JOAQUIM BRAGA SIMONE GUIDI (*Editors*)

QUANTIFYING BODIES AND HEALTH

INTERDISCIPLINARY APPROACHES





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edited by

Joaquim Braga Simone Guidi



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Chapter 6

Manufacturing Biocitizens The Quantification of Bodies as a Method for Incorporating a New Biomedical Ethics

José Carlos Pinto da Costa¹

Abstract: The quantification of bodies serves an ambivalent purpose in the political economy of promise of new biomedicine. On the one hand, it includes individuals in a new biopolitical norm, making them co-producers of new healthcare-related sociotechnical imaginaries; on the other, it urges them to explore and to overcome the deepest natural norms, distinguishing them as apparently free self-enhancers and creative developers of what Donna Haraway (2003) called naturecultures. By monitoring, recording, and supplying biometric data, individuals are included in a process for incorporating a new biomedical ethos, gradually taking on a new kind of citizenship: biocitizenship. In this chapter, I reflect on the power such incorporation has for transforming both individuals and society and advocate the need for making a critical analysis of the practices of quantification of bodies, considering these as elements of a biopolitical technology aimed at manufacturing biocitizens.

Keywords: biomedicalization, biocommunicability, biocitizenship, technologies of corporeality.

Introduction

Recent developments in information and visualization technologies, as in biomedical research, have advanced the emergence of systems biology, a holistic science that integrates information from various disciplinary areas to produce highly accurate statistical models which enable disease prediction and prevention (Alyass et al., 2015). The production of such models implies the generation, recording, integration and interpretation of a significant volume of data, which together configure what Eric Topol (2014) called the "human geographic information system". In the end, the goal is to create person-

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alised medicine; that is, a medicine that designs prevention methods and therapies according to the specificity of the association of each individual's genetic heritage with the physical and social environment in which he lives. In this chapter, I discuss the social and anthropological meaning of the narrative of this new biomedicine, in which the quantification of bodies obtains its context.

1. 4P Medicine and the Imperative of Digital Health

Recent reports point to benefits, but also to important challenges for 4P medicine, which is predictive, preventive, personalised and participatory. According to Wilsdon et al. (2018), the benefits will be visible to patients (improved efficacy through disease-specific responses, improved disease survival ratios and reduced adverse event manifestations), to medicine (development of new, more efficient, more cost-effective approaches, and more ethical, cost-effective R&D clinical trials) and to the health system and to society (focus on disease prevention and prediction, improved disease management and avoidance or delay of high-cost healthcare, allowing scarce resources to be used more efficiently). For his part, Muin Khoury (2014) lists three major challenges for personalised medicine: first, since complex chronic diseases are the result of multiple genetic and non-genetic factors, it is very difficult to know which portion of heredity is explained by which set of variables identified in a general set of genome research; secondly, specific genomic information may or may not be actionable (Khoury exemplifies this with the fact that scientific community doesn't know how to prevent Alzheimer's disease, although the allele responsible for the increased risk of the disease has been known for some time); finally, and especially significant for the present discussion, the analysis of genetic-environment interactions in population health studies is still in its infancy, and it is not actually possible to extrapolate from the results of the analysis of these interactions to the personal level of health in order to predict the occurrence of the disease and to design its related prevention plans.

Despite these challenges, the 4P model opens numerous opportunities. The impacts of its full implementation will undoubtedly be huge in the future. It is still early to concretely realize or even to predict its social impacts (Saxena and Saxena, 2018). One of the biggest challenges is to include the population in the process, thus enhancing the participation of the individual (the fourth P) in the language of the emergence, marked by the invasion of the new, translated into technoscientific discursivity that the population is not used to perceiving or using. This issue will be explored later in this chapter. For now, I think it is important to look at the function of digitization in pursuing the goal of personalizing medicine, which configures the ideal of healthy citizenship.

The central idea of digitalization applied to health, or the "digital health", or still "eHealth", was highlighted in the European Union's Digital Health Action Plan 2012-2020, which stresses that it consists of using...

ICT in health products, services and processes combined with organisational change in healthcare systems and new skills, in order to improve health of citizens, efficiency and productivity in healthcare delivery, and the economic and social value of health. eHealth covers the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals (European Commission, 2012, p. 3).

Promoting innovation in people's health via the use of ICT includes the monitoring of organic signals and the consequent production of significant amounts of biometric and anthropometric data. These data can be included in preventive behaviours and in the clinical decision-making processes, notably for the purpose of determining diagnosis and defining treatment plans tailored to a particular health condition. Digital health also challenges health professionals, researchers and entrepreneurs to respond to the larger problem of improving traditional care processes and systems, characterized by the standardization of procedures, making them intelligent practices and models, provided with adjustment mechanisms between resources and needs, in line with the assumptions of the formal economy and respecting the 4P's primacy of patient-centredness in healthcare. The introduction of new digital technologies in healthcare and medical treatments is seen as an opportunity to think about this adjustment. In this process, it is necessary to mobilize resources within reach. Michael Porter's model of value-based healthcare finds its basic philosophy here.

2. Biological Citizenship and the Discursivity of Biomedicalization

In terms of the social analysis of the discursiveness of 4P medicine and digital health, the Foucauldian concept of biopower and Isabelle Stengers' image of cosmopolitics are particularly noteworthy. From the first emerges the notion of biopolitics as the exercise of governing bodies and populations (Foucault, 2004); from the second emerges the figure of the "passing fright that scares self-assurance" (Stengers, 2005, p. 996), which impels the majority of the population located outside the place of production of that discursiveness to ask: "what are we busy doing?" (Stengers, 2005, p. 996), directing this question to the world's decision makers/designers. Bringing together these two interpellations, an essential tension between visions and imaginaries about possible futures emerges, which evolves from the way in which the relationship between healthcare systems and populations is managed (Costa, 2020). This tension configures a plateau from which we may visualize how the political economy of 4P medicine transforms the way societies manage healthcare-related issues. This kind of transformation is the main feature of the process of biomedicalization (Clarke et al., 2010).

Biomedicalization appears in the context of New Public Management discursivity and the neoliberal inspiration of governments (particularly the socalled "Westerners") and becomes more robust with the emergence of the relationships between biomedical knowledge, technologies, capital, services and the environment (Andreassen and Dyb, 2010; Clarke et al., 2010). Biomedicalization is characterized by the confluence of five processes: privatization and commercialization; risk and surveillance; expansive technoscientific practices; production and distribution of knowledge; and transformation of bodies and subjectivities (Clarke et al., 2010). The difference between biomedicalization and the traditional medicalization arising from French hygienist political economy, noted by Foucault, is that while medicalization practices emphasize the control of medical phenomena, biomedicalization practices emphasize the transformation of these phenomena and bodies (Clarke et al., 2010).

The transformation of medical phenomena and bodies changes the practice of and access to medicine. Medical practices and "going to the doctor" behaviours tend not to be simply exercises for providing/prescribing care and therapies or for seeking help, respectively. The crossing of the boundary between the pre-patient and the patient phases gradually occupies a secondary significance. The priority is now to predict and prevent disease, and for that purpose, the participation of people is necessary, fundamentally, for them to adopt quantification practices as a regular way of behaving, then becoming more and more responsible for their health (Rose, 2010). This is where the adoption of regular quantifying behaviours becomes the adoption of behaviours to regulate behaviours.

By providing his data, the patient turns into a co-producer of a new status quo, thereby engaging in the pursuit of a utopia (Bell and Pahl, 2018). The patient - now co-producer - thus engages in a second process of greater interest for the social and anthropological study of health: biocommunication, i.e., "the process by which health-related information is produced, circulated and received" (Briggs and Hallin, 2007, p. 48). The patient co-producer contributes with his data (and possibly with his own interpretations and explanations) to the process of circulation of the different discourses linked to digital health and 4P medicine. The patient co-producer who uses the discourses that come to him because of his involvement in a given narrative is a major theme in the anthropology of digital health and personalised medicine. It is through this involvement in discursiveness that co-producing patients tactically become part of the scriptural economy that structures a normativity imposed from above, as Michel de Certeau (1984) taught us. However, while seeming to be recovering his place to drive the discourse, or taking a seat in hegemonic enrolment processes, the patient co-producer is, in fact, undergoing the moulding process of a specific model of biocommunication. He falls into the role of a consumer of services and his personal specificity is diluted into a multitude of co-producers who, like him, are structured by the force of biomedicalization discourse.

According to Briggs and Hallin (2007, 2010), the current biocommunication model is potentially hybrid, or even multiple. In the context of the access to healthcare, the medical authority model, the patient-consumer model, and the public sphere model remain combined today.² The combi-

² The medical authority model is essentially characterized by the exercise of knowl-

nation of these models in contemporary times means that the "patient" sees his status becoming a confused amalgamation of overlapping norms – a multi-normative normativity – that of the "patient", that of the "consumer" and that of the "coproducer citizen". This is the most characteristic sign of a time of transformation (rather than change or evolution). The daily work of biomedicalization happens through these processes of biocommunicability (Briggs and Hallin, 2016), and is structured in figures of biosociality (Rabinow, 1996), such as biocitizenship (Petryna, 2002) or biological citizenship (Rose and Novas, 2005), transforming both the individual and the community in the process (Ajana, 2013).³

In my view, this is the final form of the process of quantification of bodies. An extremely complex form that promotes the expression of an ambivalent reality in which characteristically utopian and dystopian planes of existence will coexist. Indeed, the figure of biocitizenship "produces new identities, communities, expertise, and hope. But it also has a disciplining and differentiating capacity, as biological citizenship generates new forms of inequality and strengthens the hegemony of biomedical frameworks" (Mulligan, 2017).

The circle closes over the individual. The allusion to the subject's recovery of sovereignty is therefore, and nevertheless, apparent. Indeed, individual participation in the processes of the new biomedicine is more a biopolitical imperative of social accountability (because health resources are a public good) for their conduct than a liberation toward complete subjectivation (Andreassen and Dyb, 2010). In contrast to the idea that the quantification of bodies promotes a new level of self-building techniques is the fact that this practice shifts the focus from subjectivity to corporeality. This seems to be the first era in human history when this happens (Suchman, 2015). Rather than being subjectivation techniques, quantification practices, such as lifelogging, are more technologies of incorporation (in the sense of making practices body) than of holistic (mind-centred) development. The difference is radical, and it is the same which Helmuth Plessner distinguished between being a

edge-power in a context of the doctor-patient relationship, in which the former has the authority (he is the one who knows) and the patient is a passive agent. According to the authors, the biomedical authority model of biocommunicability "imagines a natural, necessarily linear trajectory that moves through space, time, and states of knowledge and agency, starting from the production of knowledge about health, its codification into texts (reports, scientific articles, pronouncements by public health officials, and so on), the translation of scientific texts into popular discourse (through health education, statements to reporters by health professionals, and media coverage), its dissemination through a range of media, and its reception by 'the public'." (Briggs and Hallin, 2007, p. 49). In turn, the patient-consumer biocommunication model "significantly shifts relationships between health professionals and publics. Rather than imagining passive receivers of authoritative information, the patient-consumer model casts laypeople as individuals who make choices in the absence of their physicians and the presence of the media." (Briggs and Hallin, 2007, p. 52). Finally, in the model of the public sphere "audience is imagined as being composed of citizens, rather than of patients or consumers. [In this model,] the information is assumed to be useful because it helps citizens and policy-makers to make collective decisions about the public interest." (Briggs and Hallin, 2010,

³ Significantly for the problem of quantifying bodies, Btihaj Ajana (2012) adds the figure of "biometric citizenship".

body (*Leibsein*) and having a body (*Körperhaben*). While "being a body" implies a holistic conception of the individual, fostering techniques of subjectivation, "having a body" focuses the attention on materiality, fostering techniques of incorporation. Body enhancement will be the corollary of the use of these techniques; it is the affirmation of the expressive power of individuality by understanding the body (the property) as an extension of the self (the owner) and as a semantic vector by which the individual constructs a unique and exclusive narrative of the way he wishes to be and to become in the world.

Enhancement is the starting point for the final bioconvergence, where "bodies are technologized and conceived increasingly in technical and biotechnological terms, while correspondingly, techniques and technologies have become increasingly 'bodied'" (Steinberg and Murray, 2011, p. i). This impetus towards bioconvergence is directly inspired by a philosophy of desire, by trying to reach a utopian stage in which the products of enhancement will leave little room for the contingent.

That philosophy of desire underlies individuals' practices and hopes, driving them to this final utopian form. Here, perhaps, we may visualize Simondon's final form in a human realm, and the identity between zoë/onthos and bíos/epistēmē, in dialectical Blochian terms (cf. Bloch, 1983; Simondon, 2005).

This imagined final product is instrumentalized in political-economic terms through discursive transposition, that is, it is normalized. One of the most manifest ways to engage such normalization is through the so-called political economy of promise (cf. Joly, 2010). Directing spontaneity by means of discursive formalization, this political economy limits individuals' freedom and hopes, constituting "regimes of economics of techno-scientific promises" (Joly, 2010). Promises are not only formed by discourses and representations (Costa, 2020), they also "involve practices of exploration and experimentation; they are related to investment, and to mobilization, circulation, and accumulation of resources" (Joly, 2010, pp. 2-3). These practices make the discursivity of biomedicalization a means to conform (personal) desires with (public) needs. Society gradually becomes an arena of collective experimentation, where the resources are personal data. So, one of the main ways to achieve this new "communitarian" ethos is by promoting personal experimentation.

Personal experimentation implies the exploration of body possibilities, and, to this end, it is necessary for the individuals to know their bodies to the tiniest detail. Quantification techniques and practices serve this purpose very well. The importance of personal data to the regimes of economics of techno-scientific promises is crucial. The way in which these precious resources are accumulated and managed for the public good constitutes a paramount ethical issue in our times – as we know, it was at the basis of the reformulation of General Data Protection Regulation (GDPR) in the European Union in 2018. Thus, the quantification of bodies is not just a method

to better know yourself, it is first and foremost a new biopolitical technology which seeks to better regulate human life.

Conclusion

The quantification of bodies is a procedure that produces ambivalent figures about what humans are and can do with the human. In a constant production of imbalances between the individual freedom (for empowerment) and the datafication and appropriation of his signals for the management of bodies and life, the quantification of bodies presents itself as an instrument of formatting a new paradigm of social organization in which multiple views and multiple interests interfere. Due to the extreme complexity of these interferences and their potential for technical and material embodiment, it is not yet possible to fully understand the effects of the quantification of bodies on the production of new biopolitical agencies. However, it is certainly possible to see that the self-perceptions and social configurations of life (both organic – zöe – and political – bíos – in the distinction re-operated by Hannah Arendt) are undergoing radical transformations.

The recording of biometric signals tends to stop happening episodically in situations of crisis and become routine. The practices of monitoring, recording, signal interpretation and diagnosis tend to be no longer exclusive to technicians and physicians; they are now potentially claimed by all individuals, and, albeit a utopia, by society in general. And it is in this context that the figure of a new citizenship, girded to the biological, can fully emerge. By having access to monitoring and diagnosis technologies, citizens can respond to their body's (perceived) signals with technologies perceived as corrective. If such access becomes ubiquitous, we can imagine a future in which people will themselves become naturecultures, which, among other consequences, could lead to the realization of the biopunk ideal (and the corresponding release from the potentially totalizing biopower corset in favour of the authority of self-perception and self-concept). Then, finally, perhaps humans will voluntarily become hybridizations. More than cyborgs, they might become artisan-artwork mixed forms.

References

Ajana, Btihaj. 2012. Biometric citizenship. *Citizenship Studies* 16(7): 851-870. Ajana, Btihaj. 2013. *Governing through Biometrics: The Biopolitics of Identity*. London: Palgrave MacMillan.

Alyass, Akram, Michelle Turcotte and David Meyre. 2015. From big data analysis to personalized medicine for all: Challenges and opportunities. BMC Medical Genomics 8(33): 1-12.

Andreassen, Hege and Kari Dyb. 2010. Differences and inequalities in health. *Information, Communication & Society* 13(7): 956-975.

Bell, David and Kate Pahl. 2018. Co-production: towards a utopian approach. International Journal of Social Research Methodology 21(1): 105117.

- Bloch, Ernst. 1983. The dialectical method. *Man and World* 16: 281-313.
- Briggs, Charles and Daniel Hallin. 2007. Biocommunicability: The Neoliberal Subject and its contradictions in new coverage of health issues. *Social Text* 25(4): 43-66.
- Briggs, Charles and Daniel Hallin. 2010. Health reporting as political reporting: Biocommunicability and the public sphere. *Journalism* 11(2): 149-165.
- Briggs, Charles and Daniel Hallin. 2016. *Making Health Public: How News Coverage Is Remaking Media, Medicine, and Contemporary Life.*London and New York: Routledge.
- Clarke, Adele, Janet Shim, Laura Mamo, Jennifer Fosket and Jennifer Fishman. 2010. Biomedicalization: A theoretical and substantitve introduction. In *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, eds. Adele Clarke, Laura Mamo, Jennifer Fosket, Jennifer Fishman and Janet Shim, 1-44. Durham & London: Duke University Press.
- Costa, José. 2020. "O que estamos a fazer?" Ensaio sobre a economia política da promessa do novo imaginário biomédico. *Trabalhos de Antropologia e Etnologia* 6: 1-45.
- de Certeau, Michel. 1984. The scriptural economy. In *The Practice of Every-day Life*, 131-153. Berkeley: University of California Press.
- European Commission. 2012. Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions: eHealth Action Plan 2012-2020 Innovative healthcare for the 21st century (COM(2012)736 final).
- Foucault, Michel 2004. *Naissance de la Biopolitique. Cours au Collège de France (1978-1979)*. Paris: Seuil.
- Haraway, Donna. 2003. *The companion. species manifesto: Dogs, people, and significant otherness*. Chicago: Prickly Paradigm Press.
- Joly, Pierre-Benoit. 2010. On the Economics of Techno-scientific Promises. In *Débordements: Mélanges offerts à Michel Callon*, eds. Madeleine Akrich, Yannick Barthe, Fabian Muniesa and Philippe Mustar, 203-222. Paris: Presse des Mines.
- Khoury, Muin. 2014. Nobody is average, but what to do about it? The challenge of individualized disease prevention based on genomics. https://blogs.cdc.gov/genomics/2014/07/02/nobody-is-average/. Accessed 12 January 2018.
- Mulligan, Jessica. 2017. Biological citizenship. Oxford Bibliographies. https://www.oxfordbibliographies.com/view/document/obo-9780199766567/obo-9780199766567-0164.xml. Accessed 24 April 2019.
- Petryna, Adriana. 2002. *Life Exposed: Biological: Citizens After Chernobyl.*Princeton: Princeton University Press.
- Rabinow, Paul. 1996. Artificiality and Enlightenment: From Sociobiology

- to Biosociality. In *Essays on the Anthropology of Reason*, 91-111. Princeton: Princeton University Press.
- Rose, Nikolas. 2010. Personalized Medicine: Promises, Problems and Perils of a New Paradigm for Healthcare. *Procedia Social and Behavioral Sciences* 77: 341-352.
- Rose, Nikolas and Carlos Novas 2005. Biological Citizenship. In *Global Assemblages: Technology, politics, and ethics as anthropological problems*, eds. Aihwa Ong and Stephen Collier, 439-463. Malden: Blackwell Publishing.
- Saxena, Mohit and Ankur Saxen. 2018. Personalized Medicine A Bio-Medicine derived from Big Data Analytics. Proceedings of the 12th INDIACom; INDIACom-2018; IEEE. http://studentlearning.in/wp-content/uploads/2018/08/Personalized-Medicine-A-Bio-Medicine-derived-from-Big-Data-AnalyticsMohit.pdf. Accessed 13 January 2019.
- Simondon, Gilbert. 2005. L'individuation à la lumière des notions de forme et d'information. Grenoble: Millon.
- Steinberg, Deborah and Stuart Murray. 2011. Editorial Preface: Special issue on bioconvergence. *MediaTropes eJournal* 1: i-iii.
- Stengers, Isabelle. 2005. The cosmopolitical proposal. In *Making Things Public: Atmospheres of Democracy*, eds. Bruno Latour and Peter Weibel, 994-1003. Germany and Cambridge MA: MIT Press.
- Suchman, Lucy. 2015. Situational awareness: Deadly bioconvergent at the boundaries of bodies and machines. *MediaTropes eJournal* 1: 1-24.
- Topol, Eric. 2014. Individualized Medicine: From Pre-Womb to Tomb. *Cell* 157(1): 241-253.
- Wilsdon, Tim, Anthony Barron, Guy Edwards and Ryan Lawlor. 2018. The benefits of personalised medicine to patients, society and health-care systems: Final Report. https://www.ebe-biopharma.eu/wp--content/uploads/2018/07/CRA-EBE-EFPIA-Benefits-of-PM-Final-Report-6-July-2018-STC.pdf. Accessed 21 December 2018.