

Social and Individual Features of Knowledge: The Non-Neutrality of Science in Personalized Medicine¹

Giulia Gandolfi*

Abstract: In an age marked by rising conspiracy theories and populism, discussions around the non-neutrality of science often become reductive. This article aims to critically dissect the non-neutrality of science beyond mainstream narratives, offering an epistemic-political analysis rooted in three levels: the historical context of science, its truth validation, and the environment of its practice. The study identifies two dominant elements that underpin science's non-neutrality: its inherent sociality and the individualization of knowledge responsibility. The sociality of science is discussed in light of historic-epistemological insights from Georges Canguilhem and Ludwig Fleck, emphasizing science's value-laden nature. Conversely, the article spotlights the neo-liberal shift post the mid-20th century that places knowledge responsibility squarely on individual citizens, further exacerbating social disparities. As a case study, the piece delves into Personalized Medicine, illustrating how modern knowledge production mechanisms, especially Omic techniques, potentially alienate patients from participating in their own care, reinforcing societal disparities in healthcare accessibility. The overarching intent is to illuminate the intersections between science's non-neutrality and contemporary political-economic structures.

Keywords: non-neutrality, scientific production, political epistemology, personalized medicine, knowledge responsibility.

1. *Introduction*

Considering the non-neutrality of science seems almost obvious and taken for granted today. The increasing amount of conspiracy theories and popu-

* Cà Foscari University - Paris 1 Panthéon Sorbonne.
giulia.gandolfi@unive.it

¹ I would like to thank the UNESCO Chair Water, Heritage and Sustainable Development, The Max Planck Partner Group The Water City (Berlin-Venice) and The New Institute Centre for Environmental Humanities (NICHE), Venice. This research is part of the project FARE EarlyGeo-Praxis (Grant of the Italian Ministry of University and Research, cod. R184WNSTWH).

lism have brought the discourse of “controlled science” by the powers that be to the fore. Reflecting on the non-neutrality of science today risks being reduced to these discussions. Asking what it means that science is not neutral should instead be a critical discourse in the Kantian sense of the term, that is, one that analyzes the limits of its efficacy and application. In this sense, I intend to discuss the non-neutrality of science from a point of view different from critical theory, such as that of the Frankfurt School, or from a moral point of view. My goal is to propose an analysis of two elements (the sociality of science and the individualization of the responsibility of knowing) that in the capitalist era make science non-neutral, considering what their political implications are. I would define my interest as epistemic-political, where by political epistemology I mean an approach that develops on three levels:

- The origins (roots) of science: The perspective which acknowledges the historical context underpinnings of every scientific practice.
- Validity: This involves scrutinizing the criteria for truth validation within scientific practices.
- The function of scientific practice: This aspect explores the material and cultural environment in which scientific progress unfolds².

In the first section of my work, I will analyze the first characteristic that makes science non-neutral: its sociality. Considering science as a social product implies analyzing on the one hand how scientific formation has social roots, for this reason, I will consider the historical-epistemological analysis done by Georges Canguilhem and Ludwig Fleck, and on the other hand, considering how methods of scientific diffusion are socially determined and determine the type of knowledge production. In this sense, I consider science as a normative activity, that is, as a value-laden activity.

In the second section, I will consider what I have defined as the individualization of scientific knowledge. Starting from the second half of the 20th century, neo-liberal policies have led to investing the citizen with the responsibility to know and to orient themselves within a growing mass of information. This shift highlights and exacerbates existing social inequalities. As responsibility moves away from collective institutions like governments, it inevitably privileges those who already have the resources, knowledge, and capacities to navigate complex systems. Access to knowledge becomes an elitist element capable of producing social differences.

Reflecting on this, I will propose an example of the sociality of science and the individualization of the responsibility of knowledge in the third section. Here I will take the example of Personalized Medicine to discuss how the

² Pietro Daniel Omodeo, *Political Epistemology: The Problem of Ideology in Science Studies*, Springer, Dordrecht 2019.

production of knowledge based on Omic techniques distances the patient from the ability to be part of their own care, increasing already existing social differences in the possibility of accessing care. The aim is to show how the non-neutrality of science takes on characteristics connected to models of political and economic management today.

2. *Social normativity of science: essence and aim of scientific knowledge production*

Georges Canguilhem in 1962-1963 gave a lecture in Sorbonne entitled *Le statut social de la science moderne*³, here, Canguilhem underscores the significance of viewing science as a “social product.” Although he does not elucidate the exact meaning of social product in this lecture, we can gain insight by considering the views he expressed on the history of science in *Ideology and Rationality*⁴. We must recognize that scientific concepts possess a history and evolve over time, influenced by cultural, social, and historical contexts. Consequently, we should view the history of science as the examination of their historical development and transformations⁵. Moreover, if we recognize that rationality in science is not static but is constructed by social entities – meaning it is subject to historical and social changes – then we can view the history of science as the study of shifts in rational systems and the transformation of scientific concept applications from a social perspective. Reflecting on Canguilhem’s lecture, it can be asserted that the entire history of science is intertwined with society, as all actions, including knowledge production, are social constructs. Science primarily emerges from various technical, or practical, problems which are later popularized and conceptualized. This popularization and conceptualization of science do not occur instantaneously.

The process of knowledge production within the scientific domain often begins with the unique insights of an individual scientist or a group of scientists. Following Canguilhem’s perspective, which views scientific knowledge as subsequent to technological activity, we recognize that the drive to discover something new often arises from the need to bridge the gap between technical success and the absence of a fitting theory. A foundational body of knowledge is not necessarily the precursor to a new theory. In fact, it is often the absence of knowledge that compels a scientist to subject their beliefs and suppositions to empirical evidence, particularly of a technological

³ George Canguilhem, *Le statut social de la science*, GC Centre d’Archives en Philosophie, Histoire et Édition des Sciences, Paris 1962.

⁴ Id., *Ideology and Rationality in the History of the Life Sciences*, MIT Press, Chicago 1988.

⁵ Ivi, pp. 1-5.

nature. Reflecting on the role of technological instruments, Canguilhem invokes Gaston Bachelard's idea of "phenotechnique". He sees the progression of science as being led by praxis, suggesting that science can only theorize after achieving a technological result. In this context, using an instrument can lead to the formulation of a theory that corresponds either to the operation of the instrument or to the results generated by the instrument itself. An illustrative example of this is the creation of maps featuring longitudes and latitudes in the 18th century. The determination of longitudes necessitated more precise calculations in astronomical science. The process of determining longitude is intricately linked to measuring lunar distances and is facilitated by the use of precise clocks and marine watches. In essence, it is underpinned by technological advancements⁶. In the 18th century, the need for improved longitude calculations converged with the economic interests of European states in colonial domain. This suggests that while new concepts can lead to novel technologies, the diffusion and adoption of specific technological instruments are often influenced by prevailing social and historical practices, which in turn serve broader socio-political goals, such as economic interests in colonial markets. The relationship between technology and theory is not linear. A theory can be contradicted by empirical evidence, and such discrepancies drive the quest for greater accuracy and refinement in theoretical frameworks. When these refined theories gain collective acceptance, they can pave the way for new technological applications.

In the process of theory development, two elements come into play: the individual scientist who engages in research, and the material environment in which they operate. However, turning to Ludwig Fleck introduces a third, pivotal element. According to Fleck, there exists a "thought collective", which he defines as a community of individuals bound together by a shared style of thinking, encompassing common ideas, values, and perceptions of the world. This communal mindset is implying a "thought style," and it profoundly shapes the way members of the collective perceive, evaluate, and generate knowledge⁷. In essence, a "thought collective" refers to a community of individuals who share, exchange, and are mutually influenced by a common set of ideas, all the while operating within a consistent style of thought. This community isn't merely the aggregate of its individual members; the interactions within the group give rise to a collective consciousness that can, often subliminally, influence each participant. Fleck underscores the significance of studying intellectual communities as foundational to epistemology. Analyzing cognitive processes solely from the perspective of individual actions

⁶ G. Canguilhem, *Le statut social de la science*, cit., pp. 38-39.

⁷ Ludwig Fleck, *Genesis and development of a scientific fact*, The University of Chicago Press, Chicago 1979.

would lead to an incomplete understanding of the broader collective cognitive process. Every piece of knowledge is socially conditioned, challenging the traditional notion that science rests solely on the subject-object dichotomy. Instead, an additional element emerges: the prevailing state of knowledge at any given moment⁸. While it is true that an idea may originate from an individual scientist, two key points stand out:

1. The genesis of an idea is deeply rooted within a social context, specifically within the thought collective. In this sense, the collective serves as a vital precondition for the idea's development.
2. Ideas are dynamic. As they flow from one individual to another within the community, they undergo transformations, and they can even return to their originator in a changed form. This dynamic is central to the evolution of a scientific concept. A concept might be introduced to the community in a form that isn't fully rationalized or objective – essentially, in a non-scientific state. However, after circulating within the community, it can (or can't) attain the rigor and objectivity necessary to fit within the realm of scientific knowledge.

Science's lack of neutrality stems from its inherent social characteristics. It is value-laden and is susceptible to change over time. We can argue that scientific production is both influenced by and shaped by the social realm. A concept emerges within the collective state of knowledge at a particular moment, and it evolves in response to that community's prevailing cognitive norms. In *Nécessité de la diffusion scientifique* Canguilhem states: "As the relationships between science and society have become such that the question of knowledge diffusion, which one could believe was outdated, arises again"⁹. Canguilhem is particularly intrigued by the role of the individual in the circulation of knowledge. The circulation of knowledge itself plays a part in its non-neutrality, as the transmission of scientific knowledge can shift based on the values applied to it. While Fleck emphasizes the idea of a collective cognition, Canguilhem takes a slightly different stance. By "social status of science", he refers both to institutions like academies or universities, but also to public opinion – especially the esteem with which experts are regarded by the general population. Therefore, Canguilhem emphasizes the "environment" of knowledge production, in tandem with the vernacular component, as crucial for groundbreaking discoveries. In his view, it isn't solely the genius of an individual that propels science forward; rather, it's a "social soul" that creates the conditions for scientific progress, as interpreted

⁸ Ivi, pp. 20-53.

⁹ G. Canguilhem, *Nécessité de la diffusion scientifique*, "Revue de l'enseignement supérieur", 3, 1961, p. 14, my translation.

and understood by the “scientific city”. For Canguilhem, if knowledge isn’t rooted in a singular subject, then the challenge arises in understanding the dissemination of science. Given that science isn’t a solitary endeavor, its application isn’t monolithic either. The diffusion of science, which encompasses all societal strata, is, in Canguilhem’s view, pivotal to the progression of science itself, owing to its universal mission. This brings us back to the central question of knowledge dissemination.

According to Canguilhem, it falls upon scholars and scientists to contemplate whether the spread of knowledge, when aligned with the objectivity of truth, is an unconditional imperative, irrespective of external factors. They must consider whether communicating research findings to a global scientific community, which transcends political boundaries, is an absolute duty or merely conditional¹⁰. When viewing knowledge as a product of social processes, we must also acknowledge that science and technology aren’t at odds with each other. Instead, they exist in a dialectical and reciprocal relationship, even as they retain their distinct identities. Technology (and technique) sets the stage for scientific exploration, while science provides the societal foundation in which practices, techniques, and technologies evolve. The interplay between science and technique is not static. It is characterized by ongoing shifts, disparities, and even ruptures. Significant imbalances between the two can sometimes lead to detrimental outcomes.

As shown in *La Nécessité de la diffusion scientifique* by Canguilhem, when science is subordinated to technology, it undergoes a transformative process: it relinquishes its inherent autonomy and normative power, merely serving to bolster and rationalize technological advancement. This naturally raises the question: what ensures a harmonious relationship between technology and science? Canguilhem’s response, elaborated in the subsequent part of his text, seems rooted in the socio-political realm and the way knowledge production is orchestrated. Managing the production of knowledge is intrinsically a socio-political endeavor, which demands an active engagement with the normative values of both science and technology. That is to say to recognize the values creativity of science. In relation to this, Canguilhem articulates: “Science is popularized by its effects before being vulgarized in its reasons and principles”¹¹. The dissemination of scientific knowledge presents two primary challenges. The first pertains to the manner – specifically, the means – through which science is disseminated. The second relates to the intent behind this dissemination, or in other words, the purpose of popularizing a specific body of knowledge. With respect to the means, Canguilhem highlights the use of scientific manuals as an example. Such manuals often

¹⁰ *Ibidem.*

¹¹ Ivi, p. 9.

present a linear account of scientific events or simply collate scientific data, phenomena, or facts, devoid of the context of their application or genesis. Thomas Kuhn similarly critiques the approach of these manuals in *The structure of scientific revolution*¹².

Similar to Canguilhem's perspective, Kuhn asserts that manuals and textbooks often overlook the social and historical shifts in the production of knowledge. Hence "by disguising such changes, the textbook tendency to make the development of science linear" and continues Kuhn, this "hides a process that lies at the heart of the most significant episodes of scientific development"¹³. This leads to a prevalent inclination to portray the history of science as linear or cumulative, an inclination that can influence even scientists reflecting on their own research. For Canguilhem, the dissemination and diffusion of knowledge isn't simply about relaying a linear and objective understanding. Instead, it should encapsulate the normative, unique, and circumstantial nature inherent to all scientific narratives¹⁴. Canguilhem believes that this perspective is deeply tied to the purpose of disseminating knowledge. A perceived linearity in science mirrors a linear interpretation of history, suggesting the ongoing evolution of a single, unified process. Such a singular narrative stifles the possibility of significant scientific breakthroughs and socio-political transformations. A purely objective and linear account may accommodate reforms, but it precludes the potential for revolutions. The key point I would like to stress here is that framing science as a linear narrative neglects its intrinsic normative aspect. By "normative", I refer to the capacity of science to define meanings. To grasp this concept of normative science, Canguilhem's perspective is enlightening. He posits that both science and technology are vital activities; they are avenues through which living entities navigate and establish norms in relation to their environment. Canguilhem delves deeper into this interplay in *Machine and Organism*, where he elucidates that science and technology must be considered as two types of activity "each of which borrows from the other sometimes its solutions, sometimes its problems"¹⁵. Since science is a vital activity¹⁶, it operates on an axiological basis, just as life does. That is to say, that science is fundamentally driven by judgment. In 1945, Canguilhem discussed this in a series of lectures on *Nature et valeur du concept*¹⁷ held at the University of Clermont-Ferrand.

¹² Thomas Kuhn, *The Structure of Scientific Revolutions*, University of Chicago Press, Chicago 1996 (1962).

¹³ Ivi, p. 165.

¹⁴ G. Canguilhem, *Nécessité de la diffusion scientifique*, cit., pp. 15-16.

¹⁵ G. Canguilhem, *Knowledge of life*, Fordham University Press, New York 2008.

¹⁶ *Ibidem*.

¹⁷ Id., *Nature et valeur du concept*, GC Centre d'Archives en Philosophie, Histoire et Édition des Sciences, Paris 1945.

In his lecture, Canguilhem delves into the normative function of science, viewing it as a process of producing judgments. He posits that knowledge entails imposing values and preferences onto the environment. Just as with any vital activity, the act of knowing embodies the realization of a choice¹⁸. Knowledge, as a value laden activity, is creation of truth value. This means that certain values are designated as truth, while others are excluded, being deemed as false. However, like all axiological activities, knowledge doesn't nullify what it excludes. The values not recognized as truth still retain their value. As Canguilhem notes scientific knowledge "is not the destruction or the annulment of a certain order of the perceived qualities" but, "it would be the subordination of such order of qualities to another order"¹⁹.

Building upon Canguilhem's perspective, it is evident that living beings create an order based on judgment, yet only humans possess the abstraction capacity derived from rationalization. This positions science as an extension of a value-laden, experimental activity, rationalizing normative actions. Thus, science is inherently non-neutral, both from within and in its interaction with the external environment. Internally, this non-neutrality stems from the essence of scientific knowledge as a normative, value-driven endeavor, embedded in the creation of norms, values, and judgments. Externally, this non-neutrality emerges from the interplay between this normative activity and its environment, a composite of both material and theoretical dimensions. Therefore, the methods and motives behind the dissemination of scientific knowledge play a crucial role in understanding the external non-neutrality of science. Scientific activity, inherently value-laden, is externally influenced by its modes of dissemination and popularization. The nuances of this relationship are not solely dependent on the individuals producing the knowledge or the society receiving and circulating it. Instead, there's an integral third component: the thought collective. This concept serves as the backdrop against which knowledge is possible, being rooted in both historical and social contexts.

3. *The individualization of knowledge: the concept of risk from 1920s to 2000s*

In the preceding section, I posited that the social determination of science is the primary feature implicating its non-neutrality. Closely linked to this is the second feature that, in my view, augments the non-neutrality of science: the individualization of knowledge responsibility. To illustrate this, I will

¹⁸ Id., *The Normal and the Pathological*, Zone Book, New York 1989, p. 122.

¹⁹ Id., *Nature et valeur du concept*, cit., p. 84, my translation.

highlight the evolution of responsibility individualization within the health domain. This process of individualization is applicable across all domains of scientific knowledge production, even though each discipline might have traversed varied trajectories to arrive at two common junctures: 1) a pronounced disparity between the expert and the non-expert (or citizen), and 2) the onus on individual citizens to discern which theory, proposition, or expert stance to embrace. Tightly intertwined with this is the shifting control of knowledge production, I will consider for instance healthcare. This control is no longer solely in the hands of the State; rather, it has increasingly been commandeered by private corporations which engage actively in public discourse to influence individual citizens' opinions. Consequently, I will explore the pivotal events that have led to the utilization of medicine in the management of public health. Furthermore, I contend that the interplay between medicine and biopolitics is deeply embedded within capitalist and neoliberal economic frameworks. Indeed, a holistic understanding of how biopolitical mechanisms shaped knowledge production in the 20th century emerges only when we consider both medical knowledge and tangible outcomes – discoveries, medications, treatments, and therapeutic practices – in conjunction with capitalist production and demand policies. This observation, however, does not insinuate that medical practices can only thrive or be effective within a capitalist economic structure. Instead, by understanding the strategies employed within capitalist paradigms, we pave the way for envisioning alternatives. In this perspective I consider the non-neutrality of science. I consider the intertwining of medicine and biopolitics as intricately linked to the entrepreneurial strategies of both states and private enterprises in the post-war era. The production of scientific knowledge in the 20th century was inextricably tied to technological advancements, particularly given that a predominant application of science for over half the century pertained to armament production. Likewise, throughout the entirety of the 20th century, knowledge production was tethered to the economic realm. It's crucial to recognize the pivotal shift that took place during the post-war years, as this transition – from state-centric control to dominion by private entities – signaled a profound transformation in knowledge production. Prior to the outbreak of the First World War, scientific and economic developments were steered by individual states but remained unimpeded by national boundaries. However, with the advent of the war, all states, both capitalist and non-capitalist (e.g., the USSR), came to view scientific research as a crucial tool for assurance, preparation, and defense against potential future conflicts. As noted by David Edgerton, this context, combined with the economic turmoil of the 1930s, compelled nation-states to strive for autarky²⁰.

²⁰ David Edgerton, *L'Etat entrepreneur de science*, in Christoph Bonneuil e Dominique Pestre (eds.), *Histoire des Sciences et des Savoirs Volume III: le siècle des technosciences 1914 – 2014*, Le

In essence, during this era, the State largely dominated the realm of knowledge production. The drives of imperialism and governmental incentives in research, particularly in the medical and industrial sectors, were manifestations of this trend. From the onset of the First World War until the Cold War, the State, especially its military arm, emerged as the principal financier of scientific research. This held true even in nations with pronounced neoliberal and capitalist orientations²¹. Such sponsorship arose from each state's desire to devise national strategies to foster the indigenous development of technologies essential for military objectives. However, it wasn't until the 1960s and 1970s that this national stronghold began to diminish, chiefly due to the colossal investments required to innovate and manufacture advanced weaponry and military technologies. These technologies carried a hefty price tag, often beyond the reach of a single State's budget for technological production. As a result, consortiums among nations began to emerge. Take nuclear power as an illustration: only a handful of nations were (and continue to be) capable of crafting efficient nuclear reactors. Rather than developing in-house capabilities, nations unable to produce these advanced systems opted to purchase reactors from the few that could. This typically occurred through agreements structured around international consortia. During this period, a significant transition took place: the dominance of state control began to recede, and the gap left in research and knowledge production was increasingly filled by the private sector.

The neoliberal policies of the 1970s and 1980s hastened the transition away from national ownership in the technological domain. The progression from autarky to consortium, and eventually to globalization, was pivotal as it compelled – and at times incentivized – countries to procure goods from abroad, adhering to standards set by the free market. The State no longer stood as the sole arbiter shaping the nexus between economy, science, and technology. Instead, this role was increasingly assumed by a supra-state entity: the capitalist economy. As Edgerton posits, during this period, the development of information and communication devices became crucial to ensure competitiveness in the marketplace²².

The domain of information and communication extends beyond just the purview of the state. In the 1980s, research and development (R&D) emerged as the most rapidly expanding sector, even as technological innovations experienced relative stagnation. R&D became the linchpin of all developmental agendas, including those in the medical-pharmacological field, prompting a significant realignment in health policies. The growth

Seuil, Paris 2015, p. 80.

²¹ For an analysis of the role of industrialization in discoveries in this period see M. Weatherall, *In Search of a Cure: A History of Pharmaceutical Discovery*, Oxford University Press, Oxford 1990.

²² D. Edgerton, *L'Etat entrepreneur de science*, cit., p. 81.

of R&D was largely propelled by private entities and institutions aiming to establish a competitive edge in the market. Examining the trajectory of drug development illustrates the evident shift from state-controlled knowledge production to dominion by the private sector. When examining the field of pharmacology, it becomes evident that what was once a monopoly controlled by the State – wherein the state granted licenses to private citizens to practice pharmacy – underwent a significant transformation. The industrialization push during the Second World War transitioned pharmacy into a major industry. As Jean-Paul Gaudillière notes, with the emergence of pharmaceuticals as a significant industrial sector, there was an extensive adoption of screening, which became a cornerstone for medicine thanks to R&D²³.

The primary goal of pharmaceutical companies shifted towards the discovery of novel molecules that could be beneficial in treating a variety of diseases. The pursuit of these molecules was predominantly steered by screening and R&D, which were tasked with understanding and addressing the evolving needs of the population. A pivotal shift contributing to the individualization of responsibility is the patentability of drugs. The privatization of ownership over a chemical formula result in a monopoly over a specific drug by private enterprises, which leverage R&D for targeted communication and development. Historically, prior to the Second World War, medicines were generally not eligible for patenting. However, from the 1960s onwards, coinciding with the emergence of industrial pharmacopoeia, pharmacological innovations became patentable²⁴. With this progression, screening and research became intertwined with the intricate steps mandated by administrative law regarding research and innovation. For instance, upon the discovery of a new molecule, it becomes imperative to:

- Seek approval from the relevant committees.
- Highlight potential side effects.
- Specify the therapeutic efficacy for a particular ailment.
- Explore potential applications for related disorders.
- Determine the permissible dosage limits.
- Conduct targeted trials on a subset of the population considered as a representative sample.

The patient's role underwent a transformation in the 1960s. Up until the 1940s and 1950s, screening and statistical research were retroactively applied

²³ Jean-Paul Gaudillière, *Une manière industrielle de savoir*, in *Histoire des Sciences et des Savoirs*, Volume III: *le siècle des technosciences 1914-2014*, pp. 85-105.

²⁴ For a detailed analysis see J.P. Gaudillière, *How pharmaceuticals became patentable: the production and appropriation of drugs in the twentieth century*, "History and Technology", XXIV, 2, 2008, pp. 99-106.

to the patient. However, with the neoliberal shift of the late 1970s, statistics began to be applied proactively, facilitated by R&D. Screening evolved from merely a tool for generating quantifiable data to an instrument where the representative sample for the screening is predetermined. It is this amalgamation of statistical studies and political imperatives that guides the development of certain drugs over others, prioritizing what are deemed as more pressing needs. Often the needs are determined by economic issues (see next section). During these years, scientific knowledge was molded by such demands. Although the distinction between basic and applied research persists, the emphasis of private enterprises has largely shifted towards applied research, given its ability to cater to specific needs. For example, the primary objective of pharmaceutical marketing is to position a particular “product” as most suitable for the patient’s requirements. However, within this framework, drugs are perceived as consumer goods within a marketplace. Knowledge becomes a tool to procure the optimal product tailored to the patient’s needs.

We are observing a profound transformation: a pivot from the pursuit of the ideal dosage and drug for a specific condition, to the identification of an ideal target – be it a segment of the population or a subset of patients – to whom a drug could be beneficial. When considering the transition from state-led to private-driven knowledge production, it’s essential to underscore that this shift is anchored in a particular theoretical framework. The rush for novel medications is paralleled by a pivotal shift in how the state manages illness and healing: what I have defined as the individualization of responsibility, both morally and economically. I aim to outline the circumstances that transitioned healthcare responsibility from the State to the individual. My objective is to highlight that if the onus to treat and prevent diseases now rests on the individual, it is a direct consequence of placing the responsibility of gaining knowledge (specifically about one’s medical condition) on the individual citizen. While the State offers tools to foster knowledge acquisition, it does not equip individuals with a framework to navigate this vast expanse of information.

Between the late nineteenth and early twentieth centuries, an era characterized by intense industrialization and pandemics, the advent of industrial hygiene became prominent. This discipline arose primarily in response to the challenges presented by the high concentrations of workers in production environments and their exposure to toxic materials like lead, silica dust, zinc phosphate, and others. These conditions gave rise to new diseases resulting from pollution and hazardous substances. Governments faced a two-pronged challenge. Firstly, they had to address the practical and theoretical dimensions of workers’ exposure to these harmful agents. Secondly, they had to balance this concern with the economic imperative of maintaining a readily available and affordable labor force. Quantitative medicine, with a significant

emphasis on toxicology, aimed to identify, quantify, and manage levels of exposure to toxic elements. The goal of safety management was to establish a clear, quantifiable safety threshold within which the population would be deemed safe from harmful effects.

However, by the 1960s, propelled by the rise of environmental movements²⁵, the broader concept of environmental health began to gain traction among governments. The ever-increasing interconnectedness between the environment and human health compelled medical professionals to re-evaluate traditional methods used to determine toxicological safety limits. This shift in understanding culminated in the 1970s, where the concept of risk assessment became foundational in health management. As Ulrich Beck argues, the industrialization associated with capitalism makes health threats not just hazards but risks²⁶. As a result, as Linda Nash states, risk “is part of the common language and culture” while risk assessment, on the other hand, “is a bureaucratic technique that transforms the notion into an operational element of environmental legislation”²⁷. The capitalist model of production inherently champions progress and continuous production as essential for its sustenance. Consequently, risk becomes an intrinsic component, a necessary by-product to ensure uninterrupted productivity. Under this framework, health is conceived not merely as a state of well-being but rather as a capacity to balance between productive demands and their subsequent ramifications.

The neoliberal policies that emerged in the early 1980s endeavored to establish a novel social contract, one where mutual acknowledgment of a certain risk threshold was expected of every citizen as a prerequisite to function within society. To operationalize this, there was an impetus to determine scientifically this threshold. Moreover, the period saw an emphasis on devising a systematic methodology to determine the pertinent criteria for its calculation.

While the 1970s and 1980s anchored the normalization of the risk notion, the late 1990s brought about a propulsive element to this paradigm. The ongoing climate crisis, which is inextricably linked with health, prompted neoliberal governments to frame the environment as inherently antagonistic to life. Within this context, risk management was expanded to incorporate the notion that governments, while recognizing the adversarial nature of the environment, should equip citizens with tools to navigate these environmental risks without fundamentally challenging their existence. This shift in responsibility, placing the onus on the individual, not only highlights but can also exacerbate existing social inequalities. As responsibility moves away

²⁵ See in particular Rachel Carson, *Silent Spring*, Houghton Mifflin Company, Boston 1962.

²⁶ Ulrich Beck, *Risk Society: Towards a New Modernity*, SAGE Publication, London 1992.

²⁷ Linda Nash, *Un siècle toxique. Les origines de la “santé environnementale”*, in *Histoire des Sciences et des Savoirs Volume III: le siècle des technosciences 1914-2014*, p. 158.

from collective institutions, it inevitably privileges those who already have the resources, knowledge, and capacities to navigate complex systems of information. Health care, being a vital and often intricate domain, becomes an area where these disparities are starkly evident.

When health care responsibilities are individualized, several factors come into play:

- Information Access: The digital age provides a deluge of information, but not everyone has equal access to reliable and relevant information, nor the literacy to discern and utilize it effectively.
- Economic Resources: Health care, especially in privatized systems, often requires significant financial resources. Those with more economic power can afford better treatments, medications, and preventive care, thus leading to better health outcomes.
- Social Networks: Those with strong social networks often have better access to recommendations, shared experiences, and support structures that can help in navigating health challenges.
- Cultural and Educational Background: Understanding the nuances of health care, advocating for oneself in medical situations, and having the cultural capital to interact effectively with health professionals can make a significant difference in the quality of care one receives.
- Institutional Discrimination: Health care institutions, like other societal structures, can have built-in biases. This can lead to differential treatment based on race, gender, socio-economic status, or other factors.

The result is a system where disparities in health outcomes become more pronounced. Those who are already marginalized, or disadvantaged may find it harder to access quality care, leading to poorer health outcomes, further entrenching cycles of inequality. This approach to health policy effectively creates a hierarchy of health based on socio-economic status and access to resources, which is fundamentally at odds with the principle of health as a universal and collective. This does not align with the narrative advanced by neo-liberal governments. According to them, the poor quality of care can be attributed to an individual's lack of attention; in other words, they believe illness results from the individual's own failings. Access to high-level treatments, such as seeing a specialist, visiting a hospital, or obtaining cutting-edge treatments, hinges largely on two variables: 1) the patient's ability to inform themselves and acquire a deeper understanding of their medical condition, which entails the capacity to engage in discussions with and question their doctor; and 2) the patient's opportunity to partake in screenings, undergo check-ups, and consult a specialist. In the following section, I will apply the two features of science's non-neutrality that I have discussed, providing examples from contemporary medicine.

4. *Personalized medicine: a new paradigm in knowledge production*

In this section, I will examine the example of Personalized Medicine to elucidate how the non-neutrality of science is frequently concealed behind what is deemed objective and rational. The definition of Personalized Medicine provided by the EU is also endorsed by the WHO and is as follows: “A medical model using characterization of individuals’ phenotypes and genotypes (eg. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention”²⁸. This definition underscores the intertwining of individuality and the economic realm. On one hand, there exists a need to optimize patient care (i.e., the desire to improve patient outcomes and discover new treatments). On the other hand, there is an imperative to optimize the economics and timing of medicine (i.e., the aim to expedite care without squandering resources). As Nikolas Rose contends, with Personalized Medicine, we witness a shift from treatment to prevention through genomic research²⁹. Ideally, genetic information would facilitate precision in selecting treatments and doses, thereby reducing mortality rates and adverse reactions, minimizing the use of ineffective drugs, decreasing costs, and enhancing efficacy. Genomics research dates back to the 1980s, but it wasn’t until the early 2000s that we witnessed a surge in sequencing projects. Preliminary discussions on the feasibility of a Human Genome Project took place between 1984 and 1986. In 1998, after a five-year plan, The Human Genome Project, outlined another five-year plan, which concluded in 2003. The subsequent year, the Human Genome Project consortium released a draft genomic sequence. The significant turning point came in 2007 when the costs of genome sequencing plummeted, making such procedures increasingly common in chemical, microbiological, and medical laboratories³⁰.

In other words, only when the cost of research decreased did the potential for expanding that research truly materialize. During the 2000s, the concept of Personalized Medicine began to increasingly intersect with the idea of individual patient genomic and genetic research. A pivotal moment came with an article published on April 16, 1999, in *The Wall Street Journal* titled *New Era of Personalized Medicine: Targeting Drugs for Each Unique Genetic Profile*, which established the connection between a personalized approach

²⁸ “Official Journal of the European Union”, C 421, December 17, 2015.

²⁹ Nikolas Rose, *Personalized Medicine: Promises, Problems and Perils of a New Paradigm for Healthcare*, “Procedia - Social and Behavioral Sciences”, LXXVII, 2013, pp. 341-352.

³⁰ See <https://www.genome.gov>.

to medicine and genetics³¹. In particular, the article describes the formation of the Single Nucleotide Polymorphisms Consortium and its role in promoting genomic research. The consortium's goal was to produce information from genetic mapping that "will help them create drugs specifically designed to target each person's unique genetic profile"³². This project is *not* dependent on federal resources, as it is the case of The Human Genome Project. It is in fact Bristol-Mayers, Smith Kline, Roche, Novartis and Glaxo Wellcome that invested \$45 million in a two-year program to map significant genetic loci for the treatments they were developing. Concurrently, both small and large pharmaceutical companies, some of which were members of the consortium, initiated parallel research endeavors. For instance, Bristol-Myers collaborated with MIT to identify genes associated with an elevated risk of heart disorders, diabetes, and asthma. Simultaneously, Genset SA in France was investigating genetic markers for prostate cancer. Building on what I have previously emphasized regarding R&D, it can be posited that Personalized Medicine refers to a medical approach where drug prescriptions are paired with specific genetic tests or particular genetic variations³³. In this context, personalized medicine derives its therapeutic potency from pharmacogenetics. This shift implies that medicine had to prioritize pharmacological research in the laboratory over the clinic. Robert Lagereth and Michael Waldholz highlight a specific kind of individuality: the genetic one. While genetics remains central, it is not the sole approach in personalized medicine today. Omics techniques, such as metabolomics, proteomics, epigenomics, and transcriptomics, play an integral role in the current landscape of personalized medicine. The individuality of a patient is fundamentally rooted in their biological traits, especially those discerned through Omics. In this light, the personalization of patient care relies on quantifiable characteristics; in other words, a patient can receive appropriate therapy based on the sequencing and study of their biological traits conducted using Omics techniques. It is evident that prioritizing biological features, analyzable through Omics technology, as the primary determinant of a patient's individuality is a deliberate choice. Clinical aspects, such as a patient's lived experiences, desires, expectations, and social environment, could also play a pivotal role in shaping the appropriate therapeutic intervention. I am not advocating for the exclusion of biological considerations. Instead, I emphasize that there are therapeutic approaches which do not primarily or solely lean on the biologi-

³¹ Robert Langreth and Michael Waldhoz, *New era of personalized medicine: targeting drugs for each unique genetic profile*, "The Oncologist", IV, 1999, pp. 426-427.

³² Ivi, p. 426.

³³ For an analysis see Xavier Guchet, *De la médecine personnalisée à l'exposomique. Environnement et santé à l'ère des big data*, "Multitudes", LXXV, 2, 2019, pp. 72-80.

cal realm for decision-making. Anchoring on biological traits, especially biomarkers, also transforms therapeutic strategies: it entails a nexus between drugs and diagnostics. In essence, a specific response to diagnostic tests dictates the choice of drug for a patient. This approach not only expedites the commercialization of drugs – justified by their targeted applicability based on diagnostic results – but also influences the parameters that define meaningful data for diagnostic tests. In this context, specific genetic and/or molecular markers are crucial to ascertain a drug's efficacy. Consequently, genetic and molecular tests emerge as vital criteria for determining the inclusion or exclusion of a patient in a clinical trial. While Phases II and III of drug development typically necessitate a broad patient base, integrating diagnosis through genetic-molecular methods with therapy allows for a comprehensive genetic mapping of the patient. If an acceptable correlation between the drug and the diagnostic test is established, any individual possessing the markers identified in the diagnostic test becomes a potential candidate for the drug. As posited by Jan Trøst Jørgensen, many contemporary cancer drugs receive approval based on metrics such as response rate and progression-free survival endpoints. Historically, the standard for FDA approval was anchored in demonstrable improvements in overall survival³⁴. Consequently, there is an increasing emphasis on identifying a biomarker and subsequently associating it with a specific drug. We can infer that a patient's individuality is closely tied to the uniqueness of their biomarkers. While this perception is not entirely misguided, it becomes intricate when environmental factors are considered. Indeed, as a patient continually interacts with their environment, it prompts a reevaluation of the very definition of a biomarker in modern medicine.

This emphasis on individualizing patients based on their biological traits heralds a paradigm shift in the application of knowledge both within the medical domain and beyond. In the framework of personalized medicine, virtually any data can be linked to biomarkers. What I've characterized as clinical features are brought back to their biological essence, suggesting that every facet of a patient's life can be translated into the biological domain via biomarkers. It's worth noting that in recent times, biomarkers have evolved beyond being exclusively associated with genetic loci. Their definition has expanded, largely because they are influenced by a patient's interaction with their surroundings. This has given rise to the concept of the Exposome. The Exposome is characterized as the entirety of exposures encountered by humans throughout their lives, encompassing all environmental factors, including lifestyle elements, from the prenatal phase onwards. Within the context of personalized medicine, the Exposome is employed as a framework that utilizes

³⁴ Jan Trøst Jørgensen, *Twenty Years with Personalized Medicine: Past, Present, and Future of Individualized Pharmacotherapy*, "The Oncologist", XXIV, 7, 2019, pp. 432-440.

biomarkers not merely to identify genetic mutations, but also as indicators of exposure, susceptibility (which can be genetic and beyond), and prevailing disease trends in populations³⁵. Health is increasingly conceptualized as the prevention and prediction of potential illnesses based on objective markers, namely biomarkers. Such a shift underscores a transformative perspective in knowledge production and research within medicine. Rather than primarily aiming to cure or act *a posteriori*, the emphasis has now predominantly shifted towards disease prevention.

The paradigm of knowledge production within the medical sphere has undergone a profound transformation, particularly with the advent of biomedicine. Biomedicine, a paradigm that melds medicine and biology, stands in stark contrast to the traditional medicine prevalent until the 1980s. Personalized medicine serves as a salient illustration of this shift. Broadly, the proliferation of information has paved the way for innovative research methodologies. By suggesting that individuals now bear the onus for their health, becoming responsible for their knowledge and actively seeking credible information, I aim to highlight that this surge in available information, especially in the medical domain, has revolutionized both the mechanics of knowledge production and our collective approach to it. In their discussion of *Biomedical Platforms*, Keating and Cambrosio emphasize the multi-layered nature of knowledge employed in medicine, one that defies simplistic, partitive definitions³⁶. For instance, in the realm of cancer diagnosis, *Personalized Medicine* shifts its lens from merely categorizing cancer based on organ specificity to a nuanced analysis across various markers. According to Peter Keating and Alberto Cambrosio, these levels are co-defined by the pivotal markers and the methodologies deployed to identify them, such as morphological, immunophenotyping, and genetic techniques. A biomedical platform, as they elucidate, can be conceived as a material, spatial, and discursive assembly that acts like a bench upon which conventions of the biological or normal interlace with conventions related to the medical or pathological. Such a platform is not merely an instrument or a device. Instead, it represents a distinct alignment of instruments and individuals, united by shared protocols and activities, anchored by standardized reagents. Consequently, a platform is less about its tangible existence and more about its orchestration – both materially and discursively. As they articulate, a platform serves as a prism,

³⁵ See Steven Morris Rappaport and Martyn T. Smith, *Epidemiology. Environment and disease risks*, in “*Science*”, XXII, 2010, pp. 460-461; and C.P. Wild, *Complementing the Genome with an “Exposome”*: *The Outstanding Challenge of Environmental Exposure Measurement in Molecular Epidemiology*, “*Cancer Epidemiology Biomarkers Prevention*”, XIV, 8, 2005, pp. 1847-1850.

³⁶ Peter Keating and Alberto Cambrosio, *Biomedical Platforms: Realigning the Normal and the Pathological in Late-Twentieth-Century Medicine*, MIT Press, London 2003.

offering a multifaceted understanding of situations or facts³⁷. Platforms in medical knowledge production are far from being neutral. Their foundation lies in specific standpoints, objectives, and methods employed in generating knowledge. Contemporary medicine's knowledge production paradigm can be characterized by its heavy reliance on data accumulation. Take Personalized Medicine as an example: it operates under the guiding principle of "the more data collected, the greater the precision and efficacy." Yet, this notion of "personalization" is somewhat paradoxical. It doesn't imply individualized attention in the truest sense. Rather than each individual receiving a tailor-made treatment, they are assigned to specific categories, derived from data analysis. These categories might range from broad to narrow, but the fundamental mechanism remains consistent: classify the patient within a category that groups them with others, ensuring they receive the treatment optimal for that group.

As I have emphasized, the driving force behind therapeutics in personalized medicine up to 2010-2015 was the principle of formalization. This involved gathering patient data to offer a "universal" and "objective" characterization of their pathology. Such categorization and formalization hinged on the enhancement of data collection methods and the tools associated with it. However, a shift occurred around 2010 with the incorporation of the Exposome concept into personalized medicine. The scope of data collection expanded beyond genetic markers, encompassing a more comprehensive view of individual life experiences. These data are then juxtaposed with inter-individual – or, at a broader scale, population-level – information, often approaching the subject from an epidemiological or preventive perspective. Medical practice began to leverage initiatives initiated by global bodies such as the EU and UN to gather lifestyle data from the populace. A case in point is the Foodome project, championed by the European Food Safety Authority. This project is a component of a broader research initiative aiming to elucidate the lifestyle factors associated with diseases like coronary heart disease and diabetes. Utilizing advanced AI techniques, the project aspires to compile an exhaustive database on food composition, bridging the current knowledge gaps about the biochemical makeup of food³⁸. Omics techniques play a pivotal role in contemporary discourses on microbiota, highlighting environmental interactions that defy conventional physical demarcations and classify matter based on microbial distinctions within samples³⁹. Microbiomics

³⁷ Ivi, pp. 44-45.

³⁸ See <https://www.efsa.europa.eu/en/art36grants/article36/gpefsaknow202202-european-foodome-project>.

³⁹ For a detailed exploration on this, refer to Roberta Raffaetà, *Metagenomic Futures: How Microbiome Research is Reconfiguring Health and What it Means to be Human*, Routledge, London 2022.

represents another omics strategy, delving into the study of microorganisms in tandem with their surrounding environment.

In recent years, the term “Sociome” has emerged to describe the examination of social determinants impacting health and disease. Initiatives launched over the past five years primarily aim to codify a spectrum of factors – spanning social, environmental, psychological, and behavioral realms – that modulate disease. These elements find expression through various socio-ecological interactions, communicated through channels like vocal intonations, olfactory signals, or bodily postures.

Phenomics, on the other hand, is dedicated to the exploration of the phenome: a collective representation of traits manifested at cellular, tissue, and organismal levels, differentiated from their genetic underpinnings. In essence, the phenome captures the totality of phenotypic attributes, scrutinized in correlation with their genetic and proteomic counterparts. Contemporary personalized medicine, buoyed by technological advancements, consolidates diverse datasets under the umbrella of “Omic” techniques. This signifies a paradigmatic shift from the erstwhile “gene-disease” monocausal framework to a multicausal model. While genetic data remains pivotal, the integration of diverse Omics data offers greater depth and insight. Modern personalized medicine deals with a significantly larger volume of data compared to its predecessors from the early 2000s. Relying solely on genetic data for diagnosis has become impractical. Rather than pinpointing a direct prescriptive diagnosis based on gene-disease correlations, there is now a focus on assessing the likelihood of an individual developing “unhealthy” conditions. This approach aids in strategically designing therapeutic interventions. Crucially, having a predisposition or an increased risk of disease onset does not equate to an actual pathological state.

Contemporary personalized medicine not only focuses on the “classical” model but also emphasizes probabilistic studies. In making this assertion, it is not my intention to imply that classical models of genetic research have been forsaken; rather, they are actively incorporated and employed within the framework of the new paradigm, as it is the case for those used to detect BRCA1 and BRCA2 mutations. Upon detection, the individual is then enrolled in a screening program. The objective is to mitigate, or if the disease does manifest, limit its progression. Consider a young man born in the Belmont neighborhood of Detroit’s suburbs, with the zip code 48227, and of Mexican ethnicity. He has a 25% chance of developing colon cancer due to his genetic lineage. Factors such as his lifestyle – including diet, occupation, and exposure to exhaust and other toxic substances – can elevate this risk by an additional 20%. Given the typical socioeconomic conditions of his environment, there’s an 18% probability that his symptoms, if he develops colon cancer, could be more severe than

average. Additionally, when one factors in his potential access to medications and specialists, it's possible to estimate a mortality rate within this modern perspective. While this isn't a definitive diagnosis, it does provide a roadmap for potential treatments the young man might require in the future. The onus lies with the individual to become informed about his condition and ensure he accesses the appropriate care when necessary.

According to Rose, we witness a rationalization of the patient⁴⁰. Transitioning from a defined group to an individual only becomes feasible when the individual is made "rationalizable." Groups, when classified within populations, are created through criteria that embody concepts of measurability, objectivity, and commensurability – in essence, rationality. For an individual to fit within a group, they must exhibit the characteristics inherent to that group. To elucidate, for an individual to qualify for a specific group, they must "possess" certain attributes mandated by that group's criteria.

However, since these attributes aren't inherently "natural," establishing commonalities between the individual and the system necessitates abstraction, formalization and choice of a hierarchy. The unique experience of a patient must align with the generalized characteristics of a group. Achieving this requires stripping the individual's experience of much of its unique and contingent nature, enabling it to become standardized and objective. Furthermore, categorizing an individual has political ramifications, such as the access to certain treatments. These outcomes are essentially born out of two processes: rationalization – attributing specific characteristics to an individual – and probability – the likelihood of an individual responding to a treatment based on their attributed characteristics. The development of drugs specifically effective for certain population groups will undoubtedly provide further incentives for pharmaceutical companies to invest in the most lucrative markets, rather than addressing the medical needs of those suffering from the most widespread diseases. According to Rose, we are witnessing a new type of racial segmentation in medicine. Consequently, new drugs – especially biologic ones that are based on genomic sequencing – require a more specific sample. This sample pertains to populations with distinct characteristics that ensure the success of the treatment. These groups can be selected based on specific biases, such as economic ones, because they are 1) increasingly refined, and 2) interlinked with both genetic and social characteristics due to the advancements in Omics technologies. As I emphasized in the previous section, when the individualization of knowledge production is viewed within the medical field, it leads to the perception of patients as individual-consumers⁴¹.

⁴⁰ N. Rose, *Personalized Medicine*, cit., p. 342.

⁴¹ Ivi, p. 348.

5. *Conclusion*

As I have emphasized, there are two primary factors, among others, that determine the non-neutrality of science, which are the sociality of science and the individualization of responsibility in knowledge production. Both are inherently political. The healthcare system serves as an illustrative example of how sociality and individual responsibility intertwine. Insurance systems, as well as mixed public-private healthcare models, increasingly assert that patients should be accountable for their own health. Everyday life attests to the significance of individual capability in generating knowledge and information. For instance, health insurance plans are often customized based on an individual's economic status and lifestyle. The trend towards privatization of care began in the 1970s. Genomic research, frequently backed by private entities like the aforementioned Single Nucleotide Polymorphisms Consortium, particularly in the pharmaceutical sector, aligns with the "open market" perspective of viewing knowledge and information as commodities.

What I aim to highlight is that, on one hand, the production of knowledge is inherently social and collective. This especially pertains to three elements: the subject, the material object of knowledge, and the "taught collective". Instead, starting from the 1970s, there has been a movement towards perceiving knowledge in a contrary manner: private and individual. When viewed historically, concerning how the individualization of a citizen's knowledge responsibility has evolved, two things become evident:

1. The privatization of knowledge production has been a significant catalyst for applied research. This research is steered by the R&D system, targeting market expansion. From the latter half of the 20th century, the progression of knowledge has been largely dictated by market requirements, spurred by neo-liberal policies.
2. These policies have precipitated the individualization of responsibility when it comes to acquiring information. The generation of knowledge isn't solely a collective endeavor anymore; it's also a private one. Indeed, only with the right knowledge can a citizen avail services, like health services. In this context, knowledge serves dual purposes: it's a tool for better service, and simultaneously, the degree of knowledge and, by extension, access to services, is contingent upon an individual's socio-economic standing. An individual in disadvantaged socio-economic conditions often grapples with acquiring knowledge. This, in turn, hinders their ability to access essential services. I contend that the shift towards individual responsibility for knowledge acquisition has positioned knowledge as a prerequisite for a fulfilling social life – one based on access to crucial services like healthcare, employment, and housing. The onus of accessing

knowledge and gathering information now rests squarely on individual citizens, marking a departure from the erstwhile collective approach to knowledge production.

The COVID-19 crisis further underscored this shift. Not only did many face challenges in accessing knowledge and consequently, services, but they also had to navigate a deluge of often contradictory information. To perceive science as a social product is to acknowledge its normative nature – its inherent ability to shape values. Constraining this normative aspect to a purely rational and objectifying paradigm, which I term the “narrative of linear science” fosters a detached view of science and knowledge. This perspective sees human actions merely as responses to immutable laws, rather than as dynamic interactions shaping and being shaped by knowledge.

Conversely, by recognizing the social underpinnings of science – its normativity and consequent non-neutrality – we pave the way for a resurgence of grassroots knowledge production. This bottom-up approach can serve as a bulwark against the pitfalls of conspiracy theories and various manifestations of populism as it preserves both the scientific and the social feature of science.

