Not so elementary, my dear Watson: a critical anthropology essay on eHealth and precision medicine's discourses[1]

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Abstract

"eHealth" and "Precision Medicine" are two major concepts in the new medical discourse. There are several signs of the implementation of a public policy generated around them. In this paper I present some of these signs, starting from the experience of attending a course on digital health and precision medicine directed to train leaders in this area. The reflection on the effects of these signals on populations and individuals' lives suggests the presence of an ambivalence in the motivations that underpin the public policy discourse on eHealth and precision medicine which results as an overvaluation of health systems' management economic aspects and an undervaluation of flexibility in healthcare providing resulting in a misadjustement to the necessarily ecological nature of individuals' and populations' lives.

Keywords: eHealth; Precision Medicine; public health policy; critical anthropology

Introduction

Discourses on public health, particularly on digital health and precision medicine, are inevitably supported by ideological motivations (Horton & Lamphere, 2006; Dubey, 2015) revealed on the "interception of medical informatics, public health and business" (Kwankam, 2004). While public policies focused on digital health and precision medicine have already several years, the inclusion of the topic in anthropology's research agenda is very recent (Ahlin & Nichter, 2015). Primarily supported by a critical perspective, which chooses to perform an anthropology *of* public health, rather than an anthropology *in* public health, as it was tradition (Castro & Singer, 2004), anthropologists start preoccupying themselves on the understanding of the connection between material effects of recent public health policies reforms and the ideological assumptions that underlie them. One of the main ways to do this, we believe, is to analyze the discourses on digital health in the wider discursive context of public health (Lupton, 1992). In a recent critical sociological analysis of this itinerary on the NHS (National Health Service), UK, Ela Klecun (2016) found that those discourses focused on two key aspects: the development of IT and the rhetoric of patient-centered care. According to the author, these two aspects divide the official discourse on the digital health in two

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[1] This essay was written in 2016, after attending a course on digital health and precision medicine. All its groundings and eventual insights shall be understood within such temporal context.
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motivations that work in tandem: the motivation for technological innovation, with the inherent inculcation of the idea of transforming individuals into entrepreneurs and the institutionalization of new technologies as fundamental elements of health governance apparatuses; and the motivation for the (re)organization of care by means of the transformation of healthcare professionals – patient interactions along the trajectory of this latter, also transforming, by extension, health professionals' work locus of control. Patient empowerment is both the cornerstone and the common ground of both speeches' rhetoric.

Indeed, the EU Action Plan for eHealth 2012-2020 (COM (2012) 736 final, from 6th December), reiterates that "the use of ICT products, services and health processes, combined with organizational change in health systems and new skills" improves "the health of citizens, the efficiency and productivity of healthcare and the economic and social value of health."

The analysis of how the ambivalence between values for the patient – the social value – and values for the industry – the economic value – is managed within the political discourse on digital health and precision medicine constitutes one of my main research interests. In this context, I enrolled in a course in 2016 with the suggestive name of Future Leaders in Digital Health & Precision Medicine. The purpose of this article is to raise some preliminary questions about how the discourse of digital health and precision medicine is transmitted as means of motivation for entrepreneurship. The goal is to reflect about some of the impressions I had while attending the course, concerning the rhetoric centered in provoking enthusiasm and appealing for the acceptance of the wonders of the new technological miracle, in a neoliberal way, as Han (2015) understands this one. The intent of this text is not to confront the status of neoliberal discourse of eHealth and Precision Medicine – it is too early to gather enough data which would allow to analyze such issue, since the discourse on digital health is in development until 2020 – nor it is to make some kind of provocation to the defenders of the industrialization of healthcare, it is, rather, to provoke anthropologists to reflect on the dangers of ignoring the effects of delivering the responsibility of health dramaturgies' playwriting to the economists and their relatives, the managers, who insist on perceiving individuals as if they are totally rational actors (Horton & Lamphere, 2006). It seems that anthropologists are relatively neglecting this kind of danger, which was pointed out in Sahlins' (1976) fundamental critique of practical reason.

Boosting innovation in the *new* era of health and well-being

The fostering of innovation in populational health is characterized, among other features, by the emergence of organic signs monitoring technologies and the consequent production of significant amounts of biometric and anthropometric data that should be included in the process of clinical decision-making, notably, in determining the diagnosis and in defining the treatment plans adequated to a given health condition. While emerging trends within healthcare policies and experts'

discursiveness, digital health and precision medicine challenge health professionals, researchers and entrepreneurs to respond to the biggest problem of improving the processes and the traditional systems of care, characterized by the standardization of procedures, in order to turn them into a new system, one that shall be intelligent, i.e., one systems that is provided within a rational adjustment between resources (which are limited) and needs (which are unlimited), in accordance to the premises of economic formalism. The introduction of new technologies in health care is seen as the opportunity to think this adjustment. In this process, it is necessary to mobilize the resources within reach. This is the underlying leitmotiv for the formalization of Future Leaders in Digital Health & Precision Medicine course which was officially put forward by the President of the United States of America, Barak Obama on 30th January 2015. The means for adjusting the resources to the needs in the eHealth and precision medicine discourses is based on a simple premise, apparently so obvious as fundamental: since each individual is unique, that is, inherits and develops a specific genetic heritage, also their health conditions are unique, since, besides they are related to that specific genetic heritage, they also result from specific interactions between unique individuals with particular socio-environmental environments. Inherently, the philosophy of eHealth and precision medicine advocates that medical treatments should also be unique and tailored to the individual specificity and his health condition particularity.

The development of genomics, and its related several omics (the transcriptome, the proteome, the metabolome, the microbiome and the epigenome) or even its complementary omics (the exposome, or the environmental exposure, enhanced by specific lifestyles) as well as the development and improvement of organic description by image or by biosensors and even exposome's graphical description through graphs and social networks, contributed decisively to the inevitable visualization of an integral *panoromic* (cf. Topol, 2014). The need to explore these needs has become a basic reason for the mobilization of targeted policies in this regard. The founder discourse of this need within the US political agenda given by Obama would cause the reaction that the policies included in the American Recovery and Reinvestment Act of 2009, in particular the encouragement of the financial package HITECH (Health Information Technology for Economic and Clinical Health), have already suggested (cf. Kocher & Roberts, 2014). With less media coverage, in the European context, this same intention had already been issued in 2004 by the Communication of European Commission COM (2004) 356 final, entitled "e-Health - making healthcare better for European citizens: an action plan for a European e-Health Area". As the title refers, this Communication set out an action plan for eHealth for the space of the European Union, which is in the interoperability phase – 2012-2020 (COM (2012)736final) – after the phase of standardization – 2010-2013 (ENTR/D/4/CA/cmd (2010) 8861). These policy stimuli are located both downstream and upstream from investigations focused on the potentiation of the semantic web benefits in health, as moreover the inventor of the project W[3], Tim Berners-Lee conceived (Berners-Lee et al., 2001), and as Gunther Eysenbach, one

of the main eHealth boosters, properly understood, by giving body to Berners-Lee's ideal on healthcare (e.g. Eysenbach, 2001, 2003).

If the know-how of Berners-Lee and the practical sense of Eysenbach placed the problem of digital health and precision medicine in the research agenda, it will be fair to say then that without these pioneering impulses would have been no possibility of mobilizing political strategies and financial instruments that allow to consistently develop a real individualised medicine supported by the digitization of the self and the consequent design of a iPOP, or an integrative Personal Omics Profile (Chen & Snyder, 2013), since this development was spurred by the mobilization of resources via the political framework of a need that only science has made possible to satisfy. It is in this context that courses like Future Leaders in Digital Health & Precision Medicine found their *raison d'être*. The challenge it intends to confront implies precisely to transfer know-how to its attendants so they can introduce this new medicine in the social fabric through the incubation of new business projects that simultaneously boost the eHealth market, taking advantage of the emanated stimulation of national and Communitary policies for the purpose, and comply with the anthropological imperative to improve people's lives, informing them, apparently giving them the possibility of allegedly capture their sovereignty though their involvement in monitoring processes and in the treatment of their own health.

From gene to behavior, through the body

After the first session of the course, which gave us the context of its implementation and the various application possibilities of eHealth and precision medicine, the second session brought two concrete examples of this application. The first, allowed us to realize the new possibilities precision medicine adds to "traditional" biomedicine in determining genomic profiles in chronic diseases, such as the case of ankylosing spondylitis; the second showed some aspects of the use of measurement technologies and monitoring of physiological signals in the design and maintenance of physical exercise programs. In the following paragraphs the main ideas are summarized.

The first presentation was illustrated with a case study showing how the definition of a genomic profile of patients suffering from ankylosing spondylitis can be critical to determine the exact diagnosis of the disease. Presenting a study of his own, which applied a methodology focused on the development of gene expression by microarray analysis, the trainer argued that this means of diagnosis, associated with traditional means of X-ray, contributes to discern the individual specificity of developing the disease and thus may help in determining the individual profile of each patient, which will motivate the realization of a precise or an individualized medicine.

Given that ankylosing spondylitis is a chronic progressive disease that challenges the scientific community to discover its causes, the option for the introduction of

the analysis of the genome, as well as several interrelated omics, in the description of its pathophysiology may prove to be a privileged way to define effective plans of treatment and/or prevention. The identification of genes with higher expression in the development of the disease, as the case of B27$^+$ suggests that this road is being traveled, though still in its early stages.

As in other cases of morbidity, the definition of a pharmacotherapy adjusted to individual specific manifestation of ankylosing spondylitis appears as a main objective of precision medical applications. In addition to increasing the medical efficacy, it is argued that the gains in rationalization of diagnostics of diseases allowed by an approach based on precision medicine causes an increase in research on the causes of ankylosing spondylitis which makes obsolete the former means of diagnosis. A diagnostic methodology involving microarray technique and the RNA (and no longer DNA, as before) sequence analysis allows to take "a picture of what is happening in the body at the genetic level."

The second part of the session focused on the impact of physical exercise to combat the increase of non-communicable diseases worldwide. The issue of the relationship between exercise, or even, between working life and health condition has occupied researchers for decades. The trainer began by describing the sociodemographic and dietary aspects significantly associated with the manifestation of poor health conditions such as obesity, which is linked to alarming values of pre-diabetic states that progress to type 2 diabetes, or with increasing risk of a cardiovascular crisis. Factors such as inactivity, diets with excess of salt and/or sugar, associated with unhealthy lifestyle habits, such as smoking or alcoholism, reflected in health conditions that absorb a large share of economic resources of the Portuguese National Health Service (between 8 and 10%) and even the general state budget (about 1%) – year 2016 data.

To this frame, we must add the fact that, since several decades ago, the age pyramids come to know a reversal in the natural growth rates, which gradually come reflecting the increase in the elderly population and the decrease of the young population. If the latter is not problematic in terms of health, on the contrary, the former is very worrying. When associated with unhealthy life, often prolonged for decades of life in the elderly, increased life expectancy and the assumption of the fourth age, which goes naturally depending on the omnipresence of medical care, this frame reveals a picture that matters to avoid. It is in this attempt that the stimulation of physical activity and the promotion of healthy lifestyles get its main justification. And it is this same attempt that proved to be necessary to develop systems for monitoring indicators which impact on people's health. Projects promoted by the United Nations as the "25 by 25", which aims to reduce premature death associated with unhealthy lifestyles by 25% by the year 2025, or the "Life's Simple 7", promoted by the American Heart Association and also focuses on the younger ages ("Life's Simple 7 for Kids") based their guidelines on the assumption that there is a positive relationship between physical activity and the reduction of

some diseases, and even the manifestation of cancer, as some studies and systematic reviews and meta-analysis show, as presented by the trainer.

The pattern recommended in several randomized clinical trials consists in doing workouts during at least 150 minutes per week of moderate activity or vigorous activity during 75 minutes in the same period, for the adults; for children, these levels should increase. The studies' results also suggest that the combination of an exercise program with a diet control plan results in substantial benefits than if we focus on only one of the factors.

Although the causes of the problem are already diagnosed, much remains to be done, especially in sensoring of biometric and physiological indicators to draw up customized intervention programs. The problem centers on the stiffness of the programs which are not designed for adjusting the individual in question, but instead in reference to an abstract pattern. It is in this field that the customization of the programs is presented as an imperative that urge to be accomplished, since the physical, mental and health conditions are different from person to person. The variability of these conditions is one of the great defenses of precision medicine itself, which is revealed by the analysis of the various omic levels. In the particular case of the relationship between activity and health, or rather, between inactivity and illness, the description and effective analysis of epigenome and exposome is central. And this is the field only social sciences, especially social anthropology, may make a big difference.

Value-based health

The third session was about to the issue of value-based health care and the sustainability of health systems.

The trainer began by broadly describe the context in which the Portugues public health system currently operates, focusing on some demographic and financial indicators. The increase in average life expectancy at birth and the decrease of infant mortality rates indicate an improvement in the human development index and show that the Portuguese health system has had a satisfactory behavior and thus has contributed to the creation of value, whereas the central indicator of this creation is the satisfaction of users/beneficiaries relating the system's behavior, which is so revealed in latent form through these values. In addition, the good behavior of the system in value creation is also visible in the decrease in the number of cases of HIV, an indicator that undoubtedly refers to the efficiency of the system, particularly regarding the processing of existing cases and the prevention of the occurrence of new cases and/or the promotion of healthy behaviors to avoid the risk of contracting the syndrome.

The results of these three key indicators place Portugal, and, by correspondence, its National Health Service, in a top position in the ranking of health systems both in the European's and the United States' geographical contexts.

The positive behavior of this indicators assumes greater impact if we include the fact that Portugal has been living in a state of exception due to the financial assistence program that it was targeted between 2011 and 2014. By this time, the NHS operating framework was pooling inheritance of a complex and expensive machine to the state coffers (with an accumulated debt of 3.7 billion euros in 2010), the imposition of a severe economic and financial crisis, which led to that formal request for international assistance, and the manifestation of difficult economic and financial conditions in a global level, which main indicator was the rampant rise in oil prices. The brutal reduction of public investment during the years of the *troika* pushed private providers of health care as key players, for example, via the NHS association agreement with Misericórdias.

Due to the various containment measures and even austerity, at the end of international assistance program, NHS reached break-even. These results are shown simultaneously as the end of a period of adjustment, which takes place in response to a serious structural situation, and as the starting point for redirecting health policies for a future centered on system efficiency. The centralization of health care in the individual, making this the protagonist of his "health career", presents herself as the focus of policies designed for the future of the NHS. Concomitantly, the need for better manage resources, both human and logistics in general, in hospitals and health centers, is presented as the other two strategic areas of intervention to improve system efficiency. The strategy looks for, in the overall context, to focus on patient and to make an efficient management of health services which shall contribute to the sustainability of the NHS and to the implementation of a value-based care.

As the main expenditure in the system was related to the medicines, the 60 defined measures developed during the troika years aimed at improving the NHS efficiency through intervention in the management of hospitals focusing mainly on changing the prescribing culture followed by physicians. The intention was to avoid wasting resources and time in carrying out unnecessary diagnostic tests and in purchasing drugs whose prescription was not justified by clinical reasons, or then by the reason to consider alternatives such as generic brands. As mentioned, the savings of resources departing from a patient-centered management planning is the motto of the NHS strategic plan. The concentration of the means of diagnosis and the freedom allowed to the patient for purchasing generic drugs are two ways to achieve this motto in the care reality. By the concentration of resources, health services regulate better the subcontracting agreements with companies outside the system while allows the patient to perform the tests at the same place where he goes for the clinical consultation. By the adoption of generic drugs, the strategy of supplying drugs adjusts to purely clinical criteria – the active principle of the drug – and not the brand criterion, relying thus the prescription in clinical guidelines resulting from meta-analyses of the effectiveness of the drugs; at the same time it gives the opportunity to the patient to choose the type of medication that she prefers, once

it accesses the information on price differentials between different drugs with the same active principle and thus all adjusted to the treatment of her condition.

In the context of primary care, the strategy focuses primarily in improving the management of human resources. Looking at the whole territory, there is a health professional shortage in primary care, however, a closer observation reveals that the number of doctors per capita is higher in Portugal than the average number recorded in the OECD. The medical deficit is therefore apparent. The problem is that they are concentrated in the region of Lisbon, where the ratio is higher than the OECD's average. In contrast, other regions of the country have a doctor per capita ratio below this average. The question is, therefore, to improve doctors-population distribution across the territory. In what regards the number of nurses, this is lower than the OECD´s average. Improving the management of human resources in primary care is thus associated with the same measures designed to deal with human resources issues found in hospitals.

In both scales of healthcare, it is intended to replace the provision based on the logic of cure, which is seen as being responsible for the emergence of silos specialized in certain clinical conditions that produce high maintenance costs, by the provision based on value creation, which ultimately is revealed as the user's satisfaction.

Final Thoughts: not so elementary, my dear Watson

The complexity of the constellations of the interactions between the individual and the environment goes beyond the organic level and is diluted in the socio-political and cultural fabric, which ultimately determine the pathogenic nature of the environment in which individuals live. To create social value, eHealth and precision medicine should generate its activities in the real adjustment to the individual-milieu interaction, otherwise, we are doing the same Procrustes did, we find ourselves "adjusting" the content to the container and not the container to the content, as it would be right.

About the intervention at the individual level (and not the population, which refers to the design of abstract and undifferentiated plans), policies should focus, in fact, in preventing disease and promoting healthy behaviors. However, the intervention at the individual level is virtually logistically impossible, so it is necessary to intervene mainly through the provision of information and health education, which competes with the need to provide skills to informal caregivers to prevent and treat the disease of their significant others, having always in mind that there is no such thing as hyper-rational subjects.

Health literacy is the cornerstone to achieve this effect – and therefore the biggest problem facing the discourse of public policies of eHealth and precision medicine. It is in this context that there is a need to inform individuals by means of both general and interactive communication channels that allow to associate in the same principle of information management both global intervention plans and specific

situations of concern which are revealed through specific help-seeking itineraries. This association is absolutely necessary for any informational architecture. Here comes the inevitable semantic web utility that allows one to associate the ontonomic plan to a folksonomic situation and personal experience, that is, allows one to add keywords generated by the user to taxa that constitute digital ontologies, and which were introduced by the programmer (see, for example, Trant, 2009). The need to relate in the same logical intelligibility popular production and specialized production of knowledge has been widely analysed in anthropology (e.g., Suchman, 1985; Fiore-Gartland & Neff, 2015).

The question goes precisely in equipping information systems with the required flexibility to include in their reasonings the practical and ecological production of informational infrastructures, which necessarily support the computer ontologies (Star & Ruhleder 1996; Nafus et al., 2016.). This is the most important problem to be solved in order to be possible to speak of an actual precision medicine and an effective digital health. Due to this central issue of the discrepancy between the algorithmic construction of care and the social and cultural effectiveness of this latter, cognitive computing fails to achieve the ultimate goal of providing people with the necessary information for them to be vested as caregivers to the image that the formal framework meant by "care". However, this investiture should be seen as a precondition for individuals extensively use digital platforms as really useful aid instruments. That is, on the one hand, it is necessary to equip individuals with skills to care, on the other, it is necessary to equip individuals with skills to access to reliable information to do so, which, in turn, is possible only if who equip them with those skills is aware, in fact, of the aspects patients need to manage in order to maintain their daily routines inside their familiar world. As a matter of fact, inside this cycle is defined the whole social intention of the concept of "personalised medicine" via and within an "eHealth" path, so, the management of this dynamics should be the primary concern of this new medicine, otherwise we are only putting old wine in new bottles, i.e., we are just moving from biomedicine to biomedicine 2.0. The biomedical philosophy, whose history shows it was excessively distant from the paramount biopsicossocial dimension of social reality, will be repeated in eHealth and Precision Medicine if we remain dazzled with the algorithmic feats of Mr. Watson. Contrarily to his friend and associate, Mr. Holmes nourished an authentic passion for humanness in its very messy way of living. His inductive reasoning is situated in the antipodes of IBM's Watson. Moved by enaction and sometimes by serendipity and cultivating an abdutive way of thinking, Holmes could say to IBM's Watson, that human health is not so elementary as it computes...

Indeed, the centralization of precision medicine in iPOP and clinical reports from which the IBM Watson builds its therapeutic decision does not include this popular production in health management processes and disease. Arthur Kleinman has long shown that the management of health and disease is not an exclusive development of biomedicine. On the contrary, he said, only about 20% of cases of illness are treated in the biomedical arena, and the popular sector, where care is really found

as being centered on the individual, the family – the first care arena – the social group and community is the place where about 80% of care is hosted (Kleinman, 1978). Furthermore, biomedicine is only a part of the culture, and, therefore, the biomedical speech, being "traditional" or in its new clothes, is a cultural product, just as the popular speech (e.g., Kleinman, 1978; Burri & Dumit, 2007). What reason is there, then, to suppress the popular discourse with its own explaining models from the hegemonic intelligibility schemes of health and disease? More, how can we make the medicine precise, by means of ICT, if we don't explore and definitely understand the decisional aspects underlying the behavior of seeking help?

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