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ORIGINAL PAPER

The Danger of Precision Medicine Hesitancy

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Abstract
Precision Medicine, Personalized Medicine, Stratified Medicine, Lifestyle Medicine: these are all names that have been given to a new medical approach, that overcomes the limitations of the one-size-fits-all approach to pharmacotherapy by grounding it in the specific genetic markup of a given individual. Albeit these terms are sometimes used as synonyms, they mark important conceptual and historical differences. The gradual modification of the meaning carried by each term over the last 30 years can lead to confusion and conceptual opacity, especially in the lay public. The unfulfilled promises of earlier versions of this approach in terms of lack of individual empowerment and tangible clinical and economic benefits may foster a sense of disillusion and mistrust. Moreover, recent technological advancements, such as wearable healthcare devices, offer a tool to exploit those feelings commercially. This paper claims that such a situation could lead to the rise of a phenomenon akin to Vaccine Hesitancy, which we call Precision Medicine Hesitancy. Such an emergence carries the risk of undermining decades of collective efforts toward a redefinition of clinical practices. It is a danger of which we should be wary, and that should be prevented.

Keywords Precision medicine · Personalized medicine · Vaccine hesitancy · Epistemic trust · Wearable healthcare devices

1 Introduction

One of the most striking advancements of contemporary medicine is Precision Medicine, an approach to pharmacotherapy that takes into account genetic, environmental, and lifestyle factors to tailor clinical intervention to the specific needs of a given patient.[1] At least on paper. What is nowadays known as Precision

[1] The first definition of the concept of Personalized Medicine, one that nowadays some authors (Yates et al. 2018) consider interchangeable with Precision Medicine, is "the tailoring of medical treatment to

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Medicine has been, and still is, often called by many names, ranging from Personalized Medicine, to Stratified Medicine, Genomic Medicine, and others. In most current medical research all these names are treated as denoting the same concept. However, for many authors (Roden and Tyndale 2013; Feldman 2015; Ali-Khan et al. 2016; Phillips 2020) the presence and variation of these various names mark not just a rhetorical difference, but a conceptual one as well: some core tenets of what constitutes Precision Medicine changed significantly over time. This paper offers a panoramic view of the most important conceptual differences behind those disparate appellations, underlines the confusion that is generated by this definitional uncertainty, points out the interactions with recent technological advancements, and warns against the emergence of a potential threat that may arise from this confusion. That threat is a sense of mistrust and rejection of Precision Medicine, its results, and its practitioners, that could lead to form of hesitancy toward the scientific results that have been achieved so far in the field. This potential form of hesitancy is compared with an established form of medical hesitancy, namely vaccine hesitancy, to highlight similarities and differences.

My argument develops as follows. The change occurred in the passage between Personalized Medicine and Precision Medicine marked not just a nomenclature change, but a conceptual one as well. Personalized medicine was promising a lot regarding patient's empowerment. The failed realization of these promises could generate a sense of mistrust in the general public about Precision medicine's current goals. This could lead to the emergence of a sentiment of hesitation and rejection of both the scientific consensus regarding precision medicine, and public initiatives grounded on it. I call this social phenomenon Precision Medicine Hesitancy. The increased availability of technological means such as wearable healthcare devices can reinforce this emergence. The support for thinking that such a phenomenon could happen is strengthened by some parallelisms with the current situation and other phenomena of hesitancy, such as vaccine hesitancy.

In Sect. 2, we will briefly describe the history of Precision Medicine in the last 30 years, and recall the salient historic roots of vaccine hesitancy. In Sect. 3 we will present the conceptual differences marked by the various names with which Precision Medicine has been called. In Sect. 4 we will elaborate on what could generate a sense of mistrust toward Precision Medicine. Lastly, in Sect. 5 we are going to consider the impact of wearable healthcare devices on the issue at hand.

2 The History So Far

When dealing with medicine uptake, one may think that the same drug, in the same dosage, would affect everyone in the same way. This is not the case. Age, gender, weight, and lifestyle are all factors that modulate drug metabolization, and the same

Footnote 1 (continued)
the individual characteristics of each patient to classify individuals into subpopulations that differ in their susceptibility to a particular disease or their response to a specific treatment." (Jain 2002).

drug that is beneficial to an individual may be ineffective or harmful to another. However, another factor contributes to these individual differences: the specific genetic markup of a person. Different genetic markups translate into different drug metabolization and uptake. In some rare cases, those genetic differences show up at a phenotypical level: one example is that redheads need higher dosages of anaesthetics to achieve the same level of sedation as non-redheads (Liem et al. 2004). In most cases, though, a look into the specificity of an individual person's genes is needed to modulate pharmaceutical prescription with precision. Genetics is involved in drug reception, uptake, and breakdown processes. For example, 20% to 25% of drugs are metabolised by the cytochrome isoenzyme P450 2D6, encoded by the CYP2D6 gene (Gervasini et al. 2010). Individuals with multiple copies of such a gene are, therefore, expected to metabolize drugs at a higher pace, and their pharmacotherapy should be modulated accordingly (Ventola 2011).

In general, genetics plays a significant role in modulating the effectiveness and the presence of potential side effects of drugs. However, for most of its history, medical practice had to cope with a lack of technological tools that would enable us to paint an accurate representation of a genome markup. The technological development promised to change the situation. The year 1990 saw the start of the Human Genome Project, an endeavour that aimed at mapping and sequencing the entirety of human genes. Some authors called for a paradigm shift[2] in medicine, one that would ground its view in the fact that "[…] our own genetic individuality [is] a potential origin of disease. We are all different—we are all genetically unique—which means our risk for disease is different from one another. Progress depends on realizing this and applying the knowledge to prevention" (Baird 1990). This approach soon started to be called "Personalized Medicine" (Langreth and Waldholz 1999). The conclusion in 2003 of the Human Genome Project accelerated the efforts for achieving this target, generating massive interest in the public and, perhaps more importantly, a vast amount of investments from both the public and the private sector. Twenty years later, however, many of these hopes have not been met, despite the enormous efforts and investments poured into this research program. Meanwhile, the concept of Personalized Medicine and its aim saw a shift, reflected in a change in denomination. The more time passed, the more the promises of Personalized Medicine remained unfulfilled and seemed increasingly out of grasp. Researchers started in greater numbers to refer to "Precision Medicine", rather than Personalized Medicine. With that term, they referred to the greater precision that the use and aggregation of enormous amounts of clinical data would allow, a trend that is part of the so-called "big data revolution" (Hopp and Baird 2018). In 2009, the number of publications per year that included the word Precision Medicine overtook the ones

[2] En passant, it should be noted the liberal overabundance of the use of the term "paradigm shift" in literature. The concept of "paradigm shift", presented by T. Kuhn in 1962, entailed a level of incommensurability between competing scientific theories, which not what even the most extreme supporter of Precision Medicine proposes. In most cases, the term is used as a fancy buzzword to say "change". This imprecision, however, carries little pragmatical impact, apart from frustrating philosophers of science to no end.

using Personalized Medicine, and the trend only got more robust from that year on[3] (Jørgensen 2019). Rather than just be a semantic change, it was a twist on the entire research program, one that reflected an increase in the ability to collect, harness, and aggregate vast amounts of clinical data. This was far from the only proposed change: variations such as "Stratified Medicine" or "Lifestyle Medicine" started to appear, each carrying its own specific goals. The result of this proliferation of names is that nowadays they have become umbrella terms for a group of concepts sometimes very far from each other, leading to a great conceptual opacity in both doctors and laypersons. This confusion leads to a series of consequences: one of the most interesting, and worrisome, is that it leaves the door open to exploitation by snake oil salesmen and merchants of doubt, who could be keen to take advantage of this confusion for their own commercial benefits.

One situation where such form of private and commercial interest was the spark of a broader social phenomenon was the emergence of vaccine hesitancy, at least in its modern form.[4] Vaccine hesitancy is defined by the WHO as the "[…] delay in acceptance or refusal of vaccines despite availability of vaccination services." (MacDonald 2015). Vaccine hesitancy has a long, convoluted, and interesting story, but for our purposes it is sufficient to remind how the start of its contemporary form can be pinpointed in 1998, when a group of British researchers led by A. Wakefield suggested a potential link between the uptake of MMR (mumps-measles-rubella) vaccine and the development of what they dubbed "autistic enterocolitis", an alleged cause of autism (Wakefield et al. 1998). The paper they published gained traction in the British media and became a national debate case. Even Tony Blair, at the time prime minister of the UK, refused to disclose whether his children were vaccinated or not with the MMR vaccine. Rates of vaccination fell (Anderson 1999). The results of that research failed to be replicated, several fatal shortcomings were pointed out in the investigation methodology, and all authors withdrew their support of the study's findings. All but Wakefield, who started to aggressively campaign to establish a link between the MMR vaccine and autism. In 2004, an extensive investigation by the journalist Brian Deer (Deer 2004–2023) disclosed how Wakefield's research showed financial conflict of interest and manipulation of evidence. After these findings, a full inquest was launched, which ended in 2010. The General Medical Council removed Wakefield from the UK medical register, and the Lancet retracted the paper (Eggertson 2010). However, Wakefield would go on in its very lucrative campaign: between the sale of test kits, books, media appearances, and other related forms of income, he earned an undisclosed amount of money, estimated to be in millions of dollars. Wakefield's success was due to a series of causes, but relevant here is the fact that his fraudulent claims were so successful also due to the confusion surrounding the matter at hand. Establishing the causes of autism has proven (and, indeed, is) difficult, and at the time the general

[3] To give an idea of the diffusion in the medical field, the Pub Med database lists 10.964 articles containing "Precision Medicine" in the title published in 2023, whereas for "Personalized Medicine" 3.606 are listed.

[4] It has to be reminded that vaccine hesitancy, as a broad phenomenon, is as old as vaccination itself.

public did not have access to a significant amount of information on multi-potent vaccines. Wakefield, and soon other epigones, exploited that confusion for their gains, arguably causing an inordinate amount of otherwise preventable sufferance and earning a lot of money and public visibility in the process.

Vaccine hesitancy, and other examples of skepticism and rejection of the scientific consensus over matters such as global warming, posed a puzzling problem for both epistemology and public communication of science. At heart, the question was: why does the public not follow scientific recommendations and does not employ scientifically-informed decisions in the contexts where it would be indicated to do so? For a time, the answer by the scholars of public communication of science was the so-called "information (or knowledge) deficit model". In a nutshell, the idea was that lack of acceptance of scientific consensus was determined by an insufficient amount of information on what that consensus was. This model, dominant from the 1980s (Miller 1983, Bodmer 1985), by the mid-nineties was beginning to buckle under the weight of both conceptual criticism and mounting amount of contrasting empirical evidence. Authors such as B. Wynne (Wynne 1991, 1996) were arguing that the laypublic, while by definition being non-experts on scientific matters, present other layers of expertise that should be taken into account in designing scientifically-informed public policies. This critique paved the way to a "contextual approach" (Miller 2001) of scientific understanding, counterposed to the deficit model. Such an approach sees the relationship between scientists and the public as a dialogue, instead of a lecture, where knowledge hold by the scientists has to be placed into the context of the local knowledge already possessed by the public, and the specific problems that concern them. This change of pace caused a push, in the field of science communication, to flank efforts to increase Public Understanding of Science (PUS) with other, more cooperative, endeavours such as Public Engagement of Science (PES) and Public Awareness of Science (PAS) (Schäfer 2009). Vaccine hesitancy is a good example of a phenomenon that contributed to such a rethinking. As tempting as it is to think that vaccine hesitancy is caused only, or mainly, by a lack of information, this is an untenable position. There is an overwhelming amount of easily available information on the safety and effectiveness of vaccines: ignorance cannot be the only culprit. Where to look, though? This was a work for the epistemologists, who started to focus more and more on the concept of *epistemic trust*.

Trust is generally (Baier 1995; Zagzebski 1996, 2012) is considered a triadic relation between a trustor, a trustee, and what is entrusted by the trustor to the trustee. Four main aspects of trust can be identified: reliance, vulnerability, confidence, and expectation (McCraw 2015). Among these, reliance is often seen as the first aspect of trust: trusting someone entails relying on that someone. This leaves open the possibility of being let down, and thus vulnerability: trusting means leaving oneself open to risk. In turn, this leads to confidence, which is a "distinctive, and affectively loaded, way of seeing the one trusted" (Jones 1996). Lastly, confidence comes into play in formulating predictions on the trustee's behaviour. *Epistemic trust* is a specific kind of trust, namely trust in someone *as a provider of information* (Wilholt 2013). The conceptualization of trust as an epistemic notion is relatively recent (Origgi 2004). However, it has assumed an increasing importance

due to the awareness that competence is a feature that is central, but distinct, from general trust. For example, I might trust completely my mother, because I know her moral and personal qualities, but I would still not entrust her to perform an oil change on my motorbike, since it's an action that leads to costly reparation if not performed with competence. At the same time, competence requirements might not be sufficient to give trust: I would not trust a mechanic I know is competent but prone to scam customers. "Epistemic trust is trust, on the one hand, in the goodwill of others, and, on the other hand, in their competence" (Origgi 2004: 64). Trust, however, is a fragile thing, one which can be eroded and lost: epistemic trust makes no difference. It is already complex for a layperson to decide which expert to trust when faced with cases of genuine expert disagreement (Goldman 2001). However, there have been cases where the narration around scientifically-informed topics, such as the effects of a nuclear fallout or the harmful status of tobacco consumption, was modulated by actors less keen on finding the truth and more attentive to achieve specific political or commercial goals (Oreskes, Conway 2011). The existence of phenomena of hesitancy and rejection of scientific consensus, therefore, has to be explained within this framework. Research scandals, misconduct, and phenomena such as regulatory capture[5] have shaken public confidence in scientific institutions and government bodies, and therefore have cast a dim light on the information they provide. Epistemic injustice (Fricker 2007), structural inequalities in access to healthcare due to race, wealth, and gender, and the (empirically well-grounded) perception of a research performed on, and for, only specific demographic cohorts (Huey 2019) have degraded public trust in the quality of medical research. The key to understand hesitancy, therefore, lies not in facing misunderstanding from the public, but mistrust (Goldenberg 2021).

Why does epistemic trust (and mistrust) matter for Precision Medicine? This paper claims that the fundamental reframing of the definition, scope and meaning of genomic medical research in the past twenty years result in great confusion on exactly what Precision Medicine is, what it can do, and what can and cannot be realistically expected by it, especially in those who are not specifically experts on the argument. The effect of this conceptual opacity is twofold. First, it may generate or reinforce already existing mistrust of institutional healthcare initiatives, hampering the efforts to digitalization and sharing of medical data currently underway in many different countries. Second, it leaves the door open to exploitation by commercially-interested players, snake oil salesmen and merchants of doubt, who are keen to take advantage of this confusion for their own benefit. These elements canvass the potential for the development of a sentiment of resistance to Precision Medicine and public initiatives based on it, which I call Precision Medicine Hesitancy.

[5] Regulatory capture is the process by which regulatory industries end up doing the bidding of the very industries they have an intrinsic duty to regulate (Stigler 1971).

3 What's in a Name? The Elusive Hunt for a Good Definition

As we have seen, there is a competitive market of names from which to choose when dealing with the description of genomic-based medicine. Even if some authors (March 2017) and institutions (Yates et al. 2018) consider the terms interchangeable, others (Roden and Tyndale 2013; Feldman 2015; Ali-Khan et al. 2016; Phillips 2020) point out how different terms mark different concepts and how this variability leads to repercussions on politics and policy-making (Chan and Erikainen 2018), ethics (Juengst and McGowan 2018) and clinical practices (Feldman 2015). It pays out, then, to point out the meanings of the terms used, in order to clarify the conceptual field in which we are moving, to canvass its complexity, and to lay the foundation of the argument over what such terminological confusion carries.

Personalized Medicine is the term that initially enjoyed the most widespread use in scientific literature (Pokorska-Bocci et al. 2014). It is defined as the "application of genomic and molecular data to better target the delivery of healthcare, to facilitate the discovery and clinical testing of new products, and to help determine a person's predisposition to a particular disease or condition" (Abrahams et al. 2005, Cascorbi 2010). It aims to deliver the "right drug at the right person at the right time at the right dose" (Abrahams 2008). In other words, its vision is an advancement in drug development, drug prescription, and clinical practices, from the "one-size-fits-all" approach of pharmaceutical prescription to one that is tailored to the specific genetic markup of one specific individual. The concept of pharmacogenetics is not new: it started to appear as a specific term in the 1960s (Kalow 1962), and it could be claimed that the concept itself was already present in the minds of XIX century pioneers in biostatistics like Karl Pearson and Francis Galton (Phillips 2020). However, it was only when technological advancement allowed us to analyse the genetic markup of individual humans that pharmacogenetics started to be considered within grasp and not just a theoretical possibility. The Human Genome Project was believed, somewhat messianically, to usher in a new era for clinical practice, one where the genetic markup of a specific individual would determine a tailored-made pharmacotherapy. The hope was that "[o]ver the longer term, perhaps in another 15 or 20 years, you will see a complete transformation in therapeutic medicine" (Collins 1999). This new approach, this "Personalized Medicine", sounded very promising. It could improve clinical practices by lowering costs and saving time. It could help in preventing avoidable Adverse Reaction effects, which at the time, like today, were and are one of the leading causes of medically-related deaths in the Global North (Squassina et al. 2010). It could lead to breakthroughs in understanding of genetic aetiology of diseases. It could bring societal change that would facilitate preventive medicine, and empower individuals by giving them the means to control and finetune their therapy. It was, indeed, a very promising approach. Unfortunately, many of these promises remain, as of today, unfulfilled (Joyner and Paneth 2019). Many of the most promising pharmacogenomic trials, such as the one on the antithrombotic *warfarin*, showed no benefit (Stergiopoulos

and Brown 2014). On the theoretical side the situation is even more worrisome. The completion of the Human Genome Project in 2003 roughly coincided with the rise of epigenetics, the studies on how the genetic markup of an individual is expressed and modulated by its interactions with its environment. Rather than be an endpoint, the complete deciphering of the human code brought even more complexity to the pharmacogenomic picture (Rasool et al. 2015). The shifting of focus from the gene to the environment as the primary cause of genetic diseases puts into discussion the very concept of gene therapy, and is leading to its gradual reformulation, if not total abandonment.

In the meanwhile, however, other technological advancements joined the fray. The expanded capability of collecting, aggregating, and analysing vast amounts of data (the so-called "big data") led to radical changes in many fields, including genomic medicine. The focus shifted from the analysis of the genetic markup of a single individual to one encompassing enormous amounts of genetic data from a given population. This change, and the shortcomings of Personalized Medicine, led to the success of another name: *Precision Medicine*. In scientific literature, the second name surpassed in popularity the first one at the beginning of 2010 (Jørgensen 2019) and soon came to be considered the standard even by political communication, with a pinnacle of interest reached in 2015, when USA President Barack Obama launched the "Precision Medicine Initiative" in his State of the Union address. The core idea of Precision Medicine does not diverge too much from what we have already seen. The focus is still on using genetic analyses to tailor pharmaceutical interventions with greater precision. What changed, however, were the means to achieve that goal. In Precision Medicine the genetic analysis of a specific individual markup is nothing but a step to an aggregation with other genetic markups that allows patterns to emerge at a population level. The increased precision of genomics zooms-in the definitional boundaries of the genetic foundation of a given disease, sub-dividing a specific population into increasingly precise sub-populations that share a specific genetic characteristic. This shift has been so influential that the term *Stratified Medicine* was introduced to better describe the kind of scientific endeavour currently undergoing.[6] This is a profound shift from the narrative encouraged by the early version of Personalized Medicine: a call for a medicine tailored to a specific individual is, in this new conception, dismissed as naïve, scientifically implausible, and potentially distorting the expectations of the general public (Feiler et al. 2017).

That general public, however, was already promised much by a scientific community excited for new discoveries and also, it has to be said, eager for funding opportunities. Some of those unfulfilled promises prompted harsh criticism. For example, the fact that medical costs have not decreased with Precision Medicine but have actually increased (Vellekoop et al. 2022) has prompted some authors to point out there is no shortage of pressing public health problems that could be treated with

[6] This shift from the individual to increasingly narrowly-defined stratification of populations has interesting repercussions from a philosophy of science perspective, for example potentiall leading to a reshape of the role and to the possible overcoming of Randomized Controlled Trials in clinical research. However, such an analysis falls outside the scope of this work.

"traditional" means and that would greatly benefit from a reallocation of resources. In this perspective, Personalized Medicine has been an enormous opportunity cost to develop other branches of medicine further (Joyner and Paneth 2019). Not everyone, however, calls for an abandonment of Precision Medicine. Some approaches aim at fulfilling the promises of a truly individually-tailored medicine. Some are still carried on within the genomic framework, such as the one focusing on the possibility of using a patient's own stem-cells to create *organoids*, in vitro self-assembling, organ-like, three-dimensional cellular structures with the same DNA of the patient body (Li et al. 2020, Zhou et al. 2021, Shiihara and Furukawa 2022), an avenue of research which is leading to interesting results in the study of diseases such as cystic fibrosis (van Mourik et al. 2019). This relatively new approach closely resembles what was thought Personalized Medicine could be at the beginning, and is sometimes called *Individualized Medicine* to distinguish it from earlier attempts. Other approaches, however, are bolder. One is the one that is increasingly referred to as *Lifestyle* (or *Wellness*) *Medicine*. Lifestyle Medicine seeks to decouple genomics from Personalized Medicine, or at least de-emphasize its role, and tries to bring back the focus on the individual patient (Gray et al. 2020). As the name suggests, it shifts the aetiology of diseases from just the genes to the combination of genetic, environmental, and lifestyle factors such as diet variety, caloric uptake, level of physical activity, stress, amount and quality of sleep, substance use, pollution, and many others. The fact that several of these factors (such as substance abuse, see Ducci and Goldman 2012) are considered to have a genetic base muddles the waters and forces their consideration from a variety of viewpoints. Some claim that the population scale of "big data" should be paired with a conversely extensive focus on the data produced from a singular individual, "small data", to be meaningful (Ma et al. 2016). Others uphold that we have reached a point where the amount of data we can collect from a single person allows for meaningful n-of-1 clinical trials (Samuel et al. 2023). These research avenues can be considered to attempt to bridge a gap between big data approaches and personalization and are still under exploration nowadays.

This (incomplete) panoramic view on the nomenclature difficulty canvass a picture that is not necessarily problematic, per se (see Table 1). Some authors point out

Table 1 Scheme of the main differences marked by different naming

Name	Narrative focus	Main target	Data collected	Reliance on big data
Personalized	Individual	Pharmaceutical development	Genomic	No
Precision	Group	Pharmaceutical development/ Aetiology comprehension	Genomic/ Epigenomic	Yes
Stratified	Group	Pharmaceutical Development	Genomic	Yes
Lifestyle/Wellness	Individual	Behavioural Change/ Prevention	Behavioural	Yes (n-of-1)

that this transformation has been seen as a step toward true personalization. L. Garrett (2023) points out that comparing scenarios between Collins (1999) and Hood and Rowen (2013), the latter place a much greater emphasis on how the employment of big data could lead to a reframing of doctor-patient relationship, with a corresponding reshape of the structure of epistemic power in the direction of a more equilibrated position. Some other authors emphasized how conceptual redefinition is welcome. As E. Juengst (2018) puts it, the "progression of a long conversation between basic scientists, physicians, and the larger society" where "[e]ach successive term represents an effort at ethical and scientific course correction in response to the pitfalls of the preceding model" can be seen as a healthy outcome of a scientific endeavour.

However, one thing is the unfolding of this endeavour within the scientific community, and another is its image and repercussion on the general public. Personalized medicine is a misleading term—but one that sticks in the minds of many non-specialists. The presence of this concept, or better, its ghost, in the general discourse may have repercussions in terms of overdiagnosis, waste of resources, lack of trust in clinical practices, and a diminishing consideration of the role of physicians, all factors that could contribute to the emergence of instances of rejection and hesitancy. In the next section we shall argue how.

4 Sources of Potential Mistrust

After clarifying the conceptual change that accompanied the evolution of genomic medicine in the past decades, we revert now to an analysis of the influence that evolution has on trust, and how it could generate mistrust. I focus on three aspects that could have a negative impact: failures of delivering promises regarding patient empowerment, perception of privacy risks, and the presence of commercial interests.

Regarding the first, it has to be reminded again how little of the promises made during the years regarding clinical improvements have actually come true. This is not to say that genomic research efforts were a waste of time and resources. The Human Genome Project, and later genomic approaches to drug development, have been an incredible boon for base science (Evans 2010). The problem is that those efforts needed funding, and in order to get those funding the hype level was set at an unreachable point. Hype is "an inappropriate exaggeration of the significance or potential value of a particular study or area of science" (Caulfield 2018). Inflated language, downplay of possible risk, emphasis of potential benefits, overly-optimistic tone regarding deadlines and deliveries: in the past decades, those elements have been increasingly crawling into most sides of the scientific discourse. As recognition of the presence of hype in science increases, there is a parallel growth in thinking that "[hype] can cause real harm, including potentially eroding public trust and support for science" (Caulfield 2018, p. 567). For what pertains to Personalized Medicine, failures to deliver promises materialized in many aspects: reduction of healthcare costs, therapeutic improvements for genetic diseases, and redefinition of disease taxonomy, to make a few examples. Nevertheless, one particular failure stands out as a specific potential cause of public mistrust in medical

research and healthcare institutions: failure to deliver patient empowerment and to obtain a healthcare focus that feels individual, personal, and close to the single patient. One of the ways in which Personalized Medicine research has been sold to the general public (which is comprised of taxpayers, and therefore is indirectly the source of a great amount of research funding) is by promising them a greater amount of epistemic and practical power over their healthcare. Shifting from the one-size-fits-all approach of pharmacotherapy to one tailored to a given individual's specific needs and particularities was considered a gateway to give individual patients more control over, and responsibility for, their health (Juengst 2018). If considered from a sociological and anthropological perspective, Precision Medicine was assumed by some authors to be a chance to bring medicine back to its roots, by treating every patient as an individual case (Iriart 2019). Yet, the conceptual shift from Personalized Medicine to Precision Medicine carried a fundamental change in that perspective. That shift meant reverting from a narrative of patient empowerment to a data-driven form of medical paternalism. That move is motivated by the fact that extracting meaning from data requires a high degree of technical, statistical, and clinical skills. As L. Garrett reminds us, "the vast expanse between data and meaning characterizes the postgenomic condition." (2023). The employment of "big data" is far from being a step in the direction of easier accessibility and control for the average patient. Despite the best wishes of those who hoped that direct access to health data would put more power in the hands of patients (Hood and Rowen 2013), the push is in the opposite direction. As E. Juengst and colleagues point out, "[due to] the professional concern over the interpretation of overwhelming amounts of genomic data […] academic and medical promoters of PGM have encouraged health professionals to (re)claim more traditional gatekeeping roles in the clinical provision of genomic information." (Juengst et al. 2016, p.26). Such a move is considered by many voices to be endangering patient's autonomy, rather than improving it (Myskja and Steinsbekk 2020). Ironically, reducing personalization to data profiling would have the unintended consequence of transforming healthcare into something even more impersonal (Horwitz 2013): how much does it feel truly personal to be analysed not as a person and a patient, but as a bunch of aggregated metadata?

Speaking of data, the second aspect that may foster mistrust is the presence of privacy risks. Clinical and genetic data are some of the most personal and intimate ones that an individual can have. The increasing "datafication" carries several risks on a privacy profile. The first one is the risk that those data would be acquired through illegal means by a third party. Cyberattacks targeting health providers and hospitals have been steadily rising in the last decades (Murray-Watson 2023) and many of them involve data breaching and theft of personal information (Haro Abad and Corbiaux 2023). The fear that one of these attacks would steal one's digitalized genetic data is legitimate and may lead to some people's preference not to share them. A second, more subtle but perhaps more concrete, worry is the one regarding a more legal, but not more welcome, acquisition of data. More common than hacking is authorized but unwelcome access to health records. That can range from a physician with unnecessary broad access to their patient's clinical data, to "compelled disclosures" of genetic data from insurance companies (Brothers and Rothstein 2015). The third problematic aspect is the regulatory vacuum of

genomic privacy which, rather than being a risk, is an unfortunate reality. Due to the relative novelty of genetic data collecting, and the different speeds at which technological advancement and regulatory systems are moving, the normative framework has not yet caught up, both in terms of data protection and agreement on sharing. For example, the 2018 signature from 21 EU states of a joint declaration for the enabling and regulation of cross-border sharing of genetic data (Saunders et al. 2019); however, its implementation and interaction with the 2016 European General Data Protection Regulation (GDPR) are still under discussion, and reaching an agreement on some points is not appearing to be a smooth process (Molnár-Gábor and Korbel 2020). Meanwhile, a disharmonious regulatory approach does not encourage public trust (Alarcòn Garavito et al. 2023). Indeed, one does not need to go for hypothetical when considering public mistrust to data-sharing initiatives: widening of legislation and introduction of data sharing infrastructures have already been met with resistance from the public in places such as Austria and Denmark (Green et al. 2023), as well as critiques for their lack of fostering epistemic diversity and epistemic justice in scientific communities (Leonelli 2024).

A third element where mistrust may arise is the structure of the commercial interests that lie behind Precision Medicine. Since the beginning of Personalized Medicine the distinction between public and commercial interests has been blurred.[7] Genomics research was not only promising new discoveries, but also hefty investment returns for pharmaceutical companies and technological startups. Advancement in genomic meant potentially entire new classes of drugs to be manufactured, and the excitement from institutions and scientists for the expected new discoveries translated into copious amounts of public funding. This is not the place to consider how many of the early promises of Personalized Medicine were realistic and how many were due to an incentive structure that would reward hyperbolic targets. It is sufficient to notice that much of the public funding passed hands from the public to the private sector, with mixed results. The funding was partially justified because the development of those new drugs was forecasted to reduce healthcare spending. In contrast, even those drugs that were actually developed and ended up being released to the public are marketed by pharmaceutical companies at higher prices. The reason, the fact that they target a small patient population, is a logical but unwelcome consequence of the increased ability to sub-stratify a target population. We can add to this picture other, smaller but highly lucrative, commercial niches that were carved in this time, such as the market for electronic health record software (EHR), which as of today remains highly proprietary (Rehm et al. 2021). There seems to be enough to consider legitimate the consideration that what today has become precision medicine "[…]has thus been much better at fulfilling its promises to reward private investment […] than at delivering savings to health services and their funders" (Sturdy 2017).

To sum up, I pointed out three main aspects that may contribute to generating a sense of mistrust toward Precision Medicine: failure of delivery promised

[7] The pros and cons of private capital involvement in scientific research lie way beyond the scope of this article.

empowerment, privacy risks, and the structure of underlying commercial interests. Such a mistrust would not be unwarranted, but it would risk undermining decades of painful and expensive scientific efforts. Not all hopes and dreams expressed in the initial phase of Personalized Medicine are going to become reality, but that does not mean that in these decades the aforementioned research program has not borne fruits. The potential emergence of an organised popular movement opposing Precision Medicine carries the risk of being a serious, perhaps fatal, setback to a redimensioned but healthy research program. So far, the critiques of Precision Medicine have been mostly expressed within the controlled boundaries of academic discourse, but the situation may change. Granted, the promises of patient empowerment and a medicine truly personalized and focused on the single individual may be unattainable. Nevertheless, those promises remain still seductive, which means that there is a market for them, especially when paired with the recent development of technological tools. Wearable healthcare devices allow (or, at least, promise) to deliver clinical control truly in the hands of an individual person. However, there are elements that cast a shadow of doubt over the feasibility of such target.

5 The Lure and Dangers of Wearable Healthcare Devices

The fact that truly individualized medicine has failed to be delivered does not mean that there is no market for it: quite the contrary. Demand is still high, and capital-raising promises still abound. There is a growing presence and demand in the market for devices that can be worn and that can provide an indication of biological and health parameters: *wearable healthcare devices*. Their purpose is to track variations in biomarkers, such as heart rate, levels of glucose or oxygen in the bloodstream, calorie intake, air quality, sleep habits, quantity and quality of physical exercise, and other (Haleem et al. 2021). They are surrounded by considerable interest for both commercial and research purposes. For the former, it is sufficient to report that the market is valued at 73.77 billion USD as of 2023, and is projected to reach 429 billion USD by 2030 (Fortune Business Insight 2023). For the latter, considerable attention is paid to the potentiality offered in terms of early disease detection, diagnosis, and treatment of conditions like arrhythmias, Lyme disease, or inflammation (Cheol Jeong et al. 2018, Babu et al. 2024).

Their development aims at four different targets. Following Canali, Schiaffonati & Aliverti (2022), we can identify four main functions served by wearable healthcare devices: *monitoring*, *screening*, *detection*, and *prediction*. Monitoring is the practice of continuous data collection, where "continuous" is the keyword. The presence of small, discreet devices that can be worn for prolonged periods without becoming a burden, or that can even be melded into objects of everyday use such as smartwatches, means that the stream of data collected does not present gaps, significantly improving their quality. Screening and Detection are other two functions that wearables can serve, identifying and detecting specific conditions or alterations from the standard or the average, and informing wearers, caretakers, and healthcare personnel, allowing for a prompt response. The last condition, Prediction, means

inferring future trends from those collected biodata. Of all the functions it is the least implemented and developed in the devices currently available, and therefore is also the less reliable. However, limited predictive capability has been deployed in the retrospective detention of COVID-19 infections (Mishra et al. 2020), prediction of the development of pulmonary diseases (Singh et al. 2020), and even age development and mortality (Pyrkov et al. 2018).

How wearable devices are presented and marketed shows remarkable similarities with early-stage Personalized Medicine (see for example Kang and Exworthy 2022). Hyperbolic promises of a "revolution" in healthcare are paired with a rhetoric of individual empowerment and focus on the individual patient's specific needs. It is yet too early to estimate which promises will be fulfilled and which ones will remain empty shells. However, we can hazard certain predictions grounded in those similarities.

One open question is data privacy and security problems surrounding wearable healthcare devices. Wearable devices inherit all the security problems of Precision Medicine and add some of their own. For example, a plethora of small devices translates into multiple points of attack for malicious third parties, allowing for more available hacking chances of both active intrusion and passive listening (Schukat et al. 2016). Another issue is that devices that perform interventions can be remotely manipulated and triggered: for example, by forcing an insulin pump to release the entire supply in one go and causing an insulin shock (Hei et al. 2014). These scenarios are walking a thin line between theoretical possibility and sci-fi. However, a third field represents a greater, and much more present, threat: the use of collected data for non-medical, private gains by tech companies. We already live in a world where data analytics is constantly used to pinpoint and analyse consumers' preference patterns. Constant data gathering from wearable healthcare devices represents a treasure trove of data, readily available to be exploited by private companies or sold to the highest bidder.

A second element to remember is how much wearable devices' commercial and scientific elements are intertwined. The overblown promises of early-stage Personalized Medicine were partially brought by an eagerness for additional research funding and exciting commercial opportunities, but the market of wearable devices brings this incentive structure one step beyond. Today, many wearable healthcare devices are nothing but software merged into non-medical wearable devices, such as a fitness trackers. These devices are both a medical tool and a consumer item. This blurs the lines between what is medically advisable and what is commercially profitable, with a scale of orders of magnitude greater than before. If previously the commercial interests of Personalized Medicine were in the hands of eager startups, now the actors are giant tech and consumer firms, such as Apple or Samsung. This is not necessarily bad per se, but it translates into the very concrete risk that in the case of a conflict between commercial feasibility and medical opportunity, the former is prioritised over the latter.

The last element to remember is the increased danger of overdiagnosis (Vogt et al. 2019) and its close relative, self-diagnosis. Wearable healthcare devices offer the possibility of monitoring a whole array of biomarkers without interruption, looking for multiple problems. However, if one observes everything, everywhere,

all the time, one is bound to find something. Biological variations that would hardly be noticed in normal conditions, and that carry no clinical interest, become relevant all of a sudden, ensuring that "abnormal" gets automatically translated to "pathologic". The ability to screen for lower-risk groups leads to the redefinition of risk factors as pathologic per se, with the correlated danger of disease-mongering (Gonzàlez-Moreno 2015). The convergence of the commercial interests of all actors involved, from tech manufacturers ("the device *needs* to find something, otherwise the customer is going to question its working and regret his purchase") to pharmaceutical firms, ensures that that trend could form unopposed, when not actively prompted. This has not only considerable repercussions in terms of overtreatment and waste of clinical resources. Combined with the narrative of patient empowerment we saw earlier, it could lead to a diminished perception of the need and the role of clinical experts. Constructing a narrative where the means and the ability, or at least a convincing perception, of self-assessment, self-diagnosis, and self-treatment, are increasingly given in the hands of the individual patients, carries the risk of increasing the trust gap between laypeople and medical experts.

6 Vaccine Hesitancy and Precision Medicine: Affinities and Divergences

At this point, we have analyzed many critical elements in the history, conceptualization, narrative, and commercial ramifications of Precision Medicine. Those elements might push toward a general sense of mistrust and might fan the flames of hesitancy and rejection of this research program from the public, a potential social phenomenon that I called Precision Medicine Hesitancy. However, at this point in our analysis, a weak point must addressed. Being a *potential* social phenomenon, this phenomenon is not present yet. Its description lacks any direct empirical social data that may ground its theoretical parts. Therefore, it is worthy to achieve some form of indirect empirical support by comparing it with an established social phenomenon of hesitancy and rejection of medical consensus and practices: the phenomenon of vaccine hesitancy.

The WHO defines *vaccine hesitancy* as the "[…] delay in acceptance or refusal of vaccines despite availability of vaccination services." (WHO 2015). It is a multi-faceted phenomenon, for which numerous causes have been identified (Macdonald 2015, Larson 2022).[8] As we have seen in Sect. 2, today there is a consensus that lack of trust plays a pre-eminent role in creating and maintaining it. This type of distrust is, in turn, not monolithic. At the beginning of the hesitancy movement, distrust was mostly directed toward features of the vaccines themselves, such as safety regarding

[8] Please note that *hesitancy* and *rejection* are two different concepts: one is an epistemic stance regarding some features of the vaccines, the other is a behaviour. The usual description of vaccine hesitancy as a phenomenon is that of a continuum between total acceptance and outright refusal (MacDonald 2015). Hesitancy and rejection are not necessarily linked; however, there is a strong correlation between the two. For the sake of simplicity, I will make here no specific distinction.

potential links with development of autism. In that situation, the causes of distrust by the general public were located in their relationships with, and their attitudes toward, the medical and scientific apparatus (Navin 2015). The CoViD-19 pandemic put on an additional layer of analysis. Pharmacological concerns about side effects were expanded to include suspicion of rushed development and inadequate research coverage for demographic cohorts such as pregnant women (Razai 2021). Moreover, distrust toward vaccines as a clinical tool became inextricably intertwined with distrust toward mandatory vaccination policies, and therefore vaccines were increasingly problematized as a political question, rather than a medical one. As of 2024, vaccine hesitancy remains an interesting and worrisome phenomenon. An extended analysis of it lies beyond the scope of the present work, but it's valuable to underline the main differences and similarities between salient features of this existing phenomenon and those of the potential one we have considered so far.

We start by considering two main points of divergences between vaccine hesitancy and Precision Medicine Hesitancy, to underline the potential weakness of the comparison between the two, and also to draw a modicum of optimism. The first is that there is a profound structural difference in how much the theoretical framework that lay at the foundation of, respectively, precision medicine and vaccines, is established within the research community. There still are many dissenting voices within the medical community over the benefits and opportunities offered by Precision Medicine (Rey-Lòpez 2018). Those dissenting voices, minoritarian but considered scientifically legitimate, focus on the opportunity costs of pursuing genomic targets instead of funding research on traditional medicine and preventive measures, on the epistemic and practical failures in transforming promises into realizations and viable therapies, and on the presence of competingly research programs, such as stem cells, which they claim it would be preferable to prioritize. It can be argued that a general consensus within the research community over the epistemic establishment of Precision Medicine as a branch of medicine, although very likely to eventually happen, is yet to be reached. On the contrary, this is not the case with vaccines, where dissenting voices over their role and importance in contemporary medicine are at the fringes of the scientific consensus, when not entirely outside its boundaries. It can be argued, therefore, that the strongest hesitancy toward Precision Medicine is to be found within the premises of scientific discourse, and is a healthy contribution to the discussion, whereas vaccine hesitancy lies mostly outside of it. The second point of divergence between vaccine hesitancy and Precision Medicine Hesitancy lies in the type of concerns that might arise over the two. Specifically, the reasons put forward by those who reject consensus over vaccines concern medical parameters such as safety, and personal factors regarding the protection of cultural self-identity and representation of personal values. Those factors are difficult to be found in the attitudes toward Precision Medicine. There, the focus of potential concern lies on economic parameters such as (opportunity) costs, whereas the personal factors focus more on the protection of personal data, rather than conceptions of identity.

Having said that, there are other points where there is collimation between these two phenomena. First, the consequences of theoretical limitations and (perceived) conceptual opacity. In the case of vaccines, a strong boost to the emergence of

vaccine hesitancy was the absence of aetiologic explanations of autism. From the outside, the lack of a theoretical explanation in alternative to Wakefield's theses, together with the emergence of a narrative where his ideas were suppressed, made plausible to some people in the laypublic that the scientists were opposed to those ideas not because they were wrong, but because of underlying, obscure interests. I personally think that the testing of Wakefield's hypothesis was a case of acceptable, and even healthy, scientific discourse. Leaving aside the corrupt motivations, the ill-formed sample, and the questionable statistical power of the study that led to the formulation of his hypothesis, Wakefield's hypothesis was tested, overwhelming evidence was found against it, and it has been subsequently discarded. This process, however, could be perceived as less of a quest for the truth, and more of a motivated line of research, one that first decided the answer ("we have to demonstrate Wakefield wrong") and then looked for a reason.[9] Take, on the other hand, Precision Medicine. Over the years the theoretical background, and most importantly the practical implications on the very core target of those medical practices, varied wildly. In this paper I argued that there was a profound conceptual change beyond the passage from "Personalized" to "Precision". The focus shifted from an emphasis on the single individual, to a focus on large quantities of statistical data. Yet most of the field treats it as a conceptually coherent research space. This lack of an open recognition of this change can raise the suspicion of research that is less motivated by pursuing truths, and more motivated to keep that sweet fat funding flowing. Again, I stress how I consider completely viable, and even the mark of good science, the refocusing of research questions through time: but we have to be aware of the consequences that this causes in the appearances to the general public.

The second parallelism to notice is the emphasis on the prevalence of the individual focus. In many cases of vaccine hesitancy, the reluctance to vaccine uptake does not stem from distrust in general scientific laws concerning vaccines, but from their application and viability to the singular case. The reasoning can be summarised as "I understand that vaccines are safe and effective *in a statistical sense*, but I think that they are not safe and effective enough *for me* (*and the people I care about*)". This stance can even be defended as rational, considering how it is grounded in what has been called *exception information* (Kelsall 2023): information relating to one's individual experiences, and I would add, personal knowledge, that leads to the personal refusal of vaccine uptake. Regardless of its epistemic legitimacy, it is an element that is often employed by those who benefit commercially from hesitation to vaccines. Consider now the situation surrounding Precision Medicine, where promises of a treatment truly individualized and focused on a single patient have been superseded by a reality of enormous amounts of aggregated metadata. Personalization may have been abandoned as a concept, but there is a reason if it was employed to begin with: it is very seductive. More importantly, it is way more acceptable, for someone prone to claim to have exception information. Their line of reasoning could develop in the rails of "I understand that

[9] To be completely clear, here I don't want to endorse this particular interpretation: I am merely stating how the situation has been perceived by some.

general medicine and modern Precision Medicine are working *in a statistical sense*, but I want something that applies specifically *to me*". That would create a market niche for a narrative of sense, and more importantly, for products and services, aimed at fulfilling that request.

That leads to the third parallelism: the presence of commercial interests ready to fill that market niche. For what pertains vaccine hesitancy, I am not referring here to the financial compensation received by Wakefield to perform his initial research. Rather, I am much more interested in the oversized industry that grew in the shade of vaccine rejection, an industry made of conferences, seminars, books, social media advertising, products, "alternative" medicine, and so forth. This closely mirrors the situation of the commercial interests surrounding Precision Medicine today. We see the flourish of a plethora of make-at-home genetic testing, dubiously grounded personalized therapies, and in general, a lot of quack medicine and stake-oil salesman. Moreover, the marketing behind Wearable Medical Devices keeps referring to the discontinued goals of Personalized Medicine when they are sold as consumer item, while presenting themselves as a tool for the new Precision Medicine when trying to acquire legitimacy as clinical tools. This muddles the waters even more.

To recap: three elements contributed to the emergence and the establishment of the phenomenon of vaccine hesitancy. First, a less-than-firm theoretical background. Second, the presence of an open market for "alternative" clinical practices. Third, the presence of actors ready and willing to commercially exploit that market niche. For what regards Precision Medicine, all these three elements are present now. I think that's a reason for concern.

7 Conclusions

In this paper, we have warned against the emergence of a phenomenon of mistrust and rejection of modern Precision Medicine, which I called Precision Medicine Hesitancy. To achieve this aim, we have briefly sketched the history of the emergence of Personalized Medicine as a research field, and its transformation into Precise Medicine; in parallel, we have also followed the emergence of the concept of trust as an explanation for phenomena of hesitancy. After that, we have clarified the murky waters of the conceptual differences marked by the various names employed by defining the various research programs. Subsequently, we have canvassed the aspects present in Precision Medicine that may foster potential mistrust from the general public. Thereafter, we presented the role played by an emerging technology, namely the so-called Wearable Healthcare Devices. Finally, we have considered the elements of parallelism between vaccine hesitancy and Precision Medicine Hesitancy.

There are two final elements to keep in mind in this context. The first one is that both social phenomena, the one already existing and the one potentially emergent, hinge by a complex web of trust and mistrust between policy-makers, researchers, producers, users, experts, and laypeople. One of the most interesting questions in this complex ecosystem regards the optimal and desirable levels of epistemic opacity and

transparency. This point is still a matter of discussion (John 2018, Leonelli 2023). Understanding what could possibly provoke Precision Medicine Hesitancy means much more than simply listing the factors that could make it emerge, and future studies will be necessary to draw a clearer picture of the intricate web of causes that would push for or against this phenomenon to happen. The second element is that the situation regarding the elements interplaying between scientific research, commercial players, and public perception is evolving as we speak. In September 2024, all seven directors of 23andMe, one of the most successful private genetic testing companies, resigned (Lindner 2024). This move was motivated by mounting criticism of the tenability of the company business model, by a drop in share prices (23andMe, at its peak valued $6 billion, is in the moment of writing valued at around $200 million) and a data breach that affected seven million customers. The possibility of a bankrupcy raises questions about what is going to happen to the genetic data of its 15 million customers, which are currently privately held by the firm. It remains to see how this, and other analogous situations, are going to affect public perceptions, and if this will be another step toward the establishment of Precision Medicine Hesitancy.

It can, of course, be debated that such an occurrence could never come to pass at all, and that drawing parallelisms between Precision Medicine and forms of hesitancy is illegitimate. For example, vaccine hesitancy is a phenomenon grounded in causes that are so far not completely understood, and it could seem a bold move to draw a parallel between a phenomenon not yet deciphered, and one not yet happened. The costs of not doing so, however, outweigh the risk of appearing overcautious doomsayers. Precision Medicine is, still, one of the most promising avenues of research in medical matters, and it has the potential to be one of the most significant advancements in healthcare and wellbeing of the twenty-first century. Enormous amounts of resources have been and are still poured into this endeavour. However, the combination of commercial interests, technological advancements, financial incentives, and an unwarranted narrative of empowerment carries the risk of eroding the advancements that have been achieved at great costs. Precision Medicine has changed since its beginning, and longing for the yesterday's good ol' days of unlimited potential could prevent us from seeing what can be actually reached today. It is a path we should not thread.

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