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Deposited in *Repositório ISCTE-IUL*: 2022-05-16

Deposited version: Accepted Version

Peer-review status of attached file:

Peer-reviewed

## Citation for published item:

Pereira, A da C. (2020). Ethical challenges in collecting and analysing biometric data. In Florinda Matos (Ed.), Proceedings of the European Conference on the Impact of Artificial Intelligence and Robotics, ECIAIR 2020. (pp. 108-114). Lisboa: Academic Conferences International Limited, Reading, U.K.

## Further information on publisher's website:

10.34190/EAIR.20.034

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Integrated @ Proceedings of the 2nd European Conference on the Impact of AI and Robotics, ECIAIR 2020, Iscte IUL 22-23 Oct, 2020, pp. 108-114.

### Ethical Challenges in Collecting and Analysing Biometric Data Anabela Pereira

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Abstract: This paper is a theoretical discussion of the technical, ethical, legal and social implications of the biotechnological (e.g., using AI and robotics) to neuroscience research and neuroethics. In particular, reflection will be made on the responsible use of neurotechnological devices directed to the consumer as well as on the advanced machine learning and brain imaging techniques which involve the recording, testing and analysis of biometric data. According to recent theories, the architecture of our brains determines our social behaviour and our inclusive moral dispositions, influencing the type of society we create, and vice versa. (cf., Damasio, 2017). It is now accepted that both reason and emotion influence moral judgment, as the degree of automaticity in decision-making process (analytic vs. heuristic) influence human choices and actions (cf. Greene et al., 2001; Ferreira et al., 2016). Thus, ethical challenges in collecting and analysing biometric data involve the discussion of the benefits of working with this type of data, but also, of the risks involved in their uses and applications. Such risks display levels of vulnerability related to the privacy of the mental and physical states of the users (as some technologies are used directly by consumers), and raise questions of whether biometric data has suitable treatment, as well as on the existence of legislative frameworks against which their uses can be displayed. To what extent is risk management capacity - considering risk as a constitutive condition of modernity (Beck, 1992) –, important to the implementation and results of programs when dealing with such a sensitive type of data, and what is the role of advance technologies and neuroscience research in this process? Questions of access and literacy, the use of technological tools in civil society, and regulatory issues on how to protect the privacy of biometric data collection and analysis will be addressed. The main contribution of such discussion is to point out how emergent changes caused by the biotechnological uses in society are affecting the formation of contemporary culture and humans as beings, for some of these objects can also be seen as technological extensions of the human body biological process.

Keywords: biometric data, ethics, biotechnology, cognitive science, neuroscience

#### Introduction

The purpose of this essay is to analyse the question of contemporary technological potential and how it has become decisive in neuroscience research and neuroethics. Neuroethics is an interdisciplinary field which encompasses aspects of philosophy, morals, technology, empirical sciences of the brain, sometimes religion and also social sciences. In the literature it is common to distinguish the "ethics of neurosciences" from the "neurosciences of ethics" (cf. Ribeiro, 2010; Farah, 2005). The first is equivalent to bioethics, studying, for example, questions about the "ethics of practice" such as the preparation and conduct of investigations in neurosciences or the "impact [of these] on social and legal structures", the focus of which is practice and implications of understanding the brain in society; the latter is concerned with the search for knowledge and brain functions and the identification of cortical regions related to morals and ethics and the way in which this knowledge can be useful for the performance of human behaviour, personality and conscience, in which the focus is the neurological bases of moral knowledge (cf. Ribeiro, 2010, p. 28).

Thus, reflection on the effects and impact of contemporary technological potential has become decisive to neuroscience research, particularly taking into account the technical, ethical, legal and social implications of some of the current biotechnological advances which involve the registration, collection and wide-ranging analysis of neuronal data. Usually these procedures include the use and manipulation of neurotechnological devices aimed at consumers and advanced machine-learning brain-imaging techniques. Thus, it has become important to reflect on the responsible use (privacy, consent, extended uses and applications) of processing the data collected through such techniques and methods and the practices involved in such procedures.

As Kellmeyer (2018) affirms it is important to highlight some benefits of using neuronal data for fundamental and translational research in neuroscience, such as the growth of knowledge about brain structures and

functions, allowing the identification of biomarkers of brain pathologies and improving the performance of neurotechnological devices such as brain-computer interfaces (BCIs) or brain-machine interfaces (BMIs). Also, the application of other machine-learning techniques allowing the identification and classification of emotional experiences based on EEG brainwave data (Bird et al., 2018), allowing it to be distinguished from different mental states (e.g., neutral rested or focused), positive and negative emotional states (e.g., from data collected from EEG-based brain-machine interfaces). Another example is the model proposed to explain thalamocortical dysrhythmia (TCD) allowing connectivity oscillation patterns to be identified in patients with Parkinson's disease, neuropathic pain, tinnitus, and depression (Vanneste, et al., 2018). TCD "is characterized by a common oscillatory pattern in which resting-state alpha activity is replaced by cross-frequency coupling of low- and high-frequency oscillations using machine learning techniques" (Vanneste, et al., 2018). Other devices, for instance in sports technology, have been specifically design to generate performance enhancement in professional gamers (e.g., EMOTAI band, developed by bioengineers in Portugal), but which can be applied to other realities and environments in the future. Through bio-signal tracking and a training platform, it helps players perform better with the use of a headband that tracks brainwaves and heart rate. Like other non-invasive wearable devices, the band allows access to information in real time, collecting biological signals in vivo, but using advanced data analysis by complex and high-level artificial intelligence models, allowing feedback to performers (on focus, engagement and heart rate levels), and training, making them increase skills, correct behaviour and progress in their activity (cf., https://emotai.tech/, 2019). As they understand, biofeedback and practice, allow the brain to trained to adjust in conditions of high-level stress, as well as to focus and engage more when necessary. Therefore, the growing accumulation of data is only useful due to the sophisticated machine learning algorithms, specifically artificial neural networks of deep learning, that process and decode them. Bird et al. (2019, p. 8) also demonstrate "the methods of using a low resolution, commercially available EEG headband can be effective for classifying a participant's emotional state [showing] the potential for producing classification algorithms [with] practical value for real-world decision support systems".

However, as Kellmeyer (2018) maintains, with some technologies, especially the ones used directly by consumers (e.g., applications and electronic services), there are risks related to security, methods, consent and issues concerning the commodification of neuronal data that can place individuals in a situation of vulnerability regarding the privacy of their mental and physical states. The possibility of the collected data being used for purposes other than the consented ones (e.g., risks related to the commodification and dissemination of data; risks related to the classification of specific types of personal data as blood test results, fitness application records, etc., cf. Farah 2005; Farah, 2012) is real. On the other hand, there may be technological barriers to safeguarding data on the part of companies responsible for such a task, such as Google or Facebook (e.g., encryption, transfer, protection of large amounts of data) (Cf. Kellmeyer, 2018, p. 6).

Circumstances such as these raise ethical questions of whether treatment for data is suitable and adequate in terms of legal frameworks whether data has suitable treatment and adequacy to legal frameworks as well as a discussion on the legislative answers against which the benefits and risks of biometric data uses can be displayed. For instance, the implementation of specific programs involving people's participation in emergency situations making it necessary to handle and conduct program decisions. In such scenarios, how should the collection of data be mediated, and to what extent is risk management capacity important to the implementation and results of programs when dealing with such a sensitive type of data, and what is the role of advance technologies and neuroscience research in this process?

It is now accepted that both reason and emotion influence moral judgment. Researchers no longer accept, as before, that reason has a prior or superior role over emotion, or that emotion could be retrieved from the equation in the context of decision-making and moral judgment (cf. e.g. Bird et al., 2019). With the advance of scientific investigations in the field, neural correlates involved in such a process and the nature of their interaction, in addition to the features modulating their behaviour and effects, have been exposed with investigations showing interesting results (Cf. Greene et al., 2001). However, they do not yet allow a full understanding of how the mechanisms that grant moral judgments change individuals' attitudes towards the moral judgments they make (Ibid, p. 2107). Other authors show that more or less automaticity in decision-making processes (analytic vs. heuristic) influences decisions and further choices and actions (cf. Ferreira et al., 2016), but research on how moral judgment and decision-making fully operates is still open.

#### Moral judgment, emotion and social behaviour

Ethics is usually seen as a set of moral principles or values, regulating a particular culture, group or institution. It usually involves a complex of moral rules of conduct and regulations on behavioural standards to be followed by individual agents. Such principles are a form of social mechanism which is able to control and organize human interactions as well as individual, often contrasting interests. Thus, ethics acts as a human behaviour regulator across the whole complexity of social live and cultural structures, a set of principles and norms to which people recur for everyday life to occur efficiently. Norms including legal requirements, rulings, and sanctions are central for performing individual roles and decision-making. Even representing conventions, social rules and patterns of behaviour, norms are not unchangeable or timeless; they always belong to a particular context, culture, period or epoch. This is why legal and social norms often fall off and are substituted by new ones over time. Sometimes until this happens, there are extended periods of negotiation over critical and decisive issues, but usually after a period of social and/or legal discussion, settlement is attained and social order is reinstated. That is why new social orders emerge over time.

According to recent theories (e.g., Damasio, 2017), sociocultural structures and neuronal structures develop in interdependence, and are causally relevant to each other, because symbolic representations, usually bounded to objects, environments and specific social categories, impact human actions. The architecture of our brains determines our social behaviour and our inclusive moral dispositions, influencing the type of society we create, and vice versa, i.e., our sociocultural structures also influence the development of our brains (cf. Damasio, 2017). Therefore, innovation of norms depends on the mechanisms by which new norms are conceived, the conditions under which they extend and advance through a society, the people involved, whom they reach and how they become instrumentalised by certain powers and interests.

Thus, as a society, people construct a type of higher order to regulate human behaviour, which is able to act somehow above such powers and influences – ethics as a kind of "metalaw" – a set of norms, rules or regulations as ways of making sure moral behaviours are congruent with human values. But as we know, even if "the rationalist tradition in moral psychology emphasizes the role of reason in moral judgment" recent trends in neurosciences research highlight "emotion as a correlate of moral judgment" (Green et al., 2001, pp. 2105–2108). In this study the authors showed that moral dilemmas vary systematically according to the extent of people's emotional engagement in decision-making processes, influencing moral judgment and thus actions.

As societies impose either moral values or rules, agents are required to learn both in order to behave according to them, as much as possible, and in addition, ethical decisions are connected with actions efficiency concerning good choices (cf. Greene et al., 2001). Thus, agency as social behaviour requires responsibility, a criterion for recognising and attributing a sense of expertise to behavioural patterns, and trustworthiness as a way of secure morals through reasonably social conventions within a certain cultural context. For this to be achieved, sometimes it is necessary to have the need for certain types of collaborative engagement in mind when seeking the same objectives, besides the need to yield cooperation in actions, decision-making processes, and across the exchange of positions (of thought), involving emotional understanding, empathy, and insight. As Tomasello et al., (2005) put it, people's social engagement presupposes a common "understanding and sharing of perceptions with shared goals and intentions" and often the "ability to participate with others in collaborative activities", as so-called "shared intentionality". Thus, participation in such activities requires not only "especially powerful forms of intention reading and cultural learning, but also a unique motivation to share psychological states with others and unique forms of cognitive representation for doing so" (Tomasello et al., 2005, p. 675). This could be seen as empathy or emotional intelligence, the capability to understand and share others' feelings.

Also, with the emergence of new analytical models, particularly with the advance of brain imagining technologies, consciousness has become a much more realistic object of study for the neurosciences, with the help of AI and robotics, than before (cf. Kellmeyer, 2018). This is due to the fact that now it is possible to consider important properties of the brain like its plastic, creative, emotional and culturally constructed aspects, like moral judgment as stated before, using new technologies. Consequently, neurosciences have acquired some normative relevance, as they have become crucial to an understanding of the general human disposition to build such essentially emotional normative systems (moral, social, and legal systems).

For instance, for AI and Robotics, as well as the question on the impact of social robots (cf. https://www.ieeeras.org/robot-ethics, 2020), an emergent technological challenge is to create artificial agents with autonomous reasoning, in a way that it would be recognised by a human observer as an ethical reasoning, i.e., the machine would have "the capacity to automatically compute a judgement on possible decisions that can be made in a given situation and explain why a given decision is ethically acceptable or not" (Bonnemains, et al, 2018, p.1). But this is not an easy task as it requires to consider the different sources of human subjectivity existing on the basis of ethical dilemmas and decision-making processes, which machine learning and deep learning algorithms are not yet able to reproduce entirely. However, since humans are the ones responsible for creating them, legally determining their properties and the means for them to be economically produced and exchanged, as Bryson affirms, the question to be discussed in terms of ethics is not "descriptive", regarding the moral status of those agents - as it is not the question of the moral status of the laws protecting data collection and treatment -, but "normative" of whether "the societal outcomes intended with [the] successful implementation" of those agents or laws are ethically accepted. Because, "normative ethics" is not directed to an existing society, but to an anticipated one (Bryson, 2018:15). As Bryson states "normative ethics consists of recommendations concerning what should be done" (ibid). For instance, recommendations allowing people to make data protection laws and regulations able to ensure both the privacy of individuals and legal data treatment by analysts (or intelligent systems), whether for research purposes or other applications (e.g., health systems management, security, climate, human resources, etc.), as well as the legal status of robots.

At the same time, many companies are developing increasingly sophisticated electronic devices aimed at the consumer in order to monitor and record physiological and brain activity, mainly based on electroencephalography (EEG) and biometric records of sensors transportable and usable by the consumer; ethical discussion on their use has thus become relevant (Kellmeyer, 2018; Farah 2005; Farah, 2012). Such devices make resources available for collecting multivariate data on physiology and perception for decoding the person's neurophysiological and behavioural state of mind and body. Thus, finding formal and legislative answers framing the benefits and risks of their use in the current cultural context is important. Normative questions on the treatment of neuronal and physiological data should be addressed; rules on access to data, literacy regarding biometric data collection and analysis and the use of technological tools in civil society, regulatory issues on how to protect the privacy of biometric data, in addition to questions on how to managing risk as a constitutive condition of modernity (Beck, 1992), represent important reflections for the neurosciences, AI and robotics, as well as the social sciences, particularly within the emergent situation.

#### Ethical, technical and social implications of biometric data collection and analysis

The aim is to provide interdisciplinary dialogue regarding reflection on the daily practice of professionals, whether in neurosciences, AI, robotics, or the social sciences, focusing on the human being, to whom such practices are dedicated. Considered in their multiple aspects, it is fundamental to decode the network of causal connections between the neurobiological, sociocultural and historical-contingent dimensions of technologies. To evaluate their specified character, related and shared within our particular culture and symbolic systems, it is important to discuss its growing potential for wider applications in the real world. It is also urgent to promote ethical discussion on the application of new scientific discoveries to new pathological conditions, medical cases, treatments therapies, etc., allowing this growing field to expand in responsible ways. In the context of the pandemic where so many exceptions are made in terms of values in the name of a common good, like the global public health, these questions have gained more importance, and cannot be ignored.

First, it is necessary to consider the complexity of the technologies and promote open and informative public debate on the topic. Some benefits of the use of physiological and biometric data which have already been demonstrated are, for example in neurology, the identification of brain alteration morphologies typical of Alzheimer's disease through neuroimaging; the prevention of the response of brain tumours to chemotherapy from brain images; or the distinction between typical and atypical Parkinson's syndromes. In psychiatry, some benefits involve the anticipation of psychosis results through machine-learning techniques such as the identification and intensity of depressive symptoms or the prediction of suicidal behaviour (Kellmeyer, 2018, p. 4). Consequently, according to the author, there are no risks which are especially related to the use of these

techniques related to the well-being of individuals involved in the experiments, in which data and machinelearning techniques are used for further offline analysis.

However, there are some risks related to security, privacy and real-time interaction between users and neurotechnological devices, especially in closed-circuit systems. These can affect autonomy, the sense of agency and other aspects of the user experience, such as the idea of self and personality, given the sense of authenticity of the experience itself (cf. Kellmeyer, 2018, pp. 5-8). Thus, it would be useful to study the effects of subject/device interaction "in cases in which such intelligent closed-loop devices do not only decode neural data for specific purposes, but may also actively interfere with brain states, for example, by delivering electric stimulation to the cortex, and if, and with what intensity the decision was determined solely by the device, by the system decision-making capacity" (Kellmeyer, 2018, p. 8). This may raise some questions, such as whether the participant has a full understanding of what is going on. Did he consent to alterations to his brain, fully produced by a machine, or did he just agreed to participate in one harmful experience? Therefore, ethical challenges arise regarding the platforms themselves and the purpose to which they are to be addressed, which involve not only the issues already mentioned, but also specific issues related to privacy, and the posterior uses and manipulation of the data. Namely, risks related to informed consent and methodologies. This includes consent that can be obtained for certain purposes, and then used for different purposes, for example, studies where structural and functional brain images are recorded in order to assess attitudes towards racism or aggressive behavioural tendencies , but in which the actors are led to think, at the outset, that these are studies of facial perception (Farah, 2012: 578).

Another important issue concerns the classification of different types and sources of personal data such as blood test results, data retrieved from eye-tracking equipment and software from government or enterprise websites, records from fitness and sports applications, phone movement-tracking records, or text or image records in network accounts, and whether they have adequate and proportional treatment in terms of legal and regulatory frameworks. And as the capabilities and limitations of software and equipment may put the quality of data collection at risk, the need to have data analysts with professional expertise to interpret the content of data files will also be a requirement. Some companies may also need to have service consultancy regarding the usability of some equipment, if they do not have staff who can deal adequately with such sophisticated technologies like eye tracking for instance, or the web band for players, etc. Because, even if the majority of users agree with the use of the records when they enter the applications and websites, there is still a risk that the collected data will be used for advertising and sales purposes, raising ethical questions regarding the commercialization and monopoly of supplying content and services that transform personal data into merchandise (Kellmeyer, 2018, pp. 7-8). For instance, as the author shows, there are recent studies where researchers have been able to infer the suicidal trend from analyses of electronic health records, and from user entries on Facebook, making predictions about future neurophysiological states. According to the author, these are applications that are being extensively investigated in the area of mental health and clinical neuroscience, and most of the personal information that these companies collect is based on the voluntary sending of data by users (cf. Kellmeyer, 2018, p. 2). Nonetheless, even when it is for a good outcome, if the users are not aware that such type of manipulation is going to happen, is this still an ethically acceptable principle? In such a scenario, it seems that we are in the presence of the old premise, stating that (at least sometimes) the end justifies the means.

To frame such an ethical dilemma, we could reformulate the premise and question which ends are valuable to justify the means and which are not. This would be suitable in order to decide and regulate in what cases or specific conditions people, companies, investigators, organizations or governments must be allowed to make such inferences from data manipulation, for purposes other than the original ones. Thus, web analytics will be regulated, not allowing people to do it whenever they need or want. In the context of the current pandemic situation such question is pertinent, as for example, people have given away their rights to privacy in order to accelerate scientific investigations and apparently to ensure global health. At the same time companies are being pressured by some governments at the expense and risk of not being able to comply with full security (in the testing of new medicines and vaccines), in order to meet urgent deadlines. On the other hand, it is important to bear in mind that data collection in emergency situations is essential to anchor political decisions.

Therefore, data collection which is necessary for such purpose must be based on epidemiologic competence and must not be held up if the data collection represents no risk to individuals or groups; if, however, the risk is visible, a further assessment of the situation is needed with governments organizing and supervising the implementation of a surveillance system, and the protection of peoples personal data, before making any decisions. Specific measures must be negotiated and implementation based on professional knowledge, always controlling and assessing the risk. The sociologist Ulrich Beck (1992, p. 21) defines the risk society as the result of the technical-economic advances of the industrial society in which risks escaped the control of social organizations for the first time. The risk society corresponds to the systematic way of dealing with the dangers and insecurities induced and introduced by the modernization process itself. The centre of risk awareness lies in projections for the future and not in the present, which presupposes a social process of recognition and legitimization of that same risk in which science takes a relevant role. Beck calls this the process of reflexive modernization (cf. ibid).

Therefore, as Kellmeyer (2018, pp. 11-12) affirms, limiting and at the same time assuring access to patients' data from health systems, and/or to users of technological devices and wearables involved in physiology and biometrics, seems to be an important requirement for preserving and safeguarding data and their users. At the same time the security of the use of the devices and technological systems should be guaranteed. This topic requires a reflection allowing the production of legal, formal and technological arrangements to regulate issues related to the use of data, namely related to privacy, in order to prevent potential abusive uses and practices, and even possible computer attacks and hacking. Thus, in order to guarantee the transparency and the responsible practice of data manipulation, data classification and analysis must take into consideration the way in which different agencies and governments approach the issue of technology, data protection and risk assessment, whether for political, historical or systemic reasons, as risk itself is part of the modernization process.

Finally, when dealing with sensitive biometric data, it is also necessary to consider issues of bias, through the way certain data sources are collected and categorized, where bias can operate at the level of human cognition through decision-making and choices, and in the assessment of problems (Kellmeyer, 2018, p. 5). As seen before, such processes are connected with human social conditions and cultural structures. For example, in assessing the legal status of mental states, an important question is whether existing legal concepts and instruments are sufficient to ensure the fair use of that data in court (as well as in the context of criminal investigations), and how solutions will be used in a socially responsible way. There are some cases where ethical and social barriers may inhibit data protection from unauthorized access, as in the case of patients with severe paralysis using a BCI (for which in ethical and legal terms may be of interest to keep the data record in an offline database for future uses, in order to express and enforce their will, for the case of medical emergencies involving decisions regarding their health status, Kellmeyer, 2018, p. 6).

In this sense, promoting literacy regarding the use of data, devices and applications in civil society is a measure that can reinforce the security of using such technologies, helping to protect the privacy of the biometric and physiological data of those involved at the same time. It is also necessary to develop a comprehensive approach to a data classification system managed by legitimate institutions, democratic states or supranational institutions, which aims, on one hand, to maximize individual rights (as in the case of data ownership), and on the other hand, to maximize the benefit of using data for society (Conrad et al., 2012, p. 320). Therefore, the ethical challenge will then be to guarantee transparency in the defence of the rights of the person (privacy, freedom, information), but also to preserve science from society's criticisms, ensuring that neuroscientists and researchers continue to challenge technological barriers and provoke social curiosity by trying to expand its limits (cf. ibid).

#### Conclusion

In conclusion, the problem of consciousness that for centuries has been of the exclusive domain of philosophy has become a subject of scientific research in neuroscience, AI and robotics. It is important to point out that such an advancement has made it possible to improve the quality of human life, providing effective treatments not only for degenerative diseases, but also in severe psychiatric conditions (e. g., depression; psychosis) and also for disorders of the central nervous system in which, for example, the use of increasingly technologically advanced prostheses positively affects people's lives. In addition, the theory on the physical nature of consciousness, defended by Damasio, demonstrating how consciousness is constructed in the human brain,

presents itself as a strategy for the improvement of scientific and philosophical understanding about mental phenomena changing numerous beliefs on the nature of the human being and the mechanisms of personality construction and morality (cf. Farah, 2012, pp. 586-587). On one hand, responding to emotional states can improve interaction and, for mental-health systems, contribute to the overall assessment of issues and how to solve them (Bird et al., 2019, p. 8). On the other hand, it may be precipitous to think that the current neuroscientific investigations about moral and normative judgment already point towards a better humanity, as human beings are the result not only of a complex combination of genes and neurons, but also of experiences, learning processes and the influence of socio-cultural life. This is perhaps the main challenge which the development of today's complex computing and artificial intelligence systems is facing – how to recognize and prove the influence of embodiment on emotional response, decision-making processes, sense of justice, morality and cooperation? How can the neural correlatives of perception and moral consciousness be unveiled and this knowledge used in the development of automatic machine learning and deep learning systems? Neuroscience, AI and robotics can help to understand this question by helping to link the pieces of this puzzle. Likewise, technological advancements will make it possible to monitor and manipulate the human mind with ever greater precision, through the development of increasingly sophisticated neuroimaging techniques. Then, ethics and particular neuroethics have the role of protecting, monitoring, and reconciling scientific progress with respect for the dignity of human beings.

The study of the biotechnological is a developing interdisciplinary research field and the impact of AI and Robotics has become a more and more significant subject as well. In terms of its ethical dimension such subject is complex and goes far beyond the scope of those fields. As demonstrated, the point is that for humans to be able to build a normative ethics allowing to respond to the challenges imposed by the technological development, it is necessary to incorporate also the perspectives of the cognitive and the social sciences in its discussion, as social representations on the specific technological world impact the formation of contemporary culture. At the same time, emergent changes in neuronal structures caused by the increasing technological uses in society (computers, wearables, human/automata interactions, etc.,) are affecting not just the social construction of reality, but the formation of identities as well as human agency.

#### Acknowledgements

The revision of this text was provided by the Fundação para a Ciência e a Tecnologia through the Financing of the R&D Unit UIDB/03126/2020

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