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Research article

Biotechnological Agencies in our Information Society: The Emergence of Biocitizenship and Genetic Language

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Abstract

It is not uncommon to consider deoxyribonucleic acid, most commonly called DNA, as the expression of the genesis and mutation of living species. This molecule is composed of a double helix that carries genetic instructions for all known organisms and several viruses. However, in the Molecular Age, this metaphoric landmark is moved and stretched as we discover and study new structures that impact the genome. Important work is done nowadays in order to understand the consequences and causal relations that intertwine this language and the environment, in many fields such as genetic engineering, bioinformatics and genomic medicine. By giving new access to the architecture that constitutes living beings, technological artefacts and activities translate into a biological shift that opened our lives to new susceptibilities and risks, but also new rationalities and values revolving around DNA. All those technological discoveries inevitably led to a new framework in the Information Society; the Molecular Age. This paper focuses on the new agencies that are constituted in our Molecular Age. From the technology and researches revolving around DNA emerge specific modalities of action in our biosociality. Since genomic-related technologies and researches have constituted DNA as a meaningful structure of signs and symbols we are confronted with the traditional view according to which genomics is the new determinism of the 21st century. On the contrary, however, this paper shows the constitution of new forms of active empowerment based on DNA-related issues and researches. Thereby biological agencies and subjectivities arise from the constitution of a genetic biosociality that provides biocitizens and biocommunities with a discursive, ethical and technical self-understanding, and enables them to gather around the technological and informational meanings that this new knowledge has opened.

Keywords: Biosociality; Biocitizenship; Biocommunities; Postgenomic knowledge; Optimization of life; Ethical agencies

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Special Topic:

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Научная статья

Биотехнологические факторы в информационном обществе: Появление биогражданства и генетического языка

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Аннотация

Нередко дезоксирибонуклеиновая кислота (ДНК) рассматривается как проявление генезиса и мутации живых существ. Эта молекула состоит из двойной спирали, несущей генетические инструкции для всех известных организмов и нескольких вирусов. Однако в молекулярную эпоху этот метафорический ориентир перемещается и растягивается, поскольку мы открываем и изучаем новые структуры, влияющие на геном. В настоящее время проводится важная работа для понимания последствий и причинно-следственных закономерностей, которые связывают этот язык и окружающую среду во многих областях, таких как геномная инженерия, биоинформатика и геномная медицина. Предоставляя новый доступ к архитектуре, из которой состоят живые существа, технологические артефакты и виды деятельности превращаются в биологический сдвиг, открывающий нашу жизнь новым уязвимостям и рискам, а также новым рациональностям и ценностям, вращающимся вокруг ДНК. Все эти технологические открытия неизбежно привели к созданию новой структуры информационного общества – Молекулярному веку. В этой статье основное внимание уделяется новым факторам, которые сформировались в наш молекулярный век: из технологий и исследований, вращающихся вокруг ДНК, возникают определенные способы действия в нашей биосоциальности. Поскольку геномные технологии и исследования представили ДНК как значимую структуру знаков и символов, мы сталкиваемся с традиционным взглядом, согласно которому геномика является новым детерминизмом 21 века. Напротив, эта статья показывает создание новых форм активного расширения прав и возможностей, основанных на проблемах, связанных с ДНК, и исследованиях. Таким образом, биологические факторы и субъективности возникают из конституции генетической биосоциальности, которая обеспечивает биоцианам и биосообществам дискурсивное, этическое и техническое самопонимание и позволяет им собираться вокруг технологических и информационных смыслов, которые открыли это новое знание.

Ключевые слова: Биосоциальность; Биогражданство; Биосообщества; Постгеномные знания; Оптимизация жизни; Этические факторы

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INTRODUCTION

By revealing to us the absolute mechanism of all action, and so freeing us from the self-imposed and trammelling burden of moral responsibility, the scientific principle of Heredity has become, as it were, the warrant for the contemplative life. It has shown us that we are never less free than when we try to act. [...] It is Nemesis without her mask. It is the last of the Fates, and the most terrible. It is the only one of the Gods whose real name we know.

Wilde (1891/1905)

In what is currently called Genomic era or Molecular age¹, advances in molecular biology, genomics and biochemistry have been studied in conjunction with shifts in governance and agency. The theoretical base of those works is that changes in the conception of the biological body had and still have repercussions on the political way in which appears and acts the social body and the individual agent.

The concept of *biosociality* was coined upon the notion of biopower of the French philosopher Michel Foucault, by Paul Rabinow, who is well-known for introducing the work of Foucault in the USA (Dreyfus & Rabinow, 1982; Rabinow, 1984). Biopower is defined by Foucault as “what brought life and its mechanism into the realm of explicit calculations and made knowledge-power an agent of transformation of human life.” (Foucault, 1978, p. 139)

As a result, biosociality refers to the political moment and place where biology includes itself in the social field, as a source of expertise and new practices. With the increasing weight of DNA, it sheds light on the central role of biomedical knowledge in constructing genetic identities and producing (and reproducing) social relationships. Accordingly, it does not only describe our current social framework; Rabinow coined “biosociality” in order to go beyond the banalization of the word “sociobiology”, conceived as a biological metaphor for modern societies. His own concept embodies a form of new social interactions that “will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproduct will emerge, which I call biosociality.” (Rabinow, 2010, p. 29)

Our paper acknowledges this paradigm, but focuses on highlighting how this technological agency led to a biosocial knowledge, where the political power of citizens in liberal democracies is being shaped by the rise of DNA-related researchers and practices.

It is not uncommon to consider deoxyribonucleic acid, most commonly called DNA, as the expression of the genesis and mutation of living species. This molecule is composed of a double helix that carries genetic instructions for all known organisms and several viruses. It is only logical that this expression of mutation and growth, this same coded instruction of development, was properly translated on an alphabetical

¹ This Genomic era (sometimes directly called Postgenomic era) refers to the time period from after the completion of the Human Genome Project (April 2003) to the present day. Molecular Age can also be found: it includes more broadly the rise of the knowledge and practices revolving around genetics, due to the discovery of DNA, and the beginning of biomedicine and of gene editing.



language, based on four nitrogen-containing nucleobases (cytosine [C], guanine [G], adenine [A] and thymine [T]; plus uracil [U] for the RNA). This translation is the starting point to a linguistic metaphor that shows DNA as an alphabet that can be translated through technology.

However, in the Molecular Age, this metaphoric landmark is moved and stretched as we discover and study new structures that impact the genome. Important work is done nowadays in order to understand the consequences and causal relations that intertwine this language and the environment, in many fields such as genetic engineering, bioinformatics and genomic medicine. By giving a new access to the architecture that constitutes living beings, technological artefacts and activities translate a biological shift, opening our societies to new susceptibilities and risks, but also new rationalities and values revolving around DNA. All those technological discoveries inevitably led to a new framework in the Information Society; a (genetic) biosocial knowledge in what is called the Molecular Age.

Consequently, our paper is based on philosophy of technology and medicine, to confront traditional views according to which genomics is the new determinism of the 21st century. On the contrary, it focuses on new structures that are constituted in our Molecular Age, when the technology and researches revolving around DNA roots the emergence of specific modalities of action in our biosociality. As genomic-related technologies and researches have constituted DNA as a very meaningful carrier of signs and symbols, we show the constitution of new forms of active empowerment based on DNA-related issues and researches. Thereby, we claim that biological agencies and subjectivities rise from the constitution of a genetic biosociality that provides biocitizens and biocommunities with a discursive and technical self-understanding, and enables them to gather around the technological and informational meanings that this new structure has opened. We show that this multiform biosociality comes with the emergence of dedicated systems where economics, ethics and politics intertwine.

To this end, we first make clearer the characteristics of the Molecular Age by explaining which political knowledge emerges from genetic advances and what genomic medicine is. In this medical framework, we detail the consequences of the inclusion of a third term between the normal and the pathological: namely susceptibility. We show how susceptibility impacts the paradigm of heredity, hence the individual's actions linked to his own lineage, by introducing the notion of “genetic risk”.

As the individual is part of a political process where the knowledge of genetic defects leads to an ethical responsibility that affects the very notion of family descent and the management of risk, we demonstrate how contemporary insights into genetics foster the emergence of a new political referee; a “biocitizen”, which acts as a decision-making agent in the technical environment that shapes him.

As a result, this biological citizenship is part of a new form of “vital politics”, which re-explores Foucault's sanitary-related biopolitics in the light of genetic advances. This new paradigm sets up a web of previously unheard-of institutions and engages the biocitizen in new social and political actions. In this regard, technology is a new means to communicate around a shared language, DNA, that grounds the emergence of new



biocommunities and platforms and leads to unprecedented forms of active ethical rationalities.

THE BIOLOGICAL SHIFT: HOW DID TECHNOLOGY CHANGE DNA IN A MEANINGFUL STRUCTURE?

The Biovalue of our DNA

There is a whole new consumerism based on the information that can be extracted from our genetic code. We observe the emergence of new private actors that are constituted by very diverse institutions, such as biotech companies, pharmaceutical corporations, data banks, sequencing enterprises... Those new economic structures have opened circuits of capital and investments related to what is called the production of *biovalue* (Waldby, 2000).

But the value of health is not only a biological one, it is also an economic one: health is something affordable (or not), and health services are to be paid for even in the countries where social security is guaranteed. The direct-to-consumer (DTC) genetic testing industry is a good example of the biotechnological value that comes from those institutions. Through DTC genetic testing, “individuals are able to purchase [online] personal genome tests directly from companies supplying both sequence data and interpretation of health risks.” (Kelly et al., 2018, p. 32) We can see here that the consumerism revolving around DNA information drives today’s biosociality precisely because of the importance of the citizen, seen as an active subject willing to take individual decisions on his health, to gather in biocommunities and to judge his condition partly-independently from traditional health institutions.

The Molecular Body of Genomic Medicine

The industry revolving around biovalue is mostly based on the emergence of genomic medicine, for which are developed many DNA-related tasks, such as screening, analysing, stocking, developing and marketing genetic data, tests and targeted therapies. But this genomic medicine is still quite new and ongoing. Historically, it appeared after a biological shift in the understanding of the body, based on the fact that the somatic body and the genetic body are conceived on totally different scales.

20th century medicine inherited from the 19th century a somatic conception of the body: it was seen as a living organism that encloses interconnected organs, tissues, feedbacks, controls, and so on. Michel Foucault highlighted the fact that, in the 18th and 19th centuries, European authorities were preoccupied by illness as it can develop in a social body, and set up strategies to intervene upon them on local spheres, *i.e.* towns, health institutions or families². However, the 20th (and 21st) century show the construction of more complex and hybrid technologies for the management of illnesses

² Naturally, the management of social health by the government in charge goes back before the 18th century; we can think of the political answers that were given in the Middle-Age to the plague (surveillance) and the leprosy (exclusion) (Foucault, 1976).



and reproductive activities, where “technologies” is to be understood both as practices (or techniques, as diverse as sterilization or prenatal diagnosis), and as instruments (such as new vaccines, gene engineering tools or even institutions e.g. data banks).

This biological shift was grounded in the progress of a research field, genomics, that led to visualize life phenomena at the sub-microscopic scale. The perception of life itself became molecularized, with the idea that DNA was the language that contains our digital instructions. As such, technology began to translate this structure, and dilemmas about what we are, what we can do or hope took a “molecular form”. Life was considered as a sub-cellular process, controlled by a genome – whose symbolical and concrete determinism we are only beginning to refute.

Thereby, several scientific facts need to be mentioned briefly to underline the importance of this renewal in human knowledge and genetic understanding, which constitutes genomic medicine and biomedicalization (Clarke et al., 2003).

The Constitution of Genomic Medicine:

As one of the main discoveries, it was understood that the genome of each individual differs, even for twins, and 90 percent of human DNA is “junk”³ – which was unexpected. But one of the more recent, and still-under-study, aspects of this expertise is our growing understanding of epigenetics. Epigenetics is the science of the natural mechanisms that can modify gene expression in a reversible, transmissible and adaptive manner without changing DNA sequence. For instance, the very same turtle egg can give a male or a female depending only on the environmental temperature; in this case, sex determination depends on an epigenetic phenomenon, which will determine the use of genes coding for male or for female, without any internal modification of DNA.

As a result, the development of genomic medicine led to new questions and outcomes. The Human Genome Project (1990-2003), an international scientific research project that intended to index the base pairs that make up human DNA, and to identify and *map* all of the genes of the human genome, is the framework in which genomic medicine found its impetus.

Genomic medicine stands for the reorganization of many illnesses and pathologies along a genetic axis, where DNA is seen as the new force-form of our last decades, which composes an infinite diversity in infinite combinations. “The best example of this “unlimited-finite” is DNA: an infinity of beings can and has arisen from the four bases out of which DNA is constituted⁴.” (Rabinow, 2005, p. 181) It has 3 main aspects: (1) Predictive medicine: it envisions a probabilistic future health history for each individual. (2) Preventive medicine: it places the defective genes in the context of their impact and learns how to circumvent them. (3) Personalized medicine: it treats each individual with their unique sets of genetic predispositions.

³ The molecular biologist Sydney Brenner insists that junk is not garbage. Garbage is worthless and thrown away, when junk is something one store for some unspecified future use. Rabinow concurs; “it seems highly unlikely that 90 percent of our DNA is evolutionarily irrelevant, but what its precise relevance could be remains unknown.” (Rabinow, 2005, p. 183) Another interesting perspective on our genomic “junk” is to rethink, in this specific matter, the notion of function and utility. (Brzovic & Šustar, 2020)

⁴ Theorized by Deleuze, “unlimited-finite” (“fini-illimité”) refers to the third force-form (“formes de forces”); in which something *finished* gives way to a never-ending play of forces and forms. (Deleuze, 1986, p. 140)



In this area, genomics-related researches, as the source of an increase of biological knowledge, are strengthened by new tools and systems. Genome editing tools, for instance, enable us to encode, recode and decode biological materials, like translating “wet” DNA (physical samples) into “dry” DNA (information). DNA-related systems, for their part, are mainly linked to computer-engineering and bio-engineering, like AI-aided medical procedures, genomic platforms, databases, bioinformatics and biobanks. Biobanks for the storage of biological samples; genomics platforms for generating genetic data from biological samples; databases for the storage of genetic data; bioinformatics platforms for the production of clinical information from genetic data (and other raw data). As a consequence, “the “transformation” of scientific research areas, such as genetics, bioinformatics and biostatistics, into clinical specialties has led to the emergence of a new vision of care.” (Stoeklé et al., 2018, p. 311)

Genomic medicine marks a renewal in medicine per se and reorganizes medicine along a genetic axis, by considering the body as a cluster of cells and DNA, *i.e.* as a molecular body.

The Establishment of Our Genetic Susceptibility:

By considering the body on a molecular scale, genomic medicine entails a new way to relate to care that implies to treat people before the (genetic) condition even appears on a phenotypical scale, or to try to prevent this appearance⁵. Therefore, genomic medicine looks for the susceptibility of being affected, *i.e.* looks for a genetic condition that makes a person susceptible to a disease – including in the case of epigenetics (Happe, 2018).

Susceptibility can be thus considered as the third element between the “normal” and the “pathological”, and as the moment where predictive medicine intervenes to calculate the probability of the proto-disease’s development. Although predictive medicine is nothing new in itself, the means of gathering genetic information through the study of DNA was logically unseen before the development of genomic medicine. Until its eruption into real illness, we mostly ignored symptomless proto-diseases. However, genomic medicine reverses this disregard and makes these hints of future troubles central to its diagnostic and therapeutic hopes; as such, it expands the notion of economy of hope (Novas, 2001).

As a consequence, the development of genomic medicine has created a new agent, the patient of a disease which is not here and may never be. Before the pathological state and during the normal state, it permits “to define and diagnose a state of potential disease, or protodisease, and in doing so, to render the person a “pre-patient”.” (Rose, 2007, p. 85) We observe here the emergence of a new form of active citizenship, concerned with his *statistical* health, where individuals can gather information on their

⁵ The identification of a genetic disease may be: (1) Precise, where genetic screening is able to identify the variation of DNA on one’s genotype. The precise identification of a genetic condition does not necessarily lead to the development of a disease, since several other triggering factors may not be expressed. (2) Probabilistic, depending on the identification of genetic markers associated with increased likelihood of being affected, or on the identification through family histories and heredity.



DNA instructions to prevent the onset of a disease, and monitor the malleable *risk* of contracting it.

Thereby, genomic medicine does not erase the fact that we are also subjective agents. On the contrary, genomic medicine helped to deepen our biosocial vocabulary and to create technological subjectivities and agencies, by fostering the emergence of a new citizenship. This unique citizenship must not be understood as something theoretical. It is deeply endorsed by practical factors and theories of action that lead to adapted individual behaviours and unprecedented socio-political forms of commitment. Moreover, this citizenship rarely focuses only on ideas or convictions, but on a previously unheard-of range of genetic discoveries; the main one being the genetic (hence statistical) susceptibility of having a disease, leading to a new agency based on genetic risks.

THE RISE OF BIOSOCIALITY: WHAT NEW TECHNOLOGICAL AGENCIES ENTAIL BIOLOGICAL KNOWLEDGE?

The Computability of Our Genetic Risk

One of the main aspects of this new agency is that individuals are susceptible to be labelled *genetically at risk* for a particular condition, prior to any symptoms appearing. This sends us back to a form of determinism. Indeed, it is sometimes considered that we are facing “the whole-scale geneticization of identity with the consequent reduction of the human subject to a mere expression of their genetic complement⁶.” (Rose, 2007, p. 109) This geneticization argument is strongly rooted in the idea of determinism and fatality, since to ascribe genetic identity to individuals and groups would allegedly reify them. To suffer a genetic predisposition for a disease could be “as if the individual’s nature and destiny was “marked” by this genetic flaw.” (Rose, 2007, p. 197) It could be a total cut in the potentiality to act as freely as possible for an individual.

However, this paper strongly supports that the opposite argument should be examined to understand why this shift in the understanding of our biological knowledge does not only create new (bio) patients, but an entirely new biocitizenship and, consequently, new theories of action regarding the management of our life. But how could a susceptibility to a disease open some technological agencies?

Because it is a statistical risk, only a certain percentage of individuals will suffer the disease on a phenotypical scale, and the timing of onset and severity of most disorder are unpredictable. Therefore, the generation of predictions and their analysis entails a new “biological control”, which strengthen the links between knowing and choosing; feasibility and responsibility to act.

This new responsibility rests mostly on the social significance of any genetic disease. Social is to be understood here as related to one’s family core, mainly but not only on account of heredity. For instance, an individual genetically at risk could want to

⁶ Nikolas Rose does not share this conviction, but he echoes here major technocritic views (Kass, 2004; Lippman, 1991).



avoid transmitting unsafe genes to his children. The individual who is responsible for his health sees at the same time his body through the lens of “genetic inheritance”, which is to be managed wisely. New genetic responsibilities will organize the life action plans of the individual (genetically at risk or not) and of his family. It is a new description of the management of life, where the genetic coloration of life strategies creates new ethical responsibilities, expressed in an increasing obligation to act in the present in relation to the potential futures that come into view. By making pre-patients (patients that have “only” a statistical probability of being ill), genomic medicine allows subjects to anticipate, and give genetic risk a new *computability*, after which to act.

For this reason, genetic images and imaginations, as long with their values and fears, get entangled within the language of self-description and self-judgment that is usually called the “regime of the self”. Individuals are said to increasingly recognize the “self” as the bearer of a genetic risk, around which daily routines and future plans must be organized with prudence. Active responsibility now implicates both corporeal and genetic responsibility: “one has long been responsible for the health and illness of the body, but now “somatic individuals” must also know and manage the implications of one’s own genome.” (Rose, 2007, p. 134) Embodiment itself becomes a place of association concurred by a common understanding of risks, rooted in a new socio-political age of “biological control”. “This means that we can no longer assume that the biological “itself” will impose limits on human ambitions. As a result, humans must accept much greater responsibility toward the realm of the biological, which has, in a sense, become a wholly contingent condition.” (Franklin, 2003, p. 100)

Here, a whole new theory of actions is meet through technology, considered as the medium through which DNA instructions, risks, susceptibilities and agencies are translated. As the genetic knowledge inscribes itself into the heart of corporeal existence and reshapes self-description, it creates new ways of conceiving and acting upon bodies and, consequently, in the field of biopolitics, upon social and political bodies. Therefore, the molecularization of life and the individualization of risk have given rise to a new form of agency and sociality around their management; namely *biocitizenship* (Happe et al., 2018; Rose, 2007).

As such, we will show that the new possibilities that DNA-related researches have opened, for biocitizens to manage their genetic risks or to simply understand it, created a new technological agency around the optimization of life itself, based on a biological knowledge.

The Optimisation of Active Biocitizens’ Lives:

The optimisation of life is not an idea born after the discovery of DNA, but we focus on how it was strengthened by the new modalities of agencies that arose in the last century, and followed both by governmental policies and individual health measures.

In 1950, Thomas Marshall theorized an historical evolution of citizenship. According to him, the civil rights of the 18th century called the emergence of a political citizenship in the 19th century, which led to a social citizenship in the 20th century (Marshall, 1950). This evolution brings about the notion of “citizenship project”; the



construction of citizenship by the authorities through the perception of some (but not all) individuals as citizens, and their specific actions upon them.

For instance; defining those who are entitled to vote, or to adopt children; imposing a national currency, or a single national language, etc. Nowadays, we fully understand that biological theories of actions are and always were deeply inscribed in a political way, as part of any (biological) citizenship projects; e.g. the ideas of race, species, blood line, DNA pool; or the policies around women, motherhood, and family; the controversies about homosexuality, adoption, and reproduction; or the socio-political weight of the notions of heredity, and demography. Numerous citizenship projects were framed in biological terms and this “biological citizenship” can only get strengthened by the current framework that sees the development of a new branch of knowledge revolving around the understanding of genomic instructions and causal relations. But the intensification, in the last centuries, of biological citizenship-related policies necessarily entails the rise of a new subject, the biocitizen.

If indeed there are state-supported public health measures that indicate that biocitizenship remains an issue within the (national) political rationalities, liberal democracies are nonetheless said to promote an emerging “regime of the self.” In this regard, the empowerment of *the* citizen, independently of national citizenship projects, appears clearly of paramount importance. *Biocitizenship* describes a condition where “each individual is engaged as a prudent yet enterprising individual, actively shaping his or her life course through acts of choice, activities that extend to the search for health in the face of the fear of illness, and the management of the risks – now the genetic susceptibilities – of disease⁷” (Rose, 2007, p. 154). While citizenship has long had a biological dimension, new kinds of biocitizens – with new subjectivities, new politics and new ethics – are forming around the biological understanding that genomic medicine and genetic researches provide.

Naturally, this does not concur with the decline of citizenship projects themselves, nor this signifies the complete erasure of sovereign power in favour of pervasive forms of pastoral power. The attempts to “empower” the recipients of medical care are also representative of a global shift: a biocitizenship itself is fostered by national and international policies, as exemplify the notions of “responsible consumption” (Giesler & Veresiu, 2014) and of “active citizenship⁸.”

An active and responsible biological citizen is required to be in life-long training, to perform, to improve himself (especially through consumption), to monitor and manage his health (e.g. with the modulation of his behaviour through sport, diet, lifestyle, and drug regime). This behaviour constitutes what is sometimes called a

⁷ Rose specifies that “biological citizenship is a more general version of what Deborah Heath, Rayna Rapp, and Karen-Sue Taussig have termed “genetic citizenship”: a way of understanding human differences, especially those related to health, in terms of genetic influences” (Heath et al., 2004; Rose, 2007, p. 136). We acknowledge this distinction, but we strongly believe that biocitizenship is all the more so relevant today because of the transposition of the soma *into* the gene. This *biological* shift is the starting point of a previously unheard-of range of socio-political practices and measures. The main example of a major democratic investment towards a disease which is not directly linked to DNA could be the biocitizen fight against the HIV/AIDS (Girard et al., 2019).

⁸ “Active citizenship” is a notion where organizations, enterprises, governments or educational institutions advocate that each and every citizen have roles and responsibilities towards its society and the environment. It is generally used to stimulate the people’s involvement in their communities even when they possess little decision-making power.



“good” (Lee, 2020) biocitizenship. Through genetic counselling, for instance, individuals are placed under the guidance of counselling authorities and encouraged to reflect upon their inherited constitution, with the explicit aim of affecting their daily behaviour. Pat O’Malley labelled “genetic prudence” (O’Malley, 1996) this new field of practices and discourses that introduces distinctions between right (and wrong) ethical choices regarding biological susceptibility. Those socio-political processes inscribe themselves in a specific space of competition worldwide. That is the reason why it can be considered that biopolitics today is less oriented towards health and illness, procreation and capital stock, than it is towards the (bio) *optimization of life itself*, where politics arise strongly and governments cannot be evacuated.

This bio-optimization of life is not just an idea to reduce genetic susceptibility. The main form of DNA-related biocitizenship follows concrete damages that the biological body, understood as molecularized, suffered or could have suffered.

An interesting example of strong biocitizenship endorsed by a government was studied by Adriana Petryna on her work of post-Chernobyl Ukraine. The independent Ukraine based its right to govern on the explicit will of its citizens, who claimed that they were entitled to health services and social support after the nuclear explosion *in the name of their damaged biological bodies*. Petryna (2002) explains that “the very idea of citizenship is now charged with the superadded burden of survival... a large and largely impoverished segment of the population has learned to negotiate the terms of its economic and social inclusion using the very constituent matter of life” (p. 5). Biological citizenship can thus embody a demand for particular protections, and an access to special resources or to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it. This also shows that responsible biocitizenship, or true agency in genetic decision-making, are better exercised from a place or group of cultural inclusion, where the stakes are locally understood (Reuter, 2016).

As a counterpoint, some voices are raised to promote a “bad” biocitizenship, to counter what they call a “coloniality of good biocitizenship” (Kolopenuk, 2020); as such, they underline how the optimization of life results both from a specific culture or government and from a group of subjects.

Furthermore, those aforementioned examples typically clarify a unique characteristic of biocitizenship: each case claims on political authorities and corporate entities are being made *by those who have suffered biological damage*, in terms of their “vital” rights as citizens⁹. The rise of biocitizenship is enlightened by the fact that mostly prejudiced people are likely to undertake any fight against genetic conditions; even if susceptibility to genetic risk, given their number, is universal and diverse.

⁹ This mention does not imply that only biocitizens genetically at risk feel concerned by the genetic optimization of life itself, but underline a general trend. Neither does it try to erase important reflections on biopedagogies and rescue missions, that demonstrate that an health imperative to save “bio-others” (Rail & Jette, 2015) can be promoted by private and public institutions and organizations in neoliberal societies.



The Biocitizenship in Our Information Society:

As a consequence, our information society is one of the spearheads of biocitizenship. It expands the place where responsible biocitizenship is a “local” issue by expanding the places where to exchange and gather. This major element echoes our current postmodern paradigm, where the “right to know” is seen as intrinsically linked to the enlightened exercise of active citizenship. Although this right is usually fostered by mass-media, biocitizenship also involves the collation of specialized scientific and medical sources; usual forms of activism such as campaigning for better treatment, or for the education of the population regarding a genetic condition.

It also shows the emergence of a “digital biocitizenship” (Petraçaki et al., 2021) that uses the Internet for sharing experience and making kin. With the help of contemporary information and communications technologies, biosocial dynamics are spread through online gathering platforms or social media, helped by new digital tracking devices and apps, and analyzed through quantification and agent-based models (Costa, 2021; Dyer, 2016; Sharon, 2017). Under the current circumstances of the COVID-19 pandemic, we see a demonstration of this digital biocitizenship that was promoted both by governments or citizens, for instance with the use of contact tracing apps and geolocation apps, and the creation of long covid support groups or post-covid syndrome groups (Convertino & Pileggi, 2021; Tadić & Melnik, 2020).

Those forms of democratic participation incidentally blur the boundaries between public and private interests by promoting a horizontal formation and distribution of knowledge. As a consequence, biocitizens are not “alone, required to cope with their fate only with their own family, accompanied by the advice of experts, the solitary reading of informative material. [...] It is not the fate of the citizen genetically at risk to be an isolated atom” (Rose, 2007, p. 144).

Nowadays, communication technologies and the aforementioned access to information make new forms of sociality possible, which led Frédéric Keck to make this interesting comparison: “No doubt the genetic maps of the individual body (linkage, physical, and sequence) [...] have replaced the totemic maps of the collective territory [...]. But the map is still the form of knowledge that enables us to find our bearings together in an unknown area: it provides landmarks, grips, shared markers.” (Rabinow, 2010, p. 41) It is in this mention of shared markers that lies the basis of how any technological structure addresses theories of action; through the communication between agencies and the creation of new active structures. As biocitizenship is a proper modality of action, mostly restricted in size to prejudiced people and their families, there is a special need for active gathering through biocommunities.



A SYSTEMIC BIOSOCIALITY: HOW DID THE EMERGENCE OF NEW ACTORS REACH OUT TO NEW ETHICAL RATIONALITIES?

The Emergence of Biocommunities as Structured, Operative and Discursive Agents

As a shared map, sociality is by definition intrinsically linked to the formation of groups or communities. As we said, Rabinow proposed the concept of “biosociality” to characterize these forms of collectivization organized around the commonality of a shared somatic or genetic status. Biosociality embodies not only a new paradigm, testifying of the implication of DNA both as a symbol and as matter in the lives of individuals. It gathers also group members united by a common (and somewhat new) “relationship” with their DNA. Where we had national “biological citizenship projects”, we now see the emergence of “biological citizenship communities” (*i.e.* biocommunities), whose concern about biology (and mainly genetics) is more grounded in one’s socio-political life. Those biosocial communities of active biocitizens have key roles in the structuration and the translation of genomic knowledge in the 21st century.

Biocommunities are forming through physical meetings, but also on the Web. As such, information technology itself is the language that translates another entangled structure, DNA, for different agents to understand it. Generally speaking, the Internet has been a vital tool for the development of biosociality; be it for the online availability of DNA-related information and products, or for forging those translocal biocommunities gathering individuals willing to engage in the process of biomedical self-shaping. These new de-territorialized “body-geographies” challenge local cultures of health and traditional aetiologies of disease. “A key feature of the Internet is that it does not only give access to material disseminated by professionals, it also links an individual to self-narratives written by other patients or carers.” (Rose, 2007, p. 142)

The aims and reasons to gather in biocommunities are diverse: pre-patients who share a genetic condition or a high probability to trigger it; support groups for the families... Yet, they all function with the common feeling that an active biomedical citizenship is to be raised and voiced around “technoscientific illness identities” (Sulik, 2011; Wehling, 2011). For instance, during the parent-led conferences organised in the UK between 2007 and 2010 *around the 22q11 deletion syndrome*¹⁰. This can seem too precise a genetic condition to be believable, but this example shows the kind of groups that are constituted on the basis of technologies that efficiently shed light on a few numbers of genes.

At the beginning of the nineties, Rabinow noted that “there already is, for example, neurofibromatosis groups who meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on” (Rabinow, 2005, p. 188). He also suggested, as the aforementioned example rightly confirms, that

¹⁰ This specific example was described, observed and reported as part of a multi-sited ethnography in the article *What Binds Biosociality?*, which allows it to be easily accessible (Dimond et al., 2015).



“it [was] not hard to imagine groups formed around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution.” (Rabinow, 2005, p. 188)

Biocommunities gather information and expert knowledge by themselves (doing DNA sequencing, studying the reports of medical trials, sharing and voicing other citizens’ experiences of the same condition, and so forth), rather than referring only to traditional medical instances, *i.e.* doctors, hospitals. The role of patient communities in civic societies have been well documented in raising awareness of little-known medical conditions, explaining to the public medical terms and categorizations inherent to the genetic vocabulary and knowledge; and campaigning for access to research funding and healthcare resources (Allsop et al., 2004; Swan, 2012). As another example, we also see the emergence of theories of (genetic) victimization, which try to revitalize biocitizenship and empower biocommunities by studying how genetic influences might be related to the odds of being victimized (Beaver & Joyner, 2021).

DNA is seen as a code giving very diverse instructions and advices about the structuration of one’s life. As such, individuals are empowered through the formation of translocal communities, engendering a sense of kinship, where protection and support are offered, differences normalised and values reproduced.

The Ethical Rationalities of the Biological Power:

Within those new forms of genetic citizenship, individuals and groups have made their biological existence a matter of ethical concern and a basis for political action. Between all those actors, some new ethical rationalities¹¹ must be discussed.

Rose called the biocommunities “ethical pioneers” (Rose, 2007, p. 146), as they open a way through the still unknown land of genetic citizenship, and enters exactly in the sub-governmentality¹² that was theorized as “technologies of the self”. Technologies of the self, of which the ethics of biocitizens and biocommunities pertain, refer to practices and strategies by which individuals demonstrate their own ethical self-understanding. And indeed, the actions of biocommunities do not aim at a general ethical moratorium but at the daily management of a condition (or a pre-condition), and at the freedom of decision-making processes. Mitchell Dean (1999), who considers that neoliberal governmentality rests upon the production of a particular kind of subject who understands himself in terms of making (wise) choices, and thus in terms of individual responsibility, noticed that we are now compelled to “make choices” about our health. As such, the categories of susceptibility, risk and genetic disease have become vehicles for the self-production and exercise of agencies endowed with the faculties of choice and will.

Hence, the ethics of those “pioneers” forms a counterbalance to the ethics of official health-related systems, such as national bioethics committees¹³. This situation

¹¹ By “ethical rationalities” or “ethopolitics”, we do not mean to discuss the evolutionary perspective on morality, such as the development of altruism and empathy. (Riley, 2021)

¹² “Governmentality” is a concept invented by Foucault in his lectures at the Collège de France to describe the organized practices (mentalities, rationalities, and techniques) through which subjects are governed.

¹³ Bruce Braun notes that bioethics is “a professional field which always seems to arrive too late, after biomedicine, biotechnology and finance capital have ushered in the future, and thus can act only to incorporate new biotechnological realities within law” (Braun, 2007, p. 13). However, we do not disregard the importance of official



may be compared to the ethical management of the Internet; where isolated citizens (users, tweeters, hackers, hacktivists...), groups of citizens (Anonymous, WikiLeaks...), and multinational companies (Google, Facebook, Amazon, Apple...) indisputably replace national governmentalities.

According to Nikolas Rose, this situation implicates a shift from a biopolitics of populations to an ethopolitics characterized by the individual management of the biological self. “I have suggested that we are living in an ethopolitical age, where issues as diverse as crime control and political apathy are *problematized in terms of ethics*. No longer posed in the languages of justice, welfare, or equity, ethopolitics here is about the value of different forms of life, styles of life, ways of living, and how these should be judged and governed.” (Rose, 2007, p. 97) As a direct consequence, the molecularized body has become the site of different political rationalities, gathered around the concept of “(bio) security”.

On this question, the perspective of Bruce Braun raises interesting questions. Braun considers that the current situation overtakes the concept of ethopolitics, because the management of life is intimately related *to the exercise and extension of sovereign power* (Braun, 2007). We can infer from it the rise of an independent exercise of choice-making process – independent even from ethics. Bruce Braun projects this situation on a very global scale, which includes the environment. He reminds us that Bernard Vallat, Director General of the World Organization for Animal Health (OIE), considers that we are now immersed in the “great biological cauldron” of the 21st century, where biology is virtuality (the opposite of determinism), and where the future is less about “care of the self” than it is about imminent catastrophe to manage.

This is the reason why several major ethical works turn towards the sociology of risks (Castel, 1981/2011; Chateauraynaud & Torny, 1999; Collier & Lakoff, 2004, 2008b, 2008a), as “the apparatuses that inform on the perception of environmental threats and set off collective forms of rallying.” (Rabinow, 2010, p. 44)

The length of this article prevents us from making an expeditious analysis of the balance between ethopolitics and sovereignty – if we are to understand sovereignty as the full right and power of a governing body over itself. However, if we are to understand sovereignty as the exercise of power by a state (as it is the case in international law), we already explained that governmental biocitizen projects are an important part of the biopolitical management of lives. But we also demonstrated that biosecurity itself was implemented not only by official authorities but first and foremost by biocitizens and biocommunities. As such, we can conclude here on a shift on health “cultural authority” (Epstein & Timmermans, 2021), from the social authority of physicians to the proliferation of new forms of agency, information and ethopolitics regarding health-related issues.

bioethics committees, which are becoming a necessary supplement to the imperatives of political decision making concerning the biological and social life (Wahlberg et al., 2013). They intend to fill the gap between economic imperatives and ambitions, clinical demands and citizens’ claims to treatment and rights to health “under conditions of moral uncertainty and lack of consensus.” (Rose, 2007, p. 97)



Therefore, we strongly believe that the balance between ethopolitics and state governmentality also depends on the position of private corporations and companies that strengthen the consumerism around this new biovalue that DNA embodies.

As the fertile ground for new ethical rationalities, DNA-related information and technologies meet theories of action and agency because genomics is a totally new field for ethical self-problematization. Genes themselves have been constituted as a language, which does not mean as an alphabet, but as an “ethical substance [...] working in relation to the self (genetic identity, reproduction, health) and in relation to others (siblings, kin, marriage, children).” (Rose, 2007, p. 125) Nevertheless, not just anyone can participate in building this ethical and informational web, since the growing availability of medical information on the Internet and the activism of biocommunities does not compensate for sometimes expensive scientific testing, like diagnosis or gene sequencing.

CONCLUSION

The growing knowledge we gathered on our genome those last decades impacted us in what it means to belong to our societies and act in them. The “discovery” of our DNA and of its complexity has made us genetic individuals, pertaining to new forms of democratic agencies and ethics, and created in response the rising field of biosociality. Genomic-related technologies meet theories of action because genetics is a totally new field of communication, action, consumption and values, where DNA is a proper language. Not only an alphabetical language with four nucleobases as letters, but also the support of very meaningful signs and symbols, for societies to build biosocial knowledge and power, for agents to communicate and act on, for governments to make jurisdiction on, and for more structured communities to emerge on. Here, we see the roots of the etymological meaning of “symbol”, as the Greek *symbolon* first designated a “sign of recognition”.

Since we showed that this biological shift has socio-political consequences for the ways in which individuals are governed, and the ways in which they govern themselves, we believe that criticisms posed in terms of genetic determinism may fail to recognize a significant change that occurs in the conception of life itself. In tracing out, experimenting with, and contesting the new relations between ethics, power, and economics, “active biological citizens are redefining what it means to be human today.” (Rose, 2007, p. 154) This human agency rests on the overcoming of deterministic biological structures, led by an emerging form of power that modern knowledge and researches about postgenomics entail. The active biocitizenship is not only based on the possibility to anticipate known genetic diseases and to gather in biocommunities, but on the framework of biological ownership and self-understanding – even of our genetic risks. The aforementioned changes that are now at stake in our politics are indeed reflecting ontological modifications in the understanding of mankind. Moreover, this evolution is encrusted in the development of hitherto unheard-of technoscientific tools. As an interesting starting-point for metaphysical debates, we can suggest with Nikolas



Rose that, in this process, “the human becomes not less biological, but *all the more* biological.” (Rose, 2007, p. 20)

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