Genetic prophecy and subjectification, the doctor’s appointment

Then I find myself back in a hospital consulting room. With me, in the room, the person organising my medical follow-up and the doctor who treated me - and saved me - 32 years ago. The doctor then asks for my consent to join a study: 'Your genome will be sequenced and then compared with those of other people with similar medical histories, so that we can identify the regions of the DNA associated with the different long-term consequences you experience. This will allow us to work towards a more personalised genomic medicine'[1]. For him, a formality: ask for my consent because he has to, get it in an instant and go ahead with the study. However, I refuse. This refusal takes us both into unexpected spaces, where our ways of understanding the world stop overlapping. Suddenly, the room is filled with affects, mine and the doctor's, which we tend to repress or ignore in these cold rooms. Faced with a representative of the medical institution, we can be shy, hesitant, even sometimes submissive. Perhaps we are intimidated and find it difficult to think straight, to be present and attentive. At times, it’s only after closing the door that we realise we would have liked to ask this or that question, to say something or the other. Anger, sadness or fear often only emerge at a later stage. Doctors can be a bit cold, dry or too technical, maybe condescending or authoritarian – we sense their frustration towards our questions or doubts. Most of the time, all this is rather suppressed, only slightly noticeable. On that day, I am scared, nervous and short of breath when I verbalise and try to explain my refusal. The doctor is, in chronological order, shocked, irritated, angry, then condescending and finally resigned. Let us unfold the moment and the situation.

In 1989, I was 11 years old, diagnosed with acute lymphoblastic leukaemia. Later, I told myself that modernity (capitalism and technocracy) had made me sick and then saved me. The south-east of France, at that time, was a territory where the radioactive cloud from Chernobyl had been contaminating the air, water and soil for already three years, as in most European countries. Add to that some regular bathing in a river fed by the waste of local industries... who knows what caused this leukaemia? But what seems certain is that the treatment the doctors used to cure it saved my life. At least there and then. The heavy treatment of chemotherapy and then the total body irradiation to prepare for a bone marrow self-transplant had multiple consequences on my body and my health: gynecomastia (when a cis-man[2] develops breasts resembling those of a ‘typical’ female body), various hormone levels that do not correspond to the 'normal values for men' (testosterone too low, follicle stimulating

1 The first objective of the study is, and I quote from the study’s website: 'to identify predictive factors of long-term sequelae of chemotherapy or bone marrow transplant treatments in children with leukaemia.' (https://www.cryostem.org/fr/partenariats/).

2 *Cis* people are those who identify with the gender and/or sex they were assigned at birth. That is, the majority of the population for whom the gender (social) and the sex (biological) are aligned. The term *cis* is therefore used in contrast to the term *trans*, which refers to people whose gender identity does not match the gender and/or sex they were assigned at birth. These gender/sex and social/biological dichotomies are discussed later in the text.

hormone too high, cholesterol and triglycerides too high, inhibin B too low), infertility (azoospermia, i.e., my body produces around zero spermatozoa - my sperm is unoccupied), cataract, etc. All these deviations from the norm were, generally, not that difficult to live with, although they seemed to be the source of much concern to my various doctors, depending when and where. In contrast, my recent thyroid cancer, a fairly common consequence of total body irradiation in childhood, was more difficult to deal with. There was something dizzying about this second cancer: cured by the removal of an entire organ (the thyroid - the base of my neck is unoccupied) and then by a treatment that was itself carcinogenic (radioactive iodine) and finally by a lifetime of medication (thyroxine, calcium, vitamin D)... all caused by the toxicity of the treatment of a previous cancer. A *mindfuck*.

Back in the consulting room, the doctor realises, half-way through his explanation of the study he is proposing, that I am not particularly enthusiastic. However, when it comes to say no and argue, I am petrified and wobbly. There is a certain familiarity in the atmosphere: at school facing the teacher, on the street or in a squat facing the police, at home facing the parents, unemployed facing the job centre officer... As a former biologist, I have been reading, writing and running workshops on genetics and its political aspects for several years. I am generally not afraid of scientific jargon, I can grasp the jist of a medical research paper. Yet my heart is pounding, my hand is clammy and shaking slightly, the words are hardly coming out.
What happens at the moment of the refusal is not part of the scenario for the doctor, we are no longer in his practice of medicine, in his understanding of well-being and what should be the relationship between carers and patients. The 'no' was not thought of, not expected, not even planned (later, when I went for my blood test, the hospital staff was going to take additional blood to sequence my genome; I had to check and tell them again that I had not given my consent). The doctor is stunned. I can see his jaw open, gaping and silent, under his Covid mask. Like when we are so surprised that we can't find the words, we fidget in our seats, move our hands incoherently, start but don't finish our sentences, wide-eyed... I want to articulate so much, but I find myself only arguing about the potential flaws around privacy of these public health databases like the one my genome would end up in. The doctor recovers fairly quickly from the initial shock and switches to a more offensive mode. The blackmail begins: 'But that's a shame. With this study, we will be able to help people, to understand better... You have a very specific profile, and if there are not enough people with your profile in the study, then it won't work statistically, we won't be able to find those important regions of the DNA'. I am both ungrateful and selfish. I have been saved by science and medicine, twice. And this is thanks, in part, to people who probably agreed to participate in clinical trials to develop the treatments that helped me stay alive. How could I refuse to give back? Hesitantly, I try to express that I have 'political problems' with this idea of personalised genomic medicine, which implicitly means, because I do not formulate it, that this refusal is not due to

a lack of solidarity with my comrades who survived childhood leukaemia, but to a criticism of the choice of a very specific direction of medical research and care, that of genetic reductionism[3] and of technoscience. This is the signal to move on to other affects: 'Well, what a shame... what a pity. Well... too bad... All right. So, can you now go and lie down so that I can examine you. That is, if it's not a 'political problem' for you, right?'. Here comes again the father-professor-policeman, with his condescending sarcasm and the familiar silent anger he has always provoked. I point out that if 'no' was not a possible answer, then the process of seeking informed consent did not make much sense. The doctor has little choice but to approve. Perhaps he had never thought of that?

What is at stake here, it seems to me, is a certain idea of the body, the subject, and extractivism. Extractivism is the massive exploitation of the resources of nature or the biosphere. There is of course the global, capitalist extractivism of land for oil, minerals and other materials. But we are also possibly living in a regime of extractivism of bodies.

In my research, what I question are the imaginaries conveyed by biology, medicine and genetics. Modern biology is a science in the image of modernity, i.e. obsessed with classification, compartmentalisation, separation, detachment (from oneself, from others, from the earth) and quantification. It was and still is largely based on a *centring* desire – the ontological[4] centrality of Western scientific knowledge, anthropocentrism, the central notions of species, individual or gene as primary entities of biology, the idea of the genetic programme and DNA as the matrix of the living etc. A desire to *centre* associated to a vision of organisms as machines, which has made us the engineers of the natural world. The choice of a reductionist biology centred on the obstinate search for the fundamental particle of organisms, THE single molecule that would be the source and goal of all living processes, has logically led to genetics and DNA becoming the hegemonic framework of interpretation for all the life sciences. Yet, genetics, as all human activity, is a situated practice. It is influenced by, and in turn influences, its epoch - the social, political and economic contexts and the power relations within it. Throughout its history, it has strongly contributed to the inescapable vision of

3 A vast subject. Genetic reductionism can be understood in two main ways. First, it can be understood as a way of looking at the world, i.e. ontologically (see footnote 4): all biological processes can be reduced to a limited number of causal units (e.g. genes or, ideally, elementary particles). These primary causal units are seen as the determinants of everything else. In short, what is important to explain living things is DNA. The rest (the body, the environment, their interactions, etc.) is of little importance. Second, It is also a scientific method, based on the belief that all forms of knowledge can ultimately be reduced to the results of a fundamental discipline. In the context of biology, this epistemological reductionism (epistemological = having to do with the production of knowledge) would be the belief that ultimately all biological knowledge can be reduced to genetics or translated into genetic terms.

4 The term ontology is used here as that which defines what the world is made of. It is a set of representations, beliefs, ideas, certainties, which define the reality of a time and a place, and which have the particularity of being so fundamental that they become invisible, almost impossible to question. Therefore, the ‘ontological centrality of Western scientific knowledge’ refers to the way all the sorts of knowledges (and methods of inquiry) that are different to the occidental and Western kind are considered to be at the margins, to be less legitimate or less “true” (random example, the accumulated knowledge and practice of water diviners).

progress, industrialisation, manipulation and (the illusion of) control of the living, a deterministic vision of the organism, eugenics and colonial projects. Genetic reductionism, especially in medicine, allows us to ignore the real social conditions that affect us and to biologise our diseases, behaviours or mental states in order to make them 'natural' and immutable or, at the very least, strictly under the responsibility of scientists and experts. All of this while it is justifying ruinous programmes of speculative biotechnology research at the expense of, for example, social interventions in public health. But genetics has also played a role in shaping how we perceive our bodies and our identities. One of the ways in which this shaping has occurred is through the mobilisation of some of our deep-seated fears about health: fear of disease, fear of suffering, fear of not knowing the future, fear of the unpredictable, fear of death - in short, and ultimately, fear of the body. So here is the 'theoretical' framework of my critique of biology. What remains of it after it has been put to the test by the 'doctor's appointment'?

I have been struggling with a text by Tiqqun, *The Cybernetic Hypothesis*, for some years now. Over time, it is an essay that I have found useful to the understanding of neoliberalism as *cybernetic capitalism*. I was particularly struck by this passage:

> 'Cybernetics thus emerged as a simple, inoffensive theory of information, a theory for handling information with no precise origin, always potentially present in the environment around any situation. It claims that *the control of a system is obtained by establishing an optimum degree of communication between the parties to it*. This objective calls above all for the continuous extortion of information — a process of the *separation* of beings from their qualities, of the production of differences. In other words, as it were, mastery of a uncertainty would arise from the proper *representation and memorization* of the past … Cybernetics is the project of recreating the world within an infinite feedback loop involving these two moments: representation separating, communication connecting, the first bringing death, the second mimicking life.'

After a certain amount of ramblings and divagations around these propositions, I thought about the way we are shaped as humans. About everything that is extracted from us, then processed and ordered, only to be returned to us, re-incorporated, to re-create us as new subjects. A sequence in three acts which, for me, quickly made sense. What is extracted is taken from our knowledge, our skills and our creativity as well as from our bodies and their parts, but also from our behaviours, our relationships, etc., i.e., extracted from elements and *qualities* that contribute to making us the *beings* we are (Act 1). This stage empties us, *bringing death*. What has been extracted is then catalogued, processed, sorted, arranged and

ordered according to specific and situated criteria, it is a stage of rearrangement and hierarchisation (Act 2). What has been extracted and ordered is then reintroduced into us, *fedback* (Act 3). We have been emptied and then refilled with pre-ordered content. This is the stage *mimicking life*, it recreates us.

The three-act movement appears clearly in the case of digital subjectification[5]: everything in our lives that is mediated by digital devices (shopping, relationships, mobility, health, desires, photos, tastes, interests, leisure, travel...) is captured, extracted and transformed into data (Act 1). This also applies to various skills or ways of being in the world that we literally hand over to the devices: orientation, learning and research, memorisation, organisation of time, socialising, political organisation... Then all this data is stored, analysed, processed, standardised and ordered, often to be sold to third-party companies. Correlations, patterns and regularities are sought through – and for the creation of – algorithms (Act 2). Finally, the interpreted data is fed back to us in the form of *nudges* (behavioural incentives[6]), advice, specific content, personalised advertisements, social media bubbles, injunctions, and the creation of needs to influence our behaviours, choices, decisions, votes, desires, impulses and perceptions of ourselves (Act 3).

I found this model also useful in describing how sex and gender are co-constructed. This refers to the construction of the binary system of biological sex, i.e., the way in which society and science produce identities and an understanding of the world in which one of our most important characteristics as human beings is to be a man or a woman, and only one of these two possibilities. In a first stage of extraction (Act 1) bodies, especially those of newborns, are *read* by medical and scientific institutions (the self-proclaimed experts in the interpretation of bodies). This stage has become so fundamental, so ontological, that we no longer even notice it. However, it becomes particularly visible in the rare cases of bodies that do not fit local cultural stereotypes of what a male or female body should be, such as in the case of so-called intersex bodies – where less symbolical and more concrete kinds of extraction can be carried out, such as an assessment of the shapes and sizes of genitalia and other anatomical parts, measurements of hormone levels, identification of chromosomes or certain regions of the DNA etc.
In a second stage of arrangement and ordering (Act 2) the data that has been extracted is evaluated and categorised (girl or boy), most of which is associated with certain values or qualities. The ordering stage is what we call patriarchy, the symbolic and hierarchical organisation of what is supposed to be a man or a woman. When a newborn's body is judged

5 How the digital industry, its devices and technologies shape us as human beings, as subjects.
6 *'Nudge* is a so-called 'soft' technique that combines psychology, behavioural studies, marketing and politics. It aims to influence behaviour in a predefined direction, by identifying cognitive biases and the conscious and unconscious levers to be activated in individuals'. (https://planetenudge.fr/)

as non-conforming, an example of data ordering method is the 'Prader classification' (or its satirical and activist version of the Phall-O-meter[7]) which, based on the size and shape of the genitals, creates five intermediate categories between the two 'stereotypical' or 'normal' forms (male and female) in order to classify intersex people. Finally, in a last and third step (Act 3), once the data has been extracted and categorised, not only biological sex but also gender is then assigned - *fedback* - simultaneously and then engraved in reality. In the case of intersex bodies, the feedback step can be a direct intervention on the bodies, a mutilation (described as torture by intersex groups but also by some international organisations) such as surgery to shorten a penis/clitoris considered too long, or hormonal treatment in order to ensure the correspondence between the sex (the material body) and gender (the assigned social identity). In the case of conforming bodies, the three stages of extraction-ordering-feedback are often condensed into a few seconds, the time of the first ultrasound in pregnancy or the moment after birth[8]. An example of feedback is the placing of a pink or blue bracelet on the baby to avoid future confusion about its sex/gender. Another very common feedback step is the inscription of sex/gender on identity papers, which then creates a permanent need to conform to the administrative social gender decided at birth. This third act is also particularly visible in some of the transition processes that trans people have to go through, illustrated by the demands/obligations made on them by medical, legal or administrative institutions.

What does this have to do with my refusal to have my genome sequenced?

The idea I am trying to work with is that the genetic prism, i.e., the centrality of the gene and DNA (for example in medicine) is associated with a mechanism of 'genetic subjectification'[9] which functions in the same way as described above in the case of digital subjectification or the fabrication of the binary order of sexes/genders.

Act 1. Genetic extraction

Since the mid-twentieth century, biology has constructed DNA as the molecule that holds the secret of life, as an immortal text that can replicate itself almost perfectly and be transmitted through generations. This marked the emergence of DNA as an object that reveals the essence of the present, the events of the past and the possibilities of the future. DNA is history and destiny, becoming a cultural and even religious icon. Its extraction often takes on a particularly strong symbolic, political and/or economic meaning.

7 'The Phall-O-meter is a satirical measure that critiques medical standards for normal male and female phalluses. The tool … is used to demonstrate concerns with the medical treatment of intersex bodies.' (Wikipedia)

8 As a side note, the temporal simultaneity of sex and gender assignment, as well as the medical interventions used to shape the materiality of bodies according to the social choice of gender identity, reveal a certain vacuity in the culture/nature and social/biological dichotomies associated with the gender and sex binary system.

9 The way in which genetics, its discourses, its practices and its technologies shape us as human beings, as subjects.

The extractive nature of genetics has various aspects. Firstly, it is a reality in the literal sense of the word since, after all, we do say 'extracting DNA' in the laboratory, i.e., destroying tissues and cells of plants, animals and bacteria in order to separate and then isolate the DNA molecules contained in these cells. The purpose of the study for which I had to give my consent was indeed this: to take blood and, from the cells inside, extract my DNA (my genome). From this point of view, the donation industry - of blood, organs, eggs or sperm - can also be considered extractivist in nature. Today, our genomes are collected by the millions and stored in many genetic databases, both private and state-owned. This is a stage where 'information' is extracted, but also, in a sense, created. Our DNA 'sequence' was indeed within us, and still is after extraction, but what is really inside us are molecules, living and organic matter. To represent them as a sequence, as a code, is already interpreting them in a specific way and creating a certain type of information - an interpretation that owes much to the influence of cybernetics on the development of biology and genetics in the second half of the 20th century. Genetic extractivism also takes on a particular dimension when DNA is extracted from individuals in racialised, colonised and/or indigenous populations, with the excuse of studying human diversity or explaining the genetic basis for the high incidence of certain diseases in these populations. The colonial aspect of this genetic extractivism echoes other practices such as biopiracy (the extraction of certain molecules from the medicinal plants of these same populations without consent nor retribution) and, of course, the extraction of territories (the colonial appropriation of land, the extraction of labour forces and then, in many cases, the extraction of materials from this land). But genetic extractivism is not limited to the physical extraction of the DNA molecule, it also refers to any kind of extraction of qualities considered biological or hereditary. Here the list would become particularly long, but we can mention the industrialisation of life that started in the 18th/19th century in the West (the way breeders and farmers started to seriously rationalise, measure, record and extract certain desirable traits from plants and animals in order to industrially control their reproduction) or the early 20th century with the emergence of eugenics that went hand in hand with new ways of measuring, classifying, reading and analysing human bodies in order to extract controlable data and characteristics.

Act 2. Genetic ordering

All this available genetic data is, once stored, analysed. Historically, the first type of analysis of DNA sequences was mapping - now called 'annotation'. As we know, mapping, or cartography, is not an innocent act. Any representation carries power. 'One never maps a territory that one doesn’t contemplate appropriating' a friend once told me. This is illustrated by the practice of private appropriation of life through patenting[10], which requires a vision of the organism as a

10 Here patenting applies to DNA sequences extracted from various organisms, which has be referred sometimes to as 'patenting of life forms', for purposes of profit accumulation or restricting access to certain data. The issue of the

set of distinct and autonomous units with clearly identified functions - a body made up of 'elementary bricks' that can be conceptualised and extracted independently. The compartmentalisation of a body into a catalogue of separate and independent features (some have called this *discretisation*) is accompanied by the standardisation of these features. Indeed, the methodology of genetics has been, since its inception, to compare a norm with a deviation. Genetic ordering is thus achieved through normalisation and stratification, where the 'normal' version of the genes is compared to its variants associated with non-normative traits which, in humans, are often considered to be marginal or problematic (the great classics being disability, 'genetic' diseases, homosexuality, 'criminal' behaviour or membership of certain 'biological races'). The aim of this approach is to find a genetic explanation or basis for these traits. One of the main impetus of genetics is therefore *representation* - indexing, cataloguing, naming, and compartmentalising. The DNA needs to be measured and classified, for example under the following categories:

- what is normal/pure/wild/ancestral or abnormal/hybrid/mutant/derived
- what leads to high productivity (e.g. of plant crops) or not
- what is 'functional' and what is not
- what can be patented to generate profits or not
- what is statistically useful for prediction or not

This second act of genetic ordering is based on the previous extraction stage and the construction of numerous and gigantic databases (containing genetic data but also data relating to our lifestyles, our medical and family histories...). One of the possible forms of this type of ordering is what are known as Genome Wide Association Studies[11], or GWAS, such as the one that will be conducted in the study to which I did not want to participate in. These are bioinformatics and mathematical studies that make it possible to identify different versions, or variants, of human DNA whose presence would be strongly correlated with certain characteristics - typically diseases but also, in a clear reminder of the eugenics of the early 20th century, social or psychological traits (school attainment, psychological problems, skills, risky behaviours, socio-economic situations etc.). Even claims of the genetics of voting habits (genopolitics) or DNA-based propensity for happiness appeared in the media… Genetic and digital Big Data come together to link and cross-reference different types of data that will be used to build various statistical models and algorithms to describe the functioning of organisms or predict their future.

patenting of human genes is complex and depends on the epoch and places.

11 It is called an 'association' because it is only a statistical correlation, not a causal relationship, between genes/genetic markers and certain physical, psychological or social traits.

Act 3. Genetic *feedback*

Once all this extracted data has been ordered, it is returned to the organisms. Let us quickly go through several examples of this genetic feedback step. Firstly, the age-old process of breeding and selecting farm animals and plants (e.g., to increase their nutritional, adaptive or resistance values) is, at the end of the day, not unrelated to this. But it has taken a rather different form with the GMO (Genetically Modified Organisms) industry, which is also a very good illustration of this three-step model: portions of DNA or entire genes are physically extracted from certain organisms (Act 1), then manipulated, usually modified, in all cases given a certain value (Act 2), and finally introduced into the same (cis-genesis) or other (trans-genesis) organisms for industrial purposes and profit (Act 3). This concept is identical to that of gene therapy, where genes, either the version considered healthy or a modified version, are (re-)introduced into 'sick' human bodies, this time for medical purposes and profit. With the development of these genetic engineering techniques, there is now another type of GMO. In November 2018, it was officially announced that the first genetically modified humans were born (it was in China, three girls). Again, of course, for 'medical' purposes, fulfilling the ultimate fantasy of eugenics: the techno-scientific manufacture of new types of humans according to 'improvement' criteria. The extraction-ordering-feedback model takes on a terrifying ultramodern incarnation here. However, it was at work in earlier, no less terrifying versions of eugenics. Indeed, in the early 20th century in many Western countries, once science had extracted biological or social data from the bodies of various groups of humans (skull shape, intelligence or other cognitive abilities, diseases, disabilities, poverty, social success, reproduction rate, vagrancy, degeneracy... all of which were considered to be at least partially 'hereditary'), then interpreted and classified them in a hierarchical manner, those deemed 'unworthy' of living and/or reproducing were subjected to certain forms of feedback. Countries such as the United States and Sweden conducted mass forced sterilisation campaigns. Nazi Germany, the paradigmatic example of eugenics, inspired and influenced by the Americans, also started with forced sterilisation programmes and then pushed the eugenic logic to the extreme: the extermination of millions of human beings. After the war, the Nazi example was used as a scarecrow to hide the perpetuation of eugenic thinking and practice in many countries – a thinking obsessed with heredity and a practice of controlling what kind of human beings deserves to reproduce or not. One need only think of the current practices of forced sterilisations of migrant women in detention centres in the USA, the waves of forced sterilisations and abortions by the French state in the Reunion island, or the almost unanimous support by the industry and scientists for the use of recent genetic engineering techniques to manipulate and 'improve' the human lineage - such as those used to genetically modify the three girls in China in 2018, usually referred to as CRISPR, and for which the Nobel Prize for Chemistry was awarded.

Prediction

One form of feedback of particular interest to me is that related to genetic testing, in the shape of a diagnosis or a prediction. Here, what I refer to as 'genetic feedback' is both the moment of the communication of the test's results to the patient and the consequences of this communication. First, the genetic diagnosis. In simple terms, this is the search for genetic markers (often a single marker: a gene, a mutation or an extra chromosome) that are a sign of the presence, potential transmission and/or almost certain occurrence of various conditions, such as those called monogenic diseases (Huntington's, Cystic fibrosis, Tay-Sachs disease, Sickle cell anemia etc.) or certain chromosomal disorders (such as Down syndrome). The practice of genetic diagnosis is fairly common in the context of pregnancies with the search for genetic markers of these hereditary diseases in parents, embryos or foetuses - often resulting, in the case of positive detection in the foetus, in its abortion. The type of 'diseases' diagnosed vary, of course, according to time, place, culture and available technology.
Then there are the genetic prediction tests. Here, the aim is not to find a yes/no answer from the analysis of the DNA, as in the case of genetic diagnosis, but rather to find clues as to the predisposition to certain diseases or other characteristics. The genetic prediction industry extends well beyond the medical field, as it also offers services for predicting personality, talents, behaviour, ancestry (race/ethnicity), etc. As these tests deal with so-called complex traits, also called polygenic (involving several genes) or multifactorial, they are probabilistic in nature. Their existence depends on the huge amounts of genetic data extracted from our bodies and on their correspondence with medical and family data extracted from our lives. All this resulted in the construction of new scientific objects such as, for example, the 'polygenic risk score' (PRS). The PRS is a predictive algorithm that associates a certain individual genome with a risk score. This score is a number (often expressed as a percentage) that characterises a predisposition to certain complex traits (from schizophrenia or academic success to various cancers). These prediction tests are the subject of intense research, particularly around their potential clinical applications, but also of aggressive marketing. In the private sector, they are aimed at parents, children, embryos or anyone simply 'curious to know themselves better'.

In the medical context, the genetic prediction and diagnosis testing thus offers the possibility of anticipating or detecting a 'genetic' disease, the number of which has exploded in recent years. Indeed, with the surge of available genetic data, genetic association studies, like GWAS, are multiplying. Thus, as soon as a minimal genetic correlation with the occurrence of a disease is detected, this medical condition becomes a 'genetic disease'. One of the fundamental issues with these genetic tests is what happens next. Once the diagnosis or prediction is communicated to the person, what are the effects of this announcement? What

are the possible directions? In the case of fetuses, the main question is often whether or not to abort. In other cases, the main justification for the practice of genetic testing is to offer the opportunity to 'prepare'. But prepare for what, and how? In reality, medicine has little to offer against most of the diseases considered in these tests: abandoning the child project, starting assisted reproduction procedures with embryo selection, obvious lifestyle advice (diet, exercise), medical follow-up... Apart from certain exceptional cases, prevention or treatment of these 'genetic' diseases do not yet exist (and gene therapies are still far from fulfilling their expensive promises). Medicine pushes us to make genetic diagnostic and prediction tests but does not offer many solutions to deal with the materialisation of its prophecies. This is the role of the personalised genomic medicine project: a fallacy that conveys the idea that inequalities (in this case in health) are due to genetic differences and that they can be erased individually. In this fantasy, we will be able to obtain specific individual drugs that will create a complete equality of opportunity in the face of the many genetic risks that threaten us from within.

Let us imagine my participation in the study I refused to take part of. My genome, extracted (Act 1), is inserted in an GWAS-like association study with thousands of other genomes extracted from people who survived childhood leukaemia, and who certainly have long-term physiological (secondary cancer, hormonal problems...), psychological (depression, anxiety...) or social (failure at school, difficulties in finding a job...) consequences. The study will then perhaps show that there is a statistical correlation between certain DNA sequences, for example variants that I possess, and the occurrence of a secondary cancer, for example thyroid cancer. So my DNA will have been extracted, stored as information in databases, arranged and ordered according to statistical associations with certain specific characteristics chosen by those with access to the data, and then these results will be published, I presume in the form of various Polygenic Risk Scores, in scientific articles. Certain regions of my DNA and that of thousands of other people will then become biomarkers, indicators of genetic risk and statistical predictions of certain medical conditions (Act 2). I find it difficult to anticipate what impact the knowledge of such results, of these genetic prophecies, might have on me and my future (Act 3). Would I find a way to explain, to understand or to narrate all these 'deviations from the norm' that resulted from the treatment against leukaemia? Would I be reassured: 'it was in my genes, it was written, there was nothing I could have done to prevent it'? What interest would I find to genetically essentialise the consequences of my leukaemia?

To continue with the speculation: what if these biomarkers had been available when I was ill as a child? I’m 11 years old, undergoing treatment for leukaemia, my family is more or less devastated and overwhelmed... and then the doctor says: 'If we do this treatment to try and cure your child of leukaemia, and given his genetic profile, there is a 68% chance that he will develop thyroid cancer later on as an adult. What is your decision?'. What does this type of

'choice' reveal? It echoes strongly the scientific imagination of control and prediction inherited directly from cybernetics. And I obviously share this imaginary in spite of myself: when I was diagnosed with thyroid cancer, my first instinct was to search the internet for survival rates, percentages and other statistical data related to my situation.

A first line of thought, relating to the choices that these new predictive technologies impose on us, is one that has to do with the ongoing, and overwhelming, individualisation of these medical practices – injunctions to make individual choices within a framework that is narrated to us as that of information *versus* ignorance, of control *versus* chance[12], and of responsibility *versus* carelessness (it becomes irresponsible not to seek out all the available genetic information that would allow us to make informed choices). This discourse of 'free choice' must, of course, be cleansed of the neoliberal fog that surrounds it, insofar as this 'choice' has in reality become a tool through which a whole type of governmentality through risk (genetic, medical, economic...), measurement, statistics and algorithms is exercised. The same 'free choice', without coercion, that we exercise when shopping at the supermarket, based on the fallacious idea that our choices and desires are completely separate from, or independent of, the power relations that exist at a given time and place[13]. To return to genetic prediction, it is also important to remember that this hypothetical example of a '68% chance' is a matter of probability, i.e., the chance that a given event will occur in a given population. It is not a matter of individual destiny[14]. Moreover, our genetic identity is far from being individual. The individualising obsession with personalised medicine is itself contradicted by the well-known close genetic relationships we have with members of our family. The boundaries of the genetic individual are not those of an autonomous and independent body, but are projected, at the very least, into the bodies of those closest to him[15]. A biomarker identified in a child means that one or both parents have it, perhaps a sibling, some grandparents, etc. Have these other family members decided to *know* this information, have they consented to it being created and communicated? Finally, this logic of individual 'freedoms' and 'choices', associated with the

12 The slogan of one of the leading companies offering a genomic prediction service to choose the 'best' embryo to implant in *In Vitro Fertilisation* is '*choice over chance*' https://www.youtube.com/watch?v=vwVyv91BcNU.

13 Suffice to think about the fact that the universally accepted number one criteria to select gametes (egg or sperm) in assisted reproduction is the ‘race’, or the phenotypic kind, of the donor, i.e., white people not wanting a black baby. Or rather, authorities having passed legislations that make it illegal for reproduction clinics to provide gametes extracted from black people to white ones. Could anyone really argue that this constitutes a ‘choice’ free of any social assumptions?

14 Say someone claims that within a certain population, there is a 40% risk to get lung cancer. But if you pick randomly two individuals from this population, one that smokes 2 packs of cigarettes a day, and one who doesn’t, then the chances at the individual level to get lung cancer will be of course widely different. Risk prediction and calculation is populational, and it is a logical error to use it as individual predictors. As a doctor said: ‘the concept of individual risk applied — truly applied — to any given person is an oxymoron. Risk for an individual is like a square peg for a round hole. We can never know, or estimate, one person’s risk. In fact, if you do the math, the confidence interval for a given risk estimate in one person would range from a 0% to a 100% chance of a cardiac event. Thus, risk is not ‘personalized’ and I think of risk as a ‘group-phenomenon’.’ https://blogs.jwatch.org/cardioexchange/2014/05/21/the-risk-prediction-conundrum-individual-risk-vs-population-risk/

15 And eventually to all forms of life that contain DNA.

technical possibilities of selection and genetic modification of humans, leads to other kind of admonitions: 'If you were given the choice between a healthy, intelligent and strong baby or a sick, stupid and disabled baby, which would you choose?'. What kind of social conditions makes such a questioning possible? And where do they come from? What fears are mobilised by these injunctions and why? If such questioning exists, can we refuse to answer it?

Another line of thought might be the effect of the knowledge and announcements of these genetic predictions on subjectivity. How much discernment and autonomy would I have had, aged 11, to decide what to do with this information and how to handle it? How much would I have simply internalised my parents' reaction, which of course would have been totally unpredictable? What kind of life would I have had after this choice of treatment for leukaemia or not? These questions are not new, bioethics societies (often mere lackeys of the biotech industries) ask them in terms of the child's right to autonomy and an 'open future'. Growing up and getting older, how would I have lived with the expectation of the prophetised thyroid cancer? Would this have been serene or terrifying? It is possible that even in good health, I would have been perpetually, potentially and asymptomatically ill. My senses might have led me to believe that all is well with my body, but the statistics would have brought me back to order. What should I have trusted? How much would have my choices, my fears, my personality been influenced by these predictions?

In its best form, a prediction is a story, an oracle, a ritual. It has its place in the construction of our imaginaries. Once communicated, the prophetic results of the extraction-ordering-feedback of genetic prediction change us. Of course, every event shakes us, every oracle is a story that moves us. But in what direction? Does it open us up to the world or close us in? Is the fold we take desirable? Does it increase our power to act and to connect with others and the world? In this cold and dull consulting room, faced with the doctor's request, I had to take side.