by AI based programs. Extensive research in AI has been taking place for over 60 years, and has obtained many important results, leading to the creation of several AI based systems, including expert systems, logistic optimization systems, and natural language processing systems, such as translators, search engines and information management systems. More recently, machine learning based systems, which have the ability to learn from data, have pushed the boundaries of what can achieved by AI systems, raising many acute questions, some of them old, some of them new.

Many of these questions have a strong ethical component, as the possibility of making machines 'think' intrudes into a field that was, until now, uniquely human. The many ethical questions that are raised by the development and deployment of AI technology can be categorised into four large groups:

– Loss of privacy and freedom, imposed by the ability of computers, to store and to process, with unprecedented detail and coverage, information about each and every human being on the planet;
– Decrease of mutual trust within a society, caused by the creation and dissemination of fake news, made more effective by AI technology;
– Social and economical changes imposed by the utilization of AI based programs to perform functions previously reserved for humans;
– Philosophical and metaphysical questions raised by the increasing autonomy of AI based systems, which can ultimately reach significant levels of autonomy, agency and even consciousness.

Privacy and freedom

AI based systems have been extensively deployed to explore and exploit the economic value hidden within massive amounts of data. This data has been obtained by companies and institutions, which store important information about the behaviour, preferences and choices of individual human beings. These techniques, often known by a variety of different designations – including *Data Mining*, *Analytics*, *Data Science*, *Big Data* and *Business Intelligence* – have a common denominator: they aim to explore and extract value from data in order to improve the performance of businesses or processes.

Every one of us leaves behind a significant data trail, by using the Internet or, simply, by carrying a cellphone, or by driving in a vehicle. Every website visited using a browser, every utilization of a mobile phone app, every post made in a social network, every payment made with a credit card – they all lead to the creation and storage of significant information about the behaviour of the user. In itself, each of these pieces of information may not be very valuable. But, if collected, organized and duly explored, these pieces of information can tell us a lot about the person who created them. The website contents provides information about the interests of the person; the apps can gather and store data about the person's activities; the usage of the social networks provides extensive knowledge about the friends and interests of the individual; and the payments tell (at the very least) which stores are being visited.

Many companies explore this information and it is, indeed, their main objective. These include not only well known companies such as Google or Facebook, but also many other lesser-known ones, which specialize in data brokerage, like Acxiom, Corelogic, eBureau and Palantir, among many others (Fry, 2018). In fact, dozens, if not hundreds or even thousands of companies, base their business model in creating stereotypes of consumers that provide information about billions of people in the world. This information can be used for many purposes, the main ones being marketing, sales, logistics and fraud detection.

The economic value, accrued by the process of using detailed information about individuals (and companies) to best run businesses, is undeniable. However, significant ethical issues are raised by the ability of current and future technology to obtain information that users would rather keep confidential in order to maintain their personal privacy.

One of the best known cases, because it was one of the first, occurred with a specific campaign run in 2002 by a discount chain in the United States, Target. By analyzing the products bought by the customers, the store was able to identify specific preferences for products, which were then used to target the customers with ads sent by mail. The project ran into problems when the father of a teenage girl stormed into the store to complain, in very strong terms, about the coupons directed at pregnant women, which had been sent by the store to his teenage daughter. In fact, the algorithm used by the store had identified buying patterns common among women who were pregnant. One such pattern was that pregnant women usually bought moisturizing lotion when they were in their second trimester of pregnancy. Other patterns were also identified by the algorithm, which could determine, with reasonable precision, when a given shopper was pregnant. The irate father ended up apologizing to the store manager a few days later, when it turned out that, unbeknownst to him, his daughter was indeed pregnant.

This example, certainly one in many millions, shows how behaviours, medical conditions, and other circumstances, can become known to the data mining algorithms, even before close family members are aware of them. As the technology advances, more and more precise predictions can be made, ranging from political preferences to education level and sexual tendencies. As the models become more sophisticated, and the data collected about each one of us continually grows, the privacy that each individual takes for granted becomes harder and harder to maintain. In the end, we risk losing not only privacy, but the freedom that comes from anonymity. Every move we make, every item we buy in a store, every page we visit on the Internet, every book we read, provides information that can be used, not only by companies, but also by the government, to control and manipulate us.

It is unlikely that simple solutions exist for this problem. Regulations, like the GDPR (General Data Protection Regulation) approved by the European Union may stand in the way of companies unlawfully obtaining information about users without their consent. Other, stricter regulations, may limit the ways in which companies can use the data to obtain commercial or political gains. But, in the end, the data that is stored about each one of us is cumulative and it will be unrealistic to assume that it can be controlled. More and more data will be used to construct ever better models of each human on the planet, and these models will be used to optimize commercial, industrial, logistic and political processes. Yuval Harari, in his books, has made popular a term coined by David Brooks, 'dataism' (Harari, 2016). These authors, and several others, have argued that a move towards a society where data reigns supreme – controlling businesses, populations and even politics – is unavoidable, as we keep developing technologies that enable computers to build ever improving models of each human being on the planet.

Trust

AI based systems are increasingly able to autonomously generate material that can be used to propagate and disseminate information. A significant challenge appears when this information is, in fact, fake. Fake news has been the topic of great concern recently, as it has been used to manipulate elections, to damage the reputations of individuals and organizations and, in general, to gain advantages in political or financial disputes.

Artificial Intelligence is not really the key technology in this area. Fake news can, and has been, generated without any recourse to AI. A single user, or a well-organized group of users, can create, disseminate, and propagate information that is exaggerated, dishonest, or outright fabricated. However, AI systems create new challenges in this area, because they can be used to propagate fake news in social networks and on other websites, or to create additional information that adds credibility to the fake news.

Existing AI technology can be used to generate videos, photos and audio recordings that never actually existed, but are, however, very difficult to identify as being fake. Even if experts can use advanced techniques to tell fake videos (or photos, or voice recordings) from real ones, such expert analysis can carry little weight after the information is in the public domain and the damage has been done.

AI systems can create videos of people making statements about committing actions that never happened, can fabricate photos of events that never took place, or record statements seemingly using another person's own voice. They can even create totally realistic faces of people who never existed nor will ever exist.

Although fake news is not a new ethical issue, as it has existed for many decades and even centuries, AI will make it harder to tell what is fake from what is real, increasing the importance of this particular challenge. However, AI can also play a part in solving this challenge, as AI systems can be used to patrol the Internet and also to control the dissemination of fake news.

Social and economic impact

Data science, the technology discussed previously, is already changing society in very significant ways. The largest companies in the world today are companies that deal uniquely or mostly with data, such as Google, Facebook, Amazon, Apple and Microsoft: which are also the five most valuable companies today. Only 20 years ago, only one of these companies would actually appear in a list of the five most valuable enterprises, the other places taken up by companies that dealt with producing and distributing physical materials, such oil, drugs or hardware. The fact that data is becoming more valuable than physical goods leads to a number of different phenomena, the most significant one being that such companies became larger, more powerful and more efficient. It is much easier to handle the data from every citizen in the world than it is to distribute oil to every city in the world. There is a general tendency for the dominant company in a given market to become much larger than all of the others, leading to a winner-takes-all effect. This, in turn, leads to the concentration of economic power and the establishment of monopolies, which are hard to regulate because they result from open competition.

A similar concentration effect exists in the distribution of income between skilled and unskilled people. As individual skills become more global, when they can be used to create and develop products and services with global reach, we are likely to see an increase in the asymmetry of income distribution. Indicators, like the Gini Index and several others, show that in modern societies, inequality is increasing (Brynjolfsson & McAfee, 2014). People with few skills find it hard to find interesting jobs, while people with marketable skills have more and more opportunities in a global society.

AI technologies will also be increasingly used to replace humans in jobs that are repetitive and not very creative, raising the fear of massive unemployment among the less skilled. Several professions, like call-center assistants, drivers, clerks, food servers and cashiers, can be automated using current or near future technology. Whether or not the societal and economic pressures will lead to massive automation of these types of job remains an open question. However, there is little doubt that the economic pressure towards increasing automation exists and will play a significant role in shaping the job market over the next few decades.

In the long run, over a period of several decades, there can be little doubt that a significant proportion of the jobs performed today by humans will be performed by machines. Whether or not that will raise significantly the proportion of unemployed and unemployable members of the population is a matter of hot debate. The optimists argue that new jobs will be created, and these will be of higher quality than the jobs that technology will destroy. They argue that previous technological revolutions have created more jobs than the ones that were destroyed. The pessimists point out that there is no guarantee that the phenomena observed in the previous technological revolutions will occur again this time. After all, AI systems and robots, if sufficiently advanced, will be able to perform almost all tasks currently performed by humans, and it is unlikely that all individuals will master the skills needed to outcompete robots and intelligent computers.

If a large proportion of the population becomes unable to find well-paying jobs and the levels of unemployment rise significantly above what is today considered normal, we will see a significant increase in the skew of the income distributions. Not only will global companies concentrate their income, leading to a larger proportion of economic value to be distributed to capital, but the distribution of value through salaries will become more unequal and more concentrated on a smaller proportion of the population.

These two effects, which are likely to manifest themselves in the next few decades, in a more or less strong form, will force societies to analyze the question of redistribution of income. Today, western societies, especially in Europe, but also in the United States and Japan, redistribute a significant fraction of national income in the form of social aid. In fact, the proportion of income that has been used in supporting the less well-off has been increasingly – systematically over time, and during the last century – contributing in a significant way to offset the concentration of income brought in by the development of technology.

The future evolution of the social support system that was created, in the second half of the 20th century, by almost all western societies, is difficult to predict. It is possible that we will move simply to a smooth evolution, where higher taxes will support unemployment benefits, and pay for the health and education of an increasingly larger proportion of the non-productive population. This is the less drastic scenario, but it assumes that the combined effect of unemployment and population ageing will not be enough to break down the system. A second possibility is that western societies will reduce their characteristic social safety net; a decision that will, no doubt, increase the level of rebellion of the less well-off, a phenomenon that is already present in today's politics. A third possibility is that a radical overhaul, of the way in which society redistributes income, will take place. Proposals such as Universal Basic Income (Reed & Lansley, 2016), where each citizen, independent of his or her status, has the right to a life sustaining income, has been proposed as the most humane and feasible policy, and has support from both the traditional left and the liberal right. Any of these policies can be combined with an overhaul of the fiscal system, designed to tax more heavily companies that depend more strongly on AI technology, thereby employing less people. Having the tax rate depend on the way in which a company works and employs humans (instead of robots) is a possibility, which has so far not been considered by any country. It would have the advantage of contributing to levelling the playing field between expensive human workers and cheap robots, reducing the need for more radical measures.

All in all, the problem of redistributing the income generated by the adoption of new technologies, AI based or not, will raise significant ethical and political issues, which should be addressed sooner rather than later, in order to avoid the need to introduce drastic and fast-paced changes.

Rights, responsibilities and dangers

Until now, and for the foreseeable future, AI systems are not autonomous, do not have free will, are not conscious, and are able to perform only very specific tasks. In fact, we do not know how to create systems that exhibit the so-called Artificial General Intelligence (AGI), which is a term used to denote Artificial Intelligence at a human level. The long-standing discussions, on whether AGI is even possible, remain as heated as ever. We do not know enough about the way in which the brain works to be able to engineer systems that could reproduce, even in principle, the behaviour that leads to our very human and very flexible intelligence.

Artificial Intelligence researchers have worked, over the last six decades, on algorithms that can used to solve problems that require intelligence, if solved by humans. Some of these problems turned out to be relatively easy. Proving mathematical theorems, playing some board games (such as draughts, or noughts and crosses), and solving questions in logistics and planning, turned out to be relatively easy, and were solved in the first decades of the second half of the 20th century.

Paradoxically, some other challenges, which had initially seemed much easier, were much harder to solve. Analyzing an image and understanding its contents, walking around inside a building or in the street, or recognizing human faces, turned out to be very difficult tasks, which took more than half a century to master. However, the technology has evolved and today several technologies, such as deep convolutional neural networks, can be used to identify people and objects in images and videos, to diagnose diseases from medical images, and even to drive vehicles in non-structured environments.

Today's AI systems can, therefore, combine a reasonable understanding of their visual environment with an ability to plan complex task sequences, such as driving between two specific addresses in different cities. They can also perform complex functions that require significant human expertise, such as selecting job candidates based on their CVs, or deciding (or proposing decisions) on parole requests. The ability of AI based systems to make (or propose) decisions that until now, required human intervention, creates new challenges to our understanding of the basic concepts of responsibility and rights.

If an autonomous car, made by company A, running machine learning software created by company B, trained to drive by company C, and tuned to the specific driving style of its owner, D, has an accident, whose fault is it? Is the faulty behaviour attributable to the car manufacturer, to the software company, to the company that trained the system to drive, or to the owner who provided additional examples of driving behaviour? Or could it be that the system is so complex that none of the above is correct, and it is only the car which is at fault?

This last option, which seems so outlandish today, will become less strange as time goes by and technology evolves. Increasingly, AI systems will have some sort of limited autonomy and agency, and at some point it may make sense to discuss whether they (the systems) should become responsible for their actions. This is, of course, an absurd suggestion for the systems that exist today. Today, no car stands in court because its autonomous driving system failed to detect a pedestrian crossing the road (as has, indeed, already happened). The car manufacturer, the software company or the driver will have to foot the bill, since the car is not recognized as an autonomous entity, with its own rights and responsibilities.

However, as systems become more complex, we may reach a point where we have to discuss whether the systems themselves may have such an autonomy and agency that it would make sense to make them exist with some level of their own legal entity. Today, animals already have rights and responsibilities, even though they do not exhibit human intelligence. A dog that is dangerous may be killed, and significant rights for many species of animal, under a number of different circumstances, are recognized almost everywhere.

A recent report from the European Parliament raised the question of whether AI systems should, in the future, be considered as a legal entity, with rights and responsibilities. This suggestion was not taken into consideration by the European Commission in the document 'Artificial Intelligence for Europe', drafted by the Commission and released in April 2018. Nonetheless, it is likely that such complex questions – on whether machines can, one day, have rights and responsibilities – may emerge sometime in the future (Bryson, Diamantis, & Grant, 2017). If, several decades in the future, we share life with systems that are intelligent, autonomous and, maybe, even conscious, shouldn´t these systems have some sort of rights and responsibilities?

A different, but critical question, is raised by the possibility that AI systems, which have significant autonomy and have their own goals, may become dangerous to humans and indeed, in extreme cases, to humanity itself. In time, we may have AI systems making decisions that can strongly affect humans. Such systems may be able to make crucial decisions, such as when to shutdown a power plant, who to kill using a self-directed lethal weapon, whether to avoid a pedestrian by throwing a self-driving car down a ravine, or whether to crash-land a plane in order to avoid a more serious accident.

There is even the possibility that systems, which are much more intelligent than humans may, one day, be in control of significant parts of our infrastructures and may ultimately make decisions on our behalf. The (seemingly remote) possibility that an AI system may ultimately endanger all of humanity if it decides that we (the human race) are in the way of some specific objective (which may be quite reasonable, such as stopping global warming), has received a lot of attention (Bostrom, 2014). A number of scientists, entrepreneurs, writers and politicians have argued that AI is the most serious menace to the future of the human race, an existential threat (Barrat, 2013). Most AI researchers, however, believe that this concern actually makes no sense. One famous AI researcher, Andrew Ng, said that worrying about superintelligence makes as much sense as worrying about the overpopulation of Mars. We do not have the technology to put anyone on Mars, nor do we have the technology to create a superintelligence. There is no point in worrying about these questions today.

It is undeniable that the possible creation of a superintelligence, by further developing existing AI technology, seems remote, to say the least. However, the challenges that such a technology would create for humanity would be so great that it makes sense to, at the very least, follow what experts have been saying regarding the issue. After all, the extinction of the human race at the hands of a superintelligent AI would be the ultimate ethical issue raised by Artificial Intelligence technology.

Conclusion

Intelligence has been, until now, a uniquely human ability. It is this characteristic that makes us human and distinguishes us from other evolved animals. When technology raises the possibility of creating non-human systems endowed with intelligence, a new set of ethical questions appears. Addressing these ethical questions is important, not only from a philosophical point of view, but also from a practical and very operational point of view. Questions about privacy, security, trust, equity, status, rights and responsibilities, which were, until now, purely academic and theoretical, may become far more pressing in the near future, forcing society to take clear positions about many of them. The nature of these questions, and of the possible solutions, needs to be clearly established well before they become a pressing concern, imposed on society by commercial and widely used technologies. Philosophers, politicians, scientists and engineers, as well as the general public, should all become familiar with these questions, in order to be able to voice opinions, and to intervene and influence the rules that will be adopted by society.

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New horizons on robotics: ethics challenges

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Abstract

In this chapter, the focus is on robotics development and its ethical implications, especially on some particular applications or interaction principles. In recent years, such developments have happened very quickly, based on the advances achieved in the last few decades in industrial robotics. The technological developments in manufacturing, with the implementation of Industry 4.0 strategies in most industrialized countries, and the dissemination of production strategies into services and health sectors, enabled robotics to develop in a variety of new directions. Policy making and ethical awareness addressed these issues using socio-economic knowledge and also in an effort to solve some of the application problems raised in a range of different circumstances and sectoral environments.

Keywords Robotics, roboethics, legal issues, socio-economic issue, European Parliament, human enhancement

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1. Open questions shaping the future

Robotics is considered to be an emerging technology. Not necessarily as a 'new' technology, as it was first developed in the 1960s; but because of the more recent development of certain components, fields of application and, above all, of capabilities derived from software advances, such as new Artificial Intelligence (AI) tools, and new approaches in machine learning.

In 1920, the term robot – derived from 'robota', which means subordinate labour in Slav languages – was first introduced by the Czech playwright Karel Capek in his play 'Rossum's Universal Robots (R.U.R.)'. In 1940, the ethics of interaction between robots and humans was envisaged to be governed by the three well known fundamental laws of Isaac Asimov, the Russian science fiction writer, in his novel 'Runaround'. For Asimov:

1. A robot may not harm a human being, or, through inaction, allow a human being to come to harm.
2. A robot must obey the orders given to it by human beings, except where such orders would conflict with the First Law.
3. A robot must protect its own existence, as long as such protection does not conflict with the First or Second Law.

However, in general, we can say that the early robots built in the 1960s stemmed from the confluence of two technologies: numerical control machines for precise manufacturing, and teleoperators for remote radioactive material handling. Today, one can define a manipulating industrial robot according to the ISO 8373 standard, which establishes an industrial robot as an automatically controlled, reprogrammable, multipurpose manipulator, programmable in three or more axes, which may be either fixed in place or mobile for use in industrial automation applications. The most recent version of this standard (from 2012) establishes a more general definition for a robot, as being an actuated mechanism, programmable in two or more axes, with a degree of autonomy, moving within its environment, to perform intended tasks.

When we associate it with the development of sensors and the 'internet of things' (IoT), we can recognize robotics as being one of the elements of cyber-physical systems. By the term and abbreviation 'IoT,' one can define the network of devices that contain electronics, software, sensors and actuators with the capacity of connectivity – which allows these things to connect, interact and exchange data. This means that such technology is one of the main elements of the Industry 4.0 concept, and it is becoming a central technology affecting our daily lives. **We can understand the intelligent networking of machines and processes for industry** – and for Industry 4.0 – **with the help of information and communication technology (ICT).**

In the most recent World Development Report, it is stated that 'the advent of a jobless economy raises concern because tasks traditionally performed by humans are being – or are at risk of being – taken over by robots, especially those enabled with artificial intelligence. The number of robots operating worldwide is rising quickly' (World Bank, 2019: 20).

Thus, robotics has experienced very recent changes with regard to the quality of its development. One such development is related to its capacity for autonomy; in other words, the ability of robotic equipment to become mobile, and not the heavy and fixed early versions that were initially developed in the 20th century. The first developments in terms of mobility were known as the industrial applications of AGV, or auto-guided vehicles. Even in the 1970s there was debate about the implications of automation on employment, and this debate was increasingly prevalent within the academic environment, as well as in the public arena.

More recently, with new capabilities derived from AI software, it has been possible to develop new forms of robots with completely different capacities. Those capacities were designed for new products to be applied in a wide variety of sectors, the most important ones being within the health sector, in the military arena and surveillance, and once again, in manufacturing.

With these recent developments, new questions have arisen, and a public debate has focused on emerging problems, such as:

– What is an intelligent system?
– What is an autonomous system?
– Can robots be dangerous?
– Who is responsible for what a robot does?
– How can technology support humans efficiently?
– How are robots interfering with privacy?
– Will robots take over jobs?
– Will robots replace humans?
– How far will robotics be developed?

Many of the potential answers were driven by the political community, by labour market researchers (mostly, economists and sociologists), by legal experts, and by ethicists and philosophers, with impacts on the media, and on the public at several different levels. In this sense, 'roboethics' is a new discipline, with contributions from experts and scientists from a variety of different fields.

2. Roboethics

Ethics applied to technological development is becoming an increasingly larger field and one that is the focus of much public attention. It had initially been particularly focused on biological and chemical developments, on physics and material engineering, and on environmental implications and other such fields. But it has also included more recent developments in robotics and automation, which have major implications for society in general. New specialized fields are emerging in both policy making, and in academia. The 'ethical, legal and socio-economic issues' (ELS) topics group was created and is part of euRobotics, the European Association for Robotics, which has a major role in defining the research framework programs at European levels[2].

In fact, roboethics is considered to be a branch of applied ethics that attempts to illuminate how ethical principles can be applied to address the delicate and critical ethical questions arising from using robots within our society (Tzafestas, S., 2016).

More autonomous robots may lead to less human control. In fact, autonomous systems (AS) can be considered as a network (or sets of networks) under a single control; but it is a feature of internet systems that one can define algorithmic conditions for autonomous operation: this would mean without direct human control.

In a report from the US Department of Defense, autonomy is defined as 'a capability (or a set of capabilities) that enables a particular action of a system to be automatic or, within programmed boundaries, 'self-governing" (DSB-DoD, 2012: 10). However, this does not mean that autonomous systems (AS) take independent machine (computer, robot) decisions, or that such machines have uncontrolled actions. As part of the same definition process, when one states that 'all autonomous systems are *supervised* by human operators at some level, and autonomous systems' software embodies the designed limits on the actions and decisions delegated to the computer' (*idem*), this conveys that autonomous systems in manufacturing industries or the health sector, or indeed in another sector, are or must be also supervised by humans.

Another document from the US Department of Defense states that 'dramatic progress in supporting technologies suggests that unprecedented levels of autonomy can be introduced into current and future unmanned systems' (DoD, 2011, p. 43). The developments issued from aeronautics and space research have been applied to the military field.

Finally, the definition of autonomy states that 'an automatic system can be described as self-steering or self-regulating and is able to follow an externally given path while compensating for small deviations caused by external disturbances. However, the automatic system is not able to define the path according to some given goal or to choose the goal dictating its path. By contrast, autonomous systems are self-directed toward a goal in that they do not require outside control, but rather are governed by laws and strategies that direct their behaviour' (*idem*).

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2 This topics group has the European Group on Ethics in Science and New Technologies (EGE) at the European Commission as a previous reference in the 7th Framework program.

2. Strengthening citizenship through ELSA studies

2.1. *Ethical questions*

Some questions can be raised when technology takes new developmental paths, such as with Artificial Intelligence (AI) or robotics. It is true that in order to allow humans to understand, appropriately trust, and be able to effectively manage AI, an AI application or system needs to explain why it took certain actions and why it valued certain variables more than others (GAO, 2018: 32). New decision systems can be designed and implemented in the software through approaches in machine learning. In other words, this subset of Artificial Intelligence can be considered as the scientific study of algorithms and statistical models that computer systems use to effectively perform a specific automated task without using explicit instructions. This would lead to new advances in robot applications in both industry and services, increasing the capacities for autonomous production systems and for autonomous interaction with humans. But, are the benefits of robots really worth the risks? Is it possible to embed ethics codes into robots? For example, do agents have to act in a way which is ethically correct and maximise positive consequences? Or is this just not possible?

These are typical ethical questions that can be established and discussed with those who are designing, implementing and using the relevant technology. Many ethical problems concern the possible negative consequences of such advances on human well-being (and also on that of other sentient beings).

These include safety in the workplace, dehumanization of certain environments (such as health care), and making the killing of humans in wartime easier. Of course, new technologies and their implications for the job market are ethically sensitive subjects. The same applies to extending human interactions with robots, with remote action technologies.

The US based Institute of Electrical and Electronics Engineers (IEEE), being a prestigious and large technology association, developed an ethical research and design guidance proposal which stated that 'in order to create machines that enhance human well-being, empowerment and freedom, system design methodologies should be extended to put greater emphasis on human values as a form of human rights such as those acknowledged in the Universal Declaration of Human Rights. Values-based design methodology should become an essential focus for the modern organization' (IEEE, 2016).

Even the European Parliament proposes a European Agency for robotics and Artificial Intelligence, in order to provide the technical, ethical and regulatory expertise needed to support the relevant public initiatives.

In any case, the increasing public interest in realistic applications of robotics, AI and bionics in this respect (being the application of biological methods and systems found in nature, to the study and design of engineering technology, such as with artificial neural networks or the swarm intelligence) may be exploited in order to foster the establishment of an objective, transparent, public consensus on ethically relevant issues.

2.2. *Legal problems and issues*

Robots are things and not people in the legal sense. Such an assumption is a basic one when dealing with issues relating to human-robot interaction. Liability based on fault prevents the use of malfunctioning robots, given the potential obligations regarding compensation. On the basis of a future ethical consensus, regulations which adhere to private law can be envisaged for the development of robot activities in the future. In this respect, it is important to clearly define these aspects, and to answer the following questions to establish a legal framework:

(i) What rules can be applied to robots (as is)?

(ii) What incentives do such rules provide?

(iii) Are those incentives desirable?

The major issue, when discussing civil law rules on robotics, is one of liability (for damages). In fact, the robot owner is usually only responsible for damage caused by a robot, as in the case of factories or care centres and hospitals, which are using such equipment. But the robot producer is responsible for faults in the production, design and instruction of robots, in the context of the product liability.

Automation may challenge some of the existing paradigms on the role of machines and their relationships with humans, as workers, as designers, or as objects of machine action. Increasing human-machine co-operation may also cause different sets of existing rules to overlap. Learning robots should be distinguishable from non-learning robots, as the liability for damage – between manufacturers and owners – is affected by their use of learning algorithms.

Among more specific kinds of applications, bio-robotic devices (such as intelligent prostheses, orthotics and interactive micro-implants) and human enhancements (such as brain stimulation technologies and nano-medicine) are becoming more and more critical. Technical developments take place at an increasingly fast rate and generate high market expectations. Potential applications include those related to human germline engineering, existing reproductive technologies, cosmetic surgery, brain-machine interaction and assistive technologies for disabled people. But we should also consider some more close-to-market devices, such as exoskeletons which support and protect human operators. Privacy regulation, which is derived from these developments, is of pivotal importance. It can also influence health and safety policies.

The early development of Artificial Intelligence and Autonomous Systems (AI/AS) has given rise to many complex ethical problems. The debate over autonomous driving is becoming significant in relation to new traffic regulations and urban strategies.

But it also has important implications for its use in manufacturing applications, in the light of considerations surrounding safety and working conditions.

The ethical issues relating to automation and robotics almost always directly translate into concrete legal challenges – or give rise to difficult collateral legal problems (Kroll *et al.*, 2017; Wachter, Mittelstadt and Floridi 2017). There is much for lawyers to do in this field, although so far it has attracted very few practitioners and academics despite being an area of obvious need. Lawyers should be a part of these discussions on regulation, governance, and domestic and international legislation (IEEE, 2016).

The European Parliament approved a motion which noted that 'there are no legal provisions that specifically apply to robotics, but that existing legal regimes and doctrines can be readily applied to robotics, although some aspects appear to call for specific consideration'.

At the same time, they have proposed a legislative instrument on legal questions relating to the development and use of robotics and Artificial Intelligence which might be available within the next 10 to 15 years, combined with non-legislative instruments, such as guidelines and codes of conduct (motion PE582.443v03-00).

2.3. *Principles and limitations*

Human-machine co-operation will cause product liability rules to be required. Not every machine can be designed without any flaws, or unexpected technical conflicts or limitations. This can lead to some malfunctions or even to some issues of safety. This will cause high levels of uncertainty and litigation, delaying innovation.

At the same time, there is a need for definitions concerning cyber physical systems, autonomous systems, smart autonomous robots and their subcategories. Such definitions are important to enable us to understand the technical limitations of some very advanced equipment, as is the case with regard to robots. Regulations can be proposed or established over the existing or negotiated definitions.

Human operators and software developers must create, develop and test control algorithms for AS systems. However, such systems can include at least basic machine learning procedures. Thus, the autonomous systems can develop modified strategies for themselves, selecting their behaviour or reaction modes without the interference of human operators. The most advanced automated equipment in the production field, or in the service sector, can adopt such procedures.

In manufacturing industries, an autonomous system can be self-directed, choosing the behaviour it follows in order to reach a human-directed goal. This has happened with recent developments in robotics. With military or industrial applications, various levels of autonomy in any system guide how much and how often humans need to interact or intervene with the autonomous system.

The human-robot interaction (HRI) approach has to integrate such understanding. In other cases, autonomous systems may even optimize behaviour in a goal-directed manner in unforeseen situations (where, in a given scenario, the autonomous system finds the optimal solution), such as for inspection purposes. But this is not always the case. The development of robot technology can complement human capabilities; applications utilising collaborative robotics prove this. Similarly, there are opportunities involving innovative modes of work organisation, where robots are not replacing human operators, but are complementing their tasks, substituting in heavy duty work, or the more repetitive and boring activities.

2.4. *Socio-economic issues: enhancing dialogue*

It is recognised that on average, new technology takes between 15 to 30 years to go from 10% to 90% adoption. Legal and institutional factors also influence this adjustment process. Consequently, it should not be expected that innovations will be immediately adopted by markets.

Over the last few decades, the extensive introduction of robotics in manufacturing industries has been an accepted fact. For the major sectors, and where quality control is a critical feature of production processes, automated systems are being introduced. Robots can also be effective in areas where there are skills shortages. They are particularly being used in those areas of work which are repetitive in nature and with poor working conditions; leaving the human workers to exploit the highly qualified tasks which may also require an increased involvement in the job decision-making process.

Some 94% of Europeans agree that robots are a form of technology requiring particularly careful management. In a Eurobarometer survey, it was concluded that EU citizens have very well-defined and specific attitudes regarding robots: on the one hand, they express the utilitarian view that robots are useful and good, because they do jobs that are either too hard or too dangerous for, or which are helpful to, people; on the other hand, they express a degree of caution, taking the view that robots steal people's jobs and require careful management (Eurobarometer, 2012). The report also mentioned that 'EU citizens also have well-defined views about the application areas for robots and the areas in which the use of robots should be banned: they should be used as a priority in areas that are too difficult or too dangerous for humans, like space exploration (52% priority), manufacturing (50%), military and security (41%) and search and rescue tasks (41%); there is widespread agreement that robots should be banned in the care of children, the elderly or the disabled (60%), with large minorities also wanting a ban when it comes to other 'human' areas, such as education (34%), healthcare (27%) and leisure (20%)' (Eurobarometer, 2012: 4).

In the US, some of the most advanced research on user-driven and autonomous systems is being done within the space sector[3]. In Europe, the European Space Agency

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[3] In 1987, the US National Research Council and NASA held a Symposium on 'Human Factors in Automated and Robotic Space Systems'.

(ESA) has not been dealing with such topics. Positive attitudes are more frequent among the young and those who have experience of robots in their workplace. Some cautious conclusions can be made on this topic.

In the van Est and Kool book about the robotization of society, they underline that in the first 'machine age' (according to Brynjolfsson and McAfee[4]) 'mechanization and automation chiefly hit low-skilled, physical labour. Technology was skill upgrading, and called for new skills from everyone. Investment in education meant that education always won the 'race between technology and education'. In the second machine age (as from 1980), automation also hit medium-skilled work. IT affects different groups on the labour market in different ways; up to now, higher-skilled people have chiefly benefited from new technology. Inequality consists not only in the distribution of income and wealth, but also in differences in job security; this form of inequality has also been increasing since the second machine age' (van Est and Kool, 2015: 160). In fact, this accurately summarises the socio-economic aspects relating to recent developments in robotics.

3. Position of the European Parliament: fostering scientific progress and social development

In the approved motion (PE582.443v03-00), the European Parliament considers that 'a comprehensive Union system of registration of advanced robots should be introduced within the Union's internal market where relevant and necessary for specific categories of robots, and calls on the Commission to establish criteria for the classification of robots that would need to be registered' (p. 8), and stresses that 'the development of robot technology should focus on complementing human capabilities and not on replacing them' (*idem*).

On the ethical principles, the motion suggests that a legal framework should be updated and complemented, where appropriate, by guiding ethical principles, in line with the complexity of robotics and its many social, medical and bioethical implications. An ethical framework is needed for the development, design, production, use and modification of robots. There is a need for a code of conduct for robotics engineers, of a code for research ethics committees when reviewing robotics protocols, and of model licenses for designers and users. Finally, the European Parliament considers that special attention should be paid to robots that represent a significant threat to confidentiality owing to their placement in traditionally protected and private spheres, and because they are able to extract and send personal and sensitive data (p. 9).

[4] See Brynjolfsson and McAfee, 2014.

The European Parliament also emphasizes that sufficient resources need to be devoted to the search for solutions to the social, ethical, legal and economic challenges that the technological development and its applications raise.

4. Concluding remarks

We have focused on the ethical implications of robotics development. Special attention has been given to robot applications, either within industry, or in services. But more recently, the human-robot interaction principles have also been subject to further studies relating to engineering sciences, and human and social sciences. The technological developments in robotics have been significant in recent years, and considerable resources have been applied to this field. Most of the results of such investment have been based on the developments achieved in the last few decades, with industrial robotics integrating AI approaches. These introduced massive changes to the improvement of economic innovation and to the transformation of employment structures. It started a 'second machine age' (as Brynjolfsson and McAfee referred to it), where, despite highly significant technological developments, both people and organizations may be left behind. Such improvement can lead to strong polarization of qualifications, with labour market implications: on the one hand, a number of high qualified professionals, with the best working and living conditions, whilst on the other hand, a large majority of workers, with low qualifications and precarious jobs.

The technological developments in manufacturing – with the implementation of Industry 4.0 strategies in most industrialized countries, and the dissemination of production strategies into services and health sectors – enabled the development of robotics in a variety of new directions. Today, not only industry acknowledges the technological development of new machinery and working environments. Policy making and ethical awareness have also addressed these issues, based on socio-economic knowledge, and on the application problems raised in many different circumstances and sectoral environments. New legal instruments and regulatory measures are being issued on such matters by national parliaments, as well as by international ones, such as the European Parliament. The public debate can increase the fear and alarmism surrounding potential changes, but it can also increase the awareness for a more responsible direction as regards research.

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How Are Biotechnologies Shaping Society?

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Abstract

Since the 1970s, biologists have developed increasingly powerful and sophisticated tools for modifying living things. A deepened understanding of cells, DNA, and proteins, has allowed us to intervene into the functioning of organisms on a molecular level. We can now speed up, slow down, stop, restart, remix, and edit many biological processes. These are impressive technical and scientific achievements. However, they have occurred so rapidly, that in many cases we are struggling to keep up. Our laws and policies, the norms governing social behavior, our economic and financial systems, and our moral codes are often unable to adjust so quickly to these developments. This essay outline a series of examples to show the kinds of effects that biotechnologies are having and suggest how wide and complex their impact can be. These examples are taken from different scales – the personal, the institutional, and the global – in order to suggest the diversity of effects that biotech is having. The problems and dilemmas that biotech creates cannot be handled by scientists alone. These are not purely technical problems – they involve politics, society, law, economic, and other domains. We need a multi-disciplinary effort to address them – coalitions that include sociologists, historians, philosophers, economics, and legal scholars, alongside scientists and engineers.

Keywords: reproductive technologies; biosecurity; patenting; genetically modified organisms; saviour siblings.

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1. Introduction

Biotechnologies are now a fundamental part of the way we live in the developed world: they have produced new kinds of foods, new kinds of pharmaceuticals, new ways of reproducing, and new ways of relating to one another. Genetically modified foods, *in vitro* fertilization, and many other medical technologies enabled by biotechnology are broadly accepted as a normal part of day to day life in many nations.

Humans have been modifying plants, animals, and ourselves for a very long time. For example, through selective breeding (both deliberate and accidental) we have dramatically shaped the appearance, size, taste, and texture of plants and animals. Likewise, micro-organisms – such as yeast used in the production of beer and bread – have also long been used as part of our food production processes. And, over centuries, we have experimented with the effects of many kinds plant and animal substances in our bodies in attempts to make ourselves faster, stronger, smarter, or more virile.

History also gives us some good examples of what can go wrong when such attempts to modify biology are used without restraint. In the late nineteenth century, biologists in Britain began to think about how Charles Darwin's ideas about evolution and natural selection might apply to humans and human populations. In particular, Darwin's cousin Francis Galton developed a set of ideas known as "social Darwinism" that suggested that human populations could be strengthened by selective marriages between "fit" individuals. Under the name of "eugenics," these ideas were developed and spread to the United States, Europe, and beyond. Biologists in many countries supported the idea that social ills (such as poverty or mental illness) could be bred out of populations and that the gene pool could be strengthened by preventing "unfit" people from reproducing. By the 1920s, in the United States, this contributed to the formulation of strict immigration laws (to preserve the "purity" of the population) and even, in many states, programs of forced sterilization. These ideas were taken to their most extreme conclusions in Nazi Germany in the 1930s where eugenic principles were used to justify the extermination of those perceived to be genetically inferior.

Since the 1970s, biologists have developed increasingly powerful and sophisticated tools for modifying living things. A deepened understanding of cells, DNA, and proteins, has allowed us to intervene into the functioning of organisms on a molecular level. Genetic engineering, DNA synthesis and sequencing, cloning, stem cell science, and, more recently, CRISPR, have allowed us to assert increased control over how animals, plants, and humans behave[2]. We can now speed up, slow down, stop, restart, remix, and edit many biological processes.

[2] CRISPR stands for "clustered regularly interspaced short palindromic repeats." Together with an enzyme called CAS9, these short strands of DNA can be used to precisely recognize and cut specific segments out of chromosomes. This is a powerful form of genetic editing.

These are impressive technical and scientific achievements. However, they have occurred so rapidly, that in many cases we are struggling to keep up. Our laws and policies, the norms governing social behavior, our economic and financial systems, and our moral codes are often unable to adjust so quickly to these developments. We are still in the process of working out how to respond to biotechnologies in ways that are equitable, just, fair, and ethical. This is not always straightforward. The history of eugenics offers a stark example of what can go wrong when the social and moral consequences of scientific ideas are not fully thought through. The wrongs stemming from eugenics did not arise because people set out to deliberately harm others. Many eugenicists believed, however misguidedly, that they were doing something beneficial for society. Since our present biotechnologies offer more power and more control, their use also involves more complex moral and social dilemmas.

In this essay, I will outline a series of examples to show the kinds of effects that biotechnologies are having and suggest how wide and complex their impact can be. These examples are taken from what we might call different scales – the personal, the institutional, and the global – in order to suggest the diversity of effects that biotech is having. The problems and dilemmas that biotech creates cannot be handled by scientists alone. These are not purely technical problems – they involve politics, society, law, economic, and other domains. As such, we need a multi-disciplinary effort to address them – coalitions that include sociologists, historians, philosophers, economics, and legal scholars, alongside scientists and engineers.

2.1. *Personal: Reproductive technologies*

Biotechnology now influences the most intimate aspects of our lives. In various forms, it intervenes in reproduction and plays a role in re-shaping families and relationships. This "personal" aspect of biotech is best explored by examining the development and impact of reproductive technologies, especially in-vitro fertilization (IVF).

The reproductive technology that had the most profound effect on the twentieth century was the contraceptive pill. Although the contraceptive pill is not usually considered a "biotechnology," it shares many features with more recent biotechnologies: in particular, it intervenes in human bodies on a molecular level to allow us to control them to a greater extent than was possible before. Although technologies of contraception dates back hundreds, or even thousands, of years, the contraceptive pill allowed much more reliable and permanent control over conception.

The first contraceptive pills were introduced in the United States in 1957. The drug rapidly became popular and widely used amongst married and unmarried women in western societies. Indeed, the contraceptive pill contributed to rapidly changing norms around sex and sexuality that emerged in the 1960s. In particular, for social movements supporting sexual liberation and women's rights the contraceptive pill became an important symbol of increased freedom. This example suggests how biotechnologies

– here in the form of a pharmaceutical product – has the potential to shift social norms and practices, intervening in and transforming the most personal of realms.

The first IVF (or "test tube") baby was born in 1978. Louise Brown, born in Oldham General Hospital in Manchester was the result of many decades of work attempting to understand and control the human reproductive cycle. Robert Edwards, in particular, had devoted his career to studying the development of human eggs outside the human body. His work, together with Patrick Steptoe, allowed them to perfect the balance of hormones that would allow for a successful implanted pregnancy. This was cutting edge science that challenged the limits of knowledge about the human body.

All this was only forty years ago, but now this technology has become extraordinarily widespread. As many as 400,000 test-tube babies are now born per year worldwide. This is an example of a biotechnology that has become almost fully "normalized," at least within rich and developed societies. But we are still coming to terms with the many ways in which this technology is affecting society. For instance, IVF has dramatically shifted expectations around infertility, child-rearing, and relatedness. Infertility can now be considered a "medical" condition that can be "cured" via IVF; even people who are incapable of bearing children must now make a clear choice *not* to have children via IVF. This applies even to "socially infertile" people such as same sex couples or singles. Moreover, infertile individuals who previously may have adopted children are also now faced with an additional choice between "their own" and "other" children. IVF therefore changes the value of genetic relatedness between parents and children.

But there are even more far-reaching ways in which IVF has opened up new possibilities for kinship and new kinds of family relations. These are perhaps extreme cases, but they show the kinds of profound effects biotechnologies can have on the personal or local scale.

One kind of possibility that IVF has opened up is "gestational surrogacy," sometimes called "rent a womb." In this scenario, parents – often westerners or individuals from developed countries – enter into a contract with a woman – often in a less developed nation – to carry their biological baby. Fertilization is carried out *in vitro*, but instead of implanting the egg into the woman from which it was extracted, it is implanted into a second woman who carries the baby to term, usually for a fee. The second woman effectively rents out her uterus, becoming a "gestational surrogate." The first woman remains the "genetic mother." If all goes well, at the end of the pregnancy, the baby is delivered to the genetic parents.

These practices have opened up various kinds of neo-colonial relationships. In India, where the practice of gestational surrogacy is relatively widespread, surrogate women are housed in compounds, fed pre-natal vitamins and nutritious foods, and have their diets and daily regimens closely monitored. In Thailand, the famous case of "Baby Gammy" led to the outright banning of gestational surrogacy by the government. In that instance, an Australian couple contracted with a Thai woman for surrogacy. When

"Baby Gammy" was born with Down syndrome, the Australians refused to adopt the baby, leaving the surrogate burdened with the costs and difficulties of raising a disabled child.

Beyond these difficulties, gestational surrogacy raises serious questions about kinship and relatedness – "who is the mother?" for instance. In gestational surrogacy, that is a question settled usually not by biology, but rather legally or politically. The rights and responsibilities of various parties are usually determined by a contract, with money exchanging hands. This not only has the potential to make some parties vulnerable to exploitation and unjust treatment, but also may begin to shift how we think about the definition of terms such as "mother," "child," "genetic," "family," and "relation." Those involved in gestational surrogacy are forced to work through these issues as they write contracts or exchange money for services.

Of course, families have always existed in various configurations – children were adopted, given away, stolen, and so on. But IVF is permitting or even encouraging all kinds of new forms of relatedness: gestational motherhood, but also the possibility of same sex couple parents, single-parent conception, delaying conception by freezing eggs, post-menopausal pregnancies and other possibilities. None of this is by itself good or bad, but all aspects of it bring into being new kinds of kinship possibilities that will shape how societies are structured in the future and how we think about relatedness to one another in the future. How we decide to react to the possibilities of these technologies will determine whether they end up improving society or acting in ways that are detrimental. As this example suggests, too, the benefits and drawbacks may not be evenly distributed – there is a risk with many such technologies that they exacerbate existing inequalities.

Another case, perhaps even more extreme, is that of so-called "savior siblings."

This scenario usually begins with a first child born with a fatal disease. But this disease is one of a special class that be cured by a donor with the exactly matching cells or organs, allowing for the potential of a successful transplant. When it is found that neither of the parents are a match, the parents then conceive another child via IVF to act as the "savior." They do this by screening the IVF embryos for those with the type matching the first child. Once the second child is born, its cells or organs are harvested and transplanted in order to cure the disease of the first child.

In 2000, for example, Adam Nash was born via IVF after selection of embryos for a Human Leukocyte Antigen (HLA) match with his older sister, Molly. Molly was born with Fanconi anemia, a condition that inhibits bone marrow production. Blood from Adam's umbilical cord was successfully transplanted into his sister.

This raises a host of ethical questions about "instrumentalizing" children and the practice is banned in many places, along with other kinds of "designer babies." Nevertheless, this has been done in several instances. However, aside from the ethical issues, again this show how biotech makes possible new forms of relatedness – "special" or even "designer" forms of kinship that may become more and more common in the future. If we do, as a society, choose to permit such actions, then we will need ways of accommodating such new relationships within existing social structures.

Part of the fascination with "savior siblings" revolves around the question of how such individuals will fit into a society, knowing that they have been expressly created for the purposes of saving another individual's life. Science fiction novels (and movies) have begun to think through such scenarios: Jodi Picoult's *My Sister's Keeper* is based on the Nash case, while Kazuo Ishiguro's *Never Let Me Go* also explores the lives of whole cloned populations who have been created for the purposes of organ harvesting. Such fictions help to raise important questions about what a society a dominated by new reproductive technologies could or should look like. This is not just a problem of whether or not to allow such technologies to be used. Rather, it raises questions about what kinds of biological relationships should be recognized and what rights and responsibilities do they confer.

In developed societies, individuals are also increasingly using genetic testing and the technologies of personal genomics to make reproductive decisions. In the US, it is now routine for genetic tests to be conducted on a fetus in the womb. If these tests show evidence of genetic disease, doctors and genetic counselors may recommend termination of the pregnancy. In other cases, prospective parents may be faced with difficult decisions about whether and how to raise a child with disabilities. Such testing is already exerting a significant influence on people's decisions about when, how, and with whom to reproduce.

But the implications of such testing go beyond personal choice. As some disability rights advocates have noted, the very ability to choose our offspring without disabilities potentially devalues the lives of the disabled. Such choices are based on the assumption that differently-abled lives are less worthwhile or less valuable. By reducing the number of disabled individuals in society we also run the risk of lessening our social acceptance of such disability and reducing the justification for accommodating disabilities (for example, the cost of installing wheelchair ramps or disabled-friendly toilet facilities is less acceptable to society if they serve fewer people).

In this case too, biotechnologies are gradually changing the make-up of our society – what kinds of people our society is made up of, how diverse of a society it is, and our relationship to other people within our society. Perhaps most significantly, the biotechnologies of genetic testing -- when used in making reproductive decisions – have the potential to shift our ideas about what "normal." As genetic testing and personal genomics increasingly allows us to make decisions about our offspring – not only whether or not they have particular genetic diseases, but also what physical and even mental characteristics they may develop – we run the risk of creating a more and more homogeneous (and perhaps less tolerant) society.

2.2. *Institutional: Ownership*

Beyond families and relatedness, biotechnologies continue to cause profound institutional changes. The rise of the biotech industry has reshaped science, has transformed the pharmaceutical industry, has generated whole new industries such as genetic testing and genetic counseling, and has led to the emergence of new fields of law. One of the institutions that biotechnology has influenced most strongly is that of ownership. By exploring developments in ownership, especially the ownership of living things, we can see how biotechnology is reshaping the ways social and political institutions function.

In 1980, the *Diamond vs. Chakrabarty* decision in the United States Supreme Court set off a chain reaction of changes in the way it is possible to own living things. In the early 1970s, Chakrabarty, an employee of General Electric, had devised a new kind of bacteria that he believed could be put to work to devour oil spills. The new bacteria, loaded onto straw, would be distributed onto the affected part of the ocean and the bacteria would eat up the oil, degrading it into less harmful substances. Since this was potentially useful, Chakrabarty applied for a patent.

But living things like bacteria were usually not patentable under US law. In a famous legal case in the nineteenth century, a judge had remarked that granting patents on living things would be like granting a patent on a ruby found in the ground: finding one ruby does not entitle you to a patent on all the others. But in Chakrabarty's case, he had made significant modifications to the bacteria, using sophisticated techniques from molecular biology. This seemed more like building a mechanical device than finding a ruby in the ground. After many years in the courts, eventually a majority of the Supreme court agreed with Charkrabarty: his bacteria was "made by man, not by nature," the court said, and his patent was granted.

In the wake of the decision, the ownership of living things was gradually extended: first to other engineered bacteria and single-cell organisms, then to "higher" and multi-cell organisms such as oysters, and finally to mammals such as genetically modified mice (such as *Oncomouse*, a mouse engineered for cancer experiments). Even human genes have been subject to patenting, although this remains a controversial and unsettled area of law.

One consequence of these changes in ownership was the emergence of a new industry. Amongst the patents approved soon after the Chakrabarty decision were those belonging to Genentech, the first biotechnology company. Genentech, founded in 1975 by Herbert Boyer, Stanley Cohen, and Robert Swanson, was established to take advantage of the new recombinant DNA techniques that Boyer and Cohen had invented. By the late 1970s, the company had discovered how to use their system to produce human proteins (such as insulin) inside bacterial cells. The Chakrabarty decision ensured that this new industry would be able to claim intellectual property rights over their inventions, some of which were living, genetically engineered, bacteria. This, in turn, gave investors confidence that the biotech industry could succeed. In the early

1980s, Genentech and other early biotech companies were able to raise large amounts of capital, becoming one of most successful emerging industries in the last decades of the twentieth century.

For a few years, plants remained in a separate category since they fell under different laws (especially the Plant Variety Protection Act). But agriculture and seed companies began to argue that the existing laws did not provide sufficient protection for the intellectual property contained in their new plant inventions – they wanted their seeds to be covered by regular "utility" patents just like other inventions. From the middle of the 1980s, this is exactly what began to happen.

Significantly, most such ownership has accrued to large corporations, especially agri-businesses such as Monsanto, DuPont, Pioneer Hi-Bred, and Syngenta. Of course, most of these plants that these companies own are also genetically modified; but this modification is directly connected to ownership – they can be owned *because* they have been modified, and thus considered an "invention" rather than something that belongs to "nature."

This is most obvious in the US, but it is certainly not confined to the United States. A significant percentage of crops in Canada, India, China, Brazil, and many other nations is now given over to genetically modified organisms (GMOs). This continues to grow dramatically. Now, despite the pushback against GMOs, a huge percentage of crops grown around the world are genetically modified.

Much of the opposition to this is about risks to health, safety, and the environment. These issues may certainly be worth worrying about in some cases. However, what is less often talked about explicitly are the regimes of ownership that allow such seeds to be developed, marketed, re-sold each year, etc. Because agricultural companies own the rights to the intellectual property contained in the plants, farmers who wish to use the seeds are forced to sign "technology use agreements" that specify how and when they can use the plants. In many cases this means they cannot "save seed" for replanting in next year's crop and must resort to re-purchasing seed from the company. This makes farmers continuously dependent on companies for re-sowing their fields.

In fact, there is now so much ownership over plants that lawyers and companies now talk about it in terms of "thickets" of patents – multiple, overlapping layers of patents on many elements of the plants. These ownership rights are actively enforced in various ways by the companies that own them. Monsanto has used teams of lawyers to threaten and sue farmers who plant their crops without authorization. In one well documented legal battle in Canada, Monsanto sued a farmer who claimed never to have grown Monsanto crops – seeds that had blown into his fields and begun growing there put the farmer in violation of Monsanto's intellectual property rights. It is this ownership, perhaps more than anything else, that has transformed many food plants (and some animals) into technologies.

One problem with these changes is that it transfers control over our food supply into the hands of a smaller and smaller number of corporations. These corporations increasingly own not only the seeds, but also the farms, the farming equipment, the storage and transportation technology, as well as food processing facilities.

But most problematically, this ends up affecting what we eat. What is on the supermarket shelves – the kinds of products that are available to us – is connected in complicated ways to these regimes of ownership. The extensive use of corn and soybeans in many processed foods, for example, is enabled by the regimes of ownership that surround these GMO crops. Without these regimes, the kinds of supply chains, manufacturing, and the costs of foods on the shelves would be very different. So biotechnologies are affecting what we consume every day – not just whether there is GM ingredients in a food, but the whole structure of the food supply chain, and ultimately our diet. Again, it is perhaps not so much the technology itself that is the problem here, but the structures and institutions – here especially legal and political institutions – within which it has become deeply embedded.

2.3. *Global: Biosecurity*

Examining yet a larger scale, biotechnologies also affect global institutions and relationships. Global biopolitics is now deeply intertwined with exchanges of biotechnological products and resources – DNA, proteins, viruses, tissues, cells, and pharmaceutical products and part of international trade and exchange. Ultimately, this is having an increasing impact on national security and international relations.

A particularly good example of these developments can be found in the case of Indonesia's shifting policies towards the sharing of virus samples. In 2005, Indonesia shared samples of powerful new H5N1 Avian flu virus outbreak in Indonesia with the World Health Organization (WHO) influenza surveillance network. In practice, this meant sending samples of the virus to WHO reference laboratories based at Hong Kong University and the US Centers for Disease Control and Prevention. In 2006, scientists began to report the results of the analyses of these Indonesian viruses without notifying or seeking permission from anyone in Indonesia. They had accessed the viruses directly through the WHO's repositories.

Later in 2006, a journalist revealed that an Australian company planned to use Indonesia's H5N1 samples, again presumably obtained from the reference laboratories, to develop a vaccine. Indonesia claimed that the sharing of the viruses without their permission was a violation of the terms of the WHO's own guidelines. What worried them specifically was that a vaccine might be developed by a pharmaceutical company that would then be sold at prices that were potentially too expensive for patients in Indonesia to afford. Indonesia maintained that nations should main "sovereign control" over their own biological resources and that it was a violation of such control for other scientists or companies to use their resources without permission.

This perceived "unfairness and inequity" in the global system caused Indonesia to react dramatically. In 2007, Indonesia decided to suspend its sharing of viruses with WHO. This came as a big shock to everyone, causing widespread panic within the community of virus researchers. Scientists needed access to virus samples to track virus evolution, monitor drug resistance, and, above all, develop vaccines and methods of diagnosis. Indonesia widely criticized for its move and the WHO said it was "threatening global public health." Indeed, without this kind of sharing of virus samples and data, it is much more difficult to track potential pandemics and to develop vaccines that can check them.

In fact, Indonesia went even further. Rather than sharing their samples with the WHO, the Indonesian health authorities entered into negotiations with a pharmaceutical company, Baxter International. Indonesia planned to share samples with Baxter who would assist them in developing vaccines against the relevant virus strains, while recognizing Indonesia's right to the intellectual property inhering in the virus samples and any potential vaccines developed from them. In other words, Indonesia would make its own vaccines at affordable prices.

The WHO met with the Indonesian government and health officials to attempt to address their concerns and re-start virus sharing. An agreement was reached relatively quickly and Indonesia agreed to once again share virus samples. However, they also managed to negotiate fundamental changes in how virus samples would be transferred and who had rights over them. In particular, the WHO agreed to help implement new mechanisms that would attempt to ensure equitable access to vaccines developed from samples.

Here biotechnologies – here in the form of specific biomaterials combined with the tools for analyzing them – become critical objects within regimes of biosecurity and international diplomacy. Indonesia essentially used the virus samples as a bargaining chip in negotiations about drug rights and drug prices, asserting their sovereignty over their own samples, or samples taken from their own people (or chickens). Other countries (including China) have moved to protect samples originating from their countries (especially human samples) since could be exploited for development of drugs elsewhere.

Indeed, there are many other cases in which biological and biotechnological resources have become the subjects or international disputes. In 1995, the US Department of Agriculture and the agricultural company W.R. Grace received a patent on extracts from the neem tree, a species native to India and Nepal. The Indian government and Indian scientists objected that locals had long known about the insecticidal properties of the plant; the patent was overturned in 2005. In 2003, the American biologist and entrepreneur J. Craig Venter was accused of "biopiracy" after using his yacht to obtain samples of micro-organisms from territorial waters of Ecuador. Even cases where attempts were made to share profits and benefits, this was not always successful. The International Cooperative Biodiversity Groups program, for example, attempted to collect potentially medically useful plants from Mexico and return profits to locals. In practice, it often proved hard to identify just which communities or individuals should be compensated.

Such cases all raise difficult questions about who has the rights to plants, animals, and the substances extracted from them. Do they belong to individuals, communities, or nations? Which ones? What if the plants or animals cross national borders? Who has the right to develop them? Shouldn't companies that do conduct such development be entitled to the rewards? All these questions become even more complicated when the substances in question are contained within human bodies (human genes, for instance).

I am not aiming here to provide answers for these complex questions. Rather, I wish to suggest that we need to think about biotechnologies as transforming the relationships between countries and the ways those relationships are negotiated and maintained. In other words, there is now a global biopolitics in which viruses and other biomaterials are active participants. We need to think more and more about biotechnologies and biomaterials in thinking about global interdependencies and international relationships.

3. Conclusions and recommendations

This essay has taken a handful of examples examining different ways biotechnology is affecting society. These effects are now apparent on many levels – in our families and relationships, in our political, social, and legal institutions, and on the global arena. All of these entanglements present various kinds of problems and challenges – ethical dilemmas, economic challenges, political struggles, and social inequalities.

This raises the question: what should or can we *do*, if anything, about all the ways biotech is impacting society? There is no single answer, of course, to all the problems and challenges that biotechnologies raise. However, in concluding here, I will give some recommendations for broad strategies that may help us approach these kinds of issues more productively and work towards solutions more effectively. These are not specific remedies, but rather ways of thinking that might lead towards better understanding and thinking around biotechnologies.

First, all the kinds of problems that I have described here are more than technical ones – biotechnologies are not just about objects, but objects that are enmeshed within wider social fabrics. That is, they are objects embedded within social institutions such as marriage and relationships, legal institutions, political institutions, customs or cultures of eating, and so on. For example, we might think about what it takes to make IVF "work." Of course it takes scientific and technical expertise – knowledge about which hormones to administer, expertise about growing human cells outside the body. But it also requires laws that regulate clinics that perform IVF work; it requires some sort of social acceptance of IVF practices and "test-tube" babies; and it takes international agreements about transporting of children and adoption rules.

Because of all this, any "solutions" to these problems should think about such dilemmas holistically, and from multiple points of view, taking into account how objects and practices fit within these institutions and frameworks. That means that scientists, engineers, and doctors alone cannot solve these problems. We also need experts on law, international politics, society, ethics, and so on. This must be an interdisciplinary task.

Second, examples such as Indonesia's H5N1 samples also suggests that these are not purely ethical problems in the narrow sense. That is, they are not problems that involve clear dilemmas to which we can apply principles or logical reasoning. In that case, the WHO, acting according to one set of principles, believed that sharing virus samples widely constituted the most responsible action that would best protect the global community from potential virus outbreaks. The Indonesian health authorities on the other hand, acted from a different set of principles, appealing to notions of "equity and fairness" between developed and less developed nations.

In such cases, it is not clear which principles to apply; different starting points lead in very different directions. In other cases, the very categories of analysis are in question (nature/culture; animal/human; dead/alive). We often need to start in some other place – radically supplementing the tools of bioethics with tools from sociology, history, anthropology, and other social sciences. Rather than assuming that there is a fixed set of principles from which we can logically work through a dilemma or problem, we need to use a set of multidisciplinary tools to decide which principles are most appropriate and how they might best be applied in specific contexts.

Third, much of the debate about biotech is often framed in terms of "risk." But risk is often construed as a technical category – something we can measure and assess, through technical means. Calculations of risk are often performed by assessing probabilities, computing potential harms, and weighing costs against benefits in economic or other quantifiable terms. This gets us back to problem number one. Framed in only technical terms, we are unlikely to make progress in debates about biotechnologies.

For example, in the debates about GMOs we often hear about extensive safety testing of crops. In most cases, this fails to reassure the public that these foods are "safe." But the kinds of dangers that are assessed by such testing are relatively narrow: they examine whether the plants pose health or environmental risks (do they contain known toxins or allergens, for example). But as we have seen here, GM crops pose other kinds of risks that are very difficult to capture in traditional risk assessment frameworks. For instance, the risk of monopolistic control over the food supply; or the risks of shifting towards monoculture; or the risks of displacing traditional foods; or the risks of farmer suicides due to indebtedness; or the risks of shifting a population's diet. These are political risks, social risks, cultural risks, and long-term risks. Just because they may be very difficult to capture in a traditional cost-benefit analysis does not mean they should be ignored.

We need to consider "risk" very broadly to include risks that are unknown, unforeseeable, or that includes risks to peoples values, culture, ways of life, and so on. In short, we need a much more interdisciplinary approach to risk and assessing risk.

Finally, and more optimistically, we need to escape from technological determinism. This is the idea that technologies drive or determine their own uses, or that their uses are somehow given in advance. This often leads to the view that particular technologies are inherently "good" or inherently "bad." We see constant warnings in the media that the Internet is responsible for a dumbing down of culture and a decreasing attention span. But technologies can be used and re-purposed in multiple ways – there are many examples of this from the history of technology. In computing or engineering this is sometimes called a "hack." The designers of what was to become the Internet intended it to be used for sharing scarce computing resources across the United States. They did not foresee that applications such as email would shift the usage to become primarily a technology for communication between humans rather than machines.

With this in mind, I think we need to think creatively about technologies and what possible, different, unintended, uses may exist for them. Biotechnologies, like other technologies, are not inherently "good" or "bad" – they are made by humans and can be re-made by humans for many purposes. Everything depends on how we use them. The key question is: how can we use, repurpose, re-appropriate them in ways that are more likely to be beneficial for the societies in which we live?

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Scientific research and social responsibility[1]

PEARL A. DYKSTRA[2]

Abstract

Contrary to the powerful image of ivory tower scholarship, aiming to make an impact on society has become an integral part of scholarly practices. This impact emerges through teaching, commercialization of research findings, public engagement, and advice for policy and practice. The latter role requires a solid scientific evidence base. Aligning science and policy is a well-known challenge. I describe ways in which actors ranging from individual scholars, to the organizations where they work, and macro-level players such as publishers, research funders and governments can help advance interaction and communication between the spheres of scholarship and policy. Using first-hand experience in negotiating the boundaries between research and decision making, I describe the context in which the European Commission's Group of Chief Scientific Advisors works and identify conditions which, in my personal view, make its scientific advice giving effective.

Key words: society impact of research, scientific advice, research metrics, evidence synthesis, Scientific Advice Mechanism

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[1] This is the written version of an invited talk at the 'Ethics, Science and Society' conference in Lisbon, 11 December 2018, organized by the the Luso-American Development Foundation, http://www.flad.pt/en/

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Academics[3] regularly face allegations that they inhabit an ivory tower, presumably oblivious to practice, policy and citizen engagement. It is important to note, however, that the image of ivory tower scholarship, though powerful, is not consistent with reality. Social responsibility, or, aiming to make an impact on society has become an integral part of scholarly practices (Baron, 2010). The emphasis on social responsibility has, to a certain extent, evolved from changing views within the academic community on who the customers of scientific insights might be, but clearly has also been spurred by citizen involvement, priorities of funding organizations, and governmental pressures.

The impact of scientific research on society emerges in a number of ways. The first pertains to one of universities' earliest roles: *teaching*. In recent years, concerns have been raised about the time and efforts that academics devote to educational tasks (Boyer, 2010). Given the strong emphasis on numbers of publications and obtaining external research funding, the quality of teaching receives limited credit points at many universities (Frey & Osterloh, 2010). Incentive systems tend to motivate scholars towards excellence in research rather than excellence in imparting knowledge to students. Several initiatives have been adopted in North America, Europe and Australia to redress the imbalance between teaching and research and to focus university leaders' attention on the quality of teaching and learning and on the structures to support it (Chalmers, 2011).

The *commercialization* of research findings is a second form of social impact. Caution is advised, however, in equating usefulness to society with the potential of profit making. Paths towards commercialization of research findings are rarely straightforward and predictable (Weckowska, 2015). Moreover, scientific disciplines differ in the extent to which they lend themselves to marketing of their research in patents and business products. Findings from technology, engineering and medicine are more readily translated into commercial activities than are those from the social sciences and humanities (Benneworth & Jongbloed, 2010). As pointed out by Olmos-Peñuela, Benneworth, and Elena Castro-Martínez (2015), the arts and humanities are not 'less', but 'differently' useful. One of their strengths lies in reflexivity, the capacity to recognize structural and cultural forces shaping societal developments.

Public engagement is a third form of social impact, involving activities such as lectures for the general public, presentations on personal websites, letters to the editors of newspapers, professional publications, and consultations by journalists. Disseminating scientific findings to audiences outside academia has gained increasing importance in recent decades (Weingart, 1998). On one hand, there is a greater recognition of the moral obligation to help the public understanding of science. On the other hand, seeking publicity is driven by shifting conditions for doing science, namely a greater

[3] I use the term "academics" and "scientists" interchangeably to emphasize that scholarship embraces a wide range of disciplines: not only the natural and life sciences, but also engineering, humanities and the social sciences.

prominence of having research funded or making it pay off (Marcinkowski, Kohring, Fürst, & Friedrichsmeier, 2014). The way in which researchers engage with the media has gone almost unnoticed as an area of ethical concern (Meyer & Sandøe, 2012). Transgressions against good scientific conduct involve the revelation of not yet published findings, speaking about topics that are outside one's area of expertise, overselling research findings, downplaying uncertainty or disagreement, and concealing possible conflicts of interest. Meyer and Sandøe point out that dishonesty in public relations may come back to haunt the scientific community.

A fourth form of social impact involves scientific evidence for *policy and practice.* I will devote most attention to this form of social impact because it is where I have most expertise.

Academics vis-à-vis practitioners and policymakers

A survey of the literature broadly reveals three roles for academics in their engagement with practitioners and policymakers (e.g. Marris, 1990; OECD, 2015; Pielke, 2007). The first is that of the *sense maker*, who presents what is known on the basis of the scientific literature and what is not known. A key part of sense making is the recognition and minimization of biases through the identification of the ways in which evidence is selected and interpreted (Parkhurst, 2016). The second role is that of the *engineer*, who demonstrates, relying on empirical research findings, the effectiveness of solutions and identifies the need for tailored solutions. Here it is crucial to address questions such as: what works, what does not work, and when (i.e. under what conditions) is a proposed measure likely (or less likely) to have the desired impact (Davies, Nutley, & Smith, 2000). The third role is that of the *co-developer*, who responds to questions and requests for evidence and identifies upcoming evidence needs. Continuing dialogue between the academic and the decision maker is critical in this regard, to ensure on one hand that the policy or practical issue can actually be addressed by science, and on the other hand that the science advice is timely and appropriate (Bremer, 2013).

Successful execution of these three roles requires a solid scientific evidence base. The old adage is 'garbage in, garbage out' (Tweedie, Mengersen, & Eccleston, 1994). If the quality of empirical data is poor, the science advisor has insufficient methodological grounds for drawing reliable and valid inferences. If the filter for a literature search is inappropriately focused, the advisor may miss important sources or collect a great deal of irrelevant and potentially misleading material. A seminal report published in 2018 by the Royal Society and the Academy of Medical Sciences in the United Kingdom (see also Donnelly *et al.*, 2018) makes the case for *evidence synthesis* for policy, the practice of bringing together scientific knowledge from a range of sources and disciplines to inform public debate and decision-making on specific issues. Such a synthesis relies on the availability of high-quality primary research relevant to the policy question. Poor-quality evidence severely limits the utility of the resulting synthesis evidence. According to the report, a truthful, concise and unbiased synthesis of the evidence is one of the most valuable contributions the scholarly community can offer policymakers and practitioners.

The challenge of aligning science and policy

Aligning science and policy is a well-known challenge (Cairney, Oliver, & Wellstead, 2016). In what follows I describe ways in which actors ranging from individual scholars, to the organizations where they work, and macro-level players such as publishers, research funders and governments can help advance interaction and communication between the spheres of scholarship and policy.

What can *individual researchers* do? Academics receive ample training in how to identify a research niche, a specialized corner of their scholarly field where they have the potential to bring important, new knowledge. Identifying contributions to the research literature is part and parcel of writing the introduction of a publication or conceiving a grant proposal. Academics receive considerably less instruction and practice in how to define the significance of their work for policy and practice. Ferguson (2016) provides a practical strategy. He urges researchers to consider what they have discovered, why it is important, and what they have done about their discovery. I would like to point out that building links with policymakers requires patience and resources. It helps if academics work with organisations specialising in the research-policy interface. An example of such an organization is Public Policy Exchange[4] who organise events in London and Brussels where researchers can engage in dialogue with local practitioners, civil servants and other stakeholders.

What can the *academic community* do? As Ferguson (2016, p. 455) points out: "What you measure is what you get" (see also Hicks, Wouters, Waltman, De Rijke, & Rafols, 2015; Moher, Naudet, Cristea, Miedema, Ioannidis, & Goodman, 2018). When the number of publications and citations are the dominant assessment criteria, attention is drawn away from the question of what scholars do and why their work matters. The academic community is working towards finding ways to reward scientists for research efforts that have translational impact and societal added value. Benedictus and Miedema (2016), for example, have suggested to value impact outputs as high-quality research endeavors in their own right. The academic community is also looking for ways to better enable scholars to engage with policy makers and practitioners. Tyler (2017) has suggested to set up dedicated policy-impact units staffed by professionals who are skilled at navigating policy and academia (see also Meyer, 2010). Such units should

[4] For information, see http://www.publicpolicyexchange.co.uk

provide space and time to scientists to talk about how to do impactful research and to develop and evaluate best practices.

What can *other parties* do? Monitoring and assessing whether research results have contributed to policy and practice is not a straightforward enterprise (Bornman, 2013). Impacts tend to be diffuse, to be part of a larger package, to operate across national borders, and to take a long time before they are visible, making it difficult to attribute them to specific research outcomes. Nevertheless, there are a number of ways to facilitate researchers' efforts to make an impact on society. The first is that users of scholarly information acknowledge insights from science. The Royal Society and the Academy of Medical Sciences (2108) argue that the *public sector* needs consistently to cite the academic references that have informed a policy decision. Such a practice would also enable scholars to track whether and how their work has been picked up by decision makers.

A second suggestion, again put forward by the Royal Society and the Academy of Medical Sciences (2108), is that *publishers* champion evidence synthesis articles as high-quality research in their own right. As noted above, evidence synthesis articles contain no new research, but provide a critical evaluation of existing insights relevant to an identified policy question. They differ from a standard review in that their aim is to inform policy makers, and thus are tailored to the requirements of a non-research audience. In 2018, Royal Society Publishing launched the evidence synthesis article type for three of its journals: *Proceedings A*, *Proceedings B*, and *Royal Society Open Science*.[5]

Funding organisations also have a role to play. According to Tyler (2017), they should refrain from financing research projects that treat policy impact as an afterthought. Rather, funders should support policy-relevant work only when the applicants have given serious attention to their impact plan. Good proposals will have been developed in dialogue with decision makers, and they will describe when and how stakeholders will be involved in the study—either to provide ongoing communication about the policy issues, or to be kept at a distance to avoid influencing the research process. Fundable proposals will also contain tangible outputs for decision makers such as policy briefs, reports and interactive seminars. Finally, procedures should be put in place so that discussion with policy makers can continue for years after the study is finished.

European Commission's Group of Chief Scientific Advisors

As one of the European Commission's Group of Chief Scientific Advisors (GCSA), I have firsthand experience in negotiating the boundaries between research and decision making. I gladly take the opportunity to describe the context in which the

5 For details, see https://royalsociety.org/topics-policy/projects/evidence-synthesis/

GCSA works and to identify conditions which, in my personal view, make our scientific advice giving effective.

The European Commission established the GCSA in 2015 to provide high-quality, timely and independent scientific advice on pertinent policy issues. The seven members serve in their personal capacity, and they are supported by a team of about 20 dedicated researchers (known as 'the Unit') at the Directorate-General for Research and Innovation in Brussels. The GCSA and the Unit work closely with SAPEA (Science Advice for Policy by European Academies), a consortium of approximately 100 academies and learned societies in over 40 countries across Europe, spanning the disciplines of engineering, humanities, medicine, natural sciences and social sciences. Together, the GCSA, the Unit, and SAPEA form the so-called Scientific Advice Mechanism (SAM).[6]

Soon after the GCSA was established, we devised rules of procedure,[7] which are not set in stone but might be amended as new insights arise. To emphasize our impartiality, we focus on science for policy and do not engage in policy for science. A manifestation of our independence is that we are not employed by the European Commission; neither do we in any way give the impression that we represent the views of the European Commission. We publicly report any ties with industry and non-governmental organizations. All communications are transparent and are posted on the website of the Scientific Advice Mechanism. The advice we provide can be solicited and unsolicited. At the request of the European Commission, we have worked on cybersecurity, CO_2 emissions from passenger cars, new techniques in biotechnology, food from the oceans, plant protection products, and carbon capture and utilization. Topics that we have developed ourselves are micro and nano plastics, climate change and health, sustainable food systems, and making sense of science under conditions of uncertainty and complexity.

Judging from newspaper citations and policy documents that cite our publications, but also from feedback by the European Commission, our advice is being used. A factor that has contributed to our success is that we work in a *consultative* way with Commission services during the problem scoping phase—without compromising our independence. Repeated dialogue helps clarify the policy issues for which advice is sought, and also helps determine whether, where and how science can contribute insights to aid decision making. The scoping phase ends in the identification of policy-relevant questions that call for a review of the relevant scientific evidence. The actual evidence review is carried out by SAPEA in conjunction with the Unit. An overview of the European policy landscape is conducted concomitantly by the Unit for the purpose of identifying contingencies for European Commission decision making. The evidence review together with the policy overview serves as the basis for our "scientific opinion", the actual recommendations to the European Commission. Additional factors underlying

6 For more information, see https://ec.europa.eu/research/sam/index.cfm?pg=about

7 See https://ec.europa.eu/research/sam/pdf/sam-hlg_rules_of_procedure.pdf

the effectiveness of our work emerge here. Links with the European science academies and learned societies provide us with the *best of science*, enabling us to speak with authority. Information on the policy landscape enables us to *tailor* our recommendations to relevant regulations and laws, increasing the likelihood that they will be put into practice. We present our recommendations to relevant stakeholders before publishing them, which provides an opportunity to receive input that we might have overlooked and to hear whether our views find support from interested parties. I would like to emphasize that we do not adapt our recommendations in response to stakeholder feedback.

A final word

The provision of scientific advice is of most use where the science is most contested (Gluckman, 2014). It is when the issues are urgent, complex and high on the political agenda (e.g. climate change, migration), citizens hold strong positions based on their values, and the scientific evidence is incomplete, uncertain, and derives from multiple disciplines. System thinking (Arnold & Wade, 2015) by scientists can come in to help the policy community to understand complex problems, by identifying interconnecting parts, nonlinearities, feedback processes, different levels, dynamics over time, and so forth. In addition, it is crucial to acknowledge that science is *not value-free* (Douglas, 2009). Values play in many science-related decisions, such as those about what to study, what methods to use, what constitutes sufficient evidence, and what research to finance. Importantly, the scientific approach is designed to limit (or identify and mitigate) the influence of values. There is no better alternative than the scientific approach.

Scientific advice is about presenting a rigorous and comprehensive analysis of what is known and what is not known. Scientific advice, in and of itself, does not make policy. It is only one of the resources used by policy makers (Cairney, 2016). Other inputs are public opinion, political ideology, the electoral contract, fiscal obligations, and international obligations. Scientists should identify hoe the policy process works and seek to influence it on that basis. I fully agree with Tyler (2017) who states that the academic community has a duty to ensure that research evidence is brought to bear on policy and legislation to keep democracies healthy.

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2.
From Science to Society
strengthening citizenship

The impact of technological innovation on our way of life has been amazing, changing our daily routines and how we relate to the other; changing institutions and their procedures, which ultimately shape our social existence. Most people welcome these changes, and are thrilled about them, always eager for new and spectacular achievements.

This context has almost completely eliminated the citizen's mistrust towards science which first developed after the Second World War, and which was later, in the 1970s, partially revived due to the harmful effects of industrialization, particularly on the environment.

Today, it seems that public opinion has moved from occupying one extreme position towards technology – one which is characterized by suspicion dictated by fear – to the other extreme – characterized by a fascination created by an attraction for novelty. The spreading of a atheistic faith on technological innovation has lifted it to a point where it seemingly has the capability to solve all problems, including those that it may have itself provoked; as if 'more technology' is a synonym for 'better technology'.

This perspective is particularly evident in all of the domains that have been and are still being destroyed by unregulated or insufficient regulated industrialized practices. These practices have driven us towards the multiple problems of pollution and waste production, energy production and climate change, overfishing and intensive agriculture, species extinction and biodiversity reduction, among many others. The successive (four) industrial revolutions have unfolded, systematically solving some of the old problems and creating new ones. From mechanical production (steam energy), to mass production (electricity, gas and oil energy), to automated production (internet), to digital production (automated complex tasks): the fundamental idea that to humankind nothing is impossible, has continued to thrive.

This old idea, nurtured with new resources, has driven us to believe three major current creeds. The first one is that 'new' is always 'good'. Indeed, this is not true. The old, depending on what is at stake, can be better. This hyper-valorization of the 'new' pushes all forward at an unrelenting speed, potentially neglecting and ignoring past achievements and experiences.

The second dominant creed is that the current progress of human civilization is 'unstoppable' and will continue no matter what. Indeed, this perception can lead to a dismissal of responsibility by citizens, and by society as regards the ends and the means of scientific research and technological innovation, thus leaving these decisions about our collective future to the particular interests of the few.

A third growing belief concerns the relationships between 'necessities' and 'desires'; these are quite different given the objective and common need of the first when compared with the subjective and particular interests of the second. These two realities are often confused, thus leading to claim as human right what is merely a personal wish. This confusion has been established, and is still cultivated, by the new dynamics of technological development. In the past, technology was committed to satisfying human needs. During its development, these 'needs to satisfy' were no longer sufficient to enable technological innovation to continue. Personal desires started to be stimulated and magnified, becoming the new (artificial) needs of modern civilization, as with the ever-changing supply of new and newer devices and gadgets.

It is in this context that the participation of citizens, in the dynamics of scientific research and technological innovation, is of paramount importance. The current environment requires even more participation from an ever more enlightened society. This entails a strong investment in the communication of science and technology: translation of scientific terminology into common language, without any loss of accuracy; explanation of the complexity of technological advances, mostly with regard to their potential impact on human life; creation of public spaces for debate between all stakeholders; constructing public policies according to the most pressing needs of the majority, whilst also considering public opinion.

Maria do Céu Patrão Neves

Science, Ethics and Science Communication

CARLOS FIOLHAIS[1] AND DAVID MARÇAL[2]

Abstract

Some specific ethical issues associated with current scientific research are developing very rapidly, and have enormous potential to drive human and social changes. These issues must be addressed by society and not just by scientists. There is, therefore, a strong need for science communicators (scientists, educators, journalists and other mediators) to take into account these ethical questions in their activities. Here, we focus on biomedical topics, such as genomics, artificial intelligence and vaccination; all subjects that are important to our lives and which have been at the center of public debates. We briefly present some of the ethical challenges we face in these fields and stress the need for science communicators in Portugal, and worldwide, to take up these challenges and embrace affirmative action. We argue that it is urgent that these topics are placed onto their agenda.

Keywords: Ethics, genomics, artificial intelligence, vaccination, science communication

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Introduction

We are living longer and better thanks to science and technology. Advances in science and technology also remain our best hope for living longer and better in the future. But these advances now, as before, bring ethical and legal challenges to society.

Since the Industrial Revolutions we have seen the emergence of new ethical and legal issues. For example, the dawn of commercial aviation in the twentieth century forced a debate over property rights: aviation would be impossible if all owners had to authorize overflight of their land [1]. Another well known and more recent example – which is pertinent in the digital era, and which began in 1949, with the invention of the transistor, and expanded tremendously in the 1980s and 90s with the democratization of personal computers and the World Wide Web – the ease of copying and sharing music, video, and software – still creates difficulties with regard to the management of copyright [2]. In these examples, as elsewhere, technological advances, based on scientific advances, have led to debates and new regulations.

We live at an extraordinary moment in time, where the advances that can transform our lives fall into extraordinarily complex areas. We find obvious examples of this complexity in the fields of genetics, Artificial Intelligence – AI (this field may be associated with the first), vaccines, not to mention robotics, nanotechnologies, quantum computing, etc. Ethical decisions on these issues cannot be left to scientists alone, since they belong to everyone.

However, the enemies of science are far more numerous than in the past, with science and scientists under suspicion more than ever. Even with regard to vaccination, which is a well-established medical treatment (the first vaccines, used to prevent smallpox, date back to the late eighteenth century), the field is currently under attack due to the spread of misinformation and fake news, which, in this case as elsewhere, contributes to undermining public confidence in science. The same happens outside biomedicine: for instance, with the great debate on climate change; while nowadays there is a clear consensus within the scientific community, some voices are still endeavouring to confuse the public. In this case, as in medicine, the issues involved are very complex, so that they are not always very easy for the general public to understand.

In order for the public to participate in discussion of these issues, there is a clear need for public understanding of science to an adequate degree. A public which lacks sufficient knowledge of the issues at stake cannot have and express well-informed opinions. In fact, we can never expect citizens to understand these issues in great detail, but they can and should know the basic principles behind such matters and, based upon them, be aware of the possibilities and limitations of the science and technologies involved.

However, in addition to the buzzwords adopted by the media – we often find genetics, big data, AI, vaccines, etc. contained in newspapers headlines – most people have very little access to information about many of the scientific and technological advances that are transforming our society. They have not learned about these issues at school, which they may have attended a long time ago, and it is not easy to learn more about them from the media, which tends to be more focused on immediate news and does not always provide the necessary context.

The aforementioned biomedical research topics have evolved very rapidly in recent years, giving rise to new and interesting possibilities. But this rapid evolution has been too fast to allow for its meaningful integration into formal education, since curricular changes take time. However, the decisions we have to make are imminent and not decades away.

How then can people form an opinion without some basic knowledge? Irrational fear or uncritical enthusiasm are the only options left to us. Unfortunately, we see irrational fear prevailing in the current world in which the enemies of science proliferate. In our book *Science and its Enemies* [3], with its title inspired by Karl Popper's book *The Open Society and its Enemies* [4], we classify these enemies into several different types: dictators, ignorants, snake oil sellers, obscurantists and scientists who commit fraud.

Science communication urgently needs to help people to understand what the new ethical issues are and to point out possible answers. It has a strategic and, indeed, irreplaceable role in the public understanding of these complex issues. Science communication, like formal education, was slow to react to scientific and technological changes. If, in formal education, this delay is understandable, in science communication it is inexcusable. There are, of course, some exceptions, but unfortunately they are generally isolated cases. More can and should be done.

In this paper we outline some of the current issues in biomedical science – namely genomics, AI and vaccination – and discuss the role of science communication in promoting social conscience around these topics. It is not only science that needs to be communicated, but also the ethics related to science. The cases presented here will highlight the relevance of such ethical aspects.

Challenges in Genetics

Progress in the field of human genetics [5] over the last few decades has been tremendous, and particularly so since the completion of the Human Genome Project in 2003 [6]. (The announcement of the project completion was made by Bill Clinton and Tony Blair in 2000, shortly before the start of the new millennium.) It cost billions of dollars to sequence the first genome, but one of us (CF) recently had their genome sequenced for just $700. The $100 price point 'goal' is foreseeable in the near future, so it is anticipated that a huge number of people will have their genome sequenced very soon. However, these big advances have largely gone unnoticed by the general public.

The first issue is: do we want to know our genome? There are many cases where the answer is unclear. Do we want to know that we have a high probability of developing a serious illness in the future, such as Alzheimer's, but for which there is no known effective treatment? What if there is a form of prevention, but it is very extreme? For instance, the American actress Angelina Jolie decided to undergo a double mastectomy based mainly on her genetic data (her doctors had informed her that she had an 80% chance of developing breast cancer). Her probability of developing breast cancer, although high, was not 100%. After all, it was only a probabilistic estimate, not an individual certainty. Considering the identification of genetic variations that are more likely to lead to diseases, what should we do with the knowledge of a small probability of having a serious disease in the future? Above which probability value would we be willing to make a radical preventive decision? Should any National Health Service, or indeed any type of health insurance, cover the costs, even when the patient is healthy at the time of check-up? There are also implications for the wider medical community. How often should physicians consult genomic information in their routine practice? How should they pass on probabilistic information to the patients in front of them? The way in which doctors communicate a person's propensity to have a particular disease can be crucial to the decisions that a patient will make as a consequence of that knowledge. But statistical terminology is not easy to grasp: probabilities summarize, in a few indicators, extremely complex phenomena with great variability. How can doctors assess whether the patient is able to understand them? What constitutes consent for people with no or very little health education or scientific literacy? Given the current abundance of genetic testing, these are not questions for tomorrow, but for today.

What may happen if there is no doctor to mediate the access to genetic information? If we buy an analysis of our genome from a commercial company, such as the American *23andme,* can we understand it? Will we be vulnerable to targeted marketing, based on our alleged genetic needs? It would be naive to think that companies interested in selling preventive medicine products and services will make a balanced assessment of the needs of their customers. Given the complexity of this field, the profusion of genetic quackery is a serious risk. In fact, and once again, this is not a question for tomorrow, but for today.

What about our children? Do we want to know their genomes? The issues that arise are similar and the decisions taken may have implications for their development and happiness. But the case is more serious: it is possible to know the genome of a baby before he or she is born. What should we do with this information? Should a woman decide to terminate her pregnancy based on the probability that the child will have a serious illness in their old age? Or simply because there is evidence that the child may have reduced athletic or intellectual ability? These are complex issues with enormous ethical implications.

The possibility of sequencing individual genomes also poses security and data privacy issues. Furthermore, who should have access to our genomic information?

Employers, who will undoubtedly prefer to hire healthier employees in order to reduce the occurrence of sick days? Should insurance companies be able to adjust the cost of insurance according to personal genetic risks? Genetic privacy regulations will be required. Maybe we could authorize our doctors to have access, at times, to certain locations in our genome, but the risk of violation of our genetic privacy is enormous. Just as many people today post photographs of their private lives onto often very public forums and social networks, there is a clear risk that in the future, people will share their genetic data, unaware of the implications of this act.

We are also on the verge of being able to treat genetic diseases by modifying our genes. This is largely made possible by the very recent discovery of the CRISPR / Cas-9 system (Clustered Regularly Interspaced Short Palindromic Repeats; Cas9 is a protein), a natural bacterial defense mechanism which can be used to edit the DNA of living organisms such as ours. With this tool, which is a true 'cut and paste' with DNA, we can potentially correct defective genes that predispose us to certain diseases. These corrections can be made in embryos, allowing them to be effective in all cells of the individual adult. But they are also passed on to the offspring. This represents, at the same time, both a great potential benefit and a great danger. On the one hand, we could expect a persistent genetic advantage over a number of generations: for example, additional resistance to a specific disease. But the same would happen in cases of error: it would be propagated to the following generations. The security implications of the technique are huge: both collective and generational.

We might certainly agree that only the procedures considered very safe should be carried out. But regulation of these practices in a global environment is a real challenge. There will be people who are willing to risk experimental procedures, regardless of ethical and legal approvals, if a tempting reward is anticipated, such as the instant fame provided by the media. This is not a scenario for the future, but for the present. In November 2018, the Chinese physician He Jiankui announced that he had helped to produce the first babies – twin girls – born with edited genomes. He claimed to have used the CRISPR–Cas9 genome-editing technique to modify the CCR5 gene in two embryos, which he then implanted into a woman. As this gene encodes a protein that some common strains of HIV use to infect immune cells, the babies are expected to be more resistant to HIV infection. The announcement caught everybody by surprise. The consensus of opinion within the scientific community is that there is still insufficient information available to rely on the use of this technique in humans. However, even if the claims of genetic editing of embryos are not confirmed in this particular case, it may become a reality very soon. It is very likely that we will be confronted with more cases such as this. We should stress that there is something particularly new about these techniques: we will not just be doing prenatal genetic testing to help parents to decide whether or not they want to continue with a pregnancy. The parents will face decisions that will affect the entire lives of individuals who are not yet conceived.

Another question, which arises as to the application of these techniques, concerns limits. It is natural that we want to modify our genes, not only to avoid some diseases, but also in order to live longer: for example, by adopting some gene variations which may have been identified in people living well beyond 100. But we can go even further. Future parents may choose to give their children greater athletic or intellectual aptitudes. Or make them more attractive in a given society or culture; for example, by giving them blue eyes. We are still a long way off from this scenario, given that most of these features are very complex from a genetic stand point. But eventually we will get there. To what extent would we find it reasonable to change our own genes or those of our offspring? To what extent should individual liberty prevail? For example, should germline editing be completely banned or only limited to some cases, such as with the potential creation of people with severe disabilities?

All of these ethical issues, arising from recent science developments, represent political and societal challenges. The prerequisite for any meaningful public debate is the knowledge, albeit superficial, of these techniques and their implications. Therefore, we have to make up for lost time and quickly inform the general public about the new possibilities and the new questions. Associations of scientists are fully aware of the problems raised by CRISPR - Cas9, but they alone do not have enough means to play a significative role to improve the public understanding of science. Science journalists, who are very few in number in Portugal (being almost absent on radio and television), have real difficulties in understanding some aspects of science, even when in direct dialogue with scientists themselves. Much remains to be done to ensure that the public is fully aware of this emerging science.

Challenges in AI

Further examples of ethical issues associated with science and technology concern Artificial Intelligence (AI) [7, 8], which often appears associated with big data. AI aims to create systems with intelligent behaviours (by intelligence, we mean the ability to interact with the world, the ability to model the world, reasoning, the ability to learn and adapt). On the other hand, big data concerns the potential to automatically collect large amounts of data, which can, in turn, be analyzed automatically to extract patterns and relevant knowledge. The two fields can be associated together very effectively, since AI algorithms can use large amounts of data to draw conclusions which a human mind would never reach alone. The difference between an AI program and a conventional program is that, in the first case, the program changes with the input of new data, so that there is not a clear-cut separation between data and software. The name AI dates from 1956, when researchers from different fields of science and technology gathered at a workshop at Dartmouth College, New Hampshire, United States, to discuss 'neural networks' – algorithms conceptually based on neurons – and try to understand intelligence. A landmark in this field was established in 1997, when IBM's *Deep Blue* computer defeated the world chess champion, the Russian, Garry Kasparov. Several new AI applications emerged and became available in later years, such as machine translation, computer chats, and ticket or restaurant bookings by phone, etc. Given the rate of current developments, some futurists are speculating that in 30 or 40 years, at a point they call 'singularity', machines could replace humanity [9]. They speak therefore about a 'post-human future'.

In fact, AI algorithms are already part of our lives: whenever a book is suggested to us by the Amazon store, or a movie is recommended to watch via Netflix. Cars without drivers are already being tested. In the near future, AI algorithms will make important decisions for us within the field of medicine. The IBM Watson supercomputer, a system that is able to answer questions asked in natural language (and which can beat humans in the game *Jeopardy*), is already being used to look for answers concerning the treatment of lung cancer. It is entirely possible that AI systems may quickly acquire the experience of a well-trained medical doctor to interpret X-ray or NMR imaging. Why should doctors be trained over many years if expert systems can arrive at similar results in much less time? It is also possible that AI systems may, very quickly, navigate through terabytes of clinical files belonging to thousands if not millions of patients in order to discover particular patterns and seek to expedite solutions to complex medical problems. These systems can also research the ever-growing volumes of published medical literature much faster than a human being. AI, combined with genomics, may lead to the discovery of associations between changes in specific sites of the genome, and some diseases with multigenic origin. Based on this knowledge, a medical doctor could query genomic data in order to obtain vital information which can then be interpreted, together with other sources of data provided by other diagnostic analysis.

New ethical questions arise: Who is responsible when the answers are given automatically? How much should we trust machines? How can we ensure that machines are permanently aligned with human objectives? Can we codify ethics in machines? (This is the very new field of 'artificial ethics'.) Can super-intelligent machines radically change human life to the point of having a trans-human future? This sounds like science fiction, but part of it is already a reality and the rest may become real in the not-too-distant future. Should we be afraid? Should we hinder some developments in the field because of our fears?

Again, we are faced with huge difficulties regarding societal understanding. The basics of these technologies are virtually unknown to the general public: almost no one knows what basic AI concepts like 'neural networks' or 'machine learning' actually mean. Since AI is becoming more and more relevant in our lives, it should be considered more frequently and widely as a common topic of science communications. One possibility is to bring the topic to debates broadcast by radio and TV, which may reach millions. Another option is to show exhibits about AI in science centers or museums. Either way, science communicators must be involved.

Challenges in vaccination

In vaccination, ethical decisions are also present. In fact, vaccinating is not an individual decision, since it has wider public health implications. At the head of ethical issues, we have the right of children to be vaccinated, despite any misconceptions of their parents: children have the right to the best healthcare possible. But one should also consider the mechanisms of vaccine protection: it is not only individual, but essentially collective in nature.

Vaccines are a case of unquestionable success, having resulted in the elimination or drastic reduction of various diseases in many countries throughout the twentieth century, including the eradication of smallpox all over the world in 1980. But it is also an area where there are a lot of lies and misinformation circulating. The success of vaccines makes some people believe that they are not needed. For example, the fact that many parents today have not had measles, or known anyone with measles, creates a false sense of security about the disease. The same happens with other diseases which, in many regions of the world, have become extremely rare thanks to the use of vaccines. There are also those who mistakenly believe that the risks involved with vaccines are greater than those associated with the diseases they seek to prevent. This evaluation should be done separately for each vaccine. But it is methodologically sophisticated and sometimes without causality. For example, the fact that the first signs of autism may appear in a child shortly after the MMR (measles, mumps and rubella) vaccine has been administered does not mean that the cause of autism in that child is the vaccine itself. However, there are organized groups in several countries who present alternative and erroneous assessments of the risks of vaccines, and advise others against taking them. They have, in social networks, fertile ground for their dissemination of incorrect information. They can also gain prominence through traditional media, including TV. All of this represents a potential health risk.

As there is no vaccine that is 100% effective, herd immunity is a key mechanism for the effectiveness of vaccines in preventing contagious diseases. It is generally necessary that a relatively high percentage of individuals in a population are vaccinated, so that the infectious agent does not have a propagation network. Herd immunity also makes it possible to extend the protection to persons who, for whatever reason, cannot be vaccinated. This may be the case for some immunocompromised patients, or for children too young to be given a particular vaccine. This is the case, for example, for pertussis (or whooping cough): newborn babies cannot be vaccinated, and depend on the immunity of the people around them to avoid being infected; that is not possible without high vaccination rates.

Given the social nature of the decision to vaccinate, there are obviously wider political implications. There are countries, such as Italy or Poland, who have passed compulsory vaccination laws. Others, such as Australia, have created tax penalties for families that do not vaccinate. Public participation in these debates – which have an ethical dimension – requires a certain level of knowledge concerning the salient issues. The role of health authorities and the media is fundamental (the media should not, for example, give the same status to truth and lies, as frequently happens). But, in the information arena, the role of science communicators is also essential.

The evaluation of vaccines, including which vaccines should be incorporated into national vaccination plans, is a scientific and technical issue. However, in November 2018, members of the Portuguese Parliament approved the inclusion of three vaccines in the National Vaccination Plan. This decision gave a completely incorrect signal, by replacing specialized scientific expertise with political policy making. Science should inform politics and not the other way around. All of those involved should do things correctly in order to maintain public trust in vaccines.

It is difficult for the general public to understand and fully comprehend the involved epidemiological studies used to recommend the inclusion of a vaccine in the National Vaccination Plan. Nevertheless, understanding concepts, such as bacteria, viruses, infection and immunity, is required in an informed society. In particular, social recognition of the importance of herd immunity is essential in these times of misinformation. The public needs more and better information. Transparency is a hallmark of science and more transparency is needed. The right message needs to be translated into a language that many can understand. Given their accumulated experience, nobody can do this better than science communicators.

Final considerations

We have discussed some of the current challenges in biomedical subjects: genomics, artificial intelligence and vaccination. What is common, to all of the cases discussed here, is that they are all scientifically complex, that they have ethical implications which are not sufficiently well known by the general public, and for which the available information is scarce or misleading. The proper treatment of these issues requires the convergence of efforts by various individuals. Scientists must present the choices. Democratic societies, where people are represented by politicians, must make decisions based on ethical principles. The public needs to have a basic understanding of the scientific issues involved in order to make informed decisions. Transmitting scientific knowledge, to enable meaningful debates, is the role of science communications. Indeed, there cannot be any meaningful debates without good science communications.

The price of not occupying the public arena in these matters with correct information is to leave this space for charlatans to populate. This is unfortunately already happening in the current context of manipulated social networks and fake news. At a time when extreme ignorance seems combined with extreme power, we should be aware of the strong warning which Carl Sagan made in 1998, in his book *The Demon-Haunted World: Science as a Candle in the Dark* [10]:

"We have arranged a global *civilization* in which the most crucial elements – transportation, communications, and all other industries; agriculture, medicine, education, entertainment, protecting the environment; and even the key democratic institution of voting – profoundly depend on *science* and *technology*. We have also arranged things so that almost no one understands science and technology. This is a prescription for disaster. We might get away with it for a while, but sooner or later this combustible mixture of *ignorance* and *power* is going to blow up in our faces."

There is an urgency in engaging science communication of the new complex issues with important ethical implications. The time is now, since tomorrow it will be too late.

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From Science to Society: Strengthening Scientific Citizenship

CARLOS CATALÃO ALVES[1, 2]

Abstract

The often poorly understood relationships between science and society are evolving and becoming increasingly multi-dimensional. A potentially important development, which is growing and becoming influential, concerns public engagement, participation and involvement in the policies and practices of science. This is perhaps best seen as a new component of two distinct, but overlapping, domains: *communication* and *participation*. The borders between them are not clear cut. From an education-driven perspective, the first concerns the communication of science in terms of popularization, and gives a high value to the dissemination of scientific knowledge to the masses of citizens and for the benefit of society as whole. The second favours dialogue, with a focus on transparency, *participation* and active public involvement, both in the *debate* about scientific developments, and in the *production* of scientific knowledge itself. This essay suggests that the interaction between science and society more closely resembles a fuzzy and fragmented landscape, constantly transforming itself, forced both to adapt to and be driven by the realities, constraints and contradictions of pragmatic, real-world science policy and practice.
Keywords: Science communication, public engagement, scientific citizenship.

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1. How did we get here?

Martin Bauer and colleagues have summarized the evolution of research into the science-society relationship. They identify three distinct periods, not necessarily in chronological succession[3]. These are:

- the *science literacy* period (starting from the 1960s);
- the *public understanding of science* epoch (from the 1980s); and finally,
- the *science and society* period, from the 1990s onwards.

Significantly, each of these periods are characterised by the concept of a 'deficit'; namely the problem or problems that are to be addressed by science communication and research.

For the *science literacy* period, the deficit lies with the wider public, who are perceived to be lacking basic knowledge about science. This deficit should be addressed through a wide range of initiatives, mainly designed to impart knowledge to an ignorant population. Education becomes the critical resource, and must be provided for everyone, from childhood to adulthood. This notion sees the *mission* of science communication as a process of *transmitting* scientific knowledge: a one-directional process, from the experts to the public. It became widely known to science communication scholars as the 'deficit model' and has been the subject of much criticism ever since, even though it keeps returning and is still influential today[4].

During the *public understanding of science* period, the problem changed from being one which was simply about insufficient knowledge, to one that focused on the public's *negative attitudes* towards science. The assumption is that because citizens do not possess the knowledge required to grasp the complexity of the scientific endeavour, they will be more at risk of being enticed by anti-science social movements, a phenomenon that poses a significant threat to scientific research and its associated institutions. Resulting from this analysis, the period saw an increase in the *marketing* of science. There was a boom in the creation of interactive science centres and multimedia encyclopaedias, and a great flowering of popular science magazines and books, all aiming to seduce and draw the public into the wider science arena[5].

The *science and society* paradigm exonerated the public from both the responsibility for the knowledge deficit, and any mistrust of scientists' work, placing the blame firmly on the community of experts and scientific institutions who lacked the skills to

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3 See Martin Bauer *et al.* (2007).

4 For a compilation of essays trying to answer the question '*why does the idea of the public deficit always return?*' see *Public Understanding of Science* (2016), Essay Competition, on the 'deficit concept', 25(4): 398-464.

5 See Massimiano and Trench (2008).

create the effective communication and dialogue needed to address assumptions about scientific illiteracy. This shift coincided with the publication of an influential report by the Royal Society, commissioned by the UK House of Lords, which called for strong measures to address a growing crisis of public mistrust of science[6]. The recommendations in the Royal Society Report have paved the way for most of the main trends in the science-society dialogue ever since, and in many instances they have anticipated and informed both the way in which the issue is now understood, and the core features underpinning the strategies through which it has been addressed in the new millennium.

The historical reasons behind these shifts in the relationship between science and society are multi-dimensional. In some ways, they reflect the characteristics of public mistrust in science already echoed in the *Bodmer Report*[7]. This report, also published by the Royal Society, two decades earlier (1985), had already set the standards for the communication of science to non-scientists, and resulted in the creation of the first *Committee on the Public Understanding of Science*. Yet, the anxiety of some sectors of the public towards scientific developments is still present in many current controversial debates, spanning from discussions on the benefits and risks associated with genetically-modified organisms to, more recently, scepticism regarding the validity of climate change arguments, despite an overwhelming consensus to the contrary within the scientific community[8]. All of these controversies and many others (such as those surrounding nuclear power, nanotechnologies, Artificial Intelligence, and even the boom in information generated by the digital revolution and the growth of the blogosphere) are part of a new reality. Science is no longer seen as an activity that transcends the economy, politics and ethics, independent of the social and local circumstances in which it is created.

Since Bauer and colleagues published their paper in 2007, more than a decade has passed. It would be naïve to believe that the shift from the deficit model to a more democratic science-society dialogue happened neatly, in a straight line. In fact, it is arguable that there has been no paradigm shift at all. There is still a prevalent view that ordinary citizens do not possess the kind of knowledge that is required to understand and appreciate science, let alone to get involved in the processes of making decisions about controversial scientific and technological developments. Indeed, very recent empirical work suggests that most scientists have distinctly different views regarding public engagement activities to those held by communication scholars[9]. And on the other side

6 Select Committee on Science and Technology, House of Lords, UK. February 2000 *Third Report on Science and Society*.

7 The Bodmer Report. Available at: https://royalsociety.org/~/media/Royal_Society_Content/policy/publications/1985/10700.pdf

8 See Susanne Priest (2016).

9 See Yan, S. *et al.* (2019).

of the fence, belief in the promise and the prize of public engagement, held by science mediators, also appears far from being fulfilled[10].

2. A push from the social studies of science

Changes in the way in which science is perceived began to appear throughout the 1970s, with a first distinction between the *sociology of science* and the *sociology of scientific knowledge*, commonly designated as 'science studies'. Although one could be led to regard the former as a branch of the sociology that deals with scientific knowledge, in reality the sociology of science, as informed by the work of the sociologist Robert Merton, has been primarily concerned with the macro perspective that helps to explain science as a social institution, with its norms and social networks. John Ziman, a physicist particularly known for his work in the philosophy of science, prefers to see these norms being 'presented as traditions rather than moral principles', as 'unspoken rules' faced by newcomers to research when 'they are entering a self-perpetuating 'tribe'' (2000: 31). As Ziman points out, the particular virtue of the Mertonian norms is that they emphasize practices and principles that impact directly on individuals and that generally distinguish science from other institutions and callings[11].

Indeed, the Mertonian sociology of science concentrated its efforts both on the study of the *institution* of science and on the study of the *profession* of scientists, not on the social study of *scientific knowledge*. By focusing on the latter, the advocates of the *science studies* introduced a rupture with far-reaching consequences. It is no longer only scientific *beliefs* that are seen as socially constructed – it is also the scientific *facts*. This conceptual shift determined (and was driven by) a new object of study – the *research laboratory*. The social studies of science moved away from the study of the social grounding of the scientists' interests and preferences, and set the focus on how interactions between scientists shaped their scientific assumptions. Although drawing on a variety of sources, these studies were mainly carried out under the influence of ethnomethodological studies of informal day-to-day practices, particularly with microscopic studies of various aspects of scientific experimentation and argumentation, such as the social processes of scientific replication or scientific controversies.

As a consequence, scientific inquiry stopped being depicted as a value-free activity in which scientists started from observation and proceeded via induction and experimentation to a successful outcome. Under the influence of the French philosopher, Bruno Latour, these new approaches have focused attention on 'science-in-the-making' and on the 'construction of scientific products', where scientific facts are no longer regarded

[10] See Sarah Davis (2009).

[11] See John Ziman (2000: 33).

as given entities, but instead as being socially constructed[12]. In spite of their different interpretative frameworks, studies of 'science-as-practice' share common features. Firstly, scientific facts are no longer seen as inseparable from the courses of inquiry which produce them. Secondly, with Michel Lynch and his seminal ethnographic studies of laboratory talk, the empiricist vision of the scientific method was challenged by being characterised as 'an idealized and substantially mistaken version of scientific practice'[13].

3. What is scientific citizenship?

Scientific citizenship is not an easy concept to grasp. This may be because it carries an overload of political significance, or may be simply because, as with the concept of *citizenship* itself, it has a fluid and dynamic meaning. Citizenship is usually seen as a relationship between a state and its citizens, a 'political thing', a matter of rights and duties. Nick Ellison's sociological review of contemporary literature on citizenship identifies three main perspectives[14]. A 'state-centred' notion of universal rights to social and political inclusion; a 'pluralist' view which tries to accommodate difference and challenges to universalist accounts of citizenship; and, finally, a 'post-structuralist' view that addresses issues of citizenship as a reflexive process within a rapidly changing economic, political and social landscape, where there is little room for static norms and rules of citizen engagement.

In addressing scientific citizenship, I have retained the notion of membership and social inclusion, associated with the state-centred position, while acknowledging a distinction between a 'liberal' and a 'republican' view of the relationships between the citizen and the state. This is also recognized in *Science and Citizens*, a key reference source for anyone seeking a comprehensive understanding of scientific citizenship: here, citizenship is best formulated alongside the fundamental traditions of political philosophy[15]. The *liberal perspective*, where citizens act as individuals exercising universal rights granted by the state, is seen as a benevolent entity that oversees the participative arenas where public debate of science is carried out. The *communitarian perspective* sets the intervention of citizens first and foremost within the context of a community in which the interests of each individual citizen are, therefore, framed by the common good. Both these perspectives favour activist civil society organizations and social movements. Citizen participation in science is seen and constructed as a manifestation of community-led

[12] Bruno Latour (1987).

[13] Michel Lynch (1985: 3).

[14] For a thorough review on citizenship, see Nick Ellison (1997).

[15] See Leach *et al.* (2015).

needs and expectations, with an emphasis on acting locally. Lastly, the *civic republican perspective*, provides a common basis for particular aspects of the liberal and communitarian perspectives, specifically between individual rights and the collective interest of communities, but stresses even more the political sphere that is the involvement in formal mechanisms of deliberative policy-making.

In *Scientific Citizenship in a Democratic Society*, the philosopher Vilhjálmur Árnason argues that the understanding of scientific citizenship must not be confined to the discussion of deliberative practices and its impact on policy and decision making. Árnason goes to great lengths to draw attention to the need to avoid the temptation of taking sides and placing a clear border between the 'competence model' and the 'participation model'. For him it is too simplistic to expect the dialogue between scientists and non-scientists to be carried out within a relationship of equality 'in the sense that all view-points are given equal weight'. On the contrary, in this view it appears more appropriate 'that a proper understanding of scientific citizenship needs to integrate both dimensions': for example, both the dimension of public competence, associated with one-way communication (the deficit model of knowledge), as well as the dimension of participatory dialogue, which needs to incorporate and emphasize the development of competences that enable citizens to build their own understanding of the issues[16].

This perspective of competence development within the dialogic process of scientific citizenship plays well into the notion of capacity building advocated by the science communication scholars Sara Davis and Maja Horst[17]. For them, scientific citizenship must be seen in a broader sense that also involves the promotion of scientific literacy and skills which strengthen capability for civic intervention; specifically through a wide range of activities, such as reading science news, attending debates at science centres and museums, or participating in science cafés. These are all effective ways of building networks, remaining alert to current science and political issues, or acquiring skills to support more articulated and empowered interventions, recognizing the importance of public participation in policy-making.

4. The politics of engagement

The territory of public engagement with science is best characterised as a continuous spectrum, ranging from politically oriented activities, more commonly associated with the idea of public participation, to a wide range of cultural or educational activities, such as those promoted in science museums, science festivals, or in *open days* in scientific

16 See Árnason, V. (2012: 933).

17 See Davis, S. and Horst, M. (2016).

institutions and universities[18]. Again, there exists here the same kind of ideological divide that separate competing views about the relationships between scientists and the lay public in matters of science. On the one hand, there is a strong perception that citizens have an increasingly decisive role in determining scientific and technological developments, with a stronger involvement in decision making, but also in the processes of science, as culture and practice. On the other hand, there is a persistent view that scientists, perceived as experts, define the boundaries of what science is to be discussed, how the debate is 'framed' and what, ultimately, are the rules of engagement.

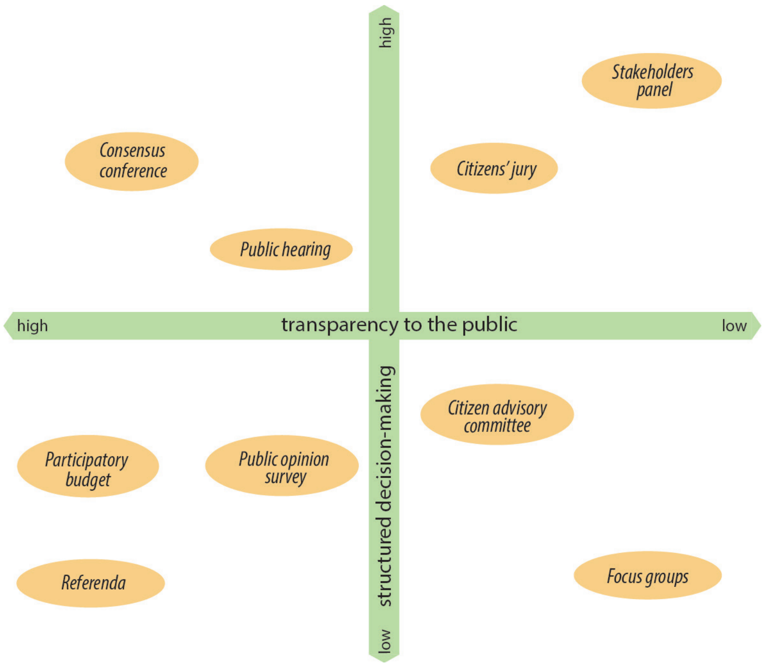

Figure 1 – *Public participation methods*
Adapted from concepts in References [19]

It is useful, at this stage, to focus attention on the idea of public participation, building on the proposals made by Gene Rowe and Lynn J. Frewer in their *Typology of Public Engagement Mechanisms19*. There, *public participation* is defined as the 'practice

[18] Back in 2007, in an in-depth study of the London Science Museum's Dana Library and Research Centre, a dedicated space for public engagement, with up to 6.000 visitors in one year, Sara Davis (2007) underlined the flexibility of the approaches, where 'education-inspired talk shows, hands-on, and science activities occur alongside with alternative forms of dialogue and debate'.

[19] Rowe, G. and Frewer, L. (2005) A typology of public engagement mechanisms. *Science, Technology, & Human Values*. 30(2): 25-:290.

of involving members of the public in the agenda-setting, decision-making and policy-forming activities of organizations/institutions responsible for policy development'.

This practice is enacted through mechanisms of communication, consultation and participation, as it is applied in a wide scope of categories, ranging from referenda, surveys, electronic consultation and opinion polls, to focus groups, citizens' juries or consensus conferences. In a previous attempt to assess the effectiveness of different techniques of participation, the Authors concluded that 'the most appropriated techniques for public participation are likely to be hybrids of more traditional methods'.[20] Again, here flexibility and attention to context are the norm. Nonetheless, there are criteria that should be taken into consideration if public participation is to be effective. Representativeness is one of these criteria. The participants should compose a sample that is, itself, illustrative of the broader universe that it represents. They also must be engaged as early as possible, so as to enable them to gather the most valuable information, and, ultimately, be made aware of the context and underlying assumptions of the decision-making process. All these are essential for an effective and valuable process of citizen participation in the discussion of science-related public affairs. It is also essential that transparency, independence and impact are fully considered, if the outcome of the participation process is to have a tangible effect on policy. This means that understanding the full extent of public participation in the science-society dialogue requires the consideration of a number of key questions.

Question one is, of course, w*ho are the participants?* How engaged or disengaged are they? Is their distrust of science in any way related to the level of democracy in their societies, or with their knowledge of science? How do scientists perceive them? In an attempt to answer this question, at the European level – i.e. who are those citizens who participate in science policy-decisions and are supportive of a democratic governance of science – Makarovs and Achterberg analysed the *Special Eurobarometer of 2010* in a search for answers across 32 nations. Unsurprisingly, they found clear positive effects on public engagement with science resulting from education and knowledge. Less clear were the findings associated with the effects of public distrust of scientists. The Authors were surprised to find that citizens who are less trustful of science and scientists are not necessarily inclined to favour democratic control of science[21].

[20] Rowe, G. and Frewer, L. (2000) Public participation methods: A framework for evaluation. *Science, Technology, & Human Values.* 25(1): 3-29.

[21] For Makarovs and Achterberg (2018), there is a possible speculative way of explaining why citizens who tend to mistrust scientists do not necessarily demand a stronger public control of science. In their own words, 'in countries with high levels of democratization, those who are highly critical of science institutions might feel assured by the idea that in these countries there is actually more democratic control of scientific activities and people are more directly engaged in science, which, in turn, yields a less strong demand for even more democratization of science'.

What do the scientists themselves think? Even though scientists tend to emphasize the importance of their own role in public debates on science, empirical research suggests that few 'view their role as an enabler of direct public participation in decision making through formats such as deliberative meetings, and do not believe there are personal benefits for investing in these activities'. This bold statement is the result of an analysis of two large-scale surveys of scientists in the UK and US, undertaken by John Besley and Mathew Nisbet[22]. But it is consistent with other studies that suggest that scientists tend to view the public as a homogeneous body, mostly unaware of the key issues at stake. Their interaction with the public is, therefore, largely perceived as a didactical exercise that aims to distribute scientific information[23].

A second key question is *what is the purpose of public participation?* Is it just about gathering citizens' views? Who defines the topics and agenda of the dialogue? What is the actual outcome of it? The rationale for public participation emanates first and foremost from the basic right of citizens to determine the governance of democratic societies. But even this assertion is not inseparable from political frameworks of interpretation. In the tradition of liberal pluralism, as the mainstream theory of democracy in American political schools of thought, citizens are supposed to join organized interest groups (e.g. political parties or civil society organizations), and democratic governance is therefore seen as the result of the interaction between these groups and the government. On the other hand, in a direct participation view of democracy, citizens are free to act on an individual basis and are entitled to exercise, as individuals, their right to a direct influence on policy. As mentioned earlier, this is the kind of philosophical divide that stands at the heart of the way in which scientific citizenship is to be perceived and practiced [24].

But it is also important to consider matters of scale and reach: whether we are looking at local, community-based citizen interventions, at nationwide initiatives or, conversely, at decision making in research agendas spanning many nations, as is the case in the European Union. There follow two cases that should shed some light on the appropriateness of the focus group approach as a public participation method aiming to elicit citizen's views and opinions about what is worth knowing in order to address their concerns and needs.

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22 The survey on the UK was funded by the Royal Society, Research Councils UK, and the Wellcome Trust, and carried out, in the fall of 2005, in a dataset of 1,277 scientists. The US survey, with the collaboration of the American Association for the Advancement of Science (AAAS), was applied to 2,535 of its own members, randomly selected. For a thorough analysis of both surveys, see Besley, J. and Nisbet, M. (2011: 644).

23 See Cook, G. et al. (2004).

24 For a deeper clarification of the debate between pluralism and direct participation in matters of technology assessment and policy, see Frank Laird (1993).

An example of these citizen-driven policies is the network of 'Public Participation Labs' *[Laboratórios de Participação Pública],* an initiative designed to promote open spaces for public debate about the advancement of scientific knowledge. The main purpose has been to stimulate processes of democratic participation in the setting of research agendas for scientific, technological and cultural development that are socially relevant, and closer to the needs and expectations of local communities. The Portuguese government intentionally launched the *Laboratórios* in a rather isolated part of Portugal, in the Trás-os-Montes sub-region, where some communities have experienced desertification, and may have also seen an extensive exodus of the younger generations. The method of choice was one of focus groups, with no more than a dozen participants in each, carried out at the local interactive science centre (Centro Ciência Viva de Bragança), alongside the Polytechnic Institute of Bragança, as a collaboration between science engagement organizations and science research institutions, which have accumulated extensive experience of scientific cultural programmes in the country over many years[25]. The initiative runs parallel to a nationwide programme, the 'Orçamento Participativo Portugal' [National Participatory Budget], where citizens are invited to put forward ideas and projects for research and innovation, amongst other subject areas, such as culture and education. Gathered in local assemblies, organized throughout the country, citizens present, debate and approve these proposals, which are later voted on at a national level, and are then supported by a budget reserved by the government for those specific purposes[26].

5. Capacity building for scientific citizenship: A Talking Science Tool

We have seen from the outset how scientists may nurture (in many cases, unwarranted) views about the capacity of the public to engage in complex science-related issues, about the homogeneity of the public's attitudes and, consequently, of its beliefs and interests. Also, the view of communication as a propagation of science that is made accessible to lay-people via the simplification of scientific information, has its historical roots in a long standing perception of science communication as a didactic enterprise, as if it were a teaching category, with the citizens playing the role of pupils. Unsurprisingly, this version of the deficit model keeps returning in science communication. Molly Simis and colleagues argue that part of this persistence may be associated with scientists' lack of training in communication, both as a talking skill and a social practice, resulting in 'an overall lack of awareness about the processes by which citizens arrive at opinions and how to communicate effectively with them'.[27]

[25] See Alves, C.C. (2001) for a more detailed description of these initiatives.

[26] For a full account of this on-going initiative, see http://opp.gov.pt

[27] See Molly J. Simis *et al.* (2016: 400).

On the other hand, it would be unjustified and wrong to deny that scientists interact effectively with citizens: they do so across a wide range of instances and locations, such as science festivals, museums and science centres, science cafés and through many other engagement activities. There is nonetheless a recognition that with few exceptions, communication skills are notably absent from the formal training of scientists. And when it does happen, it tends to be focused on writing and presentation skills applied to online, social media or video. Research, however, seems to suggest that 'there is still a substantial disconnect between the training and practice of communication scholarship'.[28]

Although the number of Doctoral programmes in science communication is still small, it is true that the picture is fast changing, and some universities in European countries, and across the Atlantic, are offering Masters courses in this area, with a focus on science journalism, multimedia and education, normally in media and communication departments. For training purposes, I have designed a self-assessment tool that is being applied in science communication capacity building programmes, and is aimed at scientists, as well as science communication mediators and communication officers, or simply at people who are interested in matters of communication and science. The resource, proposed here as a *Talking Science Tool* (TST) is a self-assessment matrix designed to help people learn how to talk science in different formats, and with a wide range of public audiences, from lectures to open debate (see Figure 3). As well as presentation and talking skills – which are essential in helping people to exercise civic responsibilities, such as attending a debate in a science centre or stating one's case in a more institutional forum – it is also essential to develop skills in holding meaningful dialogues – more focused on public discussion and deliberation – as part of a broader concept of science communication. Another instance of a learning resource for such skills, with a practical example designed to be easily adapted to a wide range of scientific domains, is presented in a learning showcase*: A Case of Stakeholder Engagement in Research*[29].

6. The citizen scientist

Although the core elements of citizen science can be traced back as far as the nineteenth century, it has been expanding rapidly in recent years, from a restrictive notion of data gathering by volunteers to a broader idea that encompasses a wide scope of

[28] See Shupei Yuan (2019: 102) and colleagues for a comparison between the views of scientists about public engagement and those of communication research.

[29] For a workshop training exercise script in stakeholder engagement in research, see Alves, C.C. (2016), pages 34 to 44.

public engagement activities[30]. These may include participation in research processes by observing, gathering and processing data, right up to designing science-related activities, such as community-based research programmes, knowledge dissemination and science communication.

The definition proposed by the *Green Paper on Citizen Science*, published by the European Commission, states that citizen science 'refers to the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort, surrounding knowledge or with their own tools and resources'.[31]

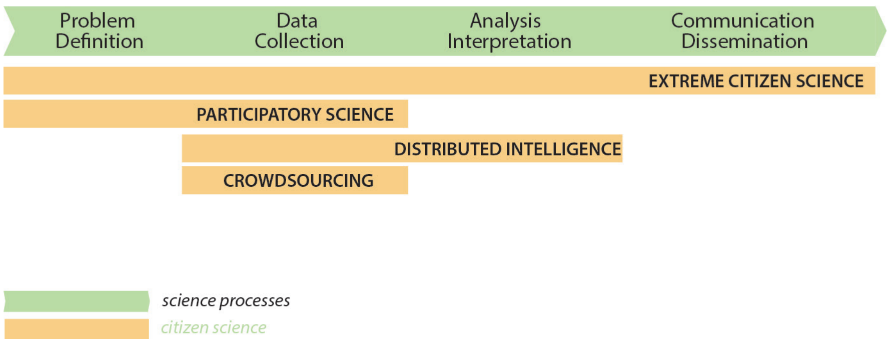

Figure 2 – *Levels of participation in citizen science*
Adapted from concepts in References [29]

The collaboration of citizens and scientists to address real-world research questions has grown a great deal in less than a decade[32]. Muki Hakley, a researcher on Geographical Information Science from ExCiteS, the University College London (UCL), Extreme Citizen Science, research group – focused on extreme citizen science projects and software – provides a suitably applicable classification framework to the variety of citizen science strands, from the classic view of citizen science, where participants are basically data collectors, as kinds of 'citizen sensors', to forms of extreme citizen science,

30 See Muki Haklay (2012).

31 See the *Green Paper on Citizen Science for Europe* (2013), available at https://ec.europa.eu/digital-single-market/en/news/green-paper-citizen-science-europe-towards-society-empowered-citizens-and-enhanced-research

32 According to an empirical study by Follett and Strezo (2015), the number of publications listed on both *Web of Science* and *Scopus* that acknowledge the use of citizen science data almost doubled from 2011 to 2014. The study shows that biology is, by far, the topic with the highest number of citizen science projects (327 out of a total of 456).

where citizens' participation is included in all phases of knowledge production. This variety is perhaps better understood when aligned with the different levels of citizens' participation in the scientific process and its stages, as proposed in Figure 2.

The underlying dynamic of many recent developments in citizen science is obviously boosted by the current digital revolution, which connects to the exponential build-up of digital platforms and applications, with a global reach. In *Smarter Citizens, Smarter State*, the American philosopher, Beth Noveck, sees the reach of scientific citizenship as being enormously amplified by what she calls the new *technologies of expertise*. The notion of 'citizen experts' (individual or collective) largely transcends the boundaries of traditional concepts of expertise, associated with academic credentials or with the professional careers of science and technology practitioners. As Noveck points out, the big data revolution brings with it the emergence of new forms of gathering; classifying; making large quantities of data, knowledge and expertise available and searchable; placing it in the hands of ordinary citizens, independent of their academic path. *ResearchGate*, *LinkedIn, Github* and *Stack Overflow* are among many well known examples of the exponential growth of Internet-enabled platforms and informal learning networks that make it possible to express, search, locate and use expertise with unprecedented speed and efficacy.

Like any other form of research and knowledge production, citizen science is subject to methodological constraints and bias; it must also respect the same legal and ethical constraints, and be subject to peer evaluation to ensure proper scientific outcomes and data quality. Unsurprisingly, scientists and citizen science practitioners do not agree on the value, usefulness and reach of citizen science activity[33].

[33] Burgess *et al.* (2017) have elicited these perceptions to explore the barriers to the acceptance of citizen science within the scientific community, particularly in the field of biology. Interestingly, the point where both scientists and citizen science project managers agreed was on the impact of citizen science in accomplishing education and increasing the public understanding of science. On the other side of the spectrum, as one would expect, the highest level of disagreement was on the answer to the question 'is citizen science a good way of accomplishing research?' – where less than 20% of scientists strongly agreed, in comparison to more than half of the citizen science project responses.

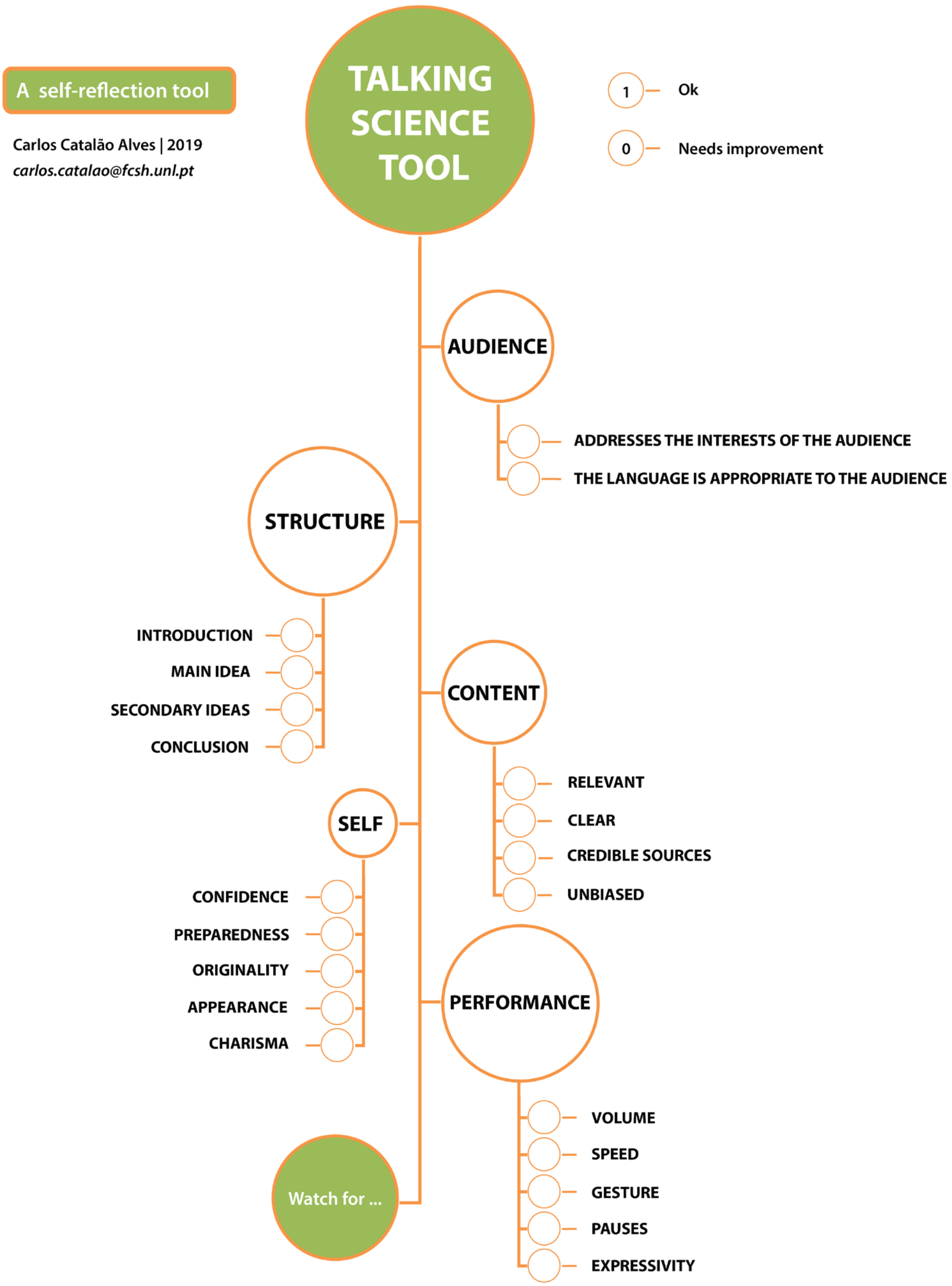

Figure 3 – *TST - A Talking Science Tool*

Although initially associated with research projects with large geographical reach and requiring huge volumes of data, more recently, citizen science has been turning to local contexts, sometimes with the stated intention to 'think global, act local'.

Community-based research and participatory science platforms have been building new forms of collaboration between scientists and citizens, into local community projects, as examples of the kind of 'situated, bottom-up practice that takes into account local needs, practices and culture'.[34]

7. Concluding remarks: Europe at the crossroads of science and society

According to the latest Eurobarometer, addressing responsible research and innovation, most Europeans agree that science has a positive impact on society, and that the more they are informed about scientific developments and achievements, the more they acknowledge and accept this belief. It is reassuring (and perhaps surprising) that more than two-thirds of European citizens agree that scientific research should be supported by governments even if it brings no obvious immediate benefits[35].

The European Commission has recently presented its new Horizon Europe framework (FP9) as the 'most ambitious Research and Innovation programme yet', calling for more openness, new research and innovation missions, a maximized innovation potential and a new generation of European partnerships.

These unparalleled opportunities and potential for research and innovation do not come without a measure of unease or risk of poorly designed developmental initiatives. Alongside the goals of a digitally-smart, zero-waste, low-carbon economy and society, there is also a realization that the rapid changes brought about by the exponential growth of digitalisation, robotics, Artificial Intelligence and big data analytics may well threaten competition and open up the field to undue influence on the market by a small number of highly profitable firms. It is clear that these research-led new technologies are profoundly changing the jobs market and the way in which people work, both in Europe and worldwide. Automation will increasingly impact many existing jobs, while at the same time creating new job opportunities.

From the outset, it has come as no surprise that there are signs of growing unease in some sectors of society, particularly among people negatively impacted by the fast pace of change. It needs to be commonly understood that this unease can only be tackled through informed citizenship, stronger engagement with science and innovation, and ultimately, increased participation by citizens in the scientific agenda setting, implementation and evaluation. The same Europeans, who perceive the impact of science and

[34] For an extensive view of extreme citizen science projects, see ExCiteS, the University College London (Department of Geography) research group, available at https://www.ucl.ac.uk/excites/projects

[35] Special Eurobarometer 401 (2013) Responsible Research and Innovation (RRI), Science and Technology. Available at http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_401_en.pdf

technology so positively, are also those who responded to the surveys (including those mentioned above) showing that public dialogue is needed when it comes to decisions being made in relation to science and technology. The new Horizon Europe/FP9 framework acknowledges this movement, with its mission to promote the openness of science, the democratization of access to scientific knowledge and data and, on a different level, to boost the practice of co-creation and co-design.

However, many advocates of public engagement – such as museums and science centres, teachers, science educators and science communicators – are concerned that the new Horizon programme does not go as far as it could in this regard[36]. There is a current perception that now, when scientists seem increasingly willing to address the societal impacts of their research, there must be scope to actively involve citizens in the scientific and innovation endeavour, and to build a more meaningful framework of relationships between science and society.

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3.
Ethics of Science and Technology
enhancing dialogue

Throughout this book, ethics is presented as being most needed for the progress of scientific research and technological innovation, acknowledging that 'progress' requires more than just advancing forwards, to reach for further knowledge and to develop new skills; it requires improvement in the well-being of humanity. Therefore, ethics is not assigned to play a role of establishing boundaries (as stressed before), but rather to build paths for individual flourishment and social development, through the contributions of scientific and technological advances. This also requires our respect for the two paramount ethical values: *human dignity,* or the recognition of the equal and absolute value of all human beings, at the personal level; and *social justice*, or the imperative of fair distribution of goods, at the communitarian level.

The partnership between ethics and science requires a trusting relationship, which will not occur if ethics is called upon, from outside the scientific realm, to evaluate and certify the outcome of a long research process. It would then be inexorably perceived as an outsider and, all too often, as an enemy. The dialogue between ethics and science cannot start at the last stage of a research project. Ethics has to be part of the process from the very beginning.

Scientists should call upon ethicists to help them in evaluating, from both a personal and a social perspective, the 'goodness' of the goals they are aiming to achieve, as well as the rightfulness of the means they employ, without fearing their advice; ethicists should try to understand the procedures which are being followed and the anticipated outcomes, recognizing that both, science and ethics, are the intellectual products of human beings. They never stand as alternative options, from which one preference must be chosen. This would imply that one is being singled out to the detriment of the other, thus deeply impoverishing the human spirit and our creative mind, and perhaps even amputating them.

It is by acknowledging and valuing the contribution of both science and ethics, for our own social development, that will ensure that their partnership will be constructed on firm foundations. Their trusting relationship will then be built and continuously reinforced throughout the entire process of research and innovation, *ab initio ad finem*. It is only within this framework that science and technology will serve the common good and, in doing so, will also fulfil their social responsibilities. Scientific research and technological innovation are recognized as ethical endeavours, overcoming particular, and often vested interests; in the right proportion, they can comply with their social responsibilities and be able to positively answer the expectations of a wider society. Otherwise, scientific and technological advances are potential sources of deeper divisions and inequalities between individuals, communities and states – as recent history has demonstrated.

The commitment of research to social responsibility entails the involvement of society, the participation of citizens in the decision-making process, this being achieved by integrating ethical considerations (as the voice of society) and fostering wide (and well informed) public debates.

This democratization of science is the key for effective public policies.

Maria do Céu Patrão Neves

Science and Technology Shaping the Future: Challenges and Responsibilities[1]

RODRIGO MARTINS[2] AND ELVIRA FORTUNATO[3]

Abstract

The objective of this chapter is to establish the future challenges capable of sustaining a harmonious development of science and technology that will shape our future. This implies commitments in relation to how to develop a more creative and innovative research environment, capable of serving multiple sectors, as well as the ethical responsibility raised by human discoveries and behaviour. To progress science and technology, we propose the *'metro station concept'*; cutting across different scientific and technological areas, where trans-disciplinary activity is promoted, together with concepts such as sustainability, responsibility and ethical values, as a way to further encourage regulation and rules for the future, based on scientific evidence.
Key words: Science and technology, future challenges; science responsibility and ethics

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1. Introduction

In recent years, science and technology have revolutionized our way of life, improving well-being and comfort for all mankind. The discovery of new materials, with unique features at the macro- and nano-levels, has played a significant part in this advancement. The possibility of producing materials, able to perform different functions and respond to external stimuli, will undoubtedly be of particular importance for the foreseeable future.

For instance, in additive manufacturing, materials will be designed and structured to perform specific operations and adapt to external conditions and variables, without the need for additional devices. In the future, we will see more and more efforts focused towards the production of completely original *intelligent materials,* able to perform different functions and to respond to external inputs, autonomously. They will be able to perform and to adapt themselves to any stimulus, without any need for electronics, also serving as interfaces to link humans to needs and promote innovation.

These intelligent materials should be able to meet application demands of multi-functionality and adaptability, dramatically reducing the complexity of systems, and making solutions simpler to implement. Consequently, these materials will enable many anticipated developments, promoting creativity and innovation across many different fields.

They will foster the transition over to an industrial society and into the information age, and will play a dominant role in economic and social development, transforming our daily lives; where the issues related to responsibility and ethics will become of great relevancy in a world where citizens will increasingly play a key role in defining the roads that scientists should follow, while ensuring comfort and welfare for all.

This will impact on our lives and on the ways in which science will need to be considered for years to come, cutting across multiple fields, including food, resources and energy shortage, pollution, climate change, overpopulation, poverty, disease and economic crisis.

They will be decisive in assisting the change from the traditional model of development, grounded in the consumption of colossal amounts of resources, to the sustainable management of our planet, where responsibility towards a better eco-sustainability will determine the planet's global future and so that of mankind.

In this chapter we will address the issues related to the science and technology challenges raised, and those to which we have to pay particular attention as regards responsibility and ethics, as the elements that not only bridge, but also fill in the gaps of our societal challenges.

2. Foundations of science and technology road maps and how to go beyond

The foundations of our development today are grounded in thematic areas, so-called silos, with a single purpose: '*to get the best that this area can give to us*'. These are the current routes of the driving forces of research in Europe as a whole, and in particular in the various different EU countries, surpassing even a European dimension. This leads to long-term specializations, which were required in the past; but today they will result in stagnation and reduced vision. The concept of silos is one which is fatally flawed and doomed to failure. We must change the attitudes involved, in order to raise the hopes for a better future, breaking the inequalities that exist within our society. This can be achieved by defining a new concept of 'mission'; targeting clear development objectives, which are key to opening up much-needed innovation to boost our future.

The *mission* should be a pursuit of a common goal that galvanizes an entire group of citizens, scientists, politicians and entrepreneurs to follow a strategic plan, to which they must contribute and whose impact must go well beyond the limits of our borders. That is, the mission should look at the whole (big) picture, and not to be a part or detail, and should clearly target a main, central commitment.

Here, the buzzwords are such as:

– *multidisciplinary* (to get every discipline that is needed to develop or produce something and join them together) – have to go further, allowing us to open up the horizons of our curiosity;
– *interdisciplinary* (the interception points of the different disciplines/areas, and how they can enhance and foster the objectives sought) – should be increasingly promoted, as the key to horizontal developments, cross-cutting fields and synergies, as required to foster progress.

To these science buzzwords guidelines, others have been added, such as:

– *pilot lines* (elements associated with a specific topic in order to greatly contribute to its development for market applications) – which typically serve a short-term strategy and act without leverage to ensure continuity.

The majority are clearly doomed to failure; the impact is an inefficient exploitation of resources, once they focus on a thematic area that with time, will be exhausted or, will create increasingly complex products. Without connecting them to regions, as magnets for medium- and long-term development strategy, it is like building a house of cards which, sooner or later, will collapse. On the other hand, to be strategic, the pilots cannot operate in one direction. We must promote diversity and connect pilots to original concepts associated to horizontal structures; cross-cutting different fields of expertise and applications, thus impacting what a mission should and must be:

– *only in this way will the pilots be consistent* – once they are flexible and capable of being moulded to prospective needs;

– *flagships* (excellent tools for the development of creativity) – but if they are not linked to applications, they will not contribute to the roots of our future. In this case, the horizon of the application needs to go further, and aim to explore an idea, and see how it can bear fruit and be applied.

We must explore the investments carried out, in terms of better science and better technology:

– *Innovative Knowledge Communities* (KICs) – their concept is excellent because it aggregates the three fundamental pillars for sustainable development – education, research and industry – but which lack a clear mission and a target to promote a focused strategy for the future.

It would be a mistake to insist on silos and only remember at the final stage of the value chain that creativity provides the certainty of a better future. On the other hand, education cannot be seen as an affectation, but as a dominant element to educate a new generation well beyond existing university levels. Otherwise we are just replicating something that already exists.

As we progress more and more, we feel the need to define a new development model to boost science and technology, whilst remembering the strength and pressure that investors, developers and researchers have to sustain, when responsibility and ethics are taken into consideration.

3. Challenges to overcome

To overcome the current limitations to achieving creative approaches to applications, and to ensure broad and consistent innovation, reducing complexity, missions, involving the trans-disciplinary culture (encouraging experts from different disciplines to think co-operatively about the best solutions needed to ensure the comfort and welfare of citizens), should target the creation of new knowledge (fundamental/ground-breaking research) and the creation of value (innovation, whose main source must be the creativity). Here, the creation of value should be obtained by a closer and continuous observation of research achievements, and the flexibility/possibility to reinforce them towards eco-sustainable products, where the ethics and responsibility issues have to be fully explored. By doing so, we may positively answer such questions as:

– How might one establish real communication channels among fields/areas to address the mission challenges?
– What can be done to avoid original ideas and innovative results becoming diffused and eventually fading in a maze of dazzling opportunities?

To address these questions, it is important to understand what we consider to be a mission and what examples we can take from the past in order to sustain the challenges we have to address.

3.1. *Missions: examples from the past*

By definition, the mission must aim to obtain a result, for which it is necessary to bring together various skills to work in unison. The following are good examples of past missions: *The period of the Portuguese discoveries*: Here, the target was to reach the Indies, for which they needed to build a ship that was relatively light and fast, enabling rapid navigation and which was flexible enough to 'negotiate' the heavy seas and destructive gales. For this they mobilized the combined efforts of the best cartographers, carpenters, locksmiths, astrologers, etc. – the great engineers of their time! Obviously, associated with this, they also had a whole set of supporting elements, starting with the nutritional component, and ensuring that the sailors were sustained on their journey.

The American and Soviet Union lunar mission – with different perspective views: For the Americans, the mission was viewed as the way to design and develop an entire industry. For the Soviets, the mission was mainly to demonstrate strength, capacity and competence, linked more to a design and demonstration of power.

For the Americans, it was a 'wake-up call'; joining the best of manufacturing and designing creativity, with amazing innovations in the areas of engineering (such as mechanics, electronics, telecommunications, food science and construction), coupled with design, architecture, physics and medicine. With their newborn areas of knowledge, not only to reach the target of going to the moon itself, but also to maximize the exploitation of all concepts and ideas, from which many other sectors would benefit, not just aerospace engineering! The great result of all this was clear industrial progress (such as the advancement of complementary metal oxide semiconductor/CMOS technology, or progress in the development of solar cells), *because the work was not only innovative, but also created new fields of application and knowledge*.

The space programme was critical for launching the competition between the Soviet and American blocs and their allies: the Soviets, with their primacy of power demonstrated (although innovative, as with their landing capsules), never explored the associated industrial creative potential! For the Americans, it felt like it was time for change, and with it, the space programme produced new creative industries which boosted economic growth, as well as job creation, much of it far beyond America, with a particularly strong impact in Europe and Japan. As a result, we have the National Aeronautics and Space Administration (NASA), which continues to be an engine of creativity and innovation, and which Europe translated into a much less consistent and effective model with the *European Space Agency* (ESA) and other partnerships; the big mistake made by the Europeans was to *enclose their activities in thematic silos, acting almost as islands or fortifications, whose primary goal was to demonstrate their leadership skills*!

The vertical alignment through thematic topics must be reviewed, and it understood that the model of development and innovation is not linear. Moreover, we should avoid errors from the past: mission concept should not be used as a fetish or a logo to keep everything the same, but as a lever to explore a strategy based on new concepts that fit citizens' needs, welfare and comfort, the great providers of the sustainable development of the future.

3.2. *What we can expect from the missions of the future*

If, in the past, such missions acted as designs driven by enlightenment, current and future missions must also aim to satisfy the needs, hopes and aspirations of the citizen, in terms of sustainable growth, jobs, comfort and quality of life, well-being and security. They clearly should be supported by a trans-disciplinary concept that brings, besides the known drivers from academia, industry and research institutes, the active involvement of the citizen. We can no longer implement or develop anything without the inclusion of society's aspirations, where scientific responsibility and ethics will be relevant issues to be considered when establishing new missions and rules to govern the science and technology.

It is as if we are at the rebirth of something that is going to enable us to achieve our targets; yet now, in addition to the scientific, technical and political promoters, we must be aware of the societal surroundings and know that there will be global consequences. For this, we must open up the mission to all areas and make them trans-disciplinary, trans-synergetic, inclusive and mutually reinforced.

The phrase that encapsulates this situation was long spoken by Archimedes: '*Give me a lever and I will lift the world*!' In this context, the lever will be the means that we have, and the world, the overall objective of our mission.

3.3. *The 'metro station concept'*

As we previously stated, the missions of the future should aim to exploit the results of research towards better applications, translated in knowledge, technology or innovative products, fully deployed from simple/non-complex systems able to serve the needs and comforts of end-users. For this new paradigm, we should properly weight the *bottom-up* and *top down approaches*, once the goal is to promote creativity for practical ends, always sustained by the best science and technology practices.

As we approach a trans-disciplinary objective able to serve multi-sectors, to foster cross-cutting development in dynamic systems, where the reference is always moving, we should seek the best sector where the developments reached so far, can be used. This means that we do not need to wait until the end of a development phase to see where it is most advantageous to exploit it. This means that we can change the field of a certain application before the programmed target. By doing so, we may reduce the timeline for the exploitation of an idea or product/system that we intend to develop, and define the sector which is most advantageous, most of the time avoiding complexity and also reducing the costs of exploitation. This is what we call the *'metro station concept'*, where the objective is to foster cross-cutting development in a dynamic system, where the reference is always moving and so, we should seek the best sector where the developments achieved so far, can be used. This means that we do not need to wait until the end of a development to decide where it is most advantageous to exploit it.

Likewise, *as in the metro, we have the lines* (representing fields of development) and the stations (the hubs to evaluate progress and stages of development with a multitude of competences) and *in each station we can change the lines*. That is, we can see where the development so far best suits the knowledge or market needs.

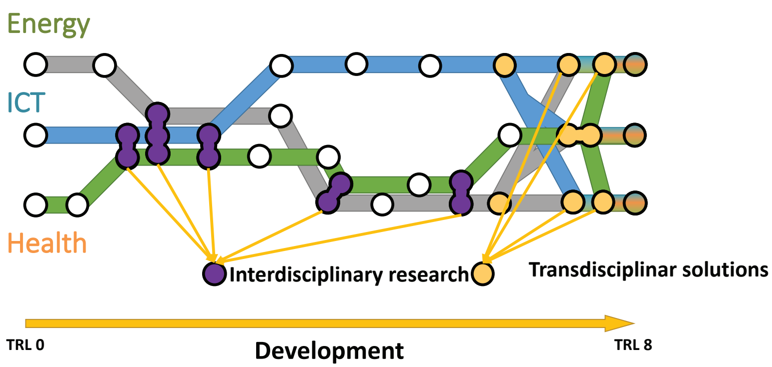

Figure 1 – Sketch of the *'metro station concept'* involving, as an example, three thematic areas: Energy, Information and Communication Technologies (ICT) and Health. Here, we emphasise hubs with a multitude concept, translated in interdisciplinary research and the final target applications, able to satisfy citizens, called trans-disciplinary solutions. Besides that, in abscissa we plot the different Technology Readiness Levels (TRL), going from ideas (TRL0) to industry market applications: product/system completed and qualified through test and demonstration (TRL8).

3.4. *Potential challenge missions to shape the future*

As the missions gain different areas of knowledge, archetypes and profiles, they should be based on the logic of re-engineering: *say what you need, and I'll say what I need to do*! That's exactly what the mission should be; but to do so, it must be clear and objective, looking always for the bigger picture. The alternative is to be conventional and try to make more of the same, without fostering the desired impact. We will list some simple examples:

– *Water*: We need to control and ensure the right quality of water for all! What do we need to do?

– *Oceans*: How might we exploit the riches there and how might we preserve them? How can we obtain energy efficiently from the sea? What do we need to do?
– *Space*: How might we interconnect and interface with space? What materials can survive on the Earth and in a vacuum? What are the transporters that we need for the future? What should they contain? How can we make the systems clearly localizable and comfortable? What do we need to do to achieve this?
– *Food*: How can we ensure a sustainable and safe food supply without waste? How can we ensure the food supply for an increasing population? What do we need to do?
– *Health for all*: How can we ensure a sustainable value chain to guarantee the prevention of illness, and ensure safety and welfare? How can we ensure quick and efficient diagnosis and screening? How might we maintain a healthy and pleasant indoor living and working environment? How might we promote the concept of controlled drugs release?
– *Mobile Smart Interfaces*: How might we ensure intelligence and autonomy to intercommunicate with human interfaces (smart robots together with artificial intelligence?), for future data processing? How can we ensure that future products and systems are reusable, recyclable and with positive impacts on both the environment and human life? How might we ensure a reduction in the use of bulk resources and an enhancement in the durability of smart materials?
– *Environment and Sustainable Energy*: Look at energy, not only as a decentralized energy source to boost our development, but also address the need to reinforce the comforts associated with the Internet of Things, for which integrating mobile platforms are the future driving force of our development, as we think in terms of energy autonomous systems. We should focus our attention towards the development of ultra-low power systems and how to collect the energy of the Cloud and, therefore, how to move to a system with integrated super capacitors, where the concept of self-harvesting integrated energy must be rethought on the basis of sustainable energy for everyone. Moreover, we have to consider how to enhance solar cell efficiency, exploiting eco-friendly materials and quantum concepts: to make renewables really economically competitive in the future, irrespective of social costs. This is an area that should be kept open to serve all, and which could and should be linked to all missions. We have to increase the autonomy and durability of batteries which are still very limited in both computers and cars, and organize the recycling chain to recover the critical raw materials to make battery sustainable as an energy source in the long term. Moreover, we have to promote scaling up the size of windmills in order to make them energy efficient, whilst also improving materials to reduce windmill maintenance costs. Beyond this, we have to imbue the solar thermal industry

with the advantages of it being a dispatchable energy, making it possible to adapt energy to demand.

– *Manufacturing Industry of the Future*: What kind of technologies should be used? How might we make them autonomous and inclusive? How will it be possible to improve the quality of 3D-printing materials, or for additive manufacturing to be used directly in industrial products? How will we go from one technology from 1d to 5d? How *might we live with the robotization of our industry* and how might we regulate it? How can big data and tradability help co-design, co-development, co-manufacturing, co-maintenance, and co-recycling?
– *Sustainable Agriculture and Nature*: How might we ensure sustainable agriculture? How might we exploit forest resources for other types of applications beyond the conventional? How might they be made safer and inclusive? We need to do this to ensure a better planet. - *Future Chemistry*: As the industry that gives more resources to Europe, how might we progress towards a green and sustainable industry? How might we move from traditional products derived from oil and over to an industry which is more bio-sustainable? How can REACH regulation (*Registration*, Evaluation, Authorisation and Restriction of Chemicals – an EU *regulation*) be a tool to encourage sustainable products and companies? The list of substances that can now be used to formulate products is becoming increasingly limited, and the cost of regulating the use of a product is huge, limiting implementation. This effect also impacts on nanoproducts, where a huge investment has been made to increase performance. What is the solution? Is it to produce outside Europe, or to develop more sustainable products? How might we do this? Should we be minimizing the use of fine chemicals? Or should we be controlling the release of additives?
– *Climate Changes*: How will this impact on our changing world and what steps might be taken to try to reverse the effects?

These are just some specific examples that need concerted efforts and actions, taken not by singular units or groups, but requiring the full engagement of all, in global terms.

3.5. *Adapt new breakthrough models for shaping the missions of the future*

We should adopt a new model that inverts the current paradigm (i.e. instead of allocating resources for R&D and then determining how to use them, reverse the process; find great challenges that mobilize all areas and put resources into these developments). As possible examples we have:

– *The airplane of the future* – which should succeed Boeing- *The European defence system* – in the light of the potential break-up of NATO- *The ocean* – balancing exploitation of resources with environmental preservation

– *The control of climate change* – through technological solutions for removing CO_2 from the atmosphere, etc.

Such challenges as these should utilize experts with known skills, or we should identify complementary centres able to meet the needs. The advantage of this model is that it boosts the disruptive evolution, targeting the clear needs of both end-users and the market. The current model favours only incremental development (with much lower results). Therefore, the mission to shape the future must be:

- *Inclusive*. It should explore what exists to the full extent of its potential, taking advantage of the level of development already achieved. It is time to take advantage of what exists, in order to benefit from what was created and provided. Obviously, this will shorten time to market and allow for better exploitation of resources, and input into research targeting innovation, whilst reviving future challenges concerning key areas of development.
- *Interconnective*. Connecting the different routes of development and knowledge, in order to obtain concrete objectives, allowing even 'change and readjustment' of the development pursuit: The *'metro station concept'* should cover all spectrums of activity, fully open to citizen creativity, to create and promote their ideas.
- *Trans-synergistic*. Exploring the synergies dispersed in different areas or groups of knowing/technology, providing a better and more efficient use of them.
- *Trans-comprehensive*. To promote cross-cutting practices and ideas from different areas, including social and human arenas, so that the development of the missions work in harmony with what citizens want and need for their well-being, comfort and safety.
- *Horizontally modelled*. Connecting dispersed interests in different areas of the '*stations of innovation*' towards applications in: energy; information and communication technologies; transportation; education; environment and the sea; security; and health, for example; and where nano-manufacturability is a lever for all the anticipated transformations.
- *Objective*. The mission should focus on a final and concrete product, and not simply be the sum of scattered ideas.

4. Science responsibility and ethics

The demands detailed above are rooted in solid and robust foundations, based on original work, which is highly relevant for end-users. Moreover, it should include the correct means of anticipating the social impact of research results on policy changes, academic excellence and public knowledge (the idea of science for society, or research on behalf of the people); foresight knowledge – which is required for assuming responsibility for the social consequences of science.

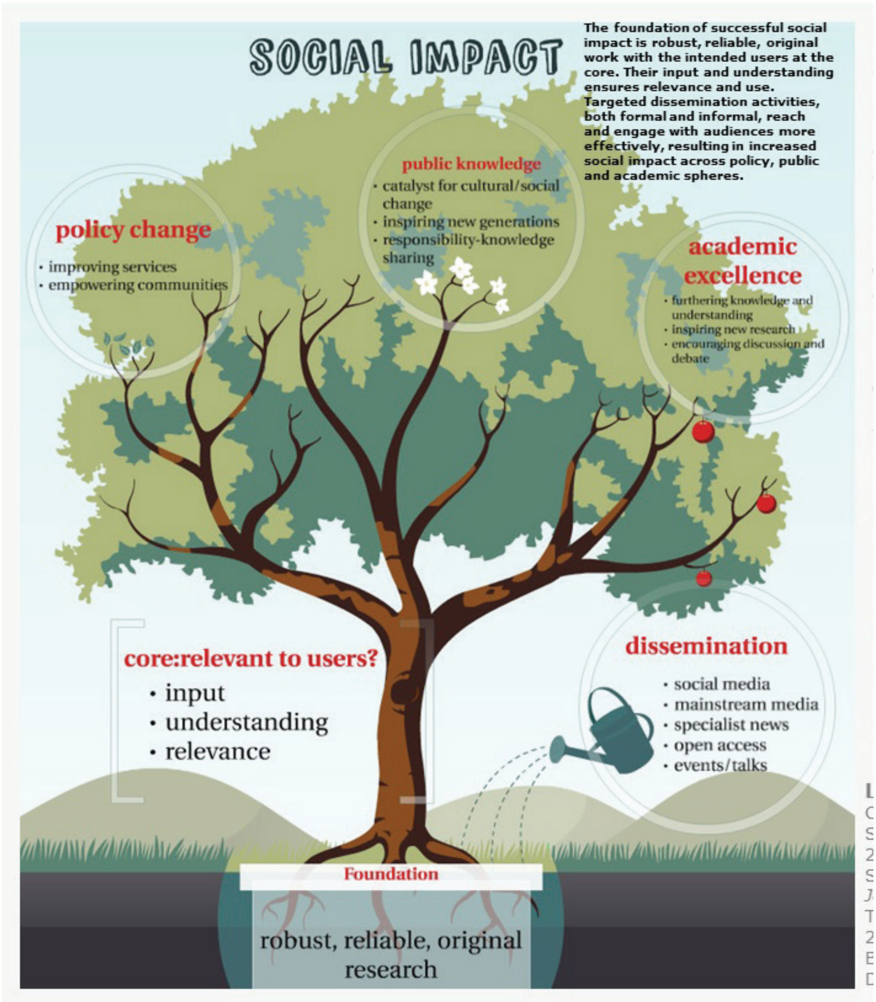

Figure 2 – Sketch aiming to explain the basis and the arms of science; starting with the roots of science and advancing to its core and dissemination drivers (simultaneously the trunk and the irrigation system of science); towards the branches of the tree and its fruits, which are policy change; public knowledge and academic excellence: taken from *https://meganbeech.wordpress.com/tag/social-impact/*.

Evolving differently may do much damage to science and technology. It is difficult and sometimes impossible to predict the course of science, driven by the creativity and inventions of researchers, who are, in the first place, also citizens. Indeed, science and technology pursue practical ambitions impacting strongly on our model of society, bringing enormous gains, but also bringing risks, connected to main drivers, and unexpected side-effects.

It is expected that researchers who become scientists may look further than ordinary people with regard to the consequences which might ensue from their discoveries and inventions. This enhanced knowledge burdens scientists with a particular responsibility that it is more demanding than the one shared by the general public. Meanwhile, some scientists and scholars believe that social responsibility for practical scientific output lies exclusively with politics. However, we believe that it is the responsibility of science to produce reliable knowledge, while politics needs to tell society the social uses to which such knowledge can be put. This is critical in order to avoid misunderstandings with the public, implying that science is driven mainly by economic and political forces, which primarily seek to make money and ensure power. This emphasizes responsibility for the process of acquiring reliable knowledge and on the impact of science on society, encouraging institutions to share responsibility for what their scientists are doing. Moreover, the proper dissemination of scientific results requires reflection and proper judgement by experts who are able to link them to citizens. Those key individuals include press officers and science journalists, who are needed to bridge the gap between the science clusters and the public. By doing so, we expect to prevent information from being contaminated by forgery and fantasy.

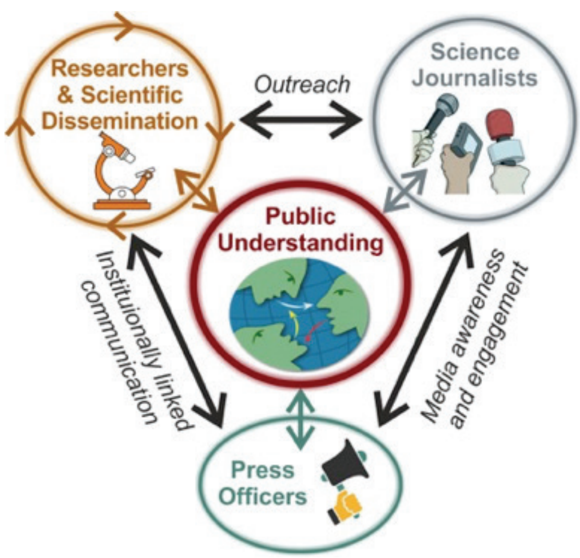

Figure 3 – Sketch of the interactions between the three pillars to explain properly scientific achievements to the public; from *Könneker, C.; Lugger, B. 'Public Science 2.0 – Back to the Future'. Science (2013).*

This raises another relevant issue related to epistemic responsibility. This means responsibility for the epistemic standards and practices that are brought to bear on the research. One important element is to ensure that no fraud occurs, and data are not manipulated or fabricated. Here it is important to separate fake news from any side-effects connected to experimental errors due to flawed experimental set up, methodological blunder or inappropriate statistical analysis. This requires the establishment of proper guidance rules as to how and when data should be shared and exploited with citizens, and if society rules and environmental impacts prevail upon them. Research achievements, which are to be exploited by industry and used by citizens, should fulfil ethical standards. For instance, the realigning of the drug industry's interests with those of patients, and analysing efforts to bring ethical standards to the globalized food industry; medical technology is another field in which moral demands feature prominently.

Of course, we still have plenty space for change. Reactions from the laboratory benches provide an important test-bed for judging the viability of empowering rules, conducts and behaviours. Indeed *'science isn't finished until it is communicated'* (Sir Sir Mark Walport, UK Government Chief Scientific Advisor).

Figure 4 – Sketch of the ethics rules that science and technology should follow.

5. Conclusions

We have identified the main scientific and technological challenges which need to be overcome, translated by our future research missions, and the ability to fill in all aspects of the value chain, from ideas to applications, where creativity and innovation are the driving concepts to be pursued. To undertake these commitments, we have proposed the *'metro station concept'*, as a way to better exploit research results, and to further speed their exploitation towards knowledge and market applications.

Moreover, the ambition to create more wealth, and human expectations for a better life, may circumvent and simultaneously promote anxiety, having available discoveries and inventions on hand to bring comfort and welfare to the citizens, but also generating a lack of public confidence in science concerning their practical ends.

These considerations bring out the ambivalent role of trust in science. On the one hand, science is in need of public trust in order to thrive, and needs to struggle to regain such public trust. On the other hand, science is thought to embody a sceptical spirit. Viewed in this way, public mistrust with respect to science should be appreciated. But large sections of the scientific community, and the general public, feel that critics, such as climate-change deniers or vaccination sceptics, have exceeded their goal by combating truthful and important insights. Lack of trust has become harmful and begins to hurt society. Accordingly, the problem is finding the right balance between trust and distrust, and, given the problematic fields mentioned, exploring effective ways in which to regain public trust. Those are critical challenges to be overcome if we really wish to shape a harmonious future.

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Respect and protection, the community of researchers, and the good of humanity

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Abstract

The ethics of scientific research highlight crucial responsibilities and obligations concerning respect for, and protection of, humans and other living beings participating in it; the idea of a common enterprise based on commitment to truth, methodological rigour and impartiality, and the line which should not be crossed in order to prevent science from becoming a threat to human dignity or the environment. Building on principles, rules and criteria enshrined in many international documents over the last few decades, it is possible to address fundamental questions, which are still open to debate and at the crossroads of ethics and society. Ethics of scientific research continue to play a decisive role with regard to the many inequalities and asymmetries which could potentially pave the way to new forms of discrimination or even exploitation. Building a global 'community' of science implies fostering access to the results of research, which should not remain a responsibility (or a privilege) just for the few. If we adopt the same perspective, the concept of 'sharing' also needs to be broadened, addressing capacity-building and inclusion, for active participation in producing scientific and technological advancements for the good of humanity.

Keywords: Ethics of research, inequality, minors, openness, sharing.

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Ethical debates, triggered by the development of science and technology, refer to both the means and the ends, in the broad perspective of interactions between humans, other living beings, and the environment. The set of headings identified for the ethics assessment and considered as being mandatory within the Horizon 2020 Framework provides an illustrative example: human embryos/fetuses; humans; human cells/tissues; protection of personal data; animals; third countries (in order to avoid risks for individuals taking part in the research and to consider benefit-sharing actions); environment; dual-use; misuse. A research project may result in critical or simply unacceptable inspection of the means (for example, the use of coercion against other human beings), of the ends (something that we must not do, even if we had the technical ability to realize it: such as human reproductive cloning), or both. Ethical issues "related to medicine, life sciences and associated technologies as applied to human beings' necessarily involve their 'social, legal and environmental dimensions'.[2] A text, which long ago accompanied a spectacular achievement in the history of science, may help us to focus on three essential aspects of this interconnection.

In 1798, Edward Jenner published his *Inquiry into the Causes and Effects of the Variolae Vaccinae*. In the very last paragraph of his text, he summarized the method, the awareness, and the goal that had inspired his scientific commitment and his work as a physician: 'Thus far have I proceeded in an inquiry, founded, as it must appear, on the basis of experiment; in which, however, conjecture has been occasionally admitted in order to present to persons well situated for such discussions, objects for a more minute investigation. In the mean time I shall myself continue to prosecute this inquiry, encouraged by the hope of its becoming essentially beneficial to mankind'.[3] The three points highlighted by Jenner remain crucial: experiments; discussions and further investigation on conjectures, involving those who are 'well situated' for them; and benefits for humanity. Looking at the most debated issues that inspired both 'soft' and 'hard' law instruments, particularly over these last few decades, it is easy to conclude that much has been done to boost *respect* and *protection* of human subjects who are participating in scientific research, to spell out the idea of a *community* of researchers, and to define content and limits of what can be considered *good for humanity*. Against this background, institutions and experts, policy makers and public opinion are all called upon to address some fundamental questions, which are still open to debate, and which are at the crossroads of ethics and society.

[2] This is the scope addressed by the Universal Declaration on Bioethics and Human Rights adopted in 2005 by the General Conference of UNESCO (see art. 1).

[3] E. Jenner, *An Inquiry into the Causes and Effects of the Variolae Vaccinae,* London, Sampson Low, 1798, pp. 74-75.

Never "merely as a means"

Starting with the *Nuremberg Code*, many normative instruments have been adopted to strengthen and continually update the principles and criteria established as an insurmountable bulwark against the risk of repeating the crimes perpetrated by the Nazi doctors, or of infringing Kant's categorical imperative not to treat humanity 'merely as a means'. Among many other influential documents, these include the Declaration of Helsinki (as last amended in Fortaleza in October 2013), the Oviedo Convention (chapter five on scientific research), and the new Ethical Guidelines (issued by the Council for International Organizations of Medical Sciences (CIOMS) in 2016). The principle of free and informed consent has been increasingly developed, and ever more detailed obligations have been introduced, to ensure the protection of vulnerable subjects. With specific regard to minors, Article 32 of the Regulation (EU) 536/2014 on clinical trials on medicinal products for human use, summarizes and imposes a long list of very strict conditions, which are *all* to be met in order for a clinical trial to be conducted. More than two hundred years of scientific research has not passed in vain: a hypothetical review of Jenner's procedure, carried out according to the rules of a 21st century Research Ethics Committee, would end in a rejection, if not with some more serious consequences for Jenner himself.[4] However, this is not to say that all of the problems and issues involved with such matters have been resolved.

Controversies concerning double standard practices have long been raising fundamental issues of global justice.[5] As to the concept of 'inducement' and *improper* inducement, the International Bioethics Committee of UNESCO, in its Report on the

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4 See, as an example of such hypothetical review, H. Davies, *Ethical Reflections on Edward Jenner's Experimental Treatment*, in 'Journal of Medical Ethics' 33(2007), n. 3, pp. 174-176. I have to thank Carlo Petrini, of the Italian Istituto Superiore di Sanità, for drawing my attention to this point, on the occasion of a round table on informed consent, which took place on 12 November 2018 at LUMSA, Rome.

5 As it is well known, some of the harshest debates referred to wealthy countries simply packing up and leaving after sponsoring research in resource-poor countries, with no resulting health benefits shared with the latter, research 'that could not – for ethical reasons – be conducted in an industrialized country, but is carried out in a developing country', the mechanisms 'for protecting rights and welfare of human subjects', wherever research is conducted (R. Macklin, *Double Standards in Medical Research in Developing Countries*, Cambridge, Cambridge University Press, 2014, pp. 2-3). Suffice it to mention the controversy on the use of placebo. One of the most debated cases was that of the trials carried out to prevent the vertical transmission of HIV infection in the 1990s, 'despite the fact that zidovudine has already been clearly shown to cut the rate of vertical transmission greatly […]' (M. Angell, *The Ethics of Clinical Research in the Third World*, in 'The New England Journal of Medicine', 337[1997], n. 12, p. 847).

Principle of sharing of benefits, finalized in 2015,[6] highlighted – along with the nature and seriousness of possible risks related to participation, and inappropriate information on the possible benefits – the impact of an offer 'on the decision making process of the subject', underlining that what 'appears as an autonomous decision given by the subjects may be caused by the circumstances that they face'.[7] Looking, in particular, at the conditions set out in many texts with regard to minors, it is also easy to acknowledge a further challenge. According to the EU Regulation, benefits should be expected on scientific grounds, either directly for the minor concerned, or for the population that he or she represents. In the latter case, however, the project for a clinical trial can be approved provided that not only do prospective benefits outweigh the risks and burdens involved, but that such risks and burdens be *minimal* 'in comparison with the standard treatment of the minor's condition'.[8] Apart from usual objections concerning the vagueness and indeterminacy of the minimal risk standard, and the difficulty to define it 'by comparing the probability and magnitude of anticipated harms with the probability and magnitude of harms ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests'',[9] we remain confronted by two questions. A minimal (additional) risk and burden is, however, more than zero. So, once we acknowledge that the participation of children and adolescents 'is indispensable for research into diseases of childhood and conditions to which they are particularly susceptible',[10] *who* is going to accept such participation as a reasonable proposition for their own children? And *why*? The EU Regulation prohibits 'incentives or financial inducements' beyond

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6 The concept of improper inducement is referred to in Article 15 of the Universal Declaration on Bioethics and Human Rights adopted in 2005 by the General Conference, which concerns exactly the sharing of benefits: 'Benefits should not constitute improper inducements to participate in research'.

7 Report of the IBC on the Principle of the Sharing of Benefits, §§ 18-21. Available at: http://unesdoc.unesco.org/images/0023/002332/233230E.pdf. Accessed on 15 December 2018.

8 See also, with reference to individuals incapable of giving informed consent, the Declaration of Helsinki, as last amended in 2013 (§ 28) and the Oviedo Convention (§ 17). CIOMS Guidelines issued in 2016 leave the possibility open that 'a minor increase above minimal risk' be permitted by a research ethics committee when the 'social value' at stake 'is compelling, and these studies cannot be conducted in adults' (CIOMS [Council for International Organizations of Medical Sciences], International Ethical Guidelines for Health-related Research Involving Humans. Fourth Edition, Geneva 2016, p. 65).

9 *Ibid.*, p. 12. CIOMS Guidelines highlight the obligation for research ethics committees to be careful 'not to make such comparisons in ways that permit participants or groups of participants from being exposed to greater risks in research merely because they are poor, members of disadvantaged groups or because their environment exposes them to greater risks in their daily lives (for example, poor road safety). Research ethics committees must be similarly vigilant about not permitting greater research risks in populations of patients who routinely undergo risky treatments or diagnostic procedures (for example, cancer patients)' (*ibidem*).

10 *Ibid.*, p. 66.

the threshold of 'compensation for expenses and loss of earnings directly related to the participation in the clinical trial'. It is essential to prevent the many facets of inequality from turning into conditions of special, persistent vulnerability. How is this prohibition to be applied, so as to avoid misunderstandings and conflicts of interpretation?

The *Nuremberg Code* highlighted the duty to keep watch over 'the intervention of any element of force, fraud, deceit, duress, over-reaching or other ulterior form of constraint or coercion'. The ethics of scientific research have indeed been powerful drivers for boosting cultural and social awareness of the concrete obligations which exist regarding dignity, rights and fundamental freedoms of individuals, and also creating impacts which reach far beyond the biomedical domain. It can be expected that such matters will remain at the very forefront of research considerations, in order to recognize and prevent the many risks related to asymmetries of information and knowledge, resources, life conditions and power.

Research integrity and openness

Respect for and protection of everyone's physical and mental integrity is a premise for all activities in the field of biomedicine. At the same time, scientific research is widely acknowledged as a 'common enterprise', which 'draws on the work of the community of researchers'.[11] This is why the 'discussions' envisaged by Jenner, in order to turn conjectures into solid knowledge or to simply dismiss them, also evoke the issue of *research* integrity, which 'calls upon an appreciation for truth and objectivity, a commitment with rigor and impartiality, in an honest attitude on all sides of professional activity – factors upon which the society's trust in science is founded. That is, 'scientific integrity' is defined through the valuation of a set of virtues, established as duties'.[12] Fabrication, falsification, or plagiarism are examples of misconduct, which are obviously incompatible with this kind of integrity. The scope of the concept is, however, much broader than that: the virtue/duty of transparency in data management is to understand together with the commitment to ensuring that access to data be 'as open as possible, as closed as necessary'; publication and dissemination are also a testing ground, including

[11] ALLEA (All European Academies), The European Code of Conduct for Research Integrity. Revised Edition, Berlin 2017, p. 3.

[12] M. Patrão Neves, *On (scientific) integrity: conceptual clarification*, in 'Medicine, Health Care and Philosophy', 21(2018), n. 2, p. 185.

'communication to the general public and in traditional and social media' and considering negative results 'to be as valid as positive findings' for them.[13]

These observations about openness and dissemination help to highlight a crucial challenge. The ethics of knowledge, including scientific knowledge, entail the question regarding its meaning as a 'good' for the community of researchers and society as a whole, about the way we understand, share, and promote it as an essential component of our vision of a *'good life'* lived with and for others, in just institutions'.[14] It is impossible to consider shaping the institutions of science and shaping the institutions of public, democratic life as two completely unrelated issues. What are, for example, the factors that can make closing free access to some data *necessary*? Respect for privacy or commercial use? What kind of 'community' are we talking about, when the boost to competition tends to trump the need for inclusive co-operation or narrow its scope?

UNESCO has recently revised the Recommendation on Science and Scientific Researchers of 1974. The commitment 'to promote access to research results and engage in the sharing of scientific data between researchers, and to policy-makers, and to the public wherever possible' is highlighted among 'the recommended responsibilities and rights' of scientific researchers. Member States, on their part, 'should recognize the international dimension' of this endeavour, and are called on to do 'everything possible to help scientific researchers', including 'ensuring equal access to science and the knowledge derived from it as not only a social and ethical requirement for human development, but also as essential for realizing the full potential of scientific communities worldwide'. At the same time, however, the researchers' responsibilities have to be met together with 'being mindful of existing rights' and States have to understand and implement their role 'ensuring that contributions to scientific knowledge are appropriately credited, and balancing between protection of intellectual property rights and the open access and sharing of knowledge […]'. Scientific research is crucial 'for the survival and well-being of humankind as a whole' and Member States should 'establish and facilitate mechanisms for collaborative open science and facilitate sharing of scientific knowledge'. However, they have an obligation to ensure – that which researchers are expected to be mindful of – that 'other rights' must be respected.[15]

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[13] The European Code of Conduct for Research Integrity, pp. 6-7. As to publications, in particular, authors must 'acknowledge important work and intellectual contributions of others, including collaborators, assistants, and funders, who have influenced the reported research in appropriate form, and cite related work correctly' (p. 7).

[14] P. Ricouer, *Oneself as Another*, Chicago and London, The University of Chicago Press, 1992, p. 172.

[15] UNESCO, Recommendation on Science and Scientific Researchers, §§ 16, 18, 19, 21. Available at: http://portal.unesco.org/en/ev.php-URL_ID=49455&URL_DO=DO_TOPIC&URL_SECTION=201.html. Accessed on 17 December 2018.

Joseph Stiglitz, in an article published in 1999, affirmed that the knowledge of a mathematical theorem clearly satisfies the two attributes for a good to be considered 'public' (nonrivalrous consumption and nonexcludability): 'If I teach you the theorem, I continue to enjoy the knowledge of the theorem at the same time that you do. By the same token, once I publish the theorem, anyone can enjoy the theorem. No one can be excluded'.[16] There is no question about non-rivalry: the amount of the good available is not reduced through sharing. On the contrary, sharing is a fundamental tool to make the good grow, to realize the full potential of scientific communities worldwide. It is also easy to acknowledge that science is intrinsically *global* as to its scope: 'A mathematical theorem is as true in Russia as it is in the United States, in Africa as it is in Australia'.[17] Things are more difficult and complex as to the requisite of non-excludability. Some forms of knowledge can be made excludable by the use of 'trade secrets'. The patent system, while imposing upon inventors the obligation to disclose the details of their invention in the patent application, provides them with the exclusive right to enjoy the *fruits* of their innovative activity over a limited period. In principle, appropriation of the returns to some forms of knowledge is not to be confused with preventing people from having access to it, but this is why 'knowledge is often thought of as an *impure* public good'.[18]

In order to think of scientific research in terms of openness, co-operation and inclusion, and to emphasize the role of knowledge as an essential driver for speeding up the development of domestic and international community, three points are worth closer examination. The first one concerns the costs of access to the essential instruments of scientific discussion, starting with the issues of open access and policies adopted by publishers of the most reputable and influential journals. Unfortunately, it is not true that anyone can enjoy a theorem as soon as it is published. Padlocks often appear on the Internet and, to date, too little has been done towards *balancing* the different interests at stake in a satisfactory way. A second difficult 'balancing' act refers to the consequences of contradictory motivations and incentives asserting influence upon institutions and researchers: 'Corporations have supported increased patents and copyright terms, while many scientists, scholars, and practitioners take actions to ensure free access to information. Universities find themselves on both sides of the commons fence, increasing their number of patents and relying more and more on corporate funding of research, while at the same time encouraging open access and establishing digital repositories for their

16 J. Stiglitz, *Knowledge as a Global Public Good*, in I. Kaul, I. Grunberg, and M. Stern (eds.), *Global Public Goods: International Cooperation in the 21st Century*, New York/Oxford, Oxford University Press, 1999, p. 308.

17 *Ibid.*, p. 310.

18 *Ibidem*.

faculty's research products'.[19] Needless to say, the choice to allocate a growing percentage of public resources, even for basic research, on the grounds of rankings which are ever more used according to 'the first past the post' principle, can weaken the attitude to co-operation, and risks turning the spirit of a community into that of a championship: not simply 'publish or perish', but 'climb up the rankings or perish'.

These are well known and widely debated issues. There is also a third, decisive point of intersection between the problem of 'costs' of access to scientific knowledge, and its role and diffusion in society. The idea that knowledge can be accessed and disseminated at no or such a low cost that it should be considered as negligible has been criticized. Competence, expertise, in short appropriate levels of education, are usually required for people to understand and make use of it, regardless of the 'best intentions' of its producers, and 'not even those efforts will guarantee that he or she will at the end manage to acquire and master the expertise'.[20] This observation applies to several aspects of the debate on science 'in', 'for', and 'from' society. In everyday life, education has an impact on the ability itself to become a conscious user of the applications of scientific development: 'to benefit from a new drug it is sufficient to swallow the pill. These cases can be labelled *turnkey knowledge*. But turnkey cases are rather exceptional'.[21] Scientific literacy, with specific reference to biomedicine, is crucial to boost the principle of autonomy, and for individuals to take responsibility for their own lives, whilst also addressing those factors that can have an impact upon their health. Higher levels of education provide the most effective filter to prevent public debate and democratic decisions on 'what to do' and 'where to go' with science and technology from being overburdened with groundless biases or even fake news. In the end, it is the commitment itself to establish a community of researchers at the global level which is conditioned and undermined by the fact that becoming active producers of scientific knowledge is not for free. This makes inclusion and exclusion in it a powerful demonstrator of persisting or even growing inequalities, which need to be addressed as a political priority.

Rules, control, sharing

Making decisions on what to do and where to go may be difficult. Eradicating smallpox was tremendously beneficial to humanity. Nowadays, however, new and unprecedented possibilities in the biomedical domain seem to recall the alternative between

[19] C. Hess and E. Ostrom, *Introduction*, in C. Hess and E. Ostrom (eds.), *Understanding knowledge as a Commons. From Theory to Practice*, Cambridge (Mass)/London 2007, The Mit Press, p. 10.

[20] D. Archibugi and A. Filippetti, *Knowledge as Global Public Good*, in *The Handbook of Global Science, Technology, and Innovation*, Oxford, Wiley, 2015, p. 485.

[21] *Ibid.*, p. 486.

promise and threat underlined in the Russel-Einstein Manifesto of 1955; when 'the awakening of a Leviathan able to potentially destroy humanity' marked once and for all the end of the illusion of a sort of pre-established harmony, and called on us to take into due account 'the human factor in science decision processes as well as the necessity for evaluating scientific progress not just in terms of intrinsic criteria of rationality, but also in terms of the increase in public benefit'.[22] The Manifesto invited readers to remember our humanity and forget the rest, in order to take a way which 'lies open to a new Paradise', rather than the risk of 'universal death'.[23] Unfortunately, remembering humanity is not sufficient, because this concept, as it is with dignity, entails too great a variety of both unifying and contrasting ideas.

In order to address this challenge and come to terms with the complex weaving of implied means and ends, the distinction between *culmination* and *comprehensive* outcomes proposed by Amartya Sen provides a first, useful tool. According to this approach, we should include in the ethical evaluation of a decision to make the process through which a state of affairs eventually emerge. In other words: a broader perspective is required. Oppenheimer's admission, and his subsequent uneasiness, about the push for scientists to 'fare forward' every time they see something that is 'technically sweet', raise the crucial question: 'Why should I only do my duty as a physicist, ignoring all other results including the miseries and deaths that would follow from my own actions?'[24] It is not only scientists who are confronted with this kind of question: this is also a responsibility for governments and private investors, who provide the resources that make scientific research possible, as well as for citizens and consumers choosing the political winner in democracies and fuelling the demand for goods and services in the market. At the same time, the commitment to doing something 'beneficial to humankind' is, by all evidence, inconsistent with limiting the benefits to the few – which makes sharing a priority. Many specific issues are on the agenda. I will underline three points that I consider to be a type of methodological premise.

The first one refers to *rules*. Complying with ethical principles may imply setting some limitations or even prohibitions. Respect for dignity, in particular, has always been understood as the acknowledgment, not only of an essential driver to help humans to thrive, but also of a threshold not to be crossed: dignity 'defines certain 'taboo' situations

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22 F. Coniglione (ed.), *Through the Mirrors of Science. New Challenges for Knowledge-based Societies*, Frankfurt-Paris-Lancaster-New Brunswick, Ontos Verlag, 2010, p. 66.

23 The text of the Manifesto is available at: https://pugwash.org/1955/07/09/statement-manifesto/ Accessed on 19/12/2018.

24 A. Sen, *The Idea of Justice*, London, Penguin Books, 2010 (First published by Allen Lane 2009), pp. 211-212. See also A. Sen, *Maximization and the Act of Choice*, in 'Econometrica', vol. 65(1997), n. 4, pp. 745-779. Together with social commitment and moral imperatives, this article pointed out reputation and indirect effects, direct welfare effects, and conventional rule following as relevant for a comprehensive evaluation of the outcome (pp. 747-748).

and emotions as the limits of civilised behaviour. This means that there are certain things that a society should just not do'.[25] The Oviedo Convention prohibits interventions on the human genome which are not motivated by preventive, diagnostic or therapeutic purposes and, in any case, those aiming at introducing modifications in the genome of any descendants (art. 13); the creation of human embryos for research purposes (art. 18); or financial gain from the human body and its parts (21). The last prohibition is also affirmed in the Charter of Nice of the European Union, along with those of eugenic practices and reproductive cloning of human beings, to spell out the right to the integrity of the person (art. 3). The fact that the Oviedo Convention was not signed and ratified by all of the Member States of the Council of Europe, and the differences which exist between the two texts, illustrate the difficulties that we face every time that we look at ethical principles as a matter of rules and, in particular, of hard law. In the meantime, the debate continued, fostered by both technological advancements and the request to consider that a rule does not necessarily mean a strict prohibition.

Two further references may contribute to a deeper insight into these challenges. Art. 19 of the Regulation (EU) 1291/2013, establishing Horizon 2020, also entails prohibitions in the form of exclusion from financing: research activities aiming at human cloning for reproductive purpose; or intended to modify the genetic heritage of human beings making such changes heritable; or intended to create human embryos solely for the purpose of research or for the purpose of stem cell procurement, including by means of somatic cell nuclear transfer. However, the Regulation recognizes that the legal framework, even at the EU level, may not be the same for all: research on both adult and embryonic stem cells may be financed looking precisely at the rules applied in the Member State involved, and no activity shall be funded in a Member State where such activity is forbidden (therefore assuming that it could be allowed and eligible for granting elsewhere). Public acceptability of some practices – as honestly admitted in the Concluding Statement by the Organizing Committee of the Second International Summit on Human Genome Editing, held in Hong Kong in November 2018 – 'will likely vary among jurisdictions, leading to differing policy responses'. This is why it is important to establish an 'ongoing international forum', in order 'to foster broad public dialogue, […] provide a clearinghouse for information about governance options, contribute to the development of common regulatory standards, and enhance co-ordination of research and clinical applications'.26 Hard law remains, at least in principle, a very effective tool, but its reach is not, and is not likely to become, global. This is even more likely when we

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[25] J.D. Rendtorff, P. Kemp, *Basic Ethical Principles in European Bioethics and Biolaw*. Vol. I: *Autonomy, Dignity, Integrity and Vulnerability,* Copenhagen and Barcelona, Centre for Ethics and Law and Institut Borja de Bioètica, 2000, p. 35.

[26] Concluding Statement by the Organizing Committee of the Second International Summit on Human Genome Editing, 29 November 2018. Available at: http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b. Accessed on 19 December 2018.

consider that spectacular achievements in this field can be realized in small laboratories scattered all over the world, using technologies available at an ever lower cost.

The Hong Kong Concluding Statement is important as it also highlights a second aspect. With respect to heritable genome editing of either embryos or gametes, it is said 'that the scientific understanding and technical requirements for clinical practice remain too uncertain and the risks too great to permit clinical trials of germline editing at this time'. However, this is not to exclude that 'germline genome editing could become acceptable in the future if these risks are addressed and if a number of additional criteria are met. These criteria include strict independent oversight, a compelling medical need, an absence of reasonable alternatives, a plan for long-term follow-up, and attention to societal effects'. This clarification helps us to understand why the 'revision' of some prohibitions does not necessarily amount to simply dismissing them. Addressing the risks potentially involved in this practice is a premise. Once this guarantee is attained, a 'green light' for interventions on the germline could be possible, but only providing that the threshold of therapeutic use is absolutely maintained. Matters of safety are not matters of dignity (of course, different considerations may always be possible as to which heading applies to specific practices) and the effort to 'situate' ethical principles in a comprehensive assessment is not to be confused with plain relativism, nor the idea that all prohibitions are about to be removed.

A further, crucial point, is the role of *sociotechnical imaginaries*; that is 'narratives that imagine present and future society, present and future science and technology, and how they interact', thus becoming 'a constitutive part of any understanding of science and technology from which one may make ethical, political and regulatory judgments'.[27] Science fiction has long been fuelling and stretching to its most dramatic outcomes the tension between fear and hope, sometimes with them even turning into each other. The effort to find a cure for some scourge of humanity, such as Alzheimer's disease – to reference the recent movie *The Rise of the Planet of the Apes*, which also revives the question of animal exploitation – may end in the spread of a human-ravaging virus worldwide. The assumption of being perfectly in control of the risks associated with some technologies may prove to be a presumptuous illusion. It is also true that over the last few decades reality itself has provided a great many examples of 'goods' for humanity, which were largely used for their apparently positive qualities, and which later proved to be poisons and killers, such as asbestos.

What is new is not simply the extent to which science fiction becomes reality, such as Jules Verne's journeys from the earth to the moon or under the sea. Nor is it simply the awareness of the unintended, ever more risky consequences of introducing powerful

[27] R. Strand and M. Kaiser, Report on Ethical Issues Raised by Emerging Sciences and Technologies. Report written for the Council of Europe, Committee on Bioethics, University of Bergen, Centre for the Study of the Sciences and the Humanities, 23 January 2015, p. 13. Available at: https://rm.coe.int/168030751d. Accessed on 20 December 2018.

technologies in everyday life. The impact of in vitro fertilization, upon ethical and legal understanding and regulation of parenthood and family, epitomizes the breadth of the new challenges with which we are confronted. The concept of 'control', in particular, is undergoing a groundbreaking transformation and prompting a profound reshaping (also as a consequence of 'converging' technologies) of the 'natural' understanding of notions such as identity and integrity, but also of freedom and responsibility, which are the very foundations of our individual and social lives. The debate about enhancement is one of the most illustrative examples, especially when it comes to neurosciences and *moral* enhancement. Some scholars strongly oppose the idea of our conduct being the result of a will *controlled* by some external and artificial stimulus; but others point out that, 'although technological moral enhancement is only a distant prospect, it can serve as a complement to, not a replacement of, traditional social and educational modes of moral improvement', enabling individuals 'to be functional parents, providers, and engaged citizens'.[28] Obviously, privacy is also an issue, when we examine the possibility of this power becoming a sort of *Panopticon*, which would control every single aspect of individuals' lives without being controlled or even perceived by them. At the same time, Artificial Intelligence is seen as being on the verge of making humans redundant in ever more highly-skilled jobs and activities.

Against this background, the idea of *sharing* also needs rethinking and broadening as to its components. Filling the gaps remains imperative, in a world where the first targets of Goal 3 (good health and well-being) of the 2030 Agenda (concerning maternal mortality, neonatal mortality and under-5 mortality) are difficult to achieve for many countries, and would be considered to be a catastrophic lowering of standards by others. Being aware of all the potential factors involved is as important. I started recalling Jenner and smallpox. The example of vaccines can be seen as evidence of persisting inequalities. The World Health Organization (WHO) recommends reaching all children with two doses of the measles vaccine, but the percentage of target population receiving the second dose in 2017 ranged from 90% in the European Region to 25% in the African Region.[29] At the same time, however, outbreaks in North America and Europe emphasized that measles 'can easily spread even in countries with mature health system', contributing to illustrate 'how easily hard-won gains are lost'.[30] Such steps backwards may be the consequence of inadequate policy-making, low individual and social responsibility, and a lack of dissemination of sound knowledge and information

[28] Presidential Commission *for the* Study of Bioethical Issues, *Gray Matters*. Vol. 2: *Topics at the Intersection of Neuroscience, Ethics, and Society*, Washington, D.C. 2015, pp. 44-45.

[29] Source: https://www.who.int/immunization/monitoring_surveillance/data/en/. Accessed on 23 December 2018.

[30] SAGE (Strategic Advisory Group of Experts on Immunization), *2018 Assessment Report of the Global Vaccine Action Plan*, Geneva, WHO, 2018, pp. 5 and IV.

(fake-news creates confusion in public opinion and may trigger related changes in behaviours and even in attitudes toward science). This awareness should go hand-in-hand with the commitment to foster capacity-building and inclusion in the global community of researchers. The figures are unequivocal: in 2015, there were 4,226 researchers per million inhabitants (Full Time Equivalent) in North America and Western Europe, and 96.2 in Sub-Saharan Africa (UIS Regions).[31] This asymmetry reduces the opportunities for development and slows down its pace; it is usually accompanied by a lack of skilled professionals and, consequently, slows down access to treatments of appropriate quality; at the same time, it makes scientific education and public debate more difficult, and fuels a one-way flow of researchers. Some countries have demonstrated that a transition to the role of active producers and forerunners of science and technology is possible. This is a decisive step, in order for science and technology to become a shared endeavour and boost shared ethical reflections on the subject matter.

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[2] D. Archibugi and A. Filippetti, *Knowledge as Global Public Good*, in *The Handbook of Global Science, Technology, and Innovation*, Oxford, Wiley, 2015, pp. 479-503.

[3] CIOMS (Council for International Organizations of Medical Sciences), International Ethical Guidelines for Health-related Research Involving Humans. Fourth Edition, Geneva 2016.

[4] F. Coniglione (ed.), *Through the Mirrors of Science. New Challenges for Knowledge-based Societies*, Frankfurt-Paris-Lancaster-New Brunswick, Ontos Verlag, 2010.

[5] C. Hess and E. Ostrom (eds.), *Understanding knowledge as a Commons. From Theory to Practice*, Cambridge (Mass)/London 2007.

[6] R. Macklin, *Double Standards in Medical Research in Developing Countries*, Cambridge, Cambridge University Press, 2014.

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4.
Public Policies
fostering scientific progress and social development

Our civilizations have been evolving, in the last few decades, bringing societies and people closer together, and also contributing to increasing the interdependencies among us all. In this unprecedented situation, the number and seriousness of new realities, which affect all humans worldwide, continue to increase.

Perhaps the first highly significant event in this context is one of war. During the 20th century, the two World Wars showed, beyond all doubt, that the eruption of an armed conflict, no matter where it occurs in the world, can spread far and wide, dragging with it multiple nations who did not wish to engage in any fight or conflict. After the Second World War, people all over the world gathered together to write the Universal Declaration of Human Rights (1948) – an international document adopted by the United Nations, and aimed at preserving and strengthening peace in the world, by the commitment of states to a shared core of values.

A second new reality, although of a different nature to the first – but which is also very important to stress, as there are huge common problems that affect the whole of humanity – is climate change. It was in 1972 that the first United Nations Conference on the Human *Environment* was held in Stockholm. It aimed to reach a global consensus and agreement, to draw a conjoint strategy to balance economic and other particular interests with environmental sustainability and fighting climate change. From that moment on, there have been many other summits and international documents, which have endeavoured to build a global governance to effectively tackle the environmental issues that threaten the survival of human beings, as well as the life of the entire planet as we know it.

Indeed, humanity realized that in the global world we live in, there are ever more common problems, borderless, that require international approaches, wide-ranging decision-making processes and strong collective commitment. International governance is one of today´s major challenges, in this globally interdependent world that we live in, and is one which is required for an increasing number of issues.

A third example to illustrate this requirement, for an international strategy and a collective global commitment, and one that is particularly significant in the intersection of ethics, science and society, is the protection of the human genome; this was formally announced after UNESCO's Universal Declaration on the Human Genome and Human Rights (1997). Advances in genetics made possible human germline modifications; these advancements change not only the individual's genes, but also pass them on to the next generation, thus creating a genetically modified person, or potentially, a new species of beings. Today, with the new techniques of gene-editing, namely CRISPR-Cas 9, the procedure has become much easier, faster, cheaper and more accessible to an increasingly wide number of technicians. Therefore, an international guideline, such as the proclamation of the Human Genome as Common Heritage of Mankind (1997), stands as a political commitment worldwide and a guideline for global governance and national public policies.

Today, the preservation of our universal way of life – and of being human – is threatened by genetics, but also, and at the same time, by emerging sciences – namely computer science and digital technologies, assisting neurotechnology in human enhancement. Memory growth and computer-brain interfaces can dictate, autonomously by themselves, the advent of a new human being. The universal human nature behind individual improvement and societal development could be severely endangered, leading to a deepening of current social inequalities and making real the caste system envisaged in Aldous Huxley's '*Brave New World'* dystopia, with only some select individuals having access to neural enhancement, and thus becoming superior to their 'unenhanced' counterparts.

Public policies should serve the common good, including when they are dealing with scientific research and technological innovation, which have to proceed on behalf of society as a whole, and follow established ethical requirements and guidelines. Indeed, ethical reflection should always be the primary consideration, and the most elementary foundation, when discussing the values and the will of society; the consensus which is then reached should be translated into laws to reinforce the compliance of all; these laws should subsequently be both promoted and implemented by politics.

Maria do Céu Patrão Neves

The European Commission's research ethics and research integrity policies[1]

JOHANNES KLUMPERS[2]

Abstract

After reflections on ethics, science and technology and their importance for society, the Author presents the European Commission's research ethics and research integrity policies (including the ethics appraisal procedure for projects submitted to Horizon 2020) and introduces the independent advisory group 'European Group on Ethics in Science and New Technologies' (EGE). He also presents a recent addition to the Commission's advice landscape, the Scientific Advice Mechanism, with its Group of Chief Scientific Advisors.
Keywords: Ethics, science, technology, society, European Commission, research policies.

1 This is the written version of an introductory talk to the roundtable on 'New Horizons: progress in science' at the 'Ethics, Science and Society' symposium of December 10, 2018 in Lisbon, organised by the Luso-American Development Foundation: http://www.flad.pt/en/

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1. Science and Society

The development of science and technology has played a determining role in the formulation of modern societies. Science and technology affect most aspects of our lives, such as healthcare, access and distribution of knowledge and information, communication and mobility. Scientific research and its technological applications are a primary source of innovation and long-term economic growth, enhancing productivity and job creation. It has been estimated that roughly two-thirds of the economic growth in Europe can be traced back to research and innovation.[3] Science also influences the way societies are governed, as scientific advice is used and is sometimes essential for the development of policies. Scientific research not only produces new knowledge and technological applications, but also contributes to the emergence of new modes of living and may have an impact on the way democracy is exercised.

Scientific endeavour is largely based on an implicit contract between its practitioners and society. The public accepts the allocation of public funds to scientific institutions and researchers, and expects in return the generation of reliable, evidence-based results, bringing improvements to daily life and allowing societal challenges to be addressed. As a direct consequence, the future of science largely depends on maintaining public trust and support. For this reason, promoting reliable science which respects ethical considerations is a priority for the European Commission.

2. Ethics in Science and Technology

As discussed above, the advancement of sciences and new technologies is intimately connected with the development of contemporary societies. Consequently, the ethical implications of science and new technologies must be integrated throughout the Commission's policies, from the very practical – the application of ethics at the laboratory bench – through to 'big picture' consideration of major societal questions: what kind of European Union do we seek to achieve? What kind of society do we wish to create for future generations?

Two tools employed to embed ethics in European Commission policies reflect the diverse scope of this endeavour: the ethics appraisal procedure (applied to EU-funded research), and the work of the European Group on Ethics in Science and New Technologies (EGE).

[3] European Commission, Directorate-General for Research and Innovation, *The economic rationale for public R&I funding and its impact,* 2017.

2.1. *The Ethics Appraisal Procedure*

Ethics ought to be an integral part of research from beginning to end. It is only by getting the ethics right that research excellence can be achieved. Ethical research conduct implies the application of fundamental ethical principles and legislation to scientific research, in all possible domains of study and research.

The ethics issues most frequently encountered in research may concern, among others, the involvement of children, patients or vulnerable populations, research on animals, the use of human embryonic stem cells or other human cells and tissues, privacy and data protection issues, and potential misuse of research results.

Ethics is given the highest priority in EU-funded research: all the activities carried out under EU funding must comply with ethics principles and relevant national, EU and international legislation, such as the Charter of Fundamental Rights of the European Union (CFR) and the European Convention on Human Rights (ECHR). Ethics is also embedded in the Horizon 2020 framework programme legislation (Horizon 2020 Rules for Participation: Ethics Reviews (Article 14), Horizon 2020 - Regulation of Establishment: Ethical principles (Article 19) and the Model Grant Agreement: Ethics (Article 34)).

According to the regulation of establishment, there are three fields of research explicitly excluded from Community funding on the grounds of ethics. These exclusions concern research activities aiming at human cloning for reproductive purposes; research intended to modify the genetic heritage of human beings which could make such changes heritable; and research activities intended to create human embryos solely for the purpose of research or for the purpose of stem cell procurement.

In order to assess the ethics compliance of research activities considered for or receiving Horizon 2020 funding, an Ethics Appraisal Procedure has been put in place. This procedure includes the Ethics Review Procedure, which is conducted before the start of the project and, for a smaller number of projects, the Ethics Checks, which take place during the lifecycle of the project.

All proposals considered for funding undergo an Ethics Review carried out by independent ethics experts. The Ethics Review may lead to ethics requirements becoming contractual obligations.

The Ethics Appraisal Procedure focuses on the compliance with ethics rules and standards, relevant European legislation, international conventions and declarations, national authorizations and ethics approvals, proportionality of the research methods and the applicants' awareness of the ethics aspects and social impact of the planned research.

The rapid pace of scientific research calls for the development of a reflective ethics framework that maintains the highest standards of research ethics while, at the same time, does not hinder scientific progress and innovation. Advances in new technologies have opened a new range of exciting possibilities for humankind: developments in robotics and artificial intelligence have delivered self-driving cars and robot caregivers;

precise genome editing, enabled by CRISPR-Cas9, has many promising applications for human health and food production. So-called dual use technologies, such as lasers and drones, are also providing new possibilities for civilian applications. At the same time, such advances pose new ethics questions: Will automated decision systems act 'morally'? What will be the impact of robotics and automation on the employment market? What could be the environmental and safety implications of some CRISPR-Cas9 applications? What if dual use technologies fall into the wrong hands? Despite the rich academic debate surrounding these questions, at the moment there is very limited practical guidance on how to address these questions and ensure ethics compliance in research. With regard to this, further research on the ethics implications of new technologies and the development of concrete guidance is vital.

Beyond ethics compliance in EU-funded research, these developments also require the European Commission to embed ethics across the broad spectrum of its policymaking. One of the key pillars in the Commission's endeavour, not only to promote a responsible use of science and technology, but to effectively integrate ethics in all its policies, is the European Group on Ethics in Science and New Technologies.

2.2. *The European Group on Ethics in Science and New Technologies*

The EGE is an independent, multi-disciplinary body appointed by the President of the European Commission, and advises on all aspects of Commission policies and legislation where ethical, societal and fundamental rights dimensions intersect with the development of science and new technologies. Since its inception in 1998, the EGE has provided the Commission with high quality and independent advice on these issues.

Currently operating under its fifth mandate, the group's 15 members (appointed in 2017 for a term of two and half years) feature leading experts from Europe and worldwide, from the fields of natural and social sciences and humanities, philosophy, ethics and law. They count several former chairs of national and international ethics councils as their members, and bring a wealth of experience advising governments on the societal, ethical and human rights implications of current and future developments.

The task of the EGE is to apply the norms, values and principles enshrined in European and international treaties to challenges facing European society in connection with science and new technologies. In applying its ethical analysis, the Group draws upon the normative framework provided by the Lisbon Treaty and the Charter of Fundamental Rights, which enshrine democracy, freedom, human rights, equality and solidarity as pillars of the EU's ethical self-understanding. With full respect to pluralism and diversity across the EU, the group seeks to interpret and apply these international – as well as distinctly European – principles (such as solidarity) to emerging developments.

The Group has seen an important evolution in its scope and mandate since its beginning in 1998 (from 1991 to 1998 there was another group, the Group of Advisers on the Ethical Implications of Biotechnology, GAEIB). The creation of an advisory group on European ethics was originally prompted by the regulatory challenges faced by the EU in the wake of rapid advances in biotechnology and genetic engineering in the late 80s and early 1990s. Over time, the topics of EGE Opinions have changed, from focusing almost exclusively on ethical issues raised by trends in medical research and biotechnology, to much wider issues, raised by the growing importance of science and technologies across a broad spectrum of policy areas. Recent Opinions have covered topics as wide-ranging as nanotechnology, novel food legislation, animal welfare, embryo research, genetically modified organisms, agricultural methods, biodiversity, climate change, global trade, digital agenda, bio-security, environment protection, food security, internet governance, energy, security and surveillance, citizen participation in health and, in its latest Opinion, the future of work.

The Group addresses not only the science and technological dimensions of these questions, but grapples with wider complex ethical issues relating to rights and obligations, global and social justice, our responsibility towards future generations, the realisation of principles of freedom, dignity, solidarity and equality, and how those fundamental values are being placed under pressure and re-framed by societal, political and technological developments.

Although the EGE's advice is not legally binding on the European Commission, the Opinions of the EGE have the potential to carry considerable weight in EU policy. By dint of being appointed by the President of the European Commission and operating under the direct responsibility of Commissioner Moedas, the group is positioned to provide advice to the highest political levels of the Commission. Indeed, the EGE plays a particularly valuable role for the institution and its leadership, by addressing and defusing particularly thorny policy issues, as has been the case notably regarding clinical trials, energy choices, state and commercial surveillance, and embryonic stem cells.

3. Research Integrity

Research integrity is multi-dimensional and calls for respect of the highest professional standards in all stages of the research process. In North America, a very prominent dimension of research integrity is freedom of speech, which refers to the ability of all researchers and government research bodies, to present their research results freely.

Research misconduct such as plagiarism, fabrication or falsification of data may, thus, severely undermine public trust in research and may result in severe socio-economic consequences. Although accurate quantitative estimates of the social and economic impact of research integrity are difficult to ascertain, there is a wide range of harm at personal, institutional and societal levels. Such harm may include, for example, the misuse of public funds, harm to the health and well-being of research participants, and tarnishing the reputation of research institutions, research groups or individual researchers.

In addition, research misconduct may result in the adoption of erroneous policies, based on falsified results or biased scientific advice, or the release of unsafe products (e.g. pharmaceuticals) on to the market further to a non-rigorous validation process. Conversely, guaranteeing a generalised and consistently high level of research integrity could drastically improve the relevance, robustness, accessibility and dissemination of research results.

Refraining from obvious acts of misconduct (such as plagiarism, data falsification and fabrication) is not sufficient to safeguard research integrity. Among the most important contributing elements of integrity is the rigour of the scientific method to ensure the reliability and reproducibility of research results. Although the lack of reproducibility in itself should not necessarily be seen as an integrity issue or the evidence of poor science, documented high rates of irreproducible research results in various fields[4],[5] are a matter of concern.

Although, to date, there is no conclusive evidence regarding the exact causes of irreproducibility of research results, a number of potential factors are considered to be conducive to this phenomenon. Such factors include, among others, inappropriate statistical methods, too small or non-representative sample sizes, selective reporting of results, pressure on academics to publish, poor quality of data used in research and lack of standardization of reference measurement procedures and reference materials.

Enhancing reproducibility of research is essential in order to ensure the high quality of the research performed, the safety of research participants, as well as the prevention of wasted financial resources. Acknowledging the importance of reproducibility, the newly issued European Code of Conduct for Research Integrity underlines that 'research institutions and organisations [should] support proper infrastructure for the management and protection of data and research materials in all their forms … that are necessary for reproducibility, traceability and accountability' and that 'researchers [should] report their results in a way that is compatible with the standards of the discipline and, where applicable, can be verified and reproduced'.[6]

At a research organisation level, the promotion of rigorous scientific practices, taking into account the new research working methods prevailing in 'open science', should become a priority. In order to maximise the quality and societal impact of research, research integrity should be an integral part throughout the research process, and not be merely seen as an add-on and as a means of creating additional red tape. Instilling a research integrity culture requires education and training of researchers from an early

4 http://science.sciencemag.org/content/sci/349/6251/aac4716.full.pdf

5 https://www.nature.com/articles/483531a

6 http://www.allea.org/wp-content/uploads/2017/03/ALLEA-European-Code-of-Conduct-for-Research-Integrity-2017-1.pdf

stage in their career, and potentially structural changes and clear guidance in research performing and research funding institutions that would facilitate the promotion of research integrity and combat research misconduct.

Efforts to enhance the promotion of a research integrity culture are de facto linked with the development of a research integrity policy. On the EU level, the promotion of research integrity has increasingly become a priority for the European Commission.

In this context, and responding to the request of the Member States to ensure regular adaptation of the policies and procedures, the Commission has also played a key part in the recent revision of the European Code of Conduct for Research Integrity. The process was led by All European Academies (ALLEA) in co-operation with a broad range of stakeholders, including industry, academia and research funders, in order to maximise its take up and dissemination.

The new Code aims at promoting the responsible conducting of research to help improve its quality and reliability. Compared to its predecessor, the new Code takes account of developments in Open Science, including the growing importance of data quality and management. It also clarifies the responsibilities of research organisations, helping to promote an integrity-conscious research environment. The Commission will support the take-up of the Code at national level and, at European level, will implement it as the required standard of research integrity for projects funded under Horizon 2020, updating the Model Grant Agreement in order to reflect the new Code and its principles.

To further promote a culture of integrity in European research, and to obtain more data on research integrity, the Commission is currently funding a series of research projects aiming, among other intentions, to explore the ways research integrity and misconduct are understood in different disciplines; to define the social and financial impact of research misconduct and assess its cost; to strengthen activities of education and training in the fields of research ethics and research integrity; and to encourage networking among institutions, in order to enhance the effectiveness of research.

4. Evidence-Based Policy Making

The European Commission has made scientific evidence a key element of the policy-making process, as the better regulation agenda requires consideration of evidence, including scientific evidence at multiple levels.[7] Our societies and economies and, consequently, our security, health and well-being, have become more and more globalised

[7] https://ec.europa.eu/info/law/law-making-process/planning-and-proposing-law/better-regulation-why-and-how_en#quality

and interdependent. Issues with potential international impact, such as climate change, energy, epidemics or natural disasters, require evidence gathering and interpretation (sense making), consensus building and action at international levels. Science advice should therefore be embedded at all levels of policymaking, including at the international level. Science advice is becoming an increasingly important component of diplomatic and international relations.[8]A fundamental requirement of scientific advice is for independence and autonomy. Science advice must be provided directly and uncensored to the head of the executive government, or to the head of the relevant department. At the same time, any scientific advisory system needs to acknowledge that scientific advice is just one input of many in the political decision-making process. Any scientific adviser should seek objectivity and act as an 'honest broker of knowledge', and any system to provide direct advice to decision makers needs to be balanced with public accountability and transparency in its processes.

The Commission has created the Scientific Advice Mechanism (SAM) to provide high quality, timely and independent scientific advice for its policy-making activities.

SAM is a system that brings together evidence and insight from different disciplines and approaches, taking into consideration the specificities of EU policy making, and ensuring transparency. It will complement the work of the Joint Research Centre, the Commission's in-house scientific service, of existing specialist committees and of specialised EU agencies.

The core of SAM is the Group of seven Chief Scientific Advisors, appointed for the first time at the end of 2015, who, just like the EGE, interact directly with the highest political level of the European Commission, the Commissioners. And also, for the Group of Chief Scientific Advisors, it is Commissioner Moedas who takes responsibility for the interaction between the Commission and the Group. The Group works in close collaboration with the European Academies. A consortium of five European academy networks (Academia Europaea, ALLEA, EASAC, Euro-CASE, and FEAM) has been established, denominated SAPEA ('Science Advice for Policy by European Academies'). SAPEA is an essential part of SAM. The overall objective of the SAPEA initiative is to pull together timely, independent and evidence-based scientific expertise from more than 100 European academies in over 40 countries. The Commission is committed to ensure SAM's success, and committed to establishing closer links between science and policy-making. The ultimate aim is to deliver better, evidence-based policies for Europe that will contribute to solving global challenges in a consensual way.

[8] https://www.s4d4c.eu/s4d4c-1st-global-meeting/the-madrid-declaration-on-science-diplomacy/

5. Concluding Remarks

The strong evidence basis of science, together with the values intrinsically embedded in science, such as the research ethics and research integrity, contribute to the enhanced trust that society poses on science and scientists. Trust is the basis of our society and science evidence, research integrity and ethics research are cornerstones of a solid science and innovation policy. This article has explained the complex interlinks of this triangle and described the way the European Commission has implemented these policies during the present mandate (2014-2019).

Further Readings

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The Knowledge Society as Europe's answer to globalisation

MARIA HELENA NAZARÉ[1]

Abstract

This paper is concerned with the advances in science and technology, and with developments in the economy and education. It looks specifically at the influence that the (1st to 4th) Industrial Revolutions have had on education. The reform of Higher Education (HE) systems, known as the Bologna Process, is presented as Europe´s answer to globalisation.

The strengthening of the European economy, via a stronger focus on innovation and university business partnerships, is discussed, and implementation policy actions are presented. In particular, the outcomes of policies aimed at increasing the number of doctorates, in the expectation that they would work outside academia and have a strong impact on innovation and wealth creation, are addressed. The importance of research integrity, in promoting the necessary open access to research results and data, is also emphasized.

The paper names a number of current challenges, which are also deemed to be important; these are related to unbalanced economic and social developments, which are further compounded by adverse demographic changes.

Key words: Education, economy, industrialization, science and technology

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This paper concerns the advances in and correlation of education, science, technology, industrialization, economy, globalisation and bio-politics. Ethics, although not specifically addressed, is subjacent and of substantial dimension and relevance.

Bio-politics is a totally embracing subject, whose framework is provided by the philosophy of thought. According to Thomas Lemke in 'Biopolitics: An advanced Introduction': (i) Biopolitics is a merger of life and politics and there are two different approaches depending on which part of the word they emphasize; naturalistic concepts that take life as the basis of politics and the strand that takes life processes as the object of politics.

The first approach, developed within political science, was born in the nineteen sixties, and advanced a 'naturalistic study of politics' (Blank and Hines 2001) (ii) which consisted of using biological concepts and research methods in order to investigate the causes and forms of political behaviour; it is this approach that is used to look into several important concerns and challenges of the 20th and 21st centuries, including: racism and national socialism, environmental protection, advances in biotechnology, etc. ... Nowadays, it is accepted that biopolitics cannot be separated from the economization of life and the two strands are becoming convergent.

The analysis of biopolitical problems necessitates a transdisciplinary approach, a dialogue among different cultures of knowledge, modes of analysis and explanatory competences. The challenge is presenting and analysing the problem as part of a greater context having in mind the historical background (Lemke *et al.*) [1]. The present paper attempts to address that challenge by connecting areas and their developments, perceived as main contributors to the melting pot where biopolitics has to dwell. It is, therefore, necessary to look at education, science and technology, industrialization and the economy. These set the scene for biopolitics, as well as for globalisation's current concerns, and prepare the framework for action and future developments.

It is certainly not a spurious coincidence that the 'naturalistic study of politics' made an appearance around the same time (c1960) that the phenomenon of globalisation, shaped by trade and seen as the flow of goods, became popular. The world became flat 'again' in 1970.

The key drivers of globalisation also contributed to shaping the modern understanding of biopolitics. If it is necessary to look at these in some detail, it is also obvious that the starting point is with education, the foundation of it all. Besides, and as a corollary to this, it is clear that all countries, which have managed persistent growth in income, have also had large increases in the education and training of their labour forces, and also coincide with those where biopolitics has gathered much attention.

Although Vasco Da Gama's travels have, together with those of Cristovão Colombo, contributed strongly to the globalised world we live in, it is not necessary, at least in the context of this paper, to go so far back in time; rather it is worth keeping in mind the contradictions that globalisation entail today.

Actually globalisation goes beyond the circulation of goods and services, and the exchange of ideas which spur innovation and increase competitiveness. For many, it means unfair trade practices, job losses and the offshoring of firms, which in turn explains calls for protectionism. For large regions of the globe it is correlated with over-exploitation of natural resources and environmentally damaging practices.

Finally, the current flow of migrants and the tragedy of dislocated people – as well as the absence of adequate policies to treat the cohort aged 65+ as an opportunity and not as a burden to younger generations – all call for the attention of biopolitics.

1. The Industrial Revolution(s) and education

Throughout history, scientific and technological breakthroughs have led to radical changes in the way that we live and work. Those changes, often disruptive in nature, lead to political intervention in the shape of public policies, to deal with their social and economic impact, to capitalise on them, sometimes through monetization and/or to minimise the negative effects.

The term 'Industrial Revolution' is often used to describe the social changes which happened in Britain between the mid-18th and 19th centuries, as a consequence of the advent of steam power, which led to profound advances in the manufacture of textiles, the transportation of goods, and the development of the railways and steam ships, in addition to the whole process of industrialization. In fact, this period is known today as the first Industrial Revolution; it impacted on the individual lives of workers, and on urban life in general with the development of industrialised cities, and consequently led to profound social reforms. The cotton industry in England is a text book example of the changes that occurred in the processes of production and the impact that they had on the social and economic conditions of the workers. These changes resulted from the use of advanced scientific knowledge (thermodynamics) to produce an innovative technologic apparatus – the steam engine.

One key change, which was central to the Industrial Revolution, was the steady movement and relocation of labour out of homes and farms, and into factory plants and offices. In fact, the first Industrial Revolution brought about the creation of factories where none had existed before. The process was gradual; most firms continued to farm out some processes to domestic workers, until mechanization and technological complexity made it worthwhile to bring workers together under one roof.

With these changes, and the resulting working conditions, health issues and environment protection began to be perceived as public concerns. Nowadays strict regulations exist in Western Europe, regarding the quality of the air inside working premises; monitoring of pollutants is mandatory for most industrial plants. Today, we know only too well the consequences of factory pollution and emission gases raising global temperatures and leading to climate change. Big data methods are currently being used to anticipate some of the extreme events linked to global warming, such as hurricanes and heat waves, which may also lead on to devastating and destructive fires. At the same time, the preservation of biodiversity has become a major issue related to the massive exploitation of natural resources.

With primitive or traditional production processes, the knowledge necessary to produce items does not change much over time, and can be passed down from generation to generation in the context of home production. This situation changed dramatically with the first and second Industrial Revolutions, when processes became increasingly sophisticated and knowledge transmission became a major factor in maintaining or establishing critical advantage. Each production process requires a specific type and amount of knowledge or human capital on the part of the workers who operate it.

The so-called second Industrial Revolution concerned the development of electricity, and this led on to the automation processes of the third Industrial Revolution: they can also be linked with changes to the organisation and management of business, which had become too expensive and complex to be managed within the home. The concept of scientific management or Taylorism dates from the second half of the 20th century, and helped to restructure the operations of factories, and later entire segments of the economy.

Although the socio-economic impacts were dramatic, as increases in productivity also resulted in unemployment, with workers being displaced by machines and factories becoming obsolete in a short expanse of time, it could be argued that the major impact of the Industrial Revolution was the rise of a universal schooling system, where none had previously existed, although this relationship is difficult to precisely establish.

The concentration of workers on the same premises led to the exchange of ideas and proved to be the strongest driver of innovation. At the same time, it made feasible the training of workers to obtain the necessary skills for the work they were employed to carry out. That training, which in most cases was provided by the factory itself, was later complemented through the national schooling system. Our western model of schooling occurred as a response to the technological and economic developments. The rise of public (state) schools moved from an era of apprenticeship into a world of almost universal schooling, which came to identify and associate learning with schooling. The most striking change from the apprenticeship era to the schooling era was the state's assumption of responsibility for educating children. Education has become a path to economic advancement at both a national and a personal level.

However, both better and worse were to follow; globalisation itself was altered during the 1990s by the revolutionary changes in information and communication technology (ICT) (the so-called fourth Industrial Revolution – of which the internet is the paradigmatic example). If steam power lowered the costs of moving goods, meaning that it was all about trade, ICT lowered the cost of moving ideas (Baldwin, 2017) [3]: it began by being about flows of knowledge and their global economic impact. However, it was the advent of artificial intelligence (AI) that created a disruptive situation which was at least as important as the development of steam power had once been. In economic terms, it has the potential to lower or eliminate the costs of moving people; workers in one nation might provide services in another nation, including services that today require a physical presence (Baldwin, 2017) [3].

The biological features of human beings are now measured, observed, and understood in ways never before thought possible. This knowledge, obtained through advances in science and technology, is being used not only for advanced health care, but also for economic and social purposes, raising serious concerns.

Artificial Intelligence (AI), genetic engineering, virtual reality and digital currencies are blurring the lines between physical, digital, biological and economic spheres, and thus bringing biopolitics and its concerns and methodologies to the forefront of international discussions.

The major theme addressed by the World Economic Forum in 2016 was the impact of Artificial Intelligence; during 2017 that concern evolved further, and the focus was on the anticipated massive loss of jobs. Such losses were predicted to be felt across the globe, affecting all ages and all types of employment – not all of us are or can become a coder! Some advocated that states and governments should devise policies to deal adequately with the implicit social impact of such job losses, which obviously cannot be absorbed by the public purse alone. At the same time, others argued that the historic pattern of human upskilling would prevail and so new, more valuable jobs would replace those destroyed by technology.

Whatever the trend, universities, and Higher Education institutions in general, are being called into action. Nobody can predict what the needs of the job market will be in a decade (or even in five years time) so learning (and teaching) universal skills, is a must. Moreover, that learning needs to co-opt a diverse student population; mature and young, employed and non-employed.

Ultimately, the best safeguard against an unpredictable future is to remind ourselves of the traditional foundations and missions of a university education: to ground people in fundamental principles, to permanently question assumptions and to use critical thinking.

2. Higher Education

2.1. *The Bologna reform*

The welfare of a nation depends, in the long run, on the quality of its human resources; that is, on people and their ideas, and thus it is linked to the capacity of the Higher Education (HE) sector and the quality of its institutions [4][5]. During the last decade of the 20th century, the European Higher Education landscape has undergone tremendous changes and alterations, both at system and at institutional levels. Many of those changes were directly linked with, or driven by, the need to efficiently educate the workforce, within an appropriate span of time, and equip it with the skills required by a global competitive world market. Hence the Bologna Higher Education reforms, which brought about the restructuration of HE degrees – new methodologies focusing on the learning process instead of on teaching-centred ones, increased mobility of students and staff, and the new importance of quality improvement and quality assurance within HE. The building of the knowledge society required us to strengthen the links between the research and the teaching missions of the universities, and changes in doctoral education – the third-cycle degree within the new Bologna structure – occurred. At the same time, novel means of interrelation between university and business were developed and proved fruitful.

The solution, known as the Bologna Process, was first proposed in 1999. It implied a profound restructuring of Higher Education into a system consisting of two cycles for undergraduate and post-graduate studies respectively (later enlarged to three cycles: Bachelor, Master and Doctor), combined with a credit system for accumulation and transfer, therefore improving recognition and comparability. The approach to teaching and learning was supposed to undergo a complete transformation, from an ex-cathedra model of teaching into a student-centred approach to the learning process. Courses were to be described in terms of the learning outcomes to be expected from a student – the skills, competences and knowledge that he or she should have obtained by undertaking the course.

The mobility between cycles of study was expected to increase, as well as the mobility of students, staff and graduates across Europe. Furthermore, the employability of graduates – 1st and 2nd cycles – should also increase and present no problems across Europe.

Expectations were, and still are, that these structural changes in the European Higher Education systems would result in the early entrance into the labour market of a highly-skilled workforce; the individuals prepared for problem-solving at a variety of different levels, currently using ICT, better prepared for learning throughout life and aware of the need of so doing, and able to work (in any European nation, in fact anywhere in the world).

In 2010, almost all of the countries in the European Higher Education Area (EHEA) had introduced the Bologna reforms, with 95% of Higher Education institutions with a degree structure based on either two or three cycles, and 88% reporting the use of the European Credit Transfer System (ECTS) [6]. However, the TRENDS survey for 2010 [7] revealed that all is not well. Mobility was a particular concern: while the vertical mobility was increasing, the horizontal mobility seemed to be diminishing. At the same time, it was possible to conclude that in the vast majority of countries, the restructuring of the degrees had been accomplished in a purely formal way. In some cases, the degree programmes were sliced into two cycles, lasting three and two years, or four and one year, corresponding to Bachelor and Master degrees, without any redesign of the curricular development of the programmes, or alteration of the course content. The application of ECTS was, in many cases, based on the contact hours. Also, the process of teaching and learning had not evolved much, apart from the more extensive use of ICT.

Basically, this was because the extra funds needed to achieve better student-staff ratios, and for the staff development needed to focus the learning process onto the student, could not be provided. Hence, other sources of funding needed to be found, given the fact that, generally speaking, the public purse no longer adequately supports Higher Education. To achieve the goals of the Bologna reform, more, and not less funding is needed.As reported in 2015 [8], there is no single model of first-cycle programmes in the EHEA, which may be just as well. The last thing Europe needs is forced conformation to a sole model. A unique 180 ECTS Bachelor model exists only in the Flemish Communities of Belgium, France, Italy, Liechtenstein and Switzerland. Most countries combine programmes of 180 ECTS and 240 ECTS. In some countries, the number of (usually professional) programmes using the 210 ECTS model is significant as well. In the second-cycle, the most common model is 120 ECTS, with two-thirds of programmes following this workload. However, other models dominate, in particular countries. In Cyprus, Ireland and the United Kingdom (Scotland), 90 ECTS is the dominant model, with 60-75 ECTS in Montenegro, Serbia and Spain.

The most typical variants from the Bologna two-cycle model are the integrated programmes, including both the first- and second-cycle, and leading to a second-cycle qualification. In most cases, this kind of programme leads to qualifications in regulated professions, i.e. the fields of medicine, dentistry, veterinary – but in some countries, also in engineering and the law. One might say that the degree structures adopted by different countries reflect their past circumstances, which induced the consequential 'creative' approach to the ministerial agreements. In particular, second-cycle programmes (master) exhibit a fine structure when they are looked at closely. For instance, the second year (or 60 ECTS) may take the format of a professional project, complemented with related courses (e.g. management, entrepreneurship, leadership, human resources, etc.), or a research project, complemented with courses related with research topics in general. These variants depend very much upon (a) the national legislation, (b) the autonomy of the university and (c) the accreditation agency.

The economic dynamism of Europe, as a knowledge society, was expected to increase, and so be able to meet the challenges of an ageing population and competition from other developed economies in the world. Achieving a Knowledge Society, while building a European Research Area, depends on a vibrant community of scholars and researchers working together to create knowledge and educate a workforce at the highest level, which can find innovative ways of using their skills to improve social cohesion, and enhance economic performance and its sustainability. Obviously, the employability of graduates plays a major role.

However, those expectations have not been completely fulfilled. The mismatch, between jobs and the skills available, is still a major concern with significant economic and social costs. Many people work in jobs that do not match their talents and, at the same time, in Europe, 40% of employers report having difficulty in finding people with the necessary skills (A New Skills Agenda for Europe EU, 2016). Higher Education institutions, employers and learners all have different perceptions of how well prepared graduates are for the labour market.

2.2. *The European Research Area Science and Technology*

If Europe has managed to become a Higher Education Area (EHEA), the creation of a European Research Area (ERA) has still to be achieved, "*a unified research area, open to the world based on the Internal Market, in which researchers, scientific knowledge and technology circulate freely and through which the Union and its Member States strengthen their scientific and technological bases, their competitiveness and their capacity to collectively address grand challenges*".

The years since 2010 have been marked by the weak outlook for Europe, both in economic and demographic terms, and to which youth unemployment has also been added. This has led many governments, the European Commission and the OECD to emphasise the necessity for Higher Education to respond to economic and social needs, and to enhance the employability of graduates, including via a stronger focus on entrepreneurship and innovation, and strengthening university business partnerships.

It has been estimated that Europe will require about a million additional researchers by 2020. Hence, many countries have adopted specific policies to achieve the stated objective (2020 Strategy) [9]. An example of this strategy was the support for a policy to increase in the number of PhD holders.

Most countries have invested in research, both fundamental and applied, financed by public and private sources, and increased the number of doctorates, in the expectation that they would work outside academia and have a strong impact on innovation and wealth creation. However, the policies focused on the supply side rather than on the demand aspect. One supposes that the general expectation was to create demand once the impact of highly qualified human capital was truly realised and valued.

Doctoral programmes have changed a lot in recent years, becoming increasingly geared to outside employment, including interdisciplinary training, the development of transferable skills and operating within appropriate time durations – three to four years full-time as a rule. Nowadays, most of them offer geographical as well as inter-sectorial mobility and international collaboration within an integrated framework of co-operation between universities and other partners, in particular, enterprises and business.

From the turn of the century, the number of PhD graduates who pursue post-doctoral training has been growing, due not only to the appeal of an academic and research career, but also influenced, since 2010, by the weak outlook for Europe both in economic and demographic terms, and added to which youth unemployment has also become a factor.

There have been concerns, on both sides of the Atlantic, of the consequences of producing a high number of doctorates for the job market. However, despite those concerns, in terms of employment (rates above 92%), doctorate holders are at an advantage when compared with other tertiary degrees.

Doctorates are the workers of knowledge production and participate in its commercialisation. The funding of research has become more and more focused on the possible economic outputs, and this applies most appropriately to ICT, pharmaceuticals, and medical research and appliances, with the almost total exclusion of, or very little contribution from, humanities and social sciences. When the programme Horizon 2020 was launched, many knowledge institutions and academics had expressed their concern regarding the lack of substantial funds dedicated to support research in humanities and social sciences, as they are key to dealing with the challenges ahead. Technological expertise, without a humanistic understanding of the nature of the relationship between devices, users and society at large, entails the risk of having technology that does not serve society or reflect human demands.

A broad definition of technology is the use of knowledge to develop products (devices and/or services) to be used by human beings ('consumers'). But transhumanism is no longer an object of science fiction that aims to transform the human condition by using technologies to enhance human intellect and physiology. It is a reality and should be the object of careful attention, as the current debate on the patentability of research results on human embryonic stem cells is a paradigmatic example.

Essential to achieving the European Research Area (ERA) – namely the free circulation of *scientific knowledge and technology, so that EU Member States may strengthen their scientific and technological bases, their competitiveness and their capacity to collectively address grand challenges* – is guaranteeing research integrity and open access to publications and data. These subjects have been the object of study and debate involving the research community and the ALLEA: ALL European Academies. This last association has formulated the four basic principles of research integrity: 'Reliability' – in ensuring the quality of research; 'Honesty' – in developing, undertaking, reviewing, reporting and communicating research; 'Respect' – for colleagues, research participants, society, ecosystems, cultural heritage and the environment; and 'Accountability' – for the research from idea to publication [10]. The matter concerning open access to publications involves the business model of publishers, their economic interests and the funding of research. The position of universities and of research-performing organisations on this issue has been a very supportive one, but claiming that the transition to the model of open access entails costs which are expected to be included into the research grants. Access to data is a more complex question; it relates to privacy issues and misuse of data, which are extremely complex and outside the scope of the present paper.

Universities are expected to contribute, in a fundamental way, to answering the four questions underpinning the conditions and quality of life in the next decade: *Can we master greater connectivity? Will we create more meaningful work? Can trust and truth be revived? How much can social and organizational innovation alleviate new problems?* (Lee Rainie, 2017) [11].

2.3. *Tensions and Challenges*

The progress in science linked to innovation brought economic and social development to the world in general. However, such developments did not prevent the growing imbalances, and related tensions and challenges, due mainly to demographics, flow of people, and access to education and health:

- The demographic situation of the world is very unbalanced, with the 65+ aged population in developed countries expected to increase, due mainly to the increase in life expectancy. According to the OECD, the ratio of the population aged 65+ to the population aged 20-64 in the EU, which is already higher than that of the United States and the OECD average, will have doubled its present value, by 2050 (12), (13). This is perceived as a major threat to the sustainability of the European economy and welfare model. It is this perception which is undermining social cohesion and causing generational tensions, and not the phenomenon in itself, which should be seen and treated as an opportunity.
- The tension caused by the ageing population in developed regions of the globe, and the need to educate the younger generation in undeveloped countries, is accentuated by the widening gap between the 'haves' and 'have nots' and the increasing numbers of dislocated people. That widening gap, together with the increasing numbers of dislocated people, is making fertile ground for raising protectionism throughout the globe.
- At the same time, welcoming and integrating the *needed* immigrants requires complex and expensive public policies, which are difficult to explain to the public at large in times of financial scarcity.
- University education needs to be more universal. Interdisciplinary and transdisciplinary approaches are needed. To achieve this goal, more funding is needed, putting more pressure onto an already stressed public purse.
- Research integrity and open access have become important, albeit hot, topics in relation to research funding. Too many economic interests are at play, often against each other, concerning these subjects. The true sharing of knowledge is almost utopia.

- Access to medical care is linked to the financial capacity of families, more than ever before.

3. Summing up and concluding

Industrial Revolution (IR) is the name given to the movement by which machines changed people's way of life, as well as their methods of manufacture: (i) The 1st Industrial Revolution: used water and steam power to mechanize production and transport goods; (ii) the 2nd Industrial Revolution: used electricity to create mass production; (iii) the 3rd Industrial Revolution: used electronic and information technology to automate production; and (iv) the 4th Industrial Revolution: was a digital revolution, a fusion of technologies, a blurring of the lines between physical, digital and biological spheres. Artificial Intelligence (AI) is no longer scientific fiction. All of these revolutions were accompanied by serious societal challenges, with massive changes to the job market. Jobs being lost and new skills required. The great difference is that now the speed of change is much faster. And the impacts are previously unimaginable: they affect human life, are felt across the world and threaten human values.

Universities must lead again, and revisit their founding principles, ideals and missions to educate citizens who are not only highly skilled, but also equipped with interdisciplinary awareness and prepared to keep learning throughout life [14].

However, when all is said and done regarding reforms and new goals for Higher Education, research and technology, economic development and the re-flattening of the world, the real problem stands out as a clear and sobering element: the flow of migrants and dislocated people is of unprecedented dimensions; disasters leading to human losses are quickly displaced from public attention by tomorrow's latest 'new' news. However, human beings, particularly children, remain living and dying in subhuman conditions, often inside the borders of our developed Europe. Climate changes are a reality, as evidenced by the extreme events taking place all over the world, and they compete for funds with the migrant crisis. Sharing of knowledge is very much tied to economic capacity.

The knowledge and wisdom of all citizens, independent of their age, is overlooked by too many nations, wasting valuable resources and human capital, and creating a divide in society.

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Are we prepared for the speed of the future?

ANA COSTA FREITAS[1]

Abstract:

Today's world faces challenges never seen before, driven by the advancement of knowledge and technology, at an overwhelming scale and speed. We can, no longer, regard our planet as just a huge sum of territories, people and different realities, where the challenges are regionally positioned; global action is now needed, with our increasingly interconnected and interdependent planet. We have many challenges before us, all of them related to sustainable development. We deal with huge environmental challenges relating to climate change, and social challenges brought about by issues of wealth distribution or access to decent work, alongside those of sustainable economic growth.

Universal access to a quality education, where Higher Education is of particular importance, may not be the only way, but it is an excellent way to prepare citizens on a global scale to face the great challenges of the day.

Every day it becomes even more important that the Higher Education institutions, with their scientific output, take social responsibility for the knowledge and technological advancements which are transferred to our wider society.

Keywords: Sustainable development, global challenges, Higher Education institutions, ethically responsible science, universal access to quality education

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Debate and reflection, with regard to ethics, science and society, in all areas of science, and which addresses all societies, is not only necessary, but it is also essential in today's world. We face a number of global challenges, which can only be resolved by more education, more research, more science, and which are only limited by human preconceptions and presuppositions, providing citizens with conceptual tools to critically evaluate reality.

1.1. *The present*

We are going through times of great uncertainty concerning our collective future. The challenges are overwhelming. Simultaneously, we are dealing with climate change and its consequences, including issues with food production and food availability. Although they may not still be fully acknowledged as valid by some world leaders, these clear changes in climate influence the planet's resilience and responses; they are responsible for the exodus of people and are the cause of wars, as populations, around the globe, risk their lives simply to be able to live a decent life, to a level that was first considered in the *Universal Declaration of Human Rights* (United Nations, December, 1948). We face a population explosion in some areas of the globe, which contributes to exacerbating many existing problems, while a decreasing birth rate sends out red alerts in other parts of the world. This inbalance is not only difficult to rectify, but it is also difficult to deal with when economic values are given prominence by world leaders and in national decisions, while social and humanistic values are left far behind.

Moreover, we are far from meeting the Sustainable Development objectives set out in Agenda 2030. World peace is a distant objective, as is access to justice, or the effective functioning of institutions; the eradication of poverty and the reduction of inequalities is a utopian scenario; gender equality remains a reality yet to be achieved; universal access to quality education is still a dream; there is a long way to go towards achieving responsible production and consumption; and much remains to be done in building sustainable cities and communities, where access to safe drinking water and sanitation, as well as clean and affordable energy, should be a reality, with all the obvious consequences for global climate change. Whether due to problems such as these, or to the speed of our present lifestyles, we are facing the consequences of a growing disbelief in the pillars that define democracy, as well as progressive disbelief in political leaders, often for ethical reasons.Part of this lack of belief lies with a loss of confidence in Higher Education institutions. HEI changed dramatically, from a transversal education focused on science applied to a humanistic development, to one of science focused on economic values, forgetting that sustainable growth is required if we want our children to live in a world that is both pleasant and valued.

1.2. *The future*

The uncertainty we are facing is driven by the unstoppable advance of technology which leads to paradigm shift changes, such as in our models of work or social relations. These drive us away from the model of society we knew, towards unknown areas, which are unpredictable and sometimes totally out of control. We are moving towards responsible production and consumption patterns, yet profit is still the main factor, with the relationship between decent work and economic growth relegated to second place. Increased robotization and the use of Artificial Intelligence in production processes are necessary, and are direct products of scientific research and technology development; but the human factor tends to be misused, jeopardizing the sustainability of individuals and leading to new models of society. Faced with this technological development and the dismantling of models which have prevailed until now, universal access to a quality education is the only guarantee of sustainable development on an economically interdependent planet.

The enormous developments and advances in science and technology are seen to be responsible for most of the positive features in our lifestyles, and indeed for all of the advances that we may have experienced on Earth; but they are also responsible for our selfish nature, which leads humankind to believe that we can exhaust the planets resources (without paying any attention to the future), simply because this is necessary in order to support our current *comfortable and modern* way of life.

And all of this is happening with increasing speed. So fast and so innovative that at all levels – whether they are cultural, societal, political or scientific – stability is not considered to be a word that can be applied. Nowadays, we might assume that the established dialogue, which has been characteristic of multilateralism and of the post-war world, is getting weaker and weaker. The influence of social networks as the primary vehicles of information, and the manipulation of data associated with the free dissemination of content, leads to choices being made according to individual ideas and prejudices, and in turn leads us to ignore other ideas and even refuse proven facts and events; from here follows an impoverished debate of ideas, which influence, in a populist way, leaders decisions and thus lead to confrontation.

However, science and technology cannot, and should not, be considered to be responsible for this situation. Higher Education institutions are responsible for educating young people, not simply to just INNOVATE or DO RESEARCH; we must prepare researchers to value life and be really concerned about achieving the 2030 Sustainable Development Goals, thus contributing to a better and more sustainable future for everyone.

2. The current decision-making process

Nowadays people rely mostly on the enormous quantity of available data – rather than depending upon human relations and scientific evidence – in order to draw answers, define policies and draw conclusions.

With the slow disappearance of dialogue and confidence, everything can be built and destroyed at an intense and unpredictable speed, without giving sufficient time to evaluate results, simply because the value placed upon ethics has disappeared, and only competition or power is allowed to impact the decisions that are taken.

In this context, powered by the advancement of technology, information and communication technologies have never been as relevant as they are today. The gathering of data to inform a decision is too easy; we may get 'too much data', or we could be collecting endless data or, even more dangerously, we might be collecting the wrong data. But we can easily collect *data.*

Therefore, every day the social responsibility of Higher Education institutions, and consequently of the science produced and transferred to our wider society, becomes more important. It is not really *what we teach;* it is more *how we teach* in order to prepare for the future … to know how to take a decision.We are living in disturbing times. Higher Education institutions have always been centers of knowledge production; however, this has not always been synonymous with a wide dissemination of knowledge itself. Today, Higher Education institutions not only continue to assume this important role, but they are also forced into a permanent exercise of explaining what scientific knowledge is, and also how to maintain science which will legitimize and contribute to the informed decisions of governments. Decisions, based on scientific evidence which has been ethically achieved, always lead to a more sustainable growth model, and one which is more humanist and ethically stronger.

This is the real difference: understand that ethical values should always be behind valuable scientific advances.

3. The value of ethically-responsible science

Where science is concerned, the proximity to the truth is exponentially greater than the opinion of any guru on a *Youtube* channel or of any status posting on a *Facebook* profile. There are concepts which are unlikely to be explained in 140 characters, and changes have to come from the inside of institutions, at the level of scientific dissemination.

In essence, scientific discovery is sometimes not understood outside of the community that has the tools to comprehend it; this 'lack of pedagogy' is worrying: the compartmentalizing of ideas within institutions, but also particularly the difficulty in communicating in an accessible form. In times when science increasingly needs to be ethically communicated at all levels, we also have to realize that we are living in a society that communicates 'without talking', based on short *memes,* yet reaches thousands and thousands of people all over the globe.

If science is unable to position itself at the center of decision making, we will continue to observe climate disaster, the death of the oceans, and the disappearance of water reserves, exhausting the planet of natural resources; we will continue to live in a world marked by the asymmetry of possibilities, the growing gap between rich and poor, an industry moving away from sustainability standards, where innovation only tends to maximize profit without securing decent work alongside economic growth, and where wars – maximized by the obscurantism generated by the lack of universal access to education – replace the dialogue that would otherwise allow for longed-for prosperity. Yet too many people still refuse to see this situation.

We have recently seen the general acceptance of the term *fake news*. It is not a new concept: the rumour, the intrigue, the distortion of facts and the lie always accompanied the development of societies. The lack of ethics is not a modern trend, but the huge difference is in the scale and the speed of circulation of this 'ready to use' information.

How strong is a *meme*, perceived in fractions of a second, when compared with an *abstract*, which requires intellectual effort from the reader, or the increasingly current request for a *pitch* to express an idea? People rely on *sound bites*, titles, simple phrases, or in just a few words. Where is the science? What is the basis for a discussion or for a constructive dialogue which starts on the basis of a *meme*? For science, this is an even bigger problem: in what terms should we consider the process of disclosure of an investigation, to which the published results will no longer be exclusively confined to a complex system of scientific publication, and is disclosed to an audience consisting of the general public rather than the specialized public, but which still has to respect the intrinsic value of research?

On the other hand, we also know that universities have, for too long, worked just for themselves, assuming that if knowledge is power, the dissemination of knowledge would imply a clear loss of power, or at least a greater difficulty in exercising an unchallenged power.

But this is not a decision of universities. Political leaders globally have always understood the power of knowledge: having an uneducated country is considered, by some, to be a source of power. These times are, fortunately, in the past.

Today, knowledge is recognized as essential for building a solid democracy. The growth of extremism threatens to stifle development, or rather the dissemination of knowledge, with disastrous consequences. Some people, exercising power, refuse to accept, or recognize, scientific evidence, even when it is strong and widely accepted (indeed, perhaps almost self-evident) just to be able to sustain what they call 'economic development'.

4. Universities at the center of a sustainable future

Higher Education institutions now face a double challenge: the challenge concerning their credibility and perhaps even their sense of existence, and a second challenge – also a social responsibility – of contributing to a society that forms true citizens rather than just individuals; with all that citizenship demands, including the obligation to participate in actions taken concerning the future of society, whilst also maintaining a deep ethical thought to be critical, intelligent and responsible.

At the beginning of this paper we considered the impact of the concept of social responsibility, in addition to all of the other sectorial interventions. We now have global challenges on a scale never seen before; these transcend nations and borders, and mortgage the planet, putting into question the survival of human achievements. It is an urgent necessity that we are all aware of the importance of ethically responsible education and scientific knowledge.

This is a Herculean mission, requiring universal access to education, explaining to society what ethically responsible scientific knowledge is, and how to practice science in a way which legitimizes and contributes to informed decisions when the citizen is called to intervene in the public space. Failing in this mission, means that we are all responsible for the failed response to these most pressing challenges and we all become accomplices to obscurantism.

Ethics, science, and society are variables of the same equation; the result of the equation depends on a clear awareness by society that science is part of life and that there is no knowledge without science.

If this is not the greatest challenge to the scientific community, it will, at least, be decisive to the social weight that science will assume in the near future.

If we want to have a 'livable world' in the short term, this challenge has to be won.

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5.
Challenges for BioPolitics
towards a Declaration on BioPolitics

Following the ethical reflection on progress in sciences and their impact on the present and the future of societies, there is a need to translate the consensus reached, at the ethical level, into obligations, at the legal level. This procedure could be supported and surely should be executed at the political level, to assure a general compliance. Besides, and as it was already stressed, public policies, mostly in what concerns scientific advances and technological innovation, depend strongly on a global governance to contribute to an international compliance.

Therefore, the elaboration of a Declaration on BioPolitics, listing the most pressing guidelines for the worldwide management of the new scientific and technological powers, was firstly conveyed as a desirable outcome of this project. This Declaration would give citizens a framework to understand the major questions that are at stake in today's societies, would provide legislators with main orientations for lawmaking, and would help politicians to proceed acting more effectively on behalf of common good.

We do not refer to "biopolitics" following specifically its most immediate and perhaps well-known meaning proposed by the French philosopher Michel Foucault, in 1975-1978 (namely in "The birth of biopolitics", 1978-1979), although it is also present. Foucault introduces the concept of biopower as a new model or strategy of governing populations and life itself, pointing out how political power, then recently enabled by technology, has extended over all major processes of human life. "Biopolitics" refers to public policies regarding the application of biotechnologies to life sciences, controlling life and populations, intervening at the level of every day issues, such as reproduction or mortality, in the name of a major good, such as health.

Going back to the origin of the neologism "biopolitics", composed by the Greek words "bios", meaning "life", and "politikos", meaning what "relates to the citizen or to the state", that is, from the etymological perspective, "biopolitics" refers to the political power applied to life, either in its natural manifestation or in its artificial manipulation by bioengineering. We can, then, refer to "biopolitics", in a broader sense, as the political decisions concerning bioethical issues, that is following the ethical deliberation on the engineering of life. This perspective advocates that the ethical consensus (bioethics) should be legally established (biolaw), and politically implemented (biopolitics) in a process that should unfold at the national and international level.

In this context, a Declaration on BioPolitics, gathering a wide representation, would be highly pertinent. Nevertheless, we ought to recognize that today's societies are shaped by biotechnologies but also, and with a growing impact, by digital technologies. During the unfolding of this project it became obvious that the promotion of an international declaration would have to considerer the two technological lines of evolution. The articulation of both in a single document, if possible, required a broader team and extra time, beyond what was available.

The contribution of *Ethics, Science and Society* to a Declaration on BioPolitics is, nevertheless, important and applicable for a wider declaration on Emerging Technologies – a challenge for a near future.

Maria do Céu Patrão Neves

Ethics in and for Biopolitics

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Abstract

Ethics and politics operate in different spheres. Nevertheless, ethical advice is often sought with regard to policy areas that are particularly controversial, such as life sciences and biopolitics. In this paper, several of the ways in which ethics intersect with biopolitics are discussed: the assessment of political decisions and policy options; ethical guidance in terms of general orientation or operational guidelines; and fostering of a broad societal debate. Furthermore, the pro and cons of an ethical contribution to different political solutions, such as finding consensus, building compromise and relying on fair procedures, are discussed. Against this background, the Author argues that ethics should have a role in shaping science and technologies, particularly in times of moral pluralism, rather than primarily thinking of ethics as setting limits; while at the same time ensuring that we avoid ethics being instrumentalised and misused for political purposes.
Key words: Ethics, biopolitics, ethical guidance, pluralismSetting the scene

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Over the last three or four decades, ethics – and especially bioethics – has flourished in terms of a growing number of ethically relevant issues. One could even say that as with the development of digital technologies, there is an exponentially increasing demand for bioethics. Technologies, which enable people to do ethically controversial things – such as pre-implantation genetic diagnosis or even gene-editing of human embryos; whole genome sequencing of children and adults; or Big Data research in healthcare – are leading to an increasing demand for ethical guidance and biopolitical regulation.

It can sometimes seem that politics will inevitably set up an 'ethics committee' when a contested biopolitical issue enters into the societal arena. Is politics too weak to make its own political decisions, or does it want to pass on moral responsibility to experts rather than to exercise it by itself? Or do politicians actually not know what to do? Don't they have their own ethical awareness and responsibility? Actually, those parliamentary decisions, which are especially tricky in terms of ethical conflicts and pluralism in the area of biology and medicine, are usually left to the personal conscience of each Member of Parliament, so that they are not obliged to vote as a member of a specific parliamentary group, or along strict party lines.

What does this tell us about the relationship between ethics and politics? And what can ethics eventually contribute to good biopolitics, to ensure that both individuals, and society as a whole, flourish?

In the following paper, I will (i) reflect on the 'fit' of bioethics and biopolitics regarding their 'nature'. Against this background I will discuss (ii) the kinds of functions that ethics can have for politics. (iii) The way to find ethical political solutions in times of pluralism will also be discussed, and (iv) I will end by summarising my conclusions.

1. Ethics and Politics: What is their respective nature?

According to a widely established understanding, morals refer to the entirety of values, rules, beliefs and attitudes that guide the actions of individuals and of society as to the difference between good and evil; whereas ethics as a philosophical discipline means scientific reflection regarding morals. Different ethical theories use different measures for the assessment of actions, and they generate and justify norms in different ways.

In the biopolitical arena, mainly descriptive and normative ethics – and not metaethics – are required. The first describes morals that exist in a given society or group. Individuals live according to values and beliefs as to what is morally good or wrong. Normative ethics, by contrast, develops and argues for specific rules, norms and principles, attitudes and beliefs with regard to good actions. It scrutinises: e.g. whether existing norms, which are described by descriptive ethics, are ethically justifiable or not, and why so. Metaethics – to be complete – refers to a more abstract level, of arguing about how we think and talk about morals and ethics: e.g. whether there are moral facts and how they relate to other facts in our world.

Institutions are also ethically examined; but again, they are explored to the degree that they are relevant for their actions. They are judged ethically on whether they enable, promote or prevent morally good or bad behaviour, and enable individuals to flourish.

Furthermore, we judge people and their character as being morally good or bad not only because we value their character, but also because they actually act well or badly. From their actions and behaviour we deduce their character.

To avoid misunderstanding ethical judgements: Ethics is not about single actions, such as 'Frank saved Mike yesterday in Cologne by pulling him out of the water', but about types of actions, such as 'giving birth to', 'killing' or 'saving'.

Politics is something different. It doesn't focus on the moral quality of actions, but on shaping a political community and society by making concrete decisions which are not primarily of an ethical kind, but rather economical, power related, driven by a specific interest or goal oriented in a pragmatic way. Of course, it is preferable if the goal is a good one. But this 'good' doesn't necessarily refer to an ethical good; it can also be, for example, a financial or a cultural good. Nevertheless, politicians – and all human beings – regardless of whether it concerns private or professional life, act in a morally relevant way. As autonomous beings, no one can escape the moral and ethical dimensions of leading one's life, the difference between good and evil, and the horizon of a flourishing or a failing life.

However, broadly speaking, we can say that ethics is about the moral good and the possibility of justifying actions; politics is about common welfare and performing actions. Ethics asks for ends, goals and reasons; politics asks for solutions. Ethics demands arguable means; politics depends on pragmatic ways. Thus, on the face of it, ethics and politics are quite different. So what can ethics contribute to politics? Which function can ethics have for political decisions?

2. What kind of functions can ethics contribute to politics?

If ethics is about assessing types of actions, a first function of ethics could be to assess political decisions, such as policy options, with regard to their impact on actions.

This would imply that ethics is something higher than politics. And as pointed out previously, ethics has only one perspective on politics. Even if ethics has to take into account all relevant circumstances in which a decision is made – such as financial, cultural or legal factors– it cannot entirely cover the political power play, which is typical in democracies. But scientifically-driven developments, shaping all areas of our societies and our lives, are genuinely political questions and only partly ethical ones.

There is another problem: Bioethics seems to be able to justify whatever you want it to justify, when you only choose the most suitable theory. If you take a deontological approach and argue for human dignity concerning the early human embryo, research on human embryos, which ultimately destroys them, or late abortion as a consequence of the presence of Down´s syndrome, is ethically unjustifiable. If you – in contrast – take a utilitarian approach, you might even argue that the killing of a severely handicapped newborn is ethically preferable if you give birth to a healthy child instead, thus maximising the benefit for most of the people involved.

To a lot of people this leads to a perception of ethics as being arbitrary. But arbitrariness in ethics is, in a way, contrary to its nature: ethical statements claim to be unambiguous, reasonable and universal. Ethical norms are meant to apply to everyone. That doesn´t fit situations where some ethicists claim research on human embryos to be morally justifiable, while others assert that it has to be categorically forbidden. The controversy mainly depends on underlying assumptions about the moral status of the human embryo. Whereas some people believe that the embryo is, from the very beginning, a human being and is therefore under the protection of the need for human dignity, others are convinced that the moral status of the human embryo increases with time and with the evolution of particular functions, such as sentience and consciousness. These underlying concepts surrounding the idea of a human being can be debated with regard to their biological implications, consistency, plausibility, and suitability for life. But despite it giving us the opportunity to demonstrate that some of the views are not plausible and are contradictory, I don´t see how it allows us to find striking arguments to support only one single view. Therefore, it is not surprising that different premises and starting positions may produce different ethical outcomes.

Against this background, the ethical assessment and justification of political decisions have limits and dangers, especially with regard to public credibility. Whereas ethics professionals can understand and distinguish premises, arguments and conclusions, and know about the internal structural principles of science with a broad understanding – including humanities and ethics – the public may mostly see contradictory statements and results. There may be suspicions that the ethical justification is only added to this list. Furthermore, political decisions often entail odd compromises or the need to meet legal preconditions, resulting in laws such as those whereby research on human embryonic stem cells is possible if it is financed with private money, but is forbidden when public money is involved – as if an ethical difference in destroying human embryos depends on the way in which it is financed or funded.

A second possible function of ethics, resulting from the assessment of (hypothetical) policy options, is to give guidance. There are two facets of the word 'guidance': guidance as general orientation, as well as guidance in terms of operational guidelines.

Societies want to obtain guidance on how to deal with new technologies, and they expect that politics, not ethics experts, can provide this guidance. At least in democracies, people expect the guarantee that every individual is free to live their life according to their own values. But they want guidelines in order to trust that science and new technologies are used in an ethically sound way. Can ethics have an impact on both – on general guidance and on setting concrete norms?

In biopolitics, the ethical framework mostly refers to human rights, and to European as well as international documents, such as the Universal Declaration on Human Rights and Bioethics, or the Oviedo-Convention on Bioethics and Human Rights of the Council of Europe. A lot of progress has been achieved over the last few decades, including with regard to the protection of study participants in biomedical research and to the protection of persons with disabilities. Nevertheless, there are major and ongoing controversies regarding the most existential questions at the beginning and the end of life. And there are vivid debates on the translation of this guidance into concrete guidelines.

This leads me to consider a level of reasoning that is perhaps not explicitly referred to often enough. I think that these pluralisms, as already mentioned, are mainly based on and influenced by underlying ideas of the human being and conceptions of nature. Every one of us has a more or less conscious idea of what constitutes the human and non-human nature. For example, there are different religious, biological, humanist and postmodern ideas of humankind. Human beings and nature are perceived as an element in a divine order, as a result of evolutionary chance, as part of a social community, etc. Man is framed as having a unity of body and soul, or rather as a neurologically determined being with hardly any free will. Such perceptions influence value hierarchies, norm systems and the choice of assessment criteria. Vice versa, theories influence our ideas of human beings and conceptions of nature – these are the complex references in our history of ideas.

This becomes obvious when discussing research which uses human embryos. To my mind, it is not ethical analysis that is the decisive factor in fixing the moral status of the embryo, but rather a presumed idea of man – either as a unit having a body and being a person at the same time from the very beginning, or of being a person and in addition having specific morally relevant properties that allow for a protection claim growing over time. Consequently, the vivid and sometimes even militant debates, about abortion, research on human embryos, or brain death as a prerequisite for organ transplantation, are 'deputy debates' surrounding the question of what a human being is, and what their moral value is.

A beneficial, though demanding, third function of ethics for politics can be to inform a broad societal debate on the prerequisites and conditions of pluralism regarding images of humankind; thus ideally fostering the insight that someone who holds another position than oneself is not necessarily evil, and that debate can increase tolerance and openness. But there is no function of ethics for politics in preferring one conception of man to the other, beyond what human rights presuppose anyway.

Furthermore, there can be a good contribution to politics in translating the image of humankind and in translating human rights into specific contexts by analysing this context and pointing out the more or less hidden implications and consequences of different approaches and policies. Of course, ethics cannot do this alone, but may combine together with other disciplines involved in this area.

3. How to find an ethical political solution in times of pluralism, controversies and quarrel?

A first strategy, in order to find an ethical political solution for a contested biomedical issue, such as pre-implantation genetic diagnosis (PGD), is to identify the broadest consensus – in terms of the extent of shared persuasions, and of the number of consenting persons or groups. This consensus embraces all values and norms that are shared, without giving up parts of one's own beliefs. For example, many people will agree that PGD should not be used to select an embryo with regard to non-health related features, such as eye colour.

The main objection to such procedures is that this strategy leads to the minimal level of morals – with regard to both the extent of values, and to the level of protecting single values. Those who want to rule and to forbid more, perceive this to be not adequately respected and predict that society will further deteriorate, sliding down a slippery slope. Furthermore, this strategy doesn´t work at all in issues where there is a fundamental dissent, such as the acceptability of cloning for reproductive purposes. Finally, some people are afraid that once standards are fixed as guidelines or even as legal rules, it will not be possible to change them to stronger ones. For some countries like Germany, this has been the reason for refusing to sign and ratify the Oviedo Bioethics Convention of the Council of Europe in 1997.

On the other hand, there is at least a certain standard that can be implemented, and countries cannot fall below this protection standard. Starting from this consensus – knowing that it is a kind of minimal level – refinements and additions can be argued. The process of identifying the broadest consensus alone clarifies the precise point of dissent and differences of belief. This can contribute to tolerance, which means to acknowledge other beliefs without giving up parts of one's own position. This alone contributes to a more peaceful and fruitful understanding and coexistence.

Identifying the broadest consensus is therefore legally feasible and socially helpful, though ethically it may not be completely satisfying for all persons or groups concerned.

There is one specific opportunity for ethical theory to contribute to consensus in regulation, while at the same time allowing for dissent in evaluation: this is by elaborating on different categories of ethical appraisal. Usually the multiplicity of our moral assessment of an action or a person as cruel, helpful, brave, just, egoistic or generous has to be assigned to the ethical categories of right and wrong behaviour. This dichotomous categorization of right and wrong, or good and evil, meets the trichotomous model of deontic logic according to which an action is morally imperative, allowed or forbidden. Are actions, which are allowed, always good? Or is there a third area of moral diversity? To distinguish further categories within the realm of the morally allowed may facilitate agreement on regulating an issue that otherwise might be judged quite differently. For example, various parties can agree to allow research on human surplus embryos – some of them judging it as the lesser evil, some of them finding it desirable. So their different evaluations can be maintained while finding a shared regulation.

A second strategy to finding an ethical political solution consists of striving for a good compromise. A compromise means that at least two parties agree on actions and rules by giving up parts of their own position without being convinced as regards to content. Compromises are indispensable in everyday life and in politics, but they seem to be alien in morals and ethics, because of their categorical and universal claim. Someone who acts according to a compromise acts in a way they are not fully convinced of, whereas someone who acts according to their moral values behaves according to their own beliefs. Compromises are the results of negotiations, whereas ethical norms are the result of reasons.

There are different non-ethical factors, which influence compromises. In politics, for example, an appointment to an office is exchanged for support of a specific element in a legislative process. Friends can agree to go to the cinema, though one of them would have preferred to go the theatre and the other would have chosen a concert. In stem cell research, the implementation of a cut-off date for the import of stem cell lines derived from human embryos – the German way – is a good example of such a biopolitical compromise.

Which role can ethics play in this realm? First, it could try to argue for compromises in bioethical regulation. That´s a dangerous business, because ethics runs the risk of taking a political stance or being corrupted by non-ethical factors. In the long run, this would cause a lack of public trust in, and support of, ethics and science.

Against this background, the contribution of ethics should be a moderating one. Ethics can carve out the ethical implications of non-ethical factors, insist on ethical arguments, and finally consider the result according to ethical measures. So ethics can contribute to clarify and to minimise the ethical costs of the compromise.

A third strategy for giving ethical guidance consists of moving the justification of norm-finding and norm-giving from reasoning to procedures. So the form counts more than the content. A norm is a good norm when it is the result of a fair procedure and not primarily because it is reasonable as to its content of protecting a certain value.

Procedures have a major advantage: different groups, such as scientists, non-governmental organizations, the public and stakeholders can be involved. So many perspectives, interests, preferences and insights can be taken into account. New scientific insight can be included at short notice. Ethics can play a role here which is similar to defining a compromise: it can argue on what steps are necessary, desirable or inadequate, and it can moderate a process, but it definitely has to be cautious not to sell-out its identity. Thus, ethics has to differentiate legal, political, scientific and social aspects in the course of a procedure.

This is all the more the case if ethics is not only involved in promoting the formation and quality of guidance and regulations, but when it is also involved in controlling their application, as is the case in assessment and approval of research studies, or in assessing single cases of pre-implantation genetic diagnosis.

I want to come back to a development that has troubled me for some time. It is the rampant implementation of ethics committees. It may be supposed that their name already conveys an aura of goodness and indefeasibility to the results of their deliberations. All too often ethics is the main part of the label; but ethics is hardly the main part of the content and expertise of the members. If committees are called ethics committees – and I admit that I find it wrong and even detrimental in a lot of cases – it should be guaranteed that they can work according to the principles of ethics and not only serve as an administrational authority. There is no problem in referring to the commissions and committees, such as a stem cell commission, research committee, pre-implantation genetic diagnosis committee and so forth. Here again, in times of a bioethics boom, special attention has to be paid to ensure that there is no sell-out of ethics as a serious striving for a good individual and societal life.

4. Some final remarks

My final remark is dedicated to a widespread misunderstanding of ethics, not only in civil society, but also within sciences themselves. The role of ethics is often regarded as setting limits, so that it is perceived as a hindrance to innovation and progress. Ethicists are supposed to be doubters and, at worst, doctrinaires. Their guiding questions are perceived as limiting questions, such as: Are we allowed to do everything we can do? Where do we set limits to innovation and technological change?

However, the core concern of ethics – at least in my understanding – is different: it is about shaping science and technologies for the good of individuals and society. Ethics should be viewed as the broad normative human enterprise of evaluating what is right and wrong according to universal principles that go beyond, but nevertheless take into account, the subjective experience. According to such an understanding, a common caveat may be resolved; namely that the consideration of values delays scientific progress, and that those who proceed recklessly will be the winners. On the contrary, in the long run, the winners will be those who take societies with them, who let people participate and live up to their values, and who provide ethically sound frameworks for flourishing.

Exactly following this line of thought, ethics is meant to be at the competitive edge of Europe in developing value-based AI, an ethically-aligned AI, AI made in Europe in contrast to the approaches in the US (which are economically driven) and in China (which are driven by state power). Accordingly, the European Group on Ethics in Science and New Technologies (EGE) in its statement on AI, Robotics and 'Autonomous' Systems, focused on ethical principles and democratic prerequisites. The European Commission implemented a High Level Expert Group that shall deliver ethical guidelines for AI building on this statement.

So finally, in order to summarise, what can and what should ethics contribute to biopolitics?

- Ethics can foster awareness of the moral dimension of sciences and new technologies.
- It can contribute to guidance and it can inform guidelines.
- It can allow for consensus and it can carefully moderate compromises.
- It can define adequate procedures and again be involved in carefully putting procedures into practice.
- Eventually, it can foster societal debate about underlying images of humankind, and foster tolerance and respect in times of moral pluralism.

All of this is already a lot to contend with, but ethics should, at the same time, be careful. It should be aware of shortcomings and pitfalls in the political arena, and it should avoid risks of being ´mis´used for other purposes. Only then will it show soundness and deserve public trust.

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The impact of (bio)ethics on public policies

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Abstract

Four general questions will be addressed in this chapter: (1) Does bioethics have an impact on public policies, particularly, on biopolitics? (2) Can this impact be investigated and documented? (3) Should bioethics have an impact on public policies? (4) If so, what are the starting points and the goals of this impact?

The key words used in these questions need further clarification. Here, seven interpretations of 'biopolitics' are distinguished. If ethics is to be more than just window dressing, it should have some impact on policy-making. But impact studies raise both conceptual and methodological problems, which are illustrated here.

If we want to identify and justify ethical requirements, normative points of departure, as well as long-range goals, have to be stated clearly and argued for. Four different long-range goals are discussed, and arguments for human rights based requirements are indicated.

Several of the applications of biotechnology are controversial. Conflicts between values can be difficult to settle, because underlying basic assumptions – illustrated here – are rarely made explicit.

Towards the end of this paper some requirements for the ethical use of biotechnology are outlined, and opportunities to justify these requirements are discussed. In the final section, four challenges for a future declaration on biopolitics are identified.

Keywords: (Bio)ethics, impact, public policies, biopolitics, justification.

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1. Introduction

1.1. *Aims of this chapter*

The general aim of this chapter is to discuss the impact of bioethics on public policy, and to identify and justify requirements for the ethical use of biotechnologies.

Clearly, the breakthroughs in molecular biology have opened up new avenues of diagnostics and therapy in medicine – as well as in agriculture and food production. Some of the applications today are truly amazing and similar to yesterday's science fiction. The list of new and recent challenges is long, particularly in the wake of the development of genetics. Recent challenges in the biotech sector include problems raised by gene-editing, chimera research, artificial wombs, and sequencing of the human genome.

1.2. *Different kinds of challenges*

Many ethical challenges are related to the possibilities created by new technologies. Other challenges are concerned with controversies raised by the interpretation and extension of the precautionary principle and the principle of proportionality (Randall, 2011; Hermerén, 2012) – and of principles, such as the right to information and consent, and to self-determination, as well as to justice and fairness.

Clearly, in debates over euthanasia and physician-assisted suicide, the challenge is not related to new technologies. The issues concern whether patients should be allowed to have a say in their own destiny at the end of life; and if so, on what conditions.

2. Main Problems

2.1. *Four central questions*

Four general questions will be addressed in this chapter:

(a) Does bioethics have an impact on public policies, and particularly on biopolitics?

(b) Can this impact be investigated, identified and documented?

(c) Should bioethics have an impact on public policies?

(d) If so, what are the points of departure and the goals of this impact?

These questions are different. It may be that bioethics has an impact, but that this impact cannot be identified and documented; or it may have an impact that it should not have, or conversely, it may not have the impact that it should have. Or bioethics may finally have an impact, but the effect of this impact may clash with widely-accepted ethical principles.

The key concepts in some of these questions may need some clarification, especially the concepts of bioethics and biopolitics.

2.2. *Bioethics: two distinctions*

Here, I will just make two very basic distinctions between the different types of bioethical discourse. The first is between descriptive and normative ethics, the second between theoretical and practical ethics.

It is one thing to describe ideas regarding what is right or wrong in a given society or group at a certain time, and something else to argue for or against what is the right thing to do in a given situation. The first is a descriptive task; the second is a normative one.

In theoretical ethics, researchers critically examine arguments and the assumptions they are built on, as well as their relations to normative claims, such as the various interpretations of Kant´s ideas of human dignity and their relation to positions taken in the contemporary debate on genetic integrity. The goal is understanding, not a decision.

In practical ethics, however, you are confronted with a situation in which a decision has to be taken (such as with end of life care), on the basis of knowledge of the situation, including diagnosis and prognosis, and the estimated effects of various options, as well as the patient's wishes, situation and motives.

2.3. *Biopolitics: several senses*

A declaration on biopolitics will be very different depending on how 'biopolitics' is understood. It might then be useful to distinguish between several concepts of biopolitics.

(1) *The general sense.* The word 'biopolitics' may be used in a general and untechnical sense to refer to any public policies related to R&D in the life sciences, particularly concerning the access, use and application of life science research in the biotech industry or health care.

(2) *The focus on all forms of life*. This general sense of biopolitics can be developed in several ways, first by replacing the focus on life sciences by a focus on all forms of life (human, animal, plants, microorganisms), whether or not they are the subject of R&D in the life sciences.

(3) *The focus on specific ends.* The general sense can also be replaced by a more specific one, by developing public policies with a particular end in sight, such as to protect and preserve the environment and all forms of life on earth (Vlavianos-Arvanitis, 1996).

(4) *The Neo-Darwinian interpretation.* A very different sense of 'biopolitics' is obviously the study of the biological aspects of political behaviour. This is a research area in political science to which Albert Somit, in particular, has contributed (Somit and Peterson 1998, 1999).

(5) *The anthropological interpretation*. 'Biopolitics' may also refer to a specific anthropological methodology in the study of regulations of the sort mentioned in (1) and (3), and their impact. This approach does not limit itself to studies of policies as texts;

the aim is (to quote Hoeyer) 'rather to follow policies as they translate into practice' (2010:1868). The focus is on who does what and with what effect?

(6) *Foucault-inspired interpretations.* Finally, 'biopolitics' may also refer to the specific concept of biopolitics as characterized by Foucault in a number of works from the 1970s, related to his lectures at Collège de France (Lemke, 2010).

Foucault's somewhat anthropocentric focus is on what happens to human bodies via what is done or omitted by different people, including regulators, politicians, doctors, nurses, judges, researchers, custodians, prison guards and police, when hard or soft laws are implemented and put into practice.

Several combinations of the various senses are possible, and some variations can also be obtained, for instance of (3), depending on whether or not one is willing to make exceptions – for instance – mosquitoes carrying the Zika virus.

3. Biopolitical regulations

3.1. *The preparation of biopolitical regulations in the European Union*

The preparation of biopolitical regulations varies somewhat between countries in Europe. The European Commission has no legal competence in medical research and health care, and member states thus have autonomy in these areas. But given the right to choose health care in other countries (if not provided at home) and the insight that diseases do not respect national borders, dialogues and collaborations between countries in the European Union (EU) are taking place. There is a certain amount of harmonization via European Commission (EC) directives and regulations.

3.2. *… and in a member state*

In Sweden, there is a system of governmental and parliamentary commissions producing reports. In the past, they have dealt with topics such as the criteria for death, transplantation, organ donation, bio-banking and genetic integrity. Since these regulations have implications for what happens to human bodies, they fall under the heading of biopolitical issues, also in the sense outlined by Foucault. Based on such a report, the government may make a proposition to parliament, which may vote to accept or reject the proposition.

Since 1985, the Swedish National Council on Medical Ethics (Smer) has played an important role in the bioethical and biopolitical debate. The main task of the Council is to give advice to the Swedish Government. Its particular mission is to protect and promote respect for human dignity and integrity, particularly in the context of health care, diagnostics, treatment and prevention.

The Council co-operates with similar bodies in other countries and takes part regularly in international activities. Each year, Smer publishes reports and opinions on a number of issues, and organizes hearings and public debates. In the past, the Council has published a book series, including debate books on controversial topics such as euthanasia (1992), the beginning of human life (2000), and genetic screening (2002), as well as a widely-read introduction to ethics (several reprints and editions).

3.3. *Hard law, soft law and ethics*

As is well known, 'hard law' refers to actual binding legal instruments and laws, whereas 'soft law' refers to quasi-legal instruments which do not have any legally binding force, or whose binding force is somewhat weaker than the binding force of traditional law. Many of the resolutions and declarations of the United Nations (UN) General Assembly belong to the latter category, along with professional guidelines and codes of best practice. Soft laws can sometimes become hard law.

Hoeyer (2010) examines the cells and tissues directive of the EU. The Author makes the valid point that seemingly technical directives on safety standards can have ethical, economic and social implications when they are implemented and put into practice. Several conclusions can be drawn from this observation. Hoeyer's conclusion seems to be to question the necessity of the directive he studies.

But a different conclusion could be that we need much more discussion of these implications, more public involvement along the lines of the strategy hinted at in the introduction – and this would help to provide elbow room for ethics in the regulation of the life sciences, especially if the effect is that 'some persons and some risks are cared for at the expense of others' (Hoeyer, 2010: 1868).

Safety requirements are not ethically neutral. They come with costs, both ethical and economical. If they are strict, some will benefit; if relaxed, others may be harmed. Moreover, health care resources are always limited. So, if more resources are to be spent on something (such as safety measures), fewer resources can be spent on something else. The underlying assumptions need to be made explicit for scrutiny and debate, and that applies as well to the choices made in priority setting.

But this also indicates a genuine challenge, which I will return to towards the end of this chapter: to achieve consensus on transnational declarations with some cutting edge. The vaguer the declarations and directives are, the more difficult it will be to agree on their applications and to predict their consequences.

4. Impact of Bioethics

4.1. *Some conceptual and methodological problems*

Many of us do not want ethics to be just window dressing, but to have some impact on policy-making. However, studies on influence raise both conceptual and methodological problems (Hermerén, 1975). First, there is the problem of defining and clarifying different causal relations – including factors related to motivation and choice – and then there is the problem of separating what *looks like* impact from what *in fact* is impact. We all know that correlation is one thing, causality something else; '*post hoc*' ('after this') does not imply '*propter hoc*' ('because of this').

To take a simple example, a national council may propose a legislation allowing research on embryos up to 14 days after fertilization. But the same proposal may have been made by many others. Besides, a government may – regardless of these proposals – suggest this legislation because it is moved by other considerations, such as economic, religious or tactical reasons – for instance, in order to secure support from other parties before an election. Moreover, the impact may be direct or indirect, mediated by many other stakeholders, so there are many pitfalls in this environment.

4.2. *An example*

Having said this, I would like to illustrate what I think is an example of such an impact from my own country. Certainly, I could also have taken an example from the European Group of Ethics (EGE), which I chaired for many years. In the preface to the General Report on the Activities of the EGE during the mandate 2005-2010, the president of the European Commission, José Manuel Barroso, wrote:

> '… the Commission has drawn on the recommendations [of the EGE] to inform policymaking in areas of direct relevance for citizens.
>
> Concrete examples include the societal and ethical implications of nanotechnology as key elements for EU research, the revision of the Common Agriculture Policy, the ethical review of EU funded human embryonic stem cell research projects, the interinstitutional debate on novel food regulation addressing animal cloning for food supply, and the ethical and safety issues of synthetic biology; in all these areas, the Group's recommendations have made a valuable contribution to the work of the European Union institutions.' (EGE, 2010: 5)

But I will use an example from a national council, since this also illustrates some interesting problems.

In 1995, the National Council on Medical Ethics in Sweden (Smer) published a report on assisted reproduction. This report served as the basis for a governmental proposition to the parliament. Briefly, in this report, the Council proposed that the law

1988:711 on IVF (in vitro fertilization) should be changed, so that donated sperms could also be used in connection with IVF. The reason was that the Council did not see any relevant difference between allowing donated sperms to be used in the context of insemination and in the context of IVF – and using donated sperms in the context of insemination was then already allowed in Sweden according to the earlier law (1984:1140) on insemination.

Moreover, the Council argued that just as some men cannot produce functional sperms, some women cannot produce functional eggs; and therefore, IVF with egg donation and sperms from her husband/partner should be allowed on medical advice for women of fertile age. A genetic connection with one of the parents would be preserved in both cases. In 2003 the Parliament essentially followed the earlier proposal of the National Council. The same year, donation of unfertilized eggs was allowed.

4.3. *Accountability and democratic legitimacy*

The accountability and democratic legitimacy of national and international ethics committees has been discussed. In my view (Hermerén, 2009), there is an important division of responsibilities between politicians and council members.

The members have the responsibility to check the evidence and present it clearly and in an unbiased way, to work independently and not to serve the interests of some organization that they happen to belong to, as well as to be honest, open and explicit about their reasons and conclusions. The decision-making politicians may decide to use or not to use the recommendations of such councils or committees, and in either case, they are responsible for their choice.

What about the democratic legitimacy of such committees? Are the members duly elected? Are the criteria for eligibility advertised and known in advance? I would not be surprised if there are considerable variations between the praxis of at least some national councils, in this respect. As far as the EGE goes, there is an identification process, specified in advance, as well as criteria to ensure competence and representativity. The commission is responsible for the process. As in any representative democracy, the elected representatives of the people are accountable for their actions, as well as for their omissions.

Whether bioethics (as a discipline, in the form of a committee, or represented by individual persons) has had an influence on specific regulations is a factual question. But whether this influence is good or bad is a normative question. The answer will, at least to some extent, depend on the normative points of departure; so I shall begin by saying something about them.

5. Normative Questions

5.1. *Points of departure and goals*

If the aim of this discussion is to identify and justify requirements for the ethical use of biotechnologies, it will be important to state the normative starting points, as well as the long-range goals, clearly and, if possible, to argue for them.

Four, somewhat different, long-range goals are:

(1) To apply and implement, promote and protect human rights (to which some may add, animal rights).

(2) To maximize people's wellbeing (in terms of their health and quality of life).

(3) To promote social and societal development (culture, economy, environment …).

(4) To stimulate public debates on threats and opportunities raised by new technologies.

Each of these goals will cover a family of alternatives and can be specified in more detail. They can also pull in different directions and sometimes clash. In preparation for a normative discussion, we should consider questions of interest and power. Who decides? Who gains? Who loses?

In addition to traditional ethical starting points, including various forms of consequentialist ethics, human rights-based ethics and virtue ethics, we should also consider responsibility-based theories, along the lines suggested by the philosopher Jonas (1984). The normative framework will then include personal and societal responsibility, providing a forum for debates on how to regulate advances in the life sciences. This will require a more inclusive and participatory democracy than before, as several writers have argued.

The Oviedo Convention (Council of Europe, 1997), based on human rights, is a useful starting point in the European context. It was published in 1997, was recently revised, and is accordingly now celebrating over 20 years in existence. Human rights can be, and have been, argued for in several ways. Focus on human rights does not exclude considerations of expected utility for the various stakeholders, but can be seen as restrictions on calculations of expected utility.

There are philosophical reasons for human rights, elaborated by philosophers like Gewirth (1978, 1982, 1996), Rawls (1999), Beyleveld (2002) and others, but there are also strategic, political reasons. Politicians usually find it difficult to support proposed regulations violating human rights. Conversely, those who want to gather support for a proposal will have a strong case if they can show that their proposal is consistent with, and even required by, human rights.

It would carry us too far away from the focus of our discussions, given the limitations of space, to go through the arguments for and against these ethical points of departure, their strengths and weaknesses. The main purpose of this section is not to give a telegram-style philosophy course, but make the fairly simple and obvious point that sometimes the choice of the theoretical starting point in ethics will make a difference to the normative conclusion, simply because they are not equivalent and sometimes will clash. For instance, which is more important: promoting the common good or protecting individual rights?

5.2. *Values at stake and conflicts of interest*

There is obviously more than one value, and more principles than the famous four, proposed by Beauchamp and Childress (2013). Examples include: dignity, integrity, privacy, solidarity, health, quality of life, respect for self-determination, the pursuit of a good life, the promotion of the common good, justice and fairness – locally, globally and across generations, as well as protection of vulnerable groups.

These terms are all vague and ambiguous; several refer to both virtues and deontological principles. If principles are ambiguous, they may hide problems. A reasonable approach, recently demonstrated by Patrão Neves (2017), is to work stepwise, beginning with an etymological investigation and then moving on to examine uses in different contexts, in order to pave the way for a more systematic conceptual clarification. Ideally, after such a systematic analysis, the relevant virtues and deontological principles can be identified and presented simply and clearly.

Conflicts between values are not hard to find. Economic interests may clash with concerns for ethics. The aim to maximize profit by commercial companies may jeopardize the long-term protection of public health and of our environment. Monsanto's flagship weed killer, *Roundup,* has been in the headlines of the media on both sides of the Atlantic. It has been claimed that this weed killer causes cancer. Demonstrations have taken place, petitions have been signed.

Value conflicts can be dealt with by reinterpreting the values, or by ranking them in order of importance, relative to the problem at hand (Hermerén, 2008, 2014).

5.3. *Some basic assumptions*

There are some underlying assumptions, which are relevant to this debate on the conflicts between values. Some of these assumptions have been discussed throughout the history of philosophy and since the days of Socrates, and it would be unwise to let a declaration on biopolitics take a position on such issues.

Sören Holm has called attention to two such assumptions:

> 'The first is a discussion concerning the correct analysis of value. Are all values subjective or personal, or are there objective values? Is health good for everyone whether or not they value it, or is it only good for those who choose to pursue it? The second is a discussion concerning the degree to which society or the state is justified in interfering in personal choices, and the legitimacy of different kinds of interventions.' (Holm 2007:210)

The last issue opens up a much larger can of worms in political philosophy. Besides, which choices are purely personal and do not affect others?

6. Requirements for ethical use of biotechnology

6.1. *Initial considerations*

It is now high time to return to the opening paragraphs and the challenge to 'identify and justify the requirements for the ethical use of biotechnologies'.

If the purpose of this discussion is to identify and justify requirements for the ethical use of biotechnologies, and thus to provide more space for ethics in the biopolitical debate, the various ways in which this can be done should be debated, as well as the pros and cons of each option.

Ethical use of biotechnology can be promoted in several ways, for instance via

– International declarations such as the European Convention on Human Rights or the Oviedo Convention (Council of Europe, 1997)
– International committees (such as the EGE, the European Group on Ethics, those of UNESCO, or the Council of Europe)
– National ethics councils, such as those existing in nearly all European countries
– Debates between individuals and groups, also facilitated by social mediaThe first two are of particular interest in this context. Of course, these strategies do not exclude each other, since an important task of the first three options can be to promote the last one; the Danish Council on Ethics is an example of a national council that spends a lot of time and effort on doing exactly that.

The requirements are based on what we want to both achieve and avoid by an ethical use of biotechnologies – so I propose to begin with some general descriptions of the framework needed:

(1) The 'ethical use of biotechnologies' is characterized via a framework, providing principles and guidelines (soft law, regulating conflicts of interest).
(2) This framework is not intended to regulate details. It is based on principles that are to be interpreted when applied to specific situations. The aim is also to promote a climate that favours responsible uses of biotechnological R&D and their applications on people, animals, plants and microorganisms.
(3) The framework in its turn is related to, and based on, politically decided conventions and declarations such as – in Europe – the Fundamental Charter of the European Union, the European Convention on Protection of Human Rights, and the Convention on Human Rights and Biomedicine.(4) Or, alternatively, is supported by recommendations from a national or international ethics council referring to, and using the principles in, the conventions

mentioned in (3), and whose members meet the relevant Nolan Principles (to be discussed below).

6.2. *Identification of requirements*

The requirements outlined here are drawn from, and inspired by, three main sources: the revised European Code of Conduct for Research Integrity, a SAPEA (Science Advice for Policy by European Academies) project on quality assurance of working groups, and the Seven Principles of Public Life, also referred to as the Nolan Principles, defined by the Committee on Standards in Public Life. Of course, there is nothing completely new under the sun. Somewhat similar requirements have been proposed in other texts; for instance, by UNESCO (1997, 2005), the Singapore Statement on Research Integrity (2010) and the Global Research Council (2013).

Since international and national ethics councils or committees can also be utilised to promote ethical uses of biotechnologies, some of the requirements in what follows refer to such committees as a body, others to politicians who elect and use them, and still others to the members of such groups.

We may distinguish between requirements related to substance and to procedures.

(a) Requirements primarily related to substance:

Several of the principles proposed in the European Code of Conduct for Research Integrity seem relevant here too, in some cases with small changes; at least they can serve as a starting point for our discussion. Some of them cover both procedure and substance:

– *Reliability* – in ensuring the quality of biotechnological R&D and its applications, reflected in the design, the methodology, the analysis and the use of resources.
– *Respect* – for colleagues, research participants, users, society, ecosystems, cultural heritage and the environment.- *Accountability* – for decisions from idea to publication and application, for management and organization of biotechnological R&D and its applications, for training, supervision and mentoring, and for wider impacts.

In addition to these principles, some requirements are particularly related to specific ethical points of departure, enshrined in several of the previously mentioned codes and conventions. They include, but are not limited to:

– the obligation to respect *human dignity* – here interpreted as all human beings having the same rights, and the same right to have their rights respected.
– the obligation to promote *solidarity* – that is, the aim is not only to maximize expected benefit, but also to distribute it fairly, paying special attention to the needs of those who are vulnerable or require special attention.

– the obligation to strive for *consistency* – of the value premises used, ensuring that the same standards are used for same procedures, and that no double standards are used.

(b) Procedural requirements:

Which requirements are related to relevant procedures? Here we may focus particularly on the ethics councils involved in promoting or regulating responsible use of biotechnologies.

Some of the principles in the European Code of Conduct for Research Integrity can be understood as focusing primarily on procedural requirements:

– *Honesty* – in developing, undertaking, reviewing, reporting and communicating biotechnological R&D, as well as its applications in a transparent, fair, full and unbiased way.
– *Independence* – individuals and ethics councils or committees, in particular individuals serving on such committees, are elected in their personal capacity and are not influenced by economic, political or religious interests; an alternative formulation of this requirement, then referred to as a principle of *integrity*, can be found in one of the Nolan Principles.

Another essential requirement is:

– *Impartiality* – members of ethics councils, and the council as a body, must act and take decisions impartially, fairly and on merit, using the best evidence and without discrimination or bias.

Some of the principles highlighted in the SAPEA project on quality assurance of working groups are also relevant when it comes to the procedures. For example:

– *Legitimacy* – is essential for credibility; members of ethics councils or committees are duly elected; the criteria of selection are stated explicitly and prior to the members of the group being elected.
– *Interdisciplinarity and competence* – the group is composed of recognized experts from diverse disciplines relevant for the question(s) to be addressed.
– *Openness* – about the roles and responsibilities of the council is important for trust and confidence in the work of the council as a body; the remit of the council is clear and decided by responsible authorities.

A slight variation of the openness requirement can be found in a corresponding Nolan Principle: members of an ethics council, and the council as a body, should act and take decisions in an open and transparent manner. Information should not be withheld from the public unless there are clear and lawful reasons for so doing.

Finally, involving the stakeholders in the process is important to obtain accurate and robust recommendations concerning the best way to promote ethical uses of biotechnology:

– *Fair hearing* – all relevant stakeholders are being heard, exchange of information takes place, and adequate time for consultation is available.

Moreover, in all disciplines there is room for different views on approaches, methods, interpretations, analyses and applications. This has to be taken into account:

– *Differences of opinion* – if there are different views on the options and their consequences, these differences are not hidden; the committee or council strives to achieve consensus, but any significant diversity of opinion between members during the work of the group is fully explored and appropriately taken into account.

6.3. *Possibilities to justify requirements*

Is justification of specific requirements for the ethical use of biotechnologies (R&D and applications) possible? We first need to recapitulate and clarify what, in this context, may be meant by 'ethical use' of biotechnologies.

Let us suppose, in a preliminary step, that whether a particular biotechnology is used in an ethically acceptable way or not is decided by whether it is compatible with the values, needs, aspirations and principles of European society as expressed in documents such as the Fundamental Charter of the European Union, the European Convention on the Protection of Human Rights and the Oviedo Convention.

Then, in the next step, we may ask for specific reasons for particular requirements proposed in the light of these documents. The reasons given will then be a combination of factual assumptions and value assumptions: beliefs that the requirement, if implemented, will promote and protect the values enshrined in these documents. This may be referred to as an intermediary justification.

In the next, and final step, we may ask for justification of the values reflected in these documents. We may refer to this as an ultimate justification. In the philosophical tradition, there are two main avenues of thought relevant in this context: foundationalism and coherentism.

The foundationalists argue that there is a class of basic moral truths or moral precepts, and that the values reflected in the documents referred to above can be justified if they are members of this class or can be derived from one or more of them.

The coherentists deny that there is such a class of basic moral truths and argue that the only way to justify moral beliefs is to check if they are coherent with our other beliefs. Coherence can then be a necessary, sufficient, or both necessary and sufficient condition for justification. Rawls' (1999) reflective equilibrium is an example of a sophisticated method of this kind.

There are different versions of these theories, and arguments for and against both of them. But these theories, and the reasons for and against them, have no place in a declaration on biopolitics. A declaration cannot pretend to be a treatise in moral philosophy. We must leave something to the philosophers and settle here for intermediate justification.

6.4. *Intermediary justifications*

Some of the requirements indicated above can be justified because they are a means to states of affairs that we desire, and others because they can help to avoid states of affairs or situations that we do not desire.

These justifications are instrumental; the requirements are a means to an end, which we consider valuable in themselves. A justification inspired by utilitarian considerations, might be:

– these requirements, if met, will help to promote the maximum common good for society.

This justification can be further specified in the light of classical hedonism – it maximizes happiness; and of modern preference utilitarianism, advocated by Peter Singer (2011) and others – it maximizes interest satisfaction.

But a contractualist and alternative justification, with a Rawlsian twist, can be stated as follows:

– these requirements, if met, will help to promote a society in which I would like to live, even under the veil of ignorance, that is – in a society governed by the principles for distribution of rights, positions and resources I would have selected, if I did not know anything about my health, gender, talents, abilities, tastes, social class, economic situation or ethnic origin.

A more future oriented, and somewhat kin-related, justification might be:

– these requirements, if met, will help to promote a society that we can be proud to hand over to our children and grandchildren, and to their children and grandchildren … and so on in subsequent generations.

7. Towards a possible declaration: some challenges

7.1. *Preamble*

The main long-range goal of this discussion is said to be to identify and characterize the core issues of biopolitics and to pave the way for a declaration on biopolitics.

It may be useful to begin by reflecting on the desiderata of such a declaration. Why do we want a declaration? What to expect from it? What alternatives exist? We cannot expect a declaration of this kind to solve any controversial issue, or prevent misuse or immoral actions. But positively? Of course, it can promote reflection, stimulate debate, and serve as a guideline. But four particular challenges have to be considered:

7.2. *Differences between countries*

If the scope of a declaration on biopolitics is to be European or even global, we have to be aware of the differences between countries in terms of history, religion, economy, culture and traditions. Harmonization may be desirable in theory, but in practice very difficult to achieve. The fact that the ethical debates in Denmark and the Vatican are carried out from different points of departure is hardly surprising, but there are also considerable differences between the ethical debates in the neighbouring countries of Norway and Sweden. The church is much more influential on biopolitical regulations in Norway than in Sweden. If a declaration is to have any chance of being adopted on a European or international level, restraint and some flexibility are called for.

7.3. *Perceptions of the role of ethics*

Historically, of course, research ethics emerged and gained momentum after the Nuremberg trial. The main aim was to protect research subjects from the sort of harm that many had suffered in the concentration camps. The Cincinnati radiation experiments after World War II indicated that the battle was not easy and had not yet been won. But bioethics as a discipline does not, just like many other disciplines, speak with only one voice; there is room for different views, both when it comes to general approaches and to specific issues (Companion to Bioethics, 2001).

For example, some bioethicists propose the idea that there is a duty to participate in research, advocating a policy of 'compulsory research participation' (Rhodes, 2005), a view I do not share. An action can be good and praiseworthy without being a duty. Ideas such as those proposed by Rhodes can be supported by reference to the need to promote the common good, or some other utilitarian arguments proposed in situations when the importance of bioeconomy is growing.

7.4. *Variations in focus*

On top of all this, we must realize that the focus of biopolitical regulation can vary considerably, and we must be prepared to take into account that the issues of concern may differ in many relevant respects. The growing demand for unfertilized human eggs is one such issue, medical tourism is another, a third concerns the markets for human organs, a fourth is conditional approval, currently tried in Japan and some other countries, but also criticized (Sipp 2015; Sipp *et al.* 2017) – yet another issue includes controversies over trends and marketing in food production and protection of the environment.

There are interesting differences between these developments. Neither the economic and ethical costs nor the opportunities are the same. This may be relevant for the work on a declaration. One of these markets – the growing market for human oöcytes – is described in more detail by Waldby & Cooper (2008: 60-64).

7.5. *Distrust of top-down regulation*

An important background aspect is also the current focus on various forms of participatory democracy, and the increasing resistance to various forms of top-down governance. These societal trends must be considered and taken into account, if a declaration on biopolitics is to be a success.

The goals of a declaration on biopolitics may include stimulating debate and providing tools for this debate in order to facilitate personal responsibility and strengthen the democratic control of both biotechnological R&D and economic policy. To some extent, this also means a return to the Socratic approach to ethics (Williams 1985, Halldén 1995). Capacity-building of individuals in ethics is possible and desirable.

The challenge is then to avoid regulating details and instead to propose general principles – while at the same time avoiding the dangers of being too vague, of saying nothing, and then being regarded as a paper tiger (threatening, yet actually harmless). On closer inspection, it turns out that some desirable goals, such as improved public health, are quite complex (Fleischhauer and Hermerén, 2006: 44-56).

However, a recent attempt by a multinational and multidisciplinary group to agree on principles for biotechnology shows that such an enterprise is possible (Root Wolpe *et al.*, 2017). The ten principles they promoted cover several of the requirements indicated here and can be regarded as important steps on the road towards a declaration on biopolitics. Therefore, this document needs to be carefully considered by those who want to work towards such a declaration.

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(BIO)ETHICS, SCIENCE, AND SOCIETY:
CHALLENGES FOR BIOPOLITICS

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