

# To the edge of data protection: How brain information can push the boundaries of sensitivity

A doctrinal legal analysis of EEG and fMRI neurotechnologies under EU data protection law

Master Thesis

LL.M Law & Technology

Tilburg Law School
Tilburg University

2018

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### List of Acronyms and Abbreviations

BCI Brain Computer Interface

BOLD Blood-oxygen-level dependent

CT Computed Tomography

DOT Diffuse Optical Tomography
DPD Data Protection Directive

ECHR European Convention on Human Rights

EEG Electroencephalography
EROS Event-related Optical Signal

EU European Union

fMRI Functional Magnetic Resonance Imaging
fNIRS Functional Near-infrared Spectroscopy
GDPR General Data Protection Regulation

MEG Magnetoencephalography
MRI Magnetic Resonance Imaging
PET Positron Emission Tomography

SPECT Single-photon Emission Computed Tomography

SSRN Social Science Research Network

WP29 The Article 29 Data Protection Working Party

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# CHAPTER 1 INTRODUCTION

What a sensation stethoscopy caused! Soon we will have reached the point where every barber uses it; when he is shaving you, he will ask: 'Would you care to be stethoscoped, sir?' Then someone else will invent an instrument for listening to the pulses of the brain. That will make a tremendous stir, until in fifty years' time every barber can do it. Then, when one has had a haircut and shave and been stethoscoped (for by now it will be quite common), the barber will ask, 'Perhaps, sir, you would like me to listen to your brainpulses?'

Søren Kierkegaard – 1846<sup>1</sup>

#### 1.1. Background

In the XVII century, the French philosopher René Descartes claimed that the seat of the human soul was a little gland situated in the middle of the brain, a unitary centre of thoughts where the soul can exercise all its functions. Since the dawn of time, human beings have tried to detect the functioning of the brain in order to disclose humans' deepest secret: what is enclosed in our mind? Emotions, thoughts, and memories have been considered for centuries by poets and philosophers the real essence of each human creature. Besides that, what are emotions, thoughts, and memories if deprived of their romantic veil? In the last decades, researchers, scholars, and clinicians on different levels, as a result of the recent innovation in neurotechnologies, have attempted to answer this question by analysing and trying to decode the inner workings of the human brain.

Specifically, modern neurotechnologies have been used, among others, to map brain regions related to different neuronal functions, to provide an image of the brain, and to repair its specific damaged areas.<sup>3</sup> Electroencephalography (EEG) and functional magnetic resonance imaging (fMRI), for instance, are two neurotechnologies respectively used to record brain's electrical activity and to detect changes associated with blood flow. The EEG "measures voltage fluctuations resulting from ionic currents within the neurons of the brain", while fMRI is a specialised brain scan able "to map neural activity in the brain or

<sup>&</sup>lt;sup>1</sup> S. Kierkegaard, *Papers and Journals: A Selection*, (London-New York, Penguin Books, 1996), 46 VII 1 A 189.

<sup>&</sup>lt;sup>2</sup> R. Descartes, *Opere*, vol. II, (Laterza, Bari, 1967), 420-421.

<sup>&</sup>lt;sup>3</sup> J. Giordano (ed), *Neurotechnology. Premises, Potential, and Problems*, (Taylor and Francis Books, 2012), 2-3.

<sup>&</sup>lt;sup>4</sup> A. E. Hassanien, A. A. Taher (eds), *Brain-Computer Interfaces*. *Current Trends and Applications*, (Springer-Verlag GmbH Berlin/Heidelberg, 2015), 61.

spinal cord of humans or other animals by imaging the change in blood flow related to energy use by brain cells". Even if brain and mind are closely correlated together, they belong to two different dimensions: the physical and the mental one. While the former consists of physiological values representing the brain's neural activity, the latter consists of the further personal elaboration and interpretation by the individual. The EEG and the fMRI technologies intervene in the physical dimension, attempting to analyse pure "raw brain data", meant as solely physiological signals able to describe the inner working of nerve cells and fibres. What do these raw data tell about the individuals? Apparently, they are nothing more than a sequence of values related to the electrical activity of the brain or the level of oxygenated blood flood within it. However, in these modern times, said kind of technical information is frequently used in combination with other innovative techniques to further investigate the human mind.

Usually, the physical dimension constitutes the ground to detect and interpret the mental one, where personal emotions, thoughts, and memories are ideally deemed to be located.<sup>8</sup> Despite the great technological innovation of the recent years, whether or not scientists will ever be able to effectively and reliably read the human mind remains a question still hard to answer. However, what can already be claimed is that, during the last decade, scientists and experts have been capable of translating raw brain signals into specific thoughts, emotions, and even dreams. At the state-of-the-art new techniques and methods able to decode the human minds by interpreting mere raw brain data are being improved and slowly brought outside the laboratories settings. Braingineers, for instance, is a Dutch emotional analytics company, which uses EEG technology in combination with eye tracking and neurofeedback to detect customers' emotions and help them with purchases' decisions. As a result, it would appear plausible to imagine a close future in which these instruments, able to detect human brain's neural activity, could find a larger room in daily life, where they could be used, for instance, during job interviews in order to verify the skills of potential employees, to direct the costumers tastes or to prove a lover's betrayal. Accordingly, an analysis of the information extrapolated from the brain in order to define their characteristics, potentialities, and implications for society seems to be of paramount importance.

The particular nature of brain information has already raised specific concerns in relation to the former EU data protection law, the Directive 95/46/EC ('DPD'). 10, 11 Hallinan *et al.* 

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<sup>&</sup>lt;sup>5</sup> S. A. Huettel, A. W. Song, G. McCarty, *Functional Magnetic Resonance Imaging*, Freeman, (second edition, 2009), 26.

<sup>&</sup>lt;sup>6</sup> N. Goldblum, S. Glick, *The Brain-Shaped the Mind: What the Brain Can Tell us About the Mind*, (Cambridge University Press, 2009), 2-3.

<sup>&</sup>lt;sup>7</sup> Ibidem.

<sup>&</sup>lt;sup>8</sup> Ibidem.

<sup>&</sup>lt;sup>9</sup> See Braingineers website, available at <a href="http://braingineers.com">http://braingineers.com</a>> last accessed 12 June 2018.

<sup>&</sup>lt;sup>10</sup> Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (hereafter "the DPD").

<sup>&</sup>lt;sup>11</sup> See D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, 'Neurodata and Neuroprivacy: Data Protection Outdated?', (2014), Volume 12, Issue 1, Surveillance and Society, 65, available at

in their previous research have clearly claimed that the data protection framework was "neither equipped, nor constructed, to deal with data of such intimacy". 12 However, on the 25<sup>th</sup> May 2018, the European General Data Protection Regulation<sup>13</sup> ('GDPR') has become enforceable. 14 In the light of all the changes caused by the rapid development of technologies and globalisation, 15 it reformed the DPD in order to make it more consistent with the new challenges that the current society has to face. 16 While defining personal data as "any information relating to an identified or identifiable natural person", <sup>17</sup> Article 4 (1) of the GDPR claims that "an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person" (emphasis added). Notwithstanding this hint to physical, physiological, and mental identifiers, no explicit reference to brain information is contained in the GDPR. Does it address the specific issues that brain information seems to entail? Or does it simply deem the information extracted from the brain as any other personal data not deserving specific consideration? Answering these questions is particularly important in view of the role of data protection law in protecting the individuals' private sphere and establishing the limits for the processing of their personal information.

#### 1.2. Central question and sub-questions

The aim of this thesis is the investigation, through the European data protection law's instruments, of the peculiar nature of the information extrapolated from the human brain by modern neurotechnologies such as EEG or fMRI. Once defined its peculiarities and related implications for society, this thesis attempts to suggest a better approach starting from the current normative instruments. Therefore, the central question that I attempt to answer is:

How can the concepts of the EU data protection legal framework be adapted to better approach the peculiarities of brain information and address their legal, ethical, and social implications?

<sup>&</sup>lt;a href="https://ojs.library.queensu.ca/index.php/surveillance-and-society/article/view/neurodata/neurodata4">https://ojs.library.queensu.ca/index.php/surveillance-and-society/article/view/neurodata/neurodata4</a>, last accessed 12 June 2018.

<sup>&</sup>lt;sup>12</sup> Ibid., 70.

<sup>&</sup>lt;sup>13</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (hereafter "the GDPR").

<sup>&</sup>lt;sup>14</sup> The GDPR replaced the directive 95/46/EC. It was adopted on the 14<sup>th</sup> April 2016 and has become enforceable after a two-year transition period on the 25<sup>th</sup> May 2018. Unlike the directive, it is directly binding and applicable without any national enabling legislation required.

<sup>&</sup>lt;sup>15</sup> Recital 6 of the GDPR.

<sup>&</sup>lt;sup>16</sup> Recital 7 of the GDPR states that "Those developments require a strong and more coherent data protection framework in the Union (...)".

<sup>&</sup>lt;sup>17</sup> Article 4 (1) of the GDPR.

<sup>&</sup>lt;sup>18</sup> Ibidem.

In order to address this research question, I have formulated the following four subquestions:

- 1) What are the different types of information that can result from the current use of EEG and fMRI neurotechnologies?
- 2) What main peculiarities characterise brain information and what do these imply for society?
- 3) Do these implications mean that the information extrapolated from the brain deserve an enhanced protection under EU data protection law?
- 4) If so, how does the concept of sensitivity, as currently defined by the EU data protection legal framework, interact with the different typologies of brain information?

#### 1.3. Literature review

In order to choose the relevant literature to the scope of this master's thesis, I started with the research of pertinent articles and books related to EEG and fMRI-based neurotechnologies. Therefore, in the very first moment, keywords such as 'EEG' or 'fMRI' or, more generically, 'neurotechnologies' were typed into search engines like Google Scholar and SSRN, in order to find more scientific and technical descriptions of their inner functioning. As a second step, the attention was shifted to articles that, in analysing neurotechnologies in a more legal perspective, attempted to define the social, ethical, and legal consequences of their application. Consequently, other keywords were added such as 'mind reading' or 'dual-use', 'alternative-use' together with keywords such as 'legal issue' or 'ethical issue'.

Through this methodology, I was able to find several articles and researches written and conducted by authors such as Bandettini P. A., Farah M. J., Farahany N., Goodenough O. R., Owen D. J., Shen F. X. that in the last decades have broadly described the neurotechnologies at hand and their legal implications. However, these studies have often been conducted with particular regard to the criminal justice field and from a U.S. Constitutional law point of view. Therefore, this first literature survey was mainly adopted as a starting point to gain an essential background of the legal implications related to the use of such neurotechnologies. Subsequently, in order to direct the research to the actual scope of this thesis, more specific keywords were used like 'data protection', 'brain data' and 'neuro data', which allowed me to find more European oriented articles.

The analysis of the literature suggests that the majority of the authors recognise the significant implications for society that the advance in neuroscience and brain imaging techniques carries with them, especially in terms of legal and ethical concerns.<sup>19</sup> However,

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<sup>&</sup>lt;sup>19</sup> M. Ienca, R. Adorno, 'Towards new human rights in the age of neuroscience and neurotechnology', (2017), Volume 13, Issue 5, Life Sciences, Society and Policy, available at <a href="https://lsspjournal.springeropen.com/articles/10.1186/s40504-017-0050-1">https://lsspjournal.springeropen.com/articles/10.1186/s40504-017-0050-1</a>, last accessed 17 April 2018; M. J. Farah, J. B. Hutchinson, E. A. Phelps, A. D. Wagner, 'Functional MRI-based lie detection: scientific and

most of the researches conducted were mainly related to criminal law and to the application of neuroscience with regards to lie-detection and memory-detection techniques. While some authors recognise the current limitations in terms of reliability of modern mindreading techniques, especially when applied outside the laboratories settings, some others believed that a real and effective mind-reading will never be possible. Nevertheless, most of the authors mainly addressed their researches to the privacy issues that may be raised in the next future by a more broad and reliable use of modern neuro techniques able to investigate the human mind. However, when it comes to data protection law, on which the thesis focuses, the literature is particularly scarce. The few articles found are mainly based on the previous legal framework, namely the DPD, and do not consider in details the peculiar characteristics of brain data, nor the different shapes or status they may entail.

#### 1.4. Significance

From an academic perspective, the legal analysis object of the present research contributes to filling the gap in the existent literature as it is more focused on the mind-reading legal implications from a criminal law point of view with regard to the use of lie-detection and memory-detection techniques. Therefore, this thesis aims to enlarge the scarce existent literature related to brain information and data protection law. In that regard, the research

societal challenges', (2014), Volume 15, Neuroscience And The Law - Science And Society, available at <www.nature.com/articles/nrn3665>, last accessed 4 May 2018; O. R. Goodenough, M. Tucker, 'Law and Cognitive Neuroscience', (2010), Annual Review of Law and Social Science, 6:61-92, available at <www.annualreviews.org/doi/10.1146/annurev.lawsocsci.093008.131523>, last accessed 4 May 2018; F. X. Shen, 'Neuroscience, Mental Privacy, and The Law', (2013), Volume 36, Issue 2, Harvard Journal of Law and Public Policy, available at <www.harvard-jlpp.com/wp-content/uploads/2013/04/36\_2\_653\_Shen.pdf>, last accessed 4 May 2018.

<sup>&</sup>lt;sup>20</sup> F. X. Shen, 'Neuroscience, Mental Privacy, and The Law', (2013), Volume 36, Issue 2, Harvard Journal of Law and Public Policy, available at <www.harvard-jlpp.com/wp-content/uploads/2013/04/36\_2\_653\_Shen.pdf>, last accessed 4 May 2018; M. Kilbride, J. Iuliano, 'Neuro Lie Detection and Mental Privacy', (2015), Volume 75, Issue 1, Maryland Law Review, available at <a href="http://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=3686&context=mlr">http://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=3686&context=mlr</a>, last accessed 4 May 2018; P. R. Wolpe, K. Foster, D.D. Langleben, 'Emerging neurotechnologies for lie-detection: promises and perils', (2005), Volume 5, Issue 2, American Journal of Bioethics, available at <a href="https://www.tandfonline.com/doi/abs/10.1080/15265160590923367">https://www.tandfonline.com/doi/abs/10.1080/15265160590923367</a>, last accessed 4 May 2018.

<sup>&</sup>lt;sup>21</sup> F. A. Kozel, K. A. Johnson, Q. Mu, E. L. Grenesko, S. J. Laken, M. S. George, 'Detecting Deception Using Functional Magnetic Resonance Imaging', (2005), Volume 58, Issue 8, Biological Psychiatry, 605-613, available at <www.ncbi.nlm.nih.gov/pubmed/16185668>, last accessed 4 May 2018; O. D. Jones, J. W. Buckholtz, J. D. Schall, R. Marois, 'Brain Imaging For Legal Thinkers: A Guide For The Perplexed', (2009), Stanford Technology Law Review, 5, available at <a href="https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1563612>">https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1563612>", last accessed 4 May 2018">https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1563612>", last accessed 4 May 2018"

<sup>&</sup>lt;sup>22</sup> N. Goldblum, S. Glick, (n. 6).

<sup>&</sup>lt;sup>23</sup> M. Ienca, R. Adorno, 'Towards new human rights in the age of neuroscience and neurotechnology', (2017), 13, Society available Volume Issue 5, Life Sciences, and Policy, <a href="https://lsspjournal.springeropen.com/articles/10.1186/s40504-017-0050-1">https://lsspjournal.springeropen.com/articles/10.1186/s40504-017-0050-1</a>, last accessed 17 April 2018; F. X. Shen, 'Neuroscience, Mental Privacy, and The Law', (2013), Volume 36, Issue 2, Harvard Journal of Law and Public Policy, available at <www.harvard-jlpp.com/wp-content/uploads/2013/04/36\_2\_653\_Shen.pdf>, last accessed 4 May 2018; S. Richmond, G. Rees, S. J. L. Edwards (eds), I Know What You're Thinking, Brain Imaging and Mental Privacy, (Oxford University Press, 2012), 175-178.

<sup>&</sup>lt;sup>24</sup> See D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11).

conducted by Hallinan *et al.* has been of particular inspiration for the present work. However, in the opinion of the author, some elements of that study remained slightly underdeveloped while some others could have been addressed in a different way. For that reason, besides the application of a different legal framework, namely the GDPR, this thesis humbly tries to complement it in three different points.

- Firstly, while the mentioned study only considers 'neurodata', generally defined as "data relating to the human brain", <sup>25</sup> I distinguish among three different typologies of brain information: i) 'raw brain data', ii) 'brain data', and iii) 'mind data'. <sup>26</sup> This classification permits to better appreciate the nature and potentialities of the information generated by the human brain (generically refer to as 'brain information').
- Secondly, the article at issue is mainly focused on the legal concerns arising from the application of the data protection legal framework to neurodata. Specifically, data protection principles such as anonymity, accuracy, and sensitivity do not properly suit this novel category of personal data.<sup>27</sup> By contrast, the ethical and social concerns are only slightly addressed. Consequently, the present work mainly analyses the ethical and social implications that the use of this peculiar kind of information may involve. This, without neglecting the fact that the same legal issues already raised have not disappeared with the new legal document replacing the DPD. However, I mainly focus the legal analysis on the concept of sensitivity and the related issues.
- Lastly, this thesis tries to further develop the concept of ultra-sensitivity. Hallinan *et al.*, in fact, have already claimed that neurodata, because of their novelties, could be considered as more sensitive personal data than the ones mentioned in the DPD.<sup>28</sup> Accordingly, this thesis analyses the sensitivity with regard to each typology of brain information and suggests a different approach to the current legal notion of sensitivity as a tailor-made solution to deal with its particular characteristics.

In addition, from a more sociological perspective, other reasons make this thesis relevant. The foundation of all the current mind-reading techniques consists of physiological signals extrapolated from the brain and potentially interpreted as individuals' emotions, thoughts, or memories. Considering the great importance that modern neurotechnologies are gaining and that, undoubtedly, are destined to gain in the next future also outside the medical sector, it is of paramount importance to understand the potentialities of the information extrapolated from the human brain by EEG and fMRI-based technologies as well as the related implications for society. In the light of the contemporary spreading of innovative technologies to investigate the human mind starting from the raw values of the brain, it is essential to understand how the current legal framework could deal with such a particular kind of information in order to provide an adequate protection for the individuals.

<sup>26</sup> See Chapter 2, para 2.4.

<sup>&</sup>lt;sup>25</sup> Ibid., 70.

<sup>&</sup>lt;sup>27</sup> D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11), 66-67.

<sup>&</sup>lt;sup>28</sup> Ibid., 67-70.

On the one hand, understanding the nature of the brain information and its peculiarities will help to identify and assess the related risks for society. On the other hand, it will contribute to determine the limits of the current data protection law and, hopefully, to lead the future political discussion in order to design proper rules for the information deduced from the brain. This is even more important if it is considered that the raw values that are collected today may well be further processed tomorrow, when the available technologies will be more reliable and accessible. For that reason, in view of the great implications for the individuals' private sphere, it is essential to proactively start a legal discussion about this powerful category of personal data. Especially in consideration of the fact that modern technologies always appear particularly attractive in the eyes of the people who will likely be open to their use.

#### 1.5. Methodology

#### 1.5.1. Research methodology

In order to answer the central question, this thesis consists of a doctrinal legal research from an EU data protection point of view. Specifically, a doctrinal research "is concerned with the formulation of legal 'doctrines' through the analysis of legal rules". Accordingly, with the aim to understand the peculiar nature of the information extrapolated from the human brain and to suggest a tailor-made legal approach able to properly address said peculiar nature, I apply the main definitions offered by the current EU data protection legal framework, with specific regard to the legal provisions contained in the GDPR. In particular, by a systematic exposition of the rules and definitions governing the EU data protection law, also with regard to the interpretation given by the main EU bodies and institutions, I analyse the possible relationship between these rules and definitions and the particular kind of data object of this thesis. As a result, the last part of this research is more reform-oriented, aiming to evaluate the adequacy of the existing rules to the particular situation under analysis. Accordingly, a different approach to the concept of sensitivity is suggested which permits an actual evaluation of the latent potentialities of the information captured from the human brain and its related risks and concerns.

#### 1.5.2. Scope and limitation

As already stated, the aim of this thesis is to examine the peculiar nature of the information directly deduced from the human brain by modern neurotechnologies such as EEG or fMRI

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<sup>&</sup>lt;sup>29</sup> P. Chynoweth, 'Legal Research' in A. Knight, L. Ruddock (ed.), *Advanced Research Methods in the Built Environment*, (Blackwell Publishing Ltd, 2008), 29, available at <www.csas.ed.ac.uk/\_\_data/assets/pdf\_file/0005/66542/Legal\_Research\_Chynoweth\_-\_Salford\_Uni..pdf>, last accessed 4 May 2018.

<sup>&</sup>lt;sup>30</sup> Mainly the Article 29 Working Party as the Advisory Body established by Article 29 of the DPD (and recently replaced by the European Data Protection Board).

<sup>&</sup>lt;sup>31</sup> T. Hutchinson, N. Duncan, 'Defining and Describing What We Do: Doctrinal Legal Research', (2012) Volume 17, Issue 1, Deakin Law Review, 101, available at <www.heinonline.org/HOL/Page?public=false&handle=hein.journals/deakin17&page=83&collection=journa ls#>, last accessed 4 May 2018.

in order to identify the related concerns and, accordingly, the different safeguards that need to be in place whenever dealing with it. However, a proper determination of the peculiarities of the brain information cannot be fully achieved without a consideration of the different status it may entail when further processed and interpreted by means of innovative technologies. Therefore, starting from a scientific description of the raw values extrapolated from the brain, the scope is further extended also to more complex shapes of EEG and fMRI-based data, to the extent of including also those data as further interpreted through mind-reading techniques.

With regard to the peculiarities of this kind of information, the analysis does not claim to be complete. It mainly defines those characteristics relevant to the scope of this thesis and, thus, able to raise specific legal, ethical, and social concerns. I am, hence, aware that the complexity of the information extrapolated from the human brain, especially from a scientific and technical point of view, may well involve other important characteristics not addressed in the present research.<sup>32</sup>

The last part of this thesis is mainly focused on the applicability of the EU data protection law, as currently designed, to the particular kind of data extrapolated by the neurotechnologies at hand. The attempt to apply the current data protection law to brain information may likely arise a plurality of legal concerns, some of which have already been addressed by the existent literature.<sup>33</sup> However, the scope of this thesis is limited to the particular legal concern related to the concept of sensitivity. Specifically, in addressing the relating analysis, the final sections attempt to suggest a different conceptualisation of sensitivity more consistent with the peculiar nature of brain information. Accordingly, I propose a dynamic concept of sensitivity able to include different degrees therein, which is portrayed with the aid of a graph. This conceptualisation is possible through two distinct approaches, a qualitative and a quantitative one. However, it is out of the scope of this thesis to propose an effective regulation of brain information. The design of new rules and legal provisions is left to further researches and discussions.

#### 1.6. Structure

The structure of the thesis is mainly guided by the four sub-questions. Specifically, Chapter 2 attempts to define the outcome of EEG and fMRI techniques. What kind of information are said neurotechnologies able to extrapolate from the human brain? Therefore, the second Chapter is a technical description of the functioning of EEG and fMRI, to define what information is generally included therein. Moreover, a brief description of the distinction between brain and mind and, particularly, between brain-reading and mind-reading, allows

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<sup>&</sup>lt;sup>32</sup> For instance, for the scope of this thesis I do not consider the multifactorial nature of brain information, related to the fact that its measurements may be influenced by several factors such as eye movements, muscles, and heartbeat, but also other external and internal stimuli. See The Committee on Science and Law, 'Are Your Thoughts Your Own?: Neuroprivacy and The Legal Implications of Brain Imaging', 2005, 12, available at <www.nycbar.org/pdf/report/Neuroprivacy-revisions.pdf >, last accessed 26 June 2018.

<sup>&</sup>lt;sup>33</sup> D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11), 66-69, which specifically analyse the legal issues related to the data protection concepts of anonymity, accuracy, and sensitivity.

a classification of different typologies of information coming from the brain depending on the context of their application and the level of interpretation. This section is a vital element of this research, because it allows the proper understanding of the hidden potentialities that these kinds of data conceal.

Having defined the object of the legal analysis, Chapter 3 provides a description of four different peculiarities which particularly characterise the information extrapolated by EEG and fMRI from other categories of personal data taken into consideration by the current EU data protection law. These peculiarities, if not adequately regulated, can cause several ethical and social issues which are examined in the last section. Therefore, this Chapter argues in favour of an enhanced protection for brain information.

Finally, provided that the information at issue requires a particular protection, Chapter 4 goes further into the analysis. Once demonstrated the sensitive nature of the personal data deduce from the brain, this Chapter attempts to define different levels of sensitivity for different typologies of brain information. Starting from the assumption the GDPR might not be future-proof, these final sections suggest a different approach to sensitivity which may better suit the hidden potentialities and the particular nature of brain information.

## CHAPTER 2

# FROM EEG AND fMRI TO A TYPOLOGY OF BRAIN INFORMATION

#### 2.1. Introduction

"Neuroscience" is an interdisciplinary field of study which, by combining several areas of expertise, aims to technically understand the scientific functioning of the human nervous system.<sup>34</sup> Although the internal functioning of the human brain has always triggered the attention of both scientists and clinicians, the significant development of innovative technologies in the last decades enabled a more in-depth and accurate investigation of human nervous system's functioning. In 2010, for instance, Adrian Owen, a neuroscientist at the University of Cambridge, declared to have found a way to communicate with people in a vegetative state using brain scans.<sup>35</sup> By means of an fMRI machine, he analysed the injured brain of the so-called Patient 23.<sup>36</sup> Specifically, by detecting the changes in blood flow in response to certain questions, Owen was able to interact, for the first time, with someone who had been declared unreachable.<sup>37</sup>

In the 90's, due to the new opportunities created by innovative technologies, the interests of neuroscientists started to transcend the sole functional and structural investigation of the human brain. As a result, the specific term "cognitive neuroscience" was coined to describe a new discipline combining psychology and neuroscience, aiming to investigate the relationship between the neural functions of the brain and human behaviours.<sup>38</sup> Focusing

<sup>&</sup>lt;sup>34</sup> Stedman's Medical Dictionary for the Health Professions and Nursing, 24<sup>th</sup> edition, 949.

<sup>&</sup>lt;sup>35</sup> For the complete explanation of the methods and results of the study see M. M. Monti, A. Vanhaudenhuyse, M. R. Coleman, M. Boly, J. D. Pickard, L. Tshibanda, A. M. Owen, and S. Laureys, 'Willful Modulation of Brain Activity in Disorders of Consciousness', (2010), The New England Journal of Medicine, 579-589, available at <a href="https://www.nejm.org/doi/10.1056/NEJMoa0905370?url\_ver=Z39.88-2003&rfr\_id=ori%3Arid%3Acrossref.org&rfr\_dat=cr\_pub%3Dwww.ncbi.nlm.nih.gov&">https://www.ncbi.nlm.nih.gov&</a>, last accessed 12 June 2018.

<sup>&</sup>lt;sup>36</sup> The study conducted by Adrian Owen was based on 54 patients with severe brain injury, 23 in a vegetative state and 31 in a minimally conscious state. The so-called Patient 23 was one of the patients in a vegetative state. After a car accident, his life drastically changed at the young age of 24. Through fMRI Owen was able to detect the changes in blood flow to the patient's brain, in response to tasks and questions which had already been validated on 16 healthy patients with no history of neurological disorders. Patient 23, initially declared unreachable, immediately provided reliable responses to the scientific approach used during the study.

<sup>&</sup>lt;sup>37</sup> D. Cyranoski, 'Neuroscience: The Mind Reader', (2012), Volume 486, Nature, available at <a href="https://www.nature.com/news/neuroscience-the-mind-reader-1.10816">https://www.nature.com/news/neuroscience-the-mind-reader-1.10816</a>>, last accessed 26 June 2018.

<sup>&</sup>lt;sup>38</sup> O. R. Goodenough, M. Tucker, 'Law and Cognitive Neuroscience', (2010), Volume 6, Annual Review of Law and Social Science, 62-63, available at <a href="http://www.annualreviews.org/doi/full/10.1146/annurev.lawsocsci.093008.131523">http://www.annualreviews.org/doi/full/10.1146/annurev.lawsocsci.093008.131523</a>, last accessed 10 January 2018.

mainly on cognitive processes related to the language, the memory, or the attention, this new branch of neuroscience primarily attempts to analyse how human cognitive activities are affected by the human nervous system.

The advent of brain imaging techniques allowed researchers to directly map, detect, and monitor the different regions of the brain and to understand their specific tasks.<sup>39</sup> These innovative neurotechnologies not only revolutionised the medical field providing better knowledge of the brain and enabling a more aware response to brain diseases and neurological problems, but they also revolutionised (and still do) society by breaking the boundaries of their medical application. Unprecedented possibilities have been offered in the past years by these techniques, for instance, the detection of deception or the identification of human memories and emotions.<sup>40</sup> Accordingly, several new fields of application have recently developed such as neuro-marketing<sup>41</sup> or BCI-based<sup>42</sup> games and entertainment. The brain is becoming a means to access the human mind. As a result, the value that data directly extrapolated from the human brain is gaining - also outside the clinical sphere - is now manifest.

Brain imaging techniques made their first appearance at the beginning of the 19th century with the first human EEG record obtained by Hans Berger in 1929. 43 Since then, a wider range of neuroimaging techniques has been developed to detect and assess brain activity, such as magnetic resonance imaging (MRI), functional magnetic resonance imaging (fMRI), diffuse optical tomography (DOT), single-photon emission computed tomography (SPECT), computed tomography (CT), functional near-infrared spectroscopy (fNIRS), magnetoencephalography (MEG), event-related optical signal (EROS) or positron emission tomography (PET). 44 Until now these technologies are rarely being applied in scenarios different from scientific laboratories. Nevertheless, it is reasonable to imagine a close future

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<sup>&</sup>lt;sup>39</sup> B. Baars, N. Gage, Fundamentals of Cognitive Neuroscience. A Beginners' Guide, first edition, (Academic Press, 2013), 110-111.

<sup>&</sup>lt;sup>40</sup> J. R. Simpson (ed), H. Greely, *Neuroimaging in Forensic Psychiatry: From the Clinic to the Courtroom*, (Wiley-Blackwell, 2012), 16.

<sup>&</sup>lt;sup>41</sup> Neuro-marketing is a recently developed field of marketing mainly focused on studying costumers' cognitive responses to marketing stimuli.

<sup>&</sup>lt;sup>42</sup> The Brain-Computer Interface Project (BCI) was launched in the 1970s at the University of California by a team of researchers led by Jacques Vidal with the aim of enhancing human computer interaction by enabling a "direct communication pathway between human brain and an external device".

<sup>&</sup>lt;sup>43</sup> D. J. McFarland, J. R. Wolpaw, 'Brain-Computer interfaces for communication and control', (2002), Volume 113, Issue 6, Clinical Neurophysiology, 768, available at <a href="http://www.sciencedirect.com/science/article/pii/S1388245702000573?via%3Dihub">http://www.sciencedirect.com/science/article/pii/S1388245702000573?via%3Dihub</a>, last accessed 15 January 2018.

<sup>&</sup>lt;sup>44</sup> J. D. Moreno, S. Parashar, 'National security, brain imaging, and privacy', in S. Richmond, G. Rees, S. J. L. Edwards (eds), *I Know What You're Thinking. Brain Imaging and Mental Privacy*, (Oxford University Press, 2012), 175-178.

where they will become more reliable and more easily accessible to the extent that there will be no more obstacles for their diffused application.<sup>45</sup>

Despite the great variety of existing neurotechnologies, the most frequently used and applied, also outside the medical field, are electroencephalography and functional magnetic resonance imaging, which are both the object of this second Chapter. Specifically, the technical explanation of EEG and fMRI functioning allows a broader comprehension of their outcome, to the extent that it is possible to classify the information extracted from the human brain in three different categories on the basis of the context of application and the exploitation of its hidden potentialities. This is particularly important since the existent literature <sup>46</sup> related to this kind of data seems to be underdeveloped in these regards as it simply considers a unitary shape of brain information, without properly distinguishing between its distinct possible evolutions.

#### 2.2. What is an EEG and how does it work?

#### 2.2.1. Technical functioning

The essence of the human brain activity consists of electrical impulses created by billions of neurons which transmit information through electrical and chemical signals.<sup>47</sup> An EEG, is the registration of said electric potentials by means of an electroencephalograph, "a system for recording the electric potentials of the brain derived from electrodes attached to the scalp".<sup>48</sup> Among all other existing neurotechnologies, EEG is one of the least invasive methods to record brain values, essentially based on the simple application of electrodes along the scalp which permits, through a conductive gel or paste, the detection of "potential changes caused by the activity of neurons of the cerebral cortex".<sup>49</sup>

In brief, the foundation of EEG measurement is the polarisation/depolarisation mechanisms of brain neurons. These neurons, in order to maintain resting potential or to propagate active potential, constantly exchange ions with the extracellular environment. <sup>50</sup> The interaction

<sup>47</sup> See S. Herculano-Houzel, 'The Human Brain in Numbers: A Linearly Scaled-Up Primate Brain', (2009) Frontiers in Human Neuroscience, available at <a href="https://www.frontiersin.org/articles/10.3389/neuro.09.031.2009/full">https://www.frontiersin.org/articles/10.3389/neuro.09.031.2009/full</a>, last accessed 15 January 2018.

<sup>&</sup>lt;sup>45</sup> K. Evers and M. Sigman, 'Possibilities and limits of mind-reading: A neurophilosophical perspective', Consciousness and Cognition, issue 22, 2013, 887-897, available at <a href="https://www.sciencedirect.com/science/article/pii/S1053810013000822">www.sciencedirect.com/science/article/pii/S1053810013000822</a>, last accessed 21 June 2018, 895.

<sup>&</sup>lt;sup>46</sup> See D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11).

<sup>&</sup>lt;sup>48</sup> Stedman's Medical Dictionary for the Health Professions and Nursing, 461.

<sup>&</sup>lt;sup>49</sup> R. J. Rak, M. Kolodziej, A. Majkowski, 'Brain-Computer Interface as measurement and control system. The Review Paper', (2012), Volume XIX, Issue 3, Metrology and Measurement Systems, 431, available at <www.degruyter.com/view/j/mms.2012.19.issue-3/v10178-012-0037-4/v10178-012-0037-4.xml>, last accessed 12 June 2018.

<sup>&</sup>lt;sup>50</sup> M. Teplan, 'Fundamentals of EEG measurements', (2002), Volume 2, Section 2, Measurement Science Review, 1-2, available at <www.researchgate.net/publication/228599963\_Fundamental\_of\_EEG\_Measurement>, last accessed 26 March 2018.

between ions enables the creation of waves whose communication - made of "push" or "pull" depending on the electrical charge - with the electrons contained in the electrodes, is recorded by the EEG.<sup>51</sup> An EEG is not able to record the electric potential of each neuron.<sup>52</sup> Therefore, EEG measurement is about the synchronous activity over a network of neurons with similar spatial orientation. The voltage fluctuations recorded are then digitised and sent to an amplifier which permits the data to be displayed as a sequence of voltage values. Therefore, very simplistically, an EEG "is a graphic display of a difference in voltages from two sites of brain function recorded over time".<sup>53</sup>

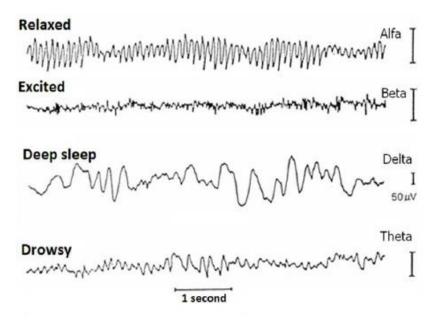


Figure 1: example of distinctive rhythms in EEG signal<sup>54</sup>

#### 2.2.2. Understanding EEG interpretation

Without proper expertise and further interpretation, electrical signals extrapolated by EEG remain a bunch of values without any specific implication. The interpretation given by experts and scientists is, thus, essential in order to decode the physical values extracted by the EEG. Therefore, it is worth mentioning the basic rules underlying the EEG's outcome interpretation. The locations of electrodes over the brain and their related names have been standardised by the International 10-20 system, which enables a universal reading of EEG raw data. <sup>55</sup> Consequently, taking into account the specific position of the electrodes and the

<sup>&</sup>lt;sup>51</sup> W. O. Tatum, *Handbook of EEG interpretation*, (2<sup>nd</sup> edition, Demos Medical Publishing, 2008), 2.

<sup>&</sup>lt;sup>52</sup> P. Nunez, R. Srinivasan, *Electric fields of the brain: The neurophysics of EEG*, (2<sup>nd</sup> edition, Oxford University Press, 2006), 44-45.

<sup>&</sup>lt;sup>53</sup> W. O. Tatum, (n. 51), 1.

<sup>&</sup>lt;sup>54</sup> R. J. Rak, M. Kolodziei, A. Majkowski, (n. 49), 431.

<sup>&</sup>lt;sup>55</sup> M. Khazi, A. Kumar, M. J. Vidya, 'Analysis of EEG Using 10:20 Electrode System', (2012) Volume 1, Issue 2, International Journal of Innovative Research in Science, Engineering and Technology, 185, available at

related voltage values, it is possible to interpret which area of the brain is responsible for processing information at a given time. Basically, human brain consists of four different regions, variously involved depending on the stimuli. <sup>56</sup> Specifically: i) Occipital Cortex which is primarily responsible for processing visual information; ii) Parietal Cortex which is important for integrating sensory information from various parts of the body; iii) Temporal Cortex, primarily responsible of processing the language and speech production (here is where *hippocampus* is, relevant for spatial and autobiographic memories); iv) Frontal Cortex, which is mostly related to cognitive control. <sup>57</sup>

Another element that needs to be taken into account when interpreting an electroencephalogram is the recorded frequency. There are six different frequency bands with different biological significance: i) Delta (frequency < 4 Hz), ii) Theta (frequency 4-7 Hz), iii) Alpha (frequency 8-15 Hz), iv) Beta (frequency 16-31 Hz), v) Gamma (frequency > 32 Hz) and vi) Mu (frequency 8-12 Hz). Frequency patterns change depending on the specific state of the brain. Therefore, knowing which region of the brain is involved and the related activity intensity makes it possible to detect the brain status in real time differentiating, for instance, between the state of anxiety, the recognition of an object, the act of closing the eyes or an active thinking activity. <sup>59</sup>

The EEG is cheap, non-invasive, portable and relatively easy to use and therefore, it has found a significant ground of application in the medical field as well as beyond it.<sup>60</sup> This innovative technique has been primarily used in medicine to detect abnormalities in the brain functioning. The analysis of the EEG-based data and their proper reading, in fact, has been used for decades to diagnose epilepsy, sleep disorders, coma, brain death, and tumours.<sup>61</sup>

#### 2.3. What is an fMRI and how does it work?

#### 2.3.1. Technical functioning

Differently from EEG technology, fMRI provides a better measurement of brain activity with higher spatial resolution, without having direct access to the brain through a more invasive

<sup>&</sup>lt;a href="https://www.ijirset.com/upload/december/9-Analysis%20of%20EEG%20using.pdf">https://www.ijirset.com/upload/december/9-Analysis%20of%20EEG%20using.pdf</a>, last accessed 26 March 2018.

<sup>&</sup>lt;sup>56</sup> M. Teplan, (n. 50), 6-7.

<sup>&</sup>lt;sup>57</sup> J. D. Haynes, 'Brain reading', in S. Richmond, G. Rees, S. J. L. Edwards (eds), *I Know What You're Thinking, Brain Imaging and Mental Privacy*, (Oxford University Press, 2012), 36-37.

<sup>&</sup>lt;sup>58</sup> International Federation of Clinical Neurophysiology, 'Recommendations for the Practice of Clinical Neurophysiology: Guidelines of the IFCN', (1999), Elsevier Science B. V., available at <a href="http://www.ifcn.info/showcontent.aspx?MenuID=1169">http://www.ifcn.info/showcontent.aspx?MenuID=1169</a>, last accessed 21 June 2018.

<sup>&</sup>lt;sup>59</sup> A. M. Owen, 'When thoughts become actions: Neuroimaging in non-responsive patients', in Sarah Richmond, Geraint Rees, Sarah J. L. Edwards (eds), *I Know What You're Thinking. Brain Imaging and Mental Privacy*, 85.

<sup>&</sup>lt;sup>60</sup> Ibidem.

<sup>&</sup>lt;sup>61</sup> W. O. Tatum, (n. 51), 1-2.

surgical intervention.<sup>62</sup> It is a specialised brain scan able "to map neural activity in the brain or spinal cord of humans or other animals by imaging the change in blood flow related to energy use by brain cells".<sup>63</sup> This technique is directly built on the earlier MRI scanning technology which uses a strong and static magnetic field to align nuclei in the detected brain region and to reveal the structure of an anatomic region of interest.<sup>64</sup> By measuring the magnetic properties of water molecules in the body,<sup>65</sup> MRI is able to provide a static structural image of brain matter. In brief, a scanner creates a magnetic field that enables the alignment of hydrogen nuclei of water molecules which are then rotated into a high energy state by a radiofrequency pulse.<sup>66</sup> When this pulse ends, the molecules return to the alignment position releasing a different amount of energy that is then detected by an electromagnetic field.<sup>67</sup> The final resulting image is nothing else than the translation of the different resonating frequencies of protons involved in the process.<sup>68</sup>

Functional MRI technique exploits the magnetic properties of the biological molecules as well, with particular regard to hemoglobin. The different magnetic susceptibilities of hemoglobin in its different oxygenation states are the foundation of the BOLD (blood-oxygen-level dependent) contrast technique used in fMRI. <sup>69</sup> In fact, oxyhemoglobin is magnetically more inactive than deoxyhemoglobin, therefore, on the basis of this principle and of the different MRI signals, it is possible to detect which area of the brain is more active in a specific moment. <sup>70</sup> When an individual is involved in particular tasks such as thinking, moving or speaking, a different brain's area is involved. Neurons of this area consequently demand more energy locally, increasing the regional blood flow and the amount of oxyhemoglobin that directly influence the detected MRI signal. <sup>71</sup> By the measurement of brain activity under resting and activated conditions, fMRI provides images of the human brain while performing different tasks or exposed to various stimuli. Since brain activity is

<sup>&</sup>lt;sup>62</sup> P. A. Bandettini, 'Twenty years of functional MRI: The science and the stories', (2012), Volume 62, Issue 2, NeuroImage, 576, available at

<sup>&</sup>lt;www.sciencedirect.com/science/article/pii/S1053811912004223?via%3Dihub>, last accessed 8 May 2018.

<sup>&</sup>lt;sup>63</sup> S. A. Huettel, A. W. Song, G. McCarty, (n. 5), 26.

<sup>&</sup>lt;sup>64</sup> Ibidem.

<sup>&</sup>lt;sup>65</sup> M. Raichle, 'What is an fMRI?', in *A Judge's Guide to Neuroscience: A Concise Introduction*, (2010), University of California, 5, available at <www.sagecenter.ucsb.edu/sites/staging.sagecenter.ucsb.edu/files/file-and-multimedia/A Judges Guide to Neuroscience%5Bsample%5D.pdf>, last accessed 13 January 2018.

<sup>&</sup>lt;sup>66</sup> European Commission, Functional Magnetic Resonance Imaging. Understanding the technique and addressing its ethical concerns with a future perspective, 2013, 4-7, available at <a href="http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-fmri\_en.pdf">http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-fmri\_en.pdf</a>, last accessed 18 January 2018.

<sup>&</sup>lt;sup>67</sup> Ibidem.

<sup>&</sup>lt;sup>68</sup> M. S. Pardo, D. Patterson, *Minds, Brains, and Law: The Conceptual Foundations of Law and Neuroscience*, (1<sup>st</sup> edition, Oxford University Press, 2013), 83-87.

<sup>&</sup>lt;sup>69</sup> K. R. Thulborn, 'My starting point: the discovery of an NMR method for measuring blood oxygenation using the transverse relaxation time of blood water', (2012), Volume 62, Issue 2, NeuroImage, 589, available at <www.sciencedirect.com/science/article/pii/S1053811911011451?via%3Dihub>, last accessed 13 January 2018.

<sup>&</sup>lt;sup>70</sup> European Commission, (n. 66), 4-7

<sup>71</sup> Ibidem.

estimated on the base of its effects on the oxygen content of blood, fMRI signals, unlike EEG, are only indirect markers of the brain activity.<sup>72</sup>

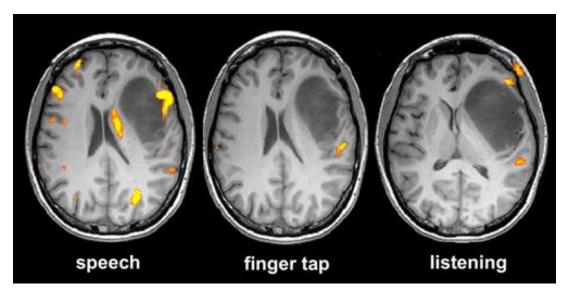


Figure 2: example of fMRI data outcome<sup>73</sup>

#### 2.3.2. Understanding fMRI interpretation

Since fMRI methodology captures changes in blood flow rather than electrical signals from neurons, the recorded values are more often open to interpretation.<sup>74</sup> As it has been pointed out by Jones *et al.*, "no fMRI brain image has automatic, self-evident significance".<sup>75</sup> Even the best well-executed fMRI, in fact, needs a proper, often complex, interpretation in order to gain significance. Therefore, having no inherent meaning, the images of the brain are not directly created by the scanners, rather by the interpretation given by the experts.<sup>76</sup> Brain

<sup>&</sup>lt;sup>72</sup> J. D. Haynes, (n. 57), 30; C. Toole, A. Zarzeczny, T. Caulfield, 'Research Ethics Challenges in Neuroimaging Research: a Canadian Perspective' in T. M. Spranger (ed.), *International Neurolaw. A Comparataive Analysis*, (Springer, 2012), 91.

<sup>&</sup>lt;sup>73</sup> Mayfield Clinic, 'Brain Mapping: functional MRI and DTI', 2013, reviewed by A. Vagal, MD, University of Cincinnati Department of Radiology, 1, available at <www.mayfieldclinic.com/PE-fMRI\_DTI.HTM>, last accessed 14 January 2018.

<sup>&</sup>lt;sup>74</sup> D. A. Leopold, 'Neuroscience: fMRI under the spotlight', (2010), Nature, 465, available at <www.ncbi.nlm.nih.gov/pmc/articles/PMC2996390/>, last accessed 14 January 2018.

<sup>&</sup>lt;sup>75</sup> O. D. Jones, J. W. Buckholtz, J. D. Schall, R. Marois, 'Brain Imaging for Legal Thinkers: A Guide for the Perplexed', (2009), Volume 5, Stanford Technology Law Review, 10, available at <a href="https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1563612">https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1563612</a>, last accessed 14 January 2018.

images created by this technology are good as long as the experiment is well designed by the scientists who decide which data to collect and how to interpret them.<sup>77</sup>

Real-time fMRI, in providing an immediate image of brain activity, allows scientists and physicians to learn how a normal, diseased or injured brain works. Advances in brain imaging techniques and, particularly, the ability of fMRI to detect real-time patients' neural responses, has provided new possibilities to decode human thoughts and intentions "based solely on the pattern of activity observed in the brain". Accordingly, fMRI has been used to map human brain identifying specific regions linked with critical functions such as speaking, sensing or planning. As a result, this technique has been primarily applied in the medical field to identify and monitor brain tumours, chronic disorders of the nervous system as well as congenital abnormalities or trauma. So

As opposed to EEG, fMRI technology is more expensive but it provides a better quality of recorded data. It is currently the only available non-invasive technique which, even without a direct access to the brain through a surgical intervention, provides a measurement of brain activity with a high spatial resolution. Moreover, being sensitive to signals from both cortical surface and deeper brain structure, it provides a more comprehensive analysis of the whole brain. Accordingly, it has also found significant applications in order to study, for instance, the differences in the brain structure between various races and ethnic groups.

#### 2.4. Brain-reading v. Mind-reading: a typology of brain information

The technical explanation of EEG and fMRI neurotechnologies showed that the information they are able to extrapolate mainly consists of two different components. On the one hand, there are the raw physiological values related to the electrical activity of the brain and the level of the oxygenated blood flow within the brain, namely the graphs with the electrical waves or the brain images obtained by the "machine". 85 On the other hand, there is the interpretation which experts and scientists give of the raw values. These interpretations are able to translate mere physiological measurements into meaningful information related to the

<sup>&</sup>lt;sup>77</sup> European Commission, (n. 66), 7-8.

<sup>&</sup>lt;sup>78</sup> A. M. Owen, (n. 59), 73.

<sup>&</sup>lt;sup>79</sup> P. A. Bandettini, (n. 62), 583-584.

<sup>&</sup>lt;sup>80</sup> The Committee on Science and Law, (n. 32), 2.

<sup>&</sup>lt;sup>81</sup> J. D. Haynes, (n. 57), 30.

<sup>82</sup> Ibidem.

<sup>&</sup>lt;sup>83</sup> G. Xue, C. Chen, Z. Lu, Q. Dong, 'Brain Imaging Techniques and Their Applications in Decision-Making Research', (2010), Acta Psychologica Sinica, 4, available at <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2849100/">www.ncbi.nlm.nih.gov/pmc/articles/PMC2849100/</a>>, last accessed 18 January 2018.

<sup>&</sup>lt;sup>84</sup> See Y. Tang, c. Hojatkashani, I. D. Dinov, B. Sun, L. Fan, X. Lin, H. Qi, X. Hua, S. Liu, A. W. Toga, 'The Construction of a Chinese MRI brain atlas: A morphometric comparison study between Chinese and Caucasian cohorts', (2010), Volume 51, Issue 1, NeuroImage, 33-41, available at <www.sciencedirect.com/science/article/pii/S105381191000159X?via%3Dihub>, last accessed 2 May 2018.
<sup>85</sup> See Fig 1 and Fig. 2 above.

health status of the individuals or, depending on the specific regions of the brain that are examined, their racial and ethnic origin.<sup>86</sup>

EEG signals and fMRI-based data have no meaning *per se*, they need to be read and decoded in order to be translated into meaningful information about the individual they originate from. In the light of the above, it is possible to distinguish two different typologies (or status) of data extracted from the human brain by EEG and fRMI neurotechnologies: i) 'raw brain data', which refer to the mere scientific values related to the electrical activity or the oxygenated blood flow level in the brain<sup>87</sup> and ii) 'brain data', which refer to the direct interpretation given by the experts.<sup>88</sup> Within these definitions, raw brain data and brain data represent the process of brain-reading, meaning the observation of brain's structure and the analysis of its inner functioning. Apparently, however, something more personal and intimate can be revealed by the raw values of the neural activity, considering that they are being used to go beyond the sole brain-reading process in order to access the human mind.

The combination of the information extrapolated by modern neurotechnologies and further methods of data interpretation and analysis involving the application of innovative software and algorithms have broadened the horizons of neuroscience giving scientists and researchers new and unimaginable opportunities. In recent years, EEG and fMRI technologies have been used as the foundation of several different procedures aimed to read human minds, such as pattern recognition, brain-computer interfaces technologies, or lie-detection machines. Specifically, the combination of fMRI with specialised statistical pattern recognition techniques enabled significant progress in brain-reading to the extent that it is now possible to capture more accurate and detailed thoughts of an individual. At the same time, other innovative methods, like EEG-based BCI technologies, allow users to control external devices by translating in real-time their brain signals into computer commands. All the mentioned technologies represent a significant technical improvement with a revolutionary potential for this modern society, albeit they still need a clear validation in terms of reliability outside laboratory settings.

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<sup>&</sup>lt;sup>86</sup> Specifically, it has been demonstrated that anatomical differences between the frontal, the temporal or the parietal regions of the brain may suggest the ethnic or racial origin of an individual. See Y. Tang, c. Hojatkashani, I. D. Dinov, B. Sun, L. Fan, X. Lin, H. Qi, X. Hua, S. Liu, A. W. Toga, (n. 84), 33-41.

<sup>&</sup>lt;sup>87</sup> See Chapter 2, para. 2.2.1. and 2.3.1.

<sup>&</sup>lt;sup>88</sup> See Chapter 2, para 2.2.2. and 2.3.2.

<sup>&</sup>lt;sup>89</sup> T. Bayne, 'How to read minds' in S. Richmond, G. Rees, S. J. L. Edwards (eds), *I Know What You're Thinking. Brain Imaging and Mental Privacy*, (Oxford University Press, 2012), 41-55.

<sup>&</sup>lt;sup>90</sup> J. D. Haynes, (n. 57), 30.

<sup>&</sup>lt;sup>91</sup> S. N. Abdulkader, A. Atia, M. S. M. Mostafa, 'Brain Computer Interfacing: Applications and challenges', (2015), Volume 16, Egyptian Informatics Journal, 214-215, available at <www.sciencedirect.com/science/article/pii/S1110866515000237>, last accessed 8 May 2018.

<sup>&</sup>lt;sup>92</sup> P. Wolpe, K. Foster, D. Langleben, 'Emerging Neurotechnologies for Lie-Detection: Promises and Perils', (2010), Volume 10, Issue 10, The American Journal of Bioethics, 42-43, available at <a href="https://www.tandfonline.com/doi/full/10.1080/15265161.2010.519238">www.tandfonline.com/doi/full/10.1080/15265161.2010.519238</a>>, last accessed 8 May 2018.

This notwithstanding, the dividing line between "brain" and "mind" is not as clear and obvious as it may seem. People wrongly tend to conflate the two concepts, taking for granted that the mind cannot be separated from the brain. 93 On the contrary, some other people, intuitively understand that there is something more in the mind than the brain, yet it is just a soft perception. However, discovering the oxygenated blood level in the brain or measuring the electrical impulses therein does not mean reading human mind. There is much more in a human thought or memory than just raw brain data. Neurotechnologies such as EEG or fMRI only process physiological signals that are then translated into real-time images of human brain activity. Mind-reading goes beyond simple raw data and attempts to interpret them in order to identify human thoughts, emotions, intentions, or memories. 94 There is no equivalence between brain and mind: the mind is the result of all the information processed by the brain. 95

Considering this distinction between brain and mind, a third typology of information extracted from the brain needs to be defined, the one which, for the scope of this thesis, I refer to as 'mind data'. This new typology of information mainly represents the further potential evolution of the raw values captured from the human brain whenever combined with and interpreted through innovative technologies or interpretative methods in order to decode human thoughts or feelings. The more the raw values of the neural activity are interpreted and further processed through special techniques ('advanced interpretation'), the more the line of brain-reading is crossed to enter the special and risky realm of mind-reading.

The classification of different typologies or status of brain information reveals that the raw values captured by EEG and fRMI technologies have some hidden potentialities that need to be adequately taken into consideration whenever dealing with them. It is of paramount importance to be aware that raw brain data are not solely physiological values but, on the contrary, they can be further translated by means of interpretation or new computational methods until revealing more personal and intimate information about the individual. Raw brain data cannot be separated from their hidden potentiality of becoming brain data or, more importantly, mind data. Even more so if we consider that, although in current times it is still not possible to completely and reliably read the human mind, today's raw brain data can likely be the mind data of tomorrow. Mind data, in fact, represent a dormant status of the raw values currently recorded which might likely be triggered in a close future. Accordingly,

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<sup>&</sup>lt;sup>93</sup> F. X. Shen, 'Neuroscience, Mental Privacy, and The Law', (2013), Volume 36, Issue 2, Harvard Journal of Law and Public Policy, 671, available at <a href="https://www.harvard-jlpp.com/wp-content/uploads/2013/04/36\_2\_653\_Shen.pdf">www.harvard-jlpp.com/wp-content/uploads/2013/04/36\_2\_653\_Shen.pdf</a>, last accessed 4 May 2018.

<sup>&</sup>lt;sup>94</sup> See K. Evers and M. Sigman, 'Possibilities and limits of mind-reading: A neurophilosophical perspective', Consciousness and Cognition, issue 22, 2013, 887-897, available at <www.sciencedirect.com/science/article/pii/S1053810013000822>, last accessed 18 June 2018. Here the authors discuss the potentialities of fMRI-based techniques to decode infant minds, to read hidden intentions and to predict visual responses to images and detect unconscious vision.

<sup>95</sup> See R. Montague, Your Brain is (Almost) Perfect: How We Make Decisions, (Penguin Putnam Inc., 2007).

when dealing with them, the implications related to their interpretation and further combination with new mind-reading techniques need to be carefully considered.

#### 2.5. Conclusions

The aim of this Chapter was to provide a description of the different types of information extrapolated from the brain by neurotechnologies such as EEG and fMRI. As we have seen, in the last decades brain imaging techniques have become much more advanced and able to provide a more precise and effective "screenshot" of the brain's activity. However, despite the emergence of new modalities to detect the nervous system, EEG and fMRI still remain the most prominent techniques used to analyse how the human brain works. While the former collects data about the electromagnetic activity of the brain, the latter indirectly measures brain activity from the brain blood flow.

Furthermore, we have seen that the values captured from the human brain and translated into either graphs of brain waves or brain images of the active areas thereof, have no meaning *per se*, both requiring a proper expertise to be read and interpreted. Accordingly, two different typologies of brain data have been defined, namely 'raw brain data', consisting of the mere physiological values representing the brain activity, and 'brain data', consisting of the interpretation given by the specialists.

Nevertheless, in the light of the basic distinction between brain and mind, modern techniques have been designed to attempt reading the human mind and translate solely physiological signals into something more intimate and personal. Applications, software, and algorithms, combined with raw brain data extrapolated by EEG and fMRI-based technologies, are now close more than ever to be able to read personal intentions or thoughts. Even though these techniques still need scientific validation in terms of effectiveness and reliability, they have already started to revolutionise society in several fields of application both inside the medical field and outside of it. Consequently, a new typology of data captured from the human brain needs to be recognised, namely the one which I refer to as 'mind data', representing the further potential evolution which raw brain data may acquire whenever combined with innovative technologies to read the human mind. Accordingly, when dealing with the raw values recorded by the neurotechnologies at issue, the implications related to their potential interpretation and further combination with new mind-reading techniques need to be carefully considered.

## CHAPTER 3

# THE PECULIAR NATURE OF BRAIN INFORMATION AND THE NEED FOR AN ENHANCED PROTECTION

#### 3.1. Introduction

This Chapter aims to determine whether the information directly captured from the human brain by means of neurotechnologies such as EEG or fMRI, requires a higher attention under the EU data protection legal framework. Accordingly, this Chapter attempts to define those peculiarities which distinguish raw brain data from other categories of personal data regulated by the current EU data protection law and which may have a significant impact on the data subjects. Having equipped the reader with the scientific and technical background necessary to proceed to the legal analysis of this thesis, the next paragraphs consist of two main parts. The first identifies four peculiarities of brain information, while the second analyses their implications from an ethical and social perspective.

Even though the technical section in the previous Chapter has described the outcome of EEG and fMRI-based neurotechnologies as a bunch of physiological values representing the electrical activity of the brain or the level of the oxygenated blood, the classification of the brain information in three typologies has shown that the raw values collected can be further interpreted and processed in order to acquire a meaningful significance. As a result, they can be translated into brain data and mind data, both capable of revealing intimate and relevant information of the individual they originate from.

Hallinan *et al.* have already examined the novelties that characterise 'neurodata'. By doing so, they paid particular attention to the legal concerns arising from the peculiar characteristics of this kind of information. Specifically, by highlighting their novel features, they concluded that the DPD was neither equipped nor designed to deal with data of such intimacy. <sup>96</sup> The legal arrangements and principles of data protection law, in fact, would hardly properly work if applied to neurodata. Not only principles such as anonymity, accuracy, and sensitivity would be difficult to apply to the information captured from the brain, but the data subjects would also difficulty exercise their rights<sup>97</sup> (i.e. right of access, right to rectification, right to erasure, right to restriction of processing, right to object). In that regard, the same legal

<sup>&</sup>lt;sup>96</sup> D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11), 70.

<sup>97</sup> Ibid., 66.

concerns still remain with the new legal document, since the GDPR is based on the same principles and definitions as the DPD. This Chapter, therefore, mainly focuses on the ethical and social concerns arising from the peculiarities of raw brain data, whose investigation was not deeply addressed in the mentioned article.

#### 3.2. Brain information is personal data

In order to identify which features make brain information more distinctive than other kinds of personal data, it is firstly necessary to address the following question: is the information extrapolated from the human brain by EEG and fMRI personal data according to the definition of the current EU data protection legal framework? This question has already been answered under the DPD by Hallinan *et al.* in their analysis of the so-called 'neurodata'. In the light of the broad scope of application of the DPD, they were able to conclude that neurodata could be included within the notion of personal data. <sup>98</sup> In fact, in order to provide an effective protection of the individuals' rights, the scope of data protection law is deliberately a wide one. <sup>99, 100</sup> The definition of "personal data", thus, reflects the intention of the European lawmaker to offer a wide notion to the extent that almost all data that can somehow be connected to an identifiable person can be considered as personal data. <sup>101, 102</sup>

The evolution that characterised the right to data protection over the years and which has led to the adoption of the new GDPR, has been mainly directed by the intention to make the available legal instruments more consistent with the social and technological changes. The scope of EU data protection law has been enlarged accordingly. <sup>103</sup> For that reason, by applying the same line of reasoning to the raw brain data at issue and the GDPR, whose scope is even broader than the one of the DPD, the same conclusion would be reached. <sup>104</sup> In view

<sup>98</sup> D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11), 63.

<sup>&</sup>lt;sup>99</sup> Article 29 Working Party, Opinion 4/2007 on the concept of personal data, ('WP136'), 2007, 5.

<sup>&</sup>lt;sup>100</sup> See N. Purtova, 'The law of everything. Broad concept of personal data and future of EU data protection law', (2017), Volume 10, Issue 1, Law, Innovation and Technology, available at <a href="https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=3036355">https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=3036355</a>, last accessed 8 May 2018.

<sup>&</sup>lt;sup>101</sup> Article 29 Working Party, Opinion 4/2007 on the concept of personal data, (n. 99), 4.

<sup>&</sup>lt;sup>102</sup> As the Commission pointed out in its original proposal, "a broad definition is adopted in order to cover all information which may be linked to an individual". (COM (90) 314 final, 13.9.1990, 19 (commentary on Article 2).

<sup>&</sup>lt;sup>103</sup> This rationale is revealed by Recital 6 of the GDPR which claims: "Rapid technological developments and globalisation have brought new challenges for the protection of personal data. The scale of the collection and sharing of personal data has increased significantly. Technology allows both private companies and public authorities to make use of personal data on an unprecedented scale in order to pursue their activities. Natural persons increasingly make personal information available publicly and globally. Technology has transformed both the economy and social life, and should further facilitate the free flow of personal data within the Union and the transfer to third countries and international organisations, while ensuring a high level of the protection of personal data".

<sup>&</sup>lt;sup>104</sup> Moreover, it is possible to conclude that brain information is personal data also through the analysis of the legal definition of personal data. In fact, a thorough examination of the four elements prescribed by Article 4 (1) of the GDPR (i) 'any information', ii) 'relating to', iii) 'an identified or identifiable', iv) 'natural person') would show that brain information falls within each of them.

of the wide scope of the GDPR and of the higher level of protection that it aims to achieve, it can be said that the raw brain data also fall within its protection.

For the sake of completeness, it must be pointed out that, if brain information, in its raw status, falls within the definition provided by Article 4 of the GDPR, the same can also be said with regard to its further complex status. Brain data and mind data are the further potential evolutions of raw brain data which, by means of specific expertise or innovative technologies, acquire extra significance. Therefore, what is deemed valid for the raw status of the information captured by EEG and fMRI, will be also valid *a fortiori* for its evolved status. <sup>105</sup> Accordingly, if, for instance, a graph displaying the difference in the electrical activity between two sites of the brain comes within the definition of personal data, then it could be concluded that also the interpretation and further processing of those raw values (as brain data and mind data), being able to disclose more personal information of the individuals, do even more so.

Nevertheless, despite the information captured from the human brain do fall within the definition of personal data, the new legal framework implemented by the GDPR still does not explicitly mention it. They certainly share some characteristics with other kinds of data explicitly taken into consideration, especially with regard to genetic data and biometric data. However, brain information has some peculiarities that significantly characterise it among the other kinds of personal data, as the following paragraphs explain.

#### 3.3. Why are brain information so special?

#### 3.3.1. The dynamic nature

The dynamic nature of brain information comes from the fact that its different typologies are not immutable but could evolve to different status. The classification of brain information into three different typologies, namely i) raw brain data, ii) brain data and iii) mind data, <sup>107</sup> has shown how the raw values originally related to the electrical activity of the brain or the level of oxygenated blood flow therein are characterised by an intrinsic changeable essence. <sup>108</sup> The dividing line between the two distinct processes of brain-reading and mind-

<sup>&</sup>lt;sup>105</sup> According to the "argumentum a fortiori", if it is possible to argue in favour of the weaker proposition (a minore), then it will be also possible to argue in favour of the stronger one (ad maius). Therefore, if raw brain data, which reveal less information than their further interpreted status, are considered to be personal data, then also brain data and, even more, mind data, as revealing more information about the data subjects they originate from, can be considered even more so.

<sup>&</sup>lt;sup>106</sup> The Committee on Science and Law, (n. 32), 9-13.

<sup>&</sup>lt;sup>107</sup> See Chapter 2, para. 2.4.

<sup>&</sup>lt;sup>108</sup> The dynamic nature of the information recorded from the brain has been already studied. However, it has been considered from a different point of view, related to the aptitude of the brain to "adapt its activity to the current perception of the environment combined with the products of its own spontaneous activity". Accordingly, under this perspective, the dynamic nature is due to the fact that the information recorded from the brain is strictly reliant on the specific time frame when the neurotechnology has been used. See D. Vidaurre, R. Abeysuriya, R. Becker, A. J. Quinn, F. Alfaro-Almagro, S. M. Smith, M. W. Woolrich, 'Discovering

reading, in fact, highlighted how mere raw brain data describing the physical functioning of the brain may well be further interpreted and processed to the extent of disclosing other information not immediately readable from their original raw status.

Therefore, the possibility of being further interpreted by experts and scientists as well as of being combined with innovative technologies, algorithms, or software, implies that raw brain data are not static but, on the contrary, are able to transform in other shapes of brain information, either brain data or mind data. These evolved status inevitably disclose further personal information about the data subject they originate from. As I discuss in the last section of this Chapter, this dynamic nature may have important implications for the individuals since what is originally recorded to disclose certain specific information about the data subject, may be used in the future to reveal more personal and intimate information, without the data subject even being aware of it.

#### **3.3.2.** The uncontrollable nature

Moreover, and here the second peculiarity of brain information is revealed, it is outside the control of the individual. 109 As it has been said in the previous Chapter, the raw brain data deduced by EEG and fMRI technologies concern, alternatively, the electrical activities of the neurons inside the brain or the level of oxygenated blood flow in different regions of the brain: activities the individuals have certainly no control of. The meaningful insight that these neurotechnologies can provide with regard to complex mental processes happening inside the human brain is something that does not fall under the conscious command of the individual. The data subjects, in fact, cannot block the process of thinking or direct the physiological functioning of the neurons inside the brain, nor the blood flow within it. The information that EEG and fMRI extrapolate is outside the intention of the individual and, therefore, to a large extent, "uncontrollable". 110 This uncontrollability is twofold: besides the lack of a wilful command of their inner complex neural processes, the individuals also lack the capacity of controlling the information hidden inside the raw values captured. There is no possibility for the individuals concerned to know how their raw brain data will be further translated into brain data or mind data and, moreover, there is no possibility for them to previously identify the personal information which may be revealed in the future.

#### 3.3.3. The predictive quality

Furthermore, brain information is characterised by a strong predictive nature. In fact, similarly to genetic data, images representing the electrical activities of brain's neurons as well as the blood flow of different regions of the brain can disclose important information

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dynamic brain networks from big data in rest and task', NeuroImage xxx, 2017, 1, available at <a href="https://reader.elsevier.com/reader/sd/E834ACABB25D6DEBDF5D23A5215841AFFF28D615B38902B181973AA2DE6306D8C078EEB4EDC1C45BA2178945FE0E46EB">https://reader.elsevier.com/reader/sd/E834ACABB25D6DEBDF5D23A5215841AFFF28D615B38902B181973AA2DE6306D8C078EEB4EDC1C45BA2178945FE0E46EB</a>, last accessed 29 June 2018.

<sup>&</sup>lt;sup>109</sup> The Committee on Science and Law, (n. 32), 11.

<sup>&</sup>lt;sup>110</sup> Ibidem.

about the individuals. They can be used to detect diseases or mental disorders, <sup>111</sup> but they can also be used to "show the likelihood of developing" them in the future. <sup>112</sup> With regard to this capacity to predict illness, brain information seems very similar to genetic data which, likewise, can uncover important information related to individuals' predispositions to certain physical abnormalities. <sup>113</sup> However, brain information can go further and can be even more predictive than genetic data. They are also capable of predicting behaviours and, potentially, human intentions. <sup>114</sup> For instance, the neural reactions to specific images have been used to identify unconscious racial attitudes. <sup>115</sup> As I discuss in the last section of this Chapter, this powerful peculiarity may be particularly risky from a social perspective if not adequately regulated since it could be of significant value in a plurality of contexts where there is the interest to know or simply influence the others' behaviours.

#### 3.3.4. The unique and direct link with the individual

Lastly, the fourth peculiarity that significantly characterises raw brain data, is the kind of link that they share with the individual they originate from. In order to understand this particular feature, it can be useful to consider the definition of personal data provided by Article 4 (1) of the GDPR. In fact, despite the significant implementation that characterised data protection law in the last decades, what did not change in the transition between the DPD and the GDPR is the definition of what personal data are, namely "any information relating to an identified or identifiable natural person". Within this definition, four main elements can be isolated, namely: i) "any information", ii) "relating to", iii) "identified or identifiable", iv) "natural person". The second and third elements of the definition allow the identification of another significant feature characterising raw brain data.

Since raw brain data have proved to fall within the definition of personal data, they should relate to an identified or identifiable natural person. Generally speaking, a piece of information relates to an individual if it says something about that individual, establishing a link. To apply data protection law, it is not essential that the information represents a direct link to the individual nor that this link is immediately self-evident. Also a piece of information that is only indirectly linked to an individual, for instance by referring to an

<sup>&</sup>lt;sup>111</sup> See Chapter 2, para. 2.2.2. and 2.3.2.

<sup>&</sup>lt;sup>112</sup> The Committee on Science and Law, (n. 32), 11.

<sup>&</sup>lt;sup>113</sup> Ibidem.

<sup>&</sup>lt;sup>114</sup> Ibid., 11,12; See also B. Garland, 'Neuroscience and the Law. Brain, Mind and the Scale of Justice', The American Association for the Advancement of Science and The Dana Foundation, 2004, 1, available at <a href="https://www.aaas.org/sites/default/files/migrate/uploads/NeuroLawSummary.pdf">www.aaas.org/sites/default/files/migrate/uploads/NeuroLawSummary.pdf</a>, last accessed 18 June 2018.

<sup>115</sup> T. Canli, H. Silvers, S. Whitfield, I. Gotlieb, and J. Gabrieli, 'Amygdala response to happy faces as a function of extraversion', Science, Volume 296, 2002, 2191, available at <a href="http://science.sciencemag.org/content/296/5576/2191.long">http://science.sciencemag.org/content/296/5576/2191.long</a>, last accessed 18 June 2018.

<sup>&</sup>lt;sup>116</sup> Article 2 (a) of the DPD and Art. 4 (1) of the GDPR.

<sup>&</sup>lt;sup>117</sup> Article 29 Working Party, Opinion 4/2007 on the concept of personal data, (n. 99), 9.

<sup>118</sup> Ibidem.

object, a process or an event, provided that it tells something about that individual, would qualify as personal data within the meaning of EU data protection law.<sup>119</sup>

Furthermore, according to the third element of the definition, the individual should be "identified" or at least "identifiable" by the information at hand. In the first case, it should be possible to distinguish that individual among a group of persons by means of said information. Whereas, in the second case, an individual cannot be identified yet, but could be through further research or other information. For instance, the average man cannot identify an individual by knowing his license plate: license plates do not say anything about an individual to the extent that they can be considered as "data about anonymous persons". However, a policeman can identify an individual by means of the license plate simply accessing the general vehicle register. Accordingly, a license plate can be qualified as personal data since it makes an individual identifiable. 123

Therefore, although a person cannot be identified by certain information, there could still be the chance to identify them through extra elements called "identifiers". According to Article 4 (1) of the GDPR, in fact, "an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as name, an identification number, location data, an online identifier or to one or more factors specific to the *physical*, *physiological*, genetic, *mental*, economic, cultural or social identity of that natural person" (emphasis added). 124

The majority of personal data allows the identification of the individuals they refer to only indirectly, by means of further information. With raw brain data, on the contrary, the connection with the data subject is a direct and unique one. 125, 126 Similarly to genetic data

<sup>&</sup>lt;sup>119</sup> Ibidem.

<sup>&</sup>lt;sup>120</sup> European Union Agency for Fundamental Rights, Council of Europe, *Handbook on European data protection law*, (2014), 39.

<sup>&</sup>lt;sup>121</sup> Ibidem.

<sup>&</sup>lt;sup>122</sup> Ibid., 40-41.

<sup>123</sup> Ibidem.

<sup>&</sup>lt;sup>124</sup> Article 4 (1) of the GDPR.

<sup>&</sup>lt;sup>125</sup> Armstrong et al., for instance, demonstrated the uniqueness of individuals' semantic memory which, "although generally similar across individuals", has been proved "highly individualized when examined in details. See B. C. Armstrong, M. V. Ruiz-Blondet, N. Khalifian, K. J. Kurtz, Z. Jin, S. Laszlo, 'Brainprint: Assessing the uniqueness, collectability, and permanence of a novel method for ERP biometrics', Neurocomputing, Volume 166 (2015), 59, available at <www.sciencedirect.com/science/article/pii/S0925231215004725>, last accessed 18 June 2018.

<sup>126</sup> Finn et al. demonstrated that functional connectivity profiles act as a 'fingerprint' able to accurately identify

subjects among a group of individuals. In particular their results indicated that even if changes in brain state may modulate connectivity patterns to some degree, "an individual's underlying intrinsic functional architecture is reliable enough across sessions and distinct enough from that of other individuals to identify him or her from the group regardless of how the brain is engaged during imaging". See E. S. Finn, X. Shen, D. Scheinost, M. D. Rosenberg, J. Huang, M. M. Chun, X. Papademetris, and R. T. Constable, 'Functional connectome fingerprinting: identifying individuals using patterns of brain connectivity', Nature Neuroscience, Volume 18, Number 11, 2015, 1664-1671, available at

and biometric data, in fact, the brain patterns captured through EEG or fMRI are able to provide "unique and personalized information" about an individual person. <sup>127</sup> Neuroimaging, as well as genetic data, thus raises concerns related to its capability of directly, uniquely, and objectively identify an individual in a permanent way. Considering the innovative applications of "brainprints" as biometrics for authentication and identification purposes, <sup>128</sup> patterns of blood flow and images of the brain while engaged in particular tasks can be considered unique identifiers as fingerprints or DNA currently are. <sup>129</sup> Even more, the certainty and directness of connection with the data subject may be even more unique than the one characterising genetic data <sup>130</sup> or biometrics <sup>131, 132</sup> since the level of uniqueness of brain patterns appear to be higher than the one of the other mentioned categories of personal data.

In that regard, it is worth stressing that, within data protection law, the link that a particular piece of information is capable of establishing with the individual, is an important aspect to consider. The closer the link to the individuals is, the stronger the connection that can be established and, accordingly, the more likely said individuals may suffer adverse effects for any misuse of such information. For that reason, it is of paramount importance to examine the potential social and ethical implications for the individuals arising from the mentioned peculiarities of raw brain data.

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<sup>&</sup>lt;a href="http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=1&sid=ef5f54d5-47b0-4f2d-b242-89698f19bfb0%40sessionmgr104">http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=1&sid=ef5f54d5-47b0-4f2d-b242-89698f19bfb0%40sessionmgr104</a>, last accessed 24 June 2018.

<sup>&</sup>lt;sup>127</sup> The Committee on Science and Law, (n. 32), 11.

<sup>&</sup>lt;sup>128</sup> Y. Narain Singh, S. Kumar Singh, and A. Kumar Ray, 'Bioelectrical Signals as Emerging Biometrics: Issues and Challanges', ISRN Signal Processing, 2012, 2, available at <a href="https://www.researchgate.net/publication/258404446\_Bioelectrical\_Signals\_as\_Emerging\_Biometrics\_Issues\_and\_Challenges">https://www.researchgate.net/publication/258404446\_Bioelectrical\_Signals\_as\_Emerging\_Biometrics\_Issues\_and\_Challenges</a>, last accessed 17 June 2018.
<sup>129</sup> Ibidem.

<sup>&</sup>lt;sup>130</sup> For instance, monozygotic twins share significant genetic similarities. For a discussion in that regard, see T. E. Van Baak, C. Coarfa, P. Dugué, G. Fiorito, E. Laritsky, M. S. Baker, N. J. Kessler, J. Dong, J. D. Duryea, M. J. Silver, A. Saffari, A. M. Prentice, S. E. Moore, A. Ghantous, M. N. Routledge, Y. Y. Gong, Z. Herceg, P. Vineis, G. Severi, J. L. Hopper, M. C. Southey, G. G. Giles, R. L. Milne, and R. A. Waterland, 'Epigenetic supersimilarity of monozygotic twin pairs', Genome Biology, Volume 19, Number 2, 2018, available at <a href="https://genomebiology.biomedcentral.com/articles/10.1186/s13059-017-1374-0">https://genomebiology.biomedcentral.com/articles/10.1186/s13059-017-1374-0</a>, last accessed 24 June 2018. <sup>131</sup> For instance, with regard to fingerprints, it has been claimed that identical (monozygotic) twins share 95% similar fingerprints. Despite the similarities and the "large class correlation", however, it has been demonstrated that by using "minutiae-based automatic fingerprint verification system" it is still possible to distinguish them. In that regard see A. K. Jaina, S. Prabhakarb, S. Pankantic, 'On the similarity of identical twin fingerprints', Recognition, 2002, 2653-2663, Volume 35, Issue 11, available < www.sciencedirect.com/science/article/pii/S0031320301002187#BIB2>, last accessed 24 June 2018.

<sup>&</sup>lt;sup>132</sup> In addition to the similarities, it should be also highlighted that it is particularly rare that two fingerprints from the same origin are completely identical in every detail. When it comes to the process of identification, there is a high risk of human errors. See J. Fisher, *Forensics under Fire: Are Bad Science and Dueling Experts Corrupting Criminal Justice?*, (Rutgers University Press, 2008).

#### 3.4. Is an enhanced protection required? Ethical and social concerns

In George Orwell's "Nineteen Eighty-Four", the only remnant of individual privacy consisted of the "few cubic centimetres" inside the skull. 133 The so-called "Thought Police" did not have the advanced technologies to capture the thoughts directly from the brain. However, in the current society, also these few cubic centimetres seem to be compromised. In a scenario where the barrier between what is private and what is public will no longer exist, and even the most intimate sphere of human individuality could be accessed and exploited, there may be several social concerns that need to be properly addressed. Especially considering that, in modern times, society is not particularly critical or selective on the use of new advanced technologies. On the contrary, it is more often open to try and use new methods and techniques without conscience and without a real perception of the related risks and implications. In that regard, the role of data protection law in establishing the limits and boundaries in the processing of the concerned personal information is of vital importance.

While the legal implications arising from the particular characteristics of brain information have already been addressed by the existent literature, <sup>134</sup> these final sections mainly focus on the ethical and social concerns related to its potential misuse. The following paragraphs, thus, in highlighting the ethical and social concerns which may likely affect society, prepare the ground to the last Chapter's discussion, where an essential concept offered by the current legal framework to provide a reinforced protection, is rethought and adapted to the peculiar kind of personal data at hand.

#### 3.4.1. Ethical implications

From an ethical perspective, the potential misuse of the innovative neurotechnologies at issue may have a significantly negative impact on the right to human dignity<sup>135</sup> and the freedom to self-determination. According to the Kantian Humanity Formulation of the Categorical Imperative, "we should never act in such a way that we treat humanity, whether in ourselves or in others, as a means only but always as an end in itself". <sup>136</sup> The moral duty that the deontology theory<sup>137</sup> places on each individual sets the dividing line between a morally right

<sup>&</sup>lt;sup>133</sup> "Nothing was your own except the few cubic centimeters of your skull", G. Orwell, *Nineteen Eighty-Four*, (Penguin Books, 1949), 32.

<sup>&</sup>lt;sup>134</sup> Hallinan *et al.* argue that the former data protection legal framework was neither equipped nor designed to deal with personal data of such intimacy. Essential data protection legal arrangements and principles such as anonymity, accuracy and sensitivity, could hardly be applied on the information extracted from the human brain. Moreover, a consistent part of the rights given to the data subjects could not be fully exercised by them. See D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11).

<sup>&</sup>lt;sup>135</sup> Article 1 of the EU Charter claims that "Human dignity is inviolable. It must be respected and protected". <sup>136</sup> R. Johnson, A. Cureton, 'Kant's Moral Philosophy', The Stanford Encyclopedia of Philosophy, Spring 2018 Edition, 9-11, available at <a href="https://plato.stanford.edu/entries/kant-moral/#HumFor">https://plato.stanford.edu/entries/kant-moral/#HumFor</a>, last accessed 18 June 2018. <sup>137</sup> Deontology is the ethical theory mostly represented by the philosopher Immanuel Kant. It, by considering the morality of actions of the basis of rules, is commonly opposed to other ethical theories such as utilitarianism or consequentialism.

action and a morally wrong one. In doing so, it discourages those activities which go against the human dignity. In that regard, the innovative neurotechnologies described in the previous sections, if not properly regulated, could easily lead to a violation of these principles.

A clear example of this is the emerging field of neuromarketing, which is increasingly leading to a phenomenon of commodification of human beings and their emotions, thoughts, and intentions. Considering the rapid spreading of neuromarketing companies, in a scenario where the major aim is to find the "buy button in the brain", <sup>138</sup> the risk of human commodification is high. As a consequence, it may be likely that people start selling their own raw data to companies in order to identify and to study the consumers' reactions and desires. This has already happened with blood samples, which people used to sell on regular basis by registering in several donations centres. <sup>139</sup>

Another negative impact, which is important to highlight, is the one related to the freedom to self-determination and the right to identity. The dynamic nature of raw brain data, together with their predictive quality allow them to reveal information about the individuals unobservable before. These peculiarities, combined with the impossibility for the concerned individuals to control the inner neural processes inside their brain and, moreover, to predict their possible interpretation in terms of thoughts, behaviours, and intentions, significantly affect their aware and conscious determination.

The same phenomenon which is currently happening with big data, will likely occur with the information deduced from the human brain. The risk is of being told "who you are" and "what you want", <sup>141</sup> instead of deciding it freely. The exploitation of the brain information and their further advanced interpretation may lead to a risky determination of the individuals' mental predispositions, intentions, preferences, and thoughts even before their conscious awareness. <sup>142</sup> The uncontrollable nature of the raw brain data and the outcome of their further

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<sup>&</sup>lt;sup>138</sup> N. Lee, A. J. Broderick, L. Chamberlain, 'What is Neuromarketing? A discussion and Agenda for future research', Science Direct, International Journal of Psychophysiology, Issue 63, 2007, 199, available at <www.ncbi.nlm.nih.gov/pubmed/16769143>, last accessed 18 June 2018.

<sup>&</sup>lt;sup>139</sup> S. Gold, 'Healthcare biometrics-defending patients and their data', Biometric Technology Today, Issue 7, 2010, 10, available at <www.sciencedirect.com/science/article/pii/S0969476510701454>, last accessed 18 June 2018.

<sup>&</sup>lt;sup>140</sup> The freedom to self-determination and the right to identity have been included within a broad interpretation of the right to private life, as claimed in Article 8 of the ECHR and Article 7 of the EU Charter.

<sup>&</sup>lt;sup>141</sup> L. Moerel, 'Big Data Protection. How to make the draft EU Regulation on Data Protection Future Proof', Lecture delivered during the public acceptance of the appointment of professor of Global ICT Law at Tilburg University on 14 February 2014, 9, available at <a href="https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=3126164">https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=3126164</a>, last accessed 18 June 2018.

<sup>&</sup>lt;sup>142</sup> Remarkably MindSign, a neuromarketing company, in its website claims the following: "At MindSign Neuromarketing, we look at the subject brain response to your ad, game, speech, or film. We look at how well and how often it engages the area for attention/emotion/memory/and personal meeting. We also look at how well it activates the brain as a whole. From this data we can tell what your audience was thinking while using your software or watching your content, moment by moment, regardless of what that content is. Were they scared or sleepy, happy or sad? Were they even paying attention? We can show you how your product is

status when translated into meaningful information, reduce the power of the individuals to decide who they are and what they like, dangerously affecting their freedom to self-determination. Being able to access the human mind is the starting point for controlling it.

#### **3.4.2. Social implications**

From a social perspective, it is important to highlight the impact that the modern neurotechnologies in combination with advanced interpretative methods may have on the privacy of the individuals. The existent literature is plenty of different classification of privacy typologies. Among them, one from Finn *et al.* appears to be particularly relevant for the scope of this thesis. He from an EU data protection perspective, in fact, they were able to identify seven typologies of privacy in the light of the threats that the modern technologies may imply for the data subjects. In consideration of the innovative applications of BCI, they sharply isolated the privacy of thought and feelings, which I will focus on.

This conceptualisation of privacy refers to the right of the individuals to decide whether having their thoughts or emotions revealed, as well as to the freedom of deciding what to think. How Moreover, the private dimension has important benefits in regards to the relation between the individuals and the State, since it allows the balance of powers. Without that balance, the individuals would be at the mercy of the State. How I have light of the potential exploitation of raw brain data and the personal information that may be disclosed whenever translated into mind data, this particular kind of privacy can likely be undermined. For this reason, it is of paramount importance to design proper safeguards to regulate the processing of raw brain data. Even more so, considering that the data subjects have no control over their

affecting the consumer brain even before the consumer is able to say anything about it", as cited by J. B. Bublitz, 'Freedom of Thought in the Age of Neuroscience. A Plea and a Proposal for the Renaissance of a Forgotten Fundamental Right', Archiv fur Rechts und Sozialphilosophie, 100(1):1, 2014, available at <www.researchgate.net/publication/261950057\_Freedom\_of\_Thought\_in\_the\_Age\_of\_Neuroscience>, last accessed 20 June 2018.

<sup>&</sup>lt;sup>143</sup> See A. F. Westin, 'Privacy And Freedom', Volume 25, Issue 1, Washington and Lee Law Review, 1968, available at <a href="https://scholarlycommons.law.wlu.edu/wlulr/vol25/iss1/20/">https://scholarlycommons.law.wlu.edu/wlulr/vol25/iss1/20/</a>, last accessed 20 June 2018; R. Clarke, 'Introduction to Dataveillance and Information Privacy, and Definitions of Terms', Roger Clarke's Home Page, available at <a href="https://www.rogerclarke.com/DV/Intro.html">https://www.rogerclarke.com/DV/Intro.html</a>, last accessed 20 June 2018; B. Koops, B. C. Newell, T. Timan, I. Skorvánek, T. Chokrevski, and M. Galič, 'A Typology of Privacy', University of Pennsylvania Journal of International Law, Volume 38, Issue 2, (2017), 483-575, available at <a href="https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=2754043">https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=2754043</a>, last accessed 21 June 2018.

<sup>&</sup>lt;sup>144</sup> See R. L. Finn, D. Wright, and M. Friedewald, 'Seven Types of Privacy', in S. Gutwirth et al. (editors), European Data Protection: Coming of Age, Springer Science, 2013, available at <www.researchgate.net/publication/261952118\_European\_Data\_Protection\_Coming\_of\_Age>, last accessed 18 June 2018.

<sup>&</sup>lt;sup>145</sup> Ibid., 9-10.

<sup>&</sup>lt;sup>146</sup> B. J, Goold, 'Surveillance and the Political Value of Privacy', Amsterdam Law Forum, Volume 1, Number 4, 2009, 5, available at <a href="http://amsterdamlawforum.org/article/view/88/152">http://amsterdamlawforum.org/article/view/88/152</a>, last accessed 18 June 2018.

mind.<sup>147</sup> The personal information hidden by the raw brain data cannot be known before they are further interpreted with specific methods and technologies. The individuals lack the capability to filter what personal mental information they want to make public and what other information they want to keep secret.

In addition, the lack of an adequate protection of the raw brain data may have other important implications. The predictive quality of the brain information which, even more than genetic data, are capable of revealing predispositions to physical and mental diseases or abnormalities as well as future behaviours and intentions can well undermine the principle of equality, <sup>148</sup> by leading to discrimination and social stigmatisation. <sup>149</sup> This information, in fact, can have discriminatory effects and can be used for denial of services in a plurality of contexts. It can be used, for instance, to discriminate people in the context of employment, education, or access to healthcare and insurance services. The access to said information, thus, requires an enhanced regulation and protection to avoid its undesired dissemination.

Lastly, in the light of all the above ethical and social concerns, a final remark should be extended to the peculiar kind of link that raw brain data share with the individuals. Considering the capability of raw brain data of directly, uniquely, and permanently being connected with the individual they originate from, <sup>150</sup> it is essential to ensure that this kind of information is adequately secured and preserved. In this regard, the EU data protection law should play an important role by providing an enhanced protection. Any undesired breach, in fact, will likely have negative ethical and social impacts on the directly identifiable data subjects and will potentially undermine other fundamental rights.<sup>151</sup>

#### 3.5. Conclusions

While the technical description has described the scientific meaning of the information extrapolated from the human brain, this Chapter has showed how such raw values, albeit dependent on specific interpretation, are able to distinguish themselves for certain peculiarities. Being able to fall within the broad scope of the EU data protection law, raw brain data are characterised by four meaningful features that make them different from other personal data. While the dynamic nature lays on the brain information's predisposition to be

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<sup>&</sup>lt;sup>147</sup> M. Ienca, R. Adorno, 'Towards new human rights in the age of neuroscience and neurotechnology', (2017), Volume 13, Issue 5, Life Sciences, Society and Policy, 13-15, available at <a href="https://lsspjournal.springeropen.com/articles/10.1186/s40504-017-0050-1">https://lsspjournal.springeropen.com/articles/10.1186/s40504-017-0050-1</a>, last accessed 17 April 2018.

<sup>&</sup>lt;sup>148</sup> Article 14 of the ECHR as well as Article 21 of the EU Charter prohibit discrimination "on any grounds, such as sex, race, colour, ethnic or social origin, genetic features, language or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation".

<sup>&</sup>lt;sup>149</sup> The Committee on Science and Law, (n. 32), 10-12.

<sup>&</sup>lt;sup>150</sup> See Chaper 3, para. 3.3.4.

<sup>&</sup>lt;sup>151</sup> According to Recital 2 of the GDPR, "the principles of, and the rules on the protection of natural persons with regard to the processing of their personal data should (…) respect their fundamental rights and freedoms, in particular their right to the protection of personal data. This Regulation is intended to contribute to the accomplishment of an area of freedom, security and justice (…)".

translated into more complex status such as brain data or mind data, three other peculiarities have been identified. Brain information, in fact, is also uncontrollable for the individuals they originate form, which cannot direct their physiological brain activity, nor the way in which the former raw values will be further interpreted in meaningful thoughts, memories, or intentions. Furthermore, they are characterised by a predictive quality even stronger than the one of genetic data, since they are able to reveal information about physical and mental diseases and predispositions as well as behaviours and intentions. Lastly, the analysis of the definition of personal data as provided by Article 4 (1) of the GDPR has been used to explain how raw brain data can be distinguished from other categories of personal data, since they are able to provide a connection with the individual in a direct, unique, and permanent way.

All these peculiarities, if not properly regulated, may have significant implications on the data subjects' lives. On the one hand, from an ethical perspective, the developing field of neuromarketing has been used to show the high risk of commodification of the individuals and, in connection with it, the threat to the human dignity and to the deontological moral duty. At the same time, the increasing access to the human mind without a conscious control from the individuals concerned, showed the risk that these emerging neurotechnologies may have on the freedom to self-determination and the right to identity. On the other hand, from a social perspective, two major concerns have been identified: the threat to mental privacy, understood as the privacy of thoughts and feeling, and the risk to discrimination and social stigmatisation, understood as a threat to the principle of equality. In the light of all the highlighted concerns, EU data protection law should provide a reinforced protection able to adequately and proactively regulate this particular kind of information deduced from the human brain which, if misused, can have a significant impact on the data subjects' lives.

# CHAPTER 4

# THE MEETING POINT BETWEEN BRAIN INFORMATION AND THE NOTION OF SENSITIVITY

#### 4.1. Introduction

The previous Chapter has shown that the information extrapolated from the human brain is characterised by specific peculiarities that make it able to generate serious concerns for the individuals it originated from. The current EU data protection legal framework is already equipped with particular instruments aiming to offer an enhanced protection in those cases where special categories of personal data are involved. The GDPR, in fact, provides enhanced protection for certain categories of personal data which, by their nature, can have a significant impact on the data subjects' lives when processed. Therefore, the processing of "sensitive data" is allowed only under specific conditions and with special safeguards in place. Specifically, according to the previous legal document, the DPD, the definition of sensitive data included those data revealing i) racial or ethnic origin, ii) political opinions, iii) religious or philosophical beliefs, iv) trade-union membership or data concerning v) health and vi) sex life. 154

With the aim to enhance personal data protection and to adapt the rules set out by the DPD to the technological innovation, the GDPR enlarged the list of data deserving a special safeguard. Accordingly, Article 9 of the GDPR<sup>155</sup> adds to the list of sensitive personal data also genetic data<sup>156</sup> and biometric data.<sup>157</sup> As a result, there are currently eight categories of

<sup>&</sup>lt;sup>152</sup> Article 29 Working Party, 'Advice Paper on special categories of data ("sensitive data")', 2011, 4.

<sup>153</sup> Ibidem.

<sup>&</sup>lt;sup>154</sup> Article 8 (1) of the DPD.

<sup>&</sup>lt;sup>155</sup> Article 9 (1) of the GDPR, named "processing of special categories of personal data", claims: "Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade-union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited".

<sup>&</sup>lt;sup>156</sup> According to Article 4 (13) of the GDPR, "genetic data means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question".

<sup>&</sup>lt;sup>157</sup> According to Article 4 (14) of the GDPR, "biometric data means personal data resulting from specific technical processing relating to the physical, physiological or behavioural characteristics of a natural person, which allow or confirm the unique identification of that natural person, such as facial images or dactyloscopic data".

information that, according to the data protection legal framework, are considered sensitive. The data related to the brain, despite all the peculiarities and related risks previously highlighted, are not explicitly mentioned within them.

The aim of this Chapter, thus, is to determine what kind of protection the current legal framework is able to provide to the information directly extrapolated from the brain and whether said protection offers adequate safeguards also for the further status raw brain data may embody. Accordingly, the first question that needs to be answered is whether the information extrapolated from the human brain can be considered sensitive data within the meaning of the EU data protection law. However, the sensitive nature of brain data cannot be truly assessed without proper consideration of their inherent qualities and their latent potential when combined with further interpretative methods and technologies. Therefore, the legal analysis will then be directed beyond its initial scope and will lead to the edge of the traditional definition of sensitivity provided by the GDPR, which will be stretched in order to include also mind data.

In order to conduct this analysis, a different notion of sensitivity is required. The dynamic nature of raw brain data, in fact, inevitably requires an idea of sensitivity with a similar nature. Therefore, I do not consider a static and univalent concept of "sensitivity", which is the traditional one, but, on the contrary, I refer to a more dynamic notion, able to entail different levels therein. This conceptualisation is made possible through the development of two distinct approaches applied to sensitivity, a qualitative and a quantitative one. While the former refers to the specificity and intensity of the insight into the individual's life that certain information may offer, the latter refers to the amount of sensitive information that may be disclosed.

With these definitions in mind, a classification of different degrees of "sensitivity" that brain information can achieve is proposed, in both a qualitative and quantitative way. This classification can have two main benefits. Firstly, it can define the different levels of risk for the individual that the processing of brain data can cause and, accordingly, it can help to determine the proper safeguards that need to be in place when dealing with this kind of data in different contexts. In fact, in case of brain information processed outside the medical field, further considerations should be made in view of the greater implications that said processing might have. Secondly, in analysing the different circumstances and purposes concerning the processing of raw brain data, the proposed classification set the boundaries and define the limits of application of the current legal framework.

#### 4.2. A first level of sensitivity: i) health data, ii) racial and ethnic origin

The definition of sensitive data currently provided by the EU data protection law is a closed one. <sup>158, 159</sup> For personal data to be considered sensitive, they have to fall within one of the categories explicitly mentioned in Article 9. Therefore, it should be verified if brain data, in their raw status are able to reveal one of the eight types of sensitive information listed in the law. In the light of this, raw brain data, which for the purpose of this thesis are either the electrical frequency of the neural activity of the brain (EEG-based brain data) or the level of oxygenated blood flow within the brain (fMRI-based brain data), are sensitive data because they may reveal, i) information related to the health of the individuals and, depending on the way the experiment is designed and the specific regions of the brain that are examined, ii) information related to the racial and ethnic origin of the individual. <sup>160</sup>

According to Recital 35 of the GDPR, "personal data concerning health should include all data pertaining to the health status of a data subject which reveal information relating to the past, current or future physical or mental health status of the data subject". Moreover, they include "(...) any information on, for example, a disease, disability, disease risk, medical history, clinical treatment or the physiological or biomedical state of the data subject independent of its source (...)". Going back to the scientific and technical description of the neurotechnologies at issue, raw brain data's capability of providing information related to the health status becomes clear. EEG and fMRI neurotechnologies were developed and

<sup>&</sup>lt;sup>158</sup> Article 29 Working Party, 'Advice Paper on special categories of data ("sensitive data")', (n. 152), 12.

Working Party with regard to the directive 95/46/EC and it is not directly related to the new Regulation (EU) 2016/679. However, it is reasonable to consider said statement still valid also with regard to the new list of sensitive data provided by the GDPR. In fact, after mentioning the eight categories of sensitive personal data and the exceptions for their processing, Article 9 (4) states: "Member States may maintain or introduce further conditions, including limitations, with regard to the processing of genetic data, biometric data or data concerning health". While explicitly allowing the Member States to add further conditions or limitations for the processing of sensitive data, nothing is said with regard to the possibilities to add further categories of personal data deserving an enhanced protection. Therefore, it is reasonable to consider that, likewise the previous legal document, the list provided by the GPPR is still a closed one. Additionally, in the mentioned Advice Paper on special categories of data, the Article 29 Working Party considers three possible approaches to the processing of sensitive data: *i*) current approach (closed list), *ii*) context approach (general prohibition of a list of data categories), and *iii*) precautionary principle approach ("sensitive data may not be processed unless domestic law provides appropriate safeguards"). The structure of the current Article 9 of the GDPR suggests that the first approach has been once again the chosen one.

<sup>&</sup>lt;sup>160</sup> It is important to clarify that only certain regions of the brain allow the determination of a particular ethnic group or race. Therefore, raw brain data are not always able to disclose such information, being necessary that they are related to those specific brain areas.

<sup>&</sup>lt;sup>161</sup> Recital 35 of the GDPR.

<sup>&</sup>lt;sup>162</sup> Ibidem; Recital 35 also states that the notion of health data "includes information about the natural person collected in the course of the registration for, or the provision of, health care services as referred to in Directive 2011/24/EU of the European Parliament and of the Council to that natural person; a number, symbol or particular assigned to a natural person to uniquely identify the natural person for health purposes; information derived from the testing or examination of a body part or bodily substance, including from genetic data and biological samples".

originally used in the medical field with the specific purpose of better investigating the human brain and being able to identify neurological problems or brain diseases. <sup>163</sup> Specifically, EEG-based brain data, namely brain waves representing the neuronal activity in different regions of the brain, are used to diagnose sleep disorders, brain death, tumours, coma, or epilepsy. <sup>164</sup> While fMRI-based brain data, by showing the changes in the oxygenation states of the blood within the brain, can offer an image of the human brain and, as a result, to identify brain tumours, chronic disorders of the nervous system, congenital abnormalities, and trauma. <sup>165</sup> The nature and the aim of the neurotechnologies used to extrapolate that kind of personal data make raw brain data intrinsically health data and, consequently, sensitive data within the meaning of Article 9 of the GDPR.

This becomes even clearer if it is considered that the definition of health data is broad. In fact, in consideration of the important implications that the processing of those data may have on the data subjects' lives (e.g. social stigmatisation, employment denial, access to insurance or social services), <sup>166</sup> the EU lawmaker meant to provide a higher protection to health data, since their misuse "is likely to have more severe consequences for the individuals' fundamental rights (...) than misuse of other, "less sensitive" types of personal data". <sup>167</sup> As a result, "ill health" does not need to be established for the data at hand to be classified as health data. <sup>168</sup> Brain information can be qualified as such and, thus, as sensitive data even though they do not discover any abnormalities or brain disorders. Because of their biomedical origin, which cannot be eliminated, data extrapolated from the human brains by EEG or fMRI neurotechnologies appear by definition as sensitive data concerning health.

However, the health information that raw brain data can disclose is not the only reason for them to be sensitive. By offering an image of the brain's structure, they are also able to reveal information related to the racial and ethnic origin of the individual. From a scientific perspective, the study of the morphological differences between various sections of the brain in different individuals allows the identification of different ethnical groups. <sup>169</sup> Anatomical differences between the frontal, the temporal or the parietal regions of the brain, in fact, may suggest the ethnic or racial origin of an individual. <sup>170</sup> Accordingly, raw brain data are also able to disclose a second kind of information, which is qualified as sensitive within the legal framework at issue, namely the racial and ethnic origin of an individual. Yet, it is important

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<sup>&</sup>lt;sup>163</sup> See Chapter 2.

<sup>&</sup>lt;sup>164</sup> See Chapter 2, section 2.2.

<sup>&</sup>lt;sup>165</sup> See Chapter 2, section 2.3.

<sup>&</sup>lt;sup>166</sup> The Committee on Science and Law, (n. 32), 11.

<sup>&</sup>lt;sup>167</sup> Article 29 Working Party, 'Annex – Health data in Apps and devices', 2015, 1.

<sup>&</sup>lt;sup>168</sup> Ibid., 2.

<sup>&</sup>lt;sup>169</sup> See M. Wei Liang Chee, H. Zheng, J. Oon Soo Goh, D. Park, B. P. Sutton, 'Brain Structure in Young and Old East Asians and Westerners: Comparison of Structural Volume and Cortical Thickness', (2011), 23 (5), Journal of Cognitive Neuroscience, available at <www.ncbi.nlm.nih.gov/pmc/articles/PMC3361742/>, last accessed 2 May 2018.

<sup>&</sup>lt;sup>170</sup> Y. Tang, c. Hojatkashani, I. D. Dinov, B. Sun, L. Fan, X. Lin, H. Qi, X. Hua, S. Liu, A. W. Toga, (n.84), 33-41.

to bear in mind that this kind of information, unlike information related to the health of the individual, are not always disclosed, since it requires the analysis of specific regions of the brain. Nevertheless, provided that the raw data at hand do refer to one of those brain regions, then it can be claimed that they do disclose information related to the racial and ethnic origin of the individual.

Therefore, as long as brain data are considered in their raw status, they belong to the special categories of personal data on the ground that they may provide information related to the individuals' health and the racial and ethnic origin. This information, even though intrinsically embedded in raw brain data, in order to acquire concrete significance, requires the intervention of experts or scientists able to read and translate it. The first level of sensitivity, therefore, specifically characterises the process of brain-reading and concerns both raw brain data and brain data, as defined in Chapter 2's last section. They are both naturally sensitive because of their biomedical origin. Being the primary and essential status of brain data, this first level of sensitivity cannot be eliminated. In this context, they are sensitive in a traditional way, notwithstanding the peculiarities highlighted in the previous Chapter. However, when processed in a more complex status, other considerations should be made with regard to the greater impact that a dual-use of brain data may entail in the lives of the data subjects concerned. In those scenarios, further hidden degrees of sensitivity are revealed depending on the desired intent and, accordingly, on the technologies brain information is combined with. But firstly, it is necessary to re-conceptualise the traditional notion of sensitivity.

# 4.3. Rethinking the concept of "sensitivity": a qualitative and a quantitative approach

From a theoretical perspective, the concept of "sensitivity" used by the GDPR is a static and univalent one. The current data protection law does not consider different types or degrees of sensitivity: personal data either are sensitive or are not. Consequently, all the listed types of information mentioned in Article 9 of the GDPR are sensitive in the same way: an individual's fingerprint is sensitive as much as their sexual orientation, to the extent that no difference in the related treatment exists. <sup>171</sup> Dealing with raw brain data, which are characterised by a particularly dynamic nature and meaningful hidden potentialities, a

<sup>&</sup>lt;sup>171</sup> Article 9 (1) of the GDPR, in mentioning those categories of personal data which require an enhanced protection, states a general prohibition of their processing. The subsequent paragraphs, on the contrary, offer ten different exceptions under which the processing of sensitive data is allowed. However, no explicit distinction among different categories is made as well as no specific reference to some of them rather than others, to the extent that all the categories listed in the first paragraph are treated in the same way within the data protection law.

different approach may be required. Therefore, the notion of "sensitivity" is rethought under a qualitative and a quantitative ideal. <sup>172</sup>

#### 4.3.1. Qualitative sensitivity

From a qualitative point of view, different types of information are able to provide a different insight into the private lives of the data subjects. In the light of this, a qualitative approach to sensitivity mainly takes into consideration the intensity of the intrusiveness in the individuals' private sphere. This intrusiveness can be defined under two different points of view. On the one hand, some types of information are qualitatively more sensitive because, unlike other types of information, are capable of providing a permanent, distinctive, and specific link with the individual they refer to. On the other hand, the same types of information are qualitatively more sensitive also because, in order to be collected from the data subjects, they require means and instruments particularly invasive of the physical sphere of the individuals. <sup>173</sup> In the light of those twofold considerations, various degrees of sensitivity can be granted to different personal data. Accordingly, a classification of all the existing special categories of personal data in terms of their qualitative degree of sensitivity can be delineated.

By applying this approach, for instance, biometric and genetic data can be considered as qualitatively more sensitive than personal data related to the religious or philosophical beliefs of the concerned individual. Biometric data and, even more, genetic data, in fact, not only provide information about the individual they refer to 174 but also allow the exact, unique, and conclusive identification of that individual throughout their entire life. 175, 176 Furthermore, in order to be collected, they require complex methods, particularly penetrative of the physical sphere of the data subjects, like the collection of blood samples or iris shapes. The same intrusiveness cannot be found in data related to the philosophical orientation or religious beliefs, which, although telling some personal (and certainly relevant) information about the individuals, do not permit their direct, permanent, and unique identification, neither require physically invasive methods of collection.

#### 4.3.2. Quantitative sensitivity

From a quantitative point of view, different types of information are able to achieve a higher degree of sensitivity because they contain a larger amount of sensitive information. Having

<sup>&</sup>lt;sup>172</sup> These two approaches aim to provide the benchmarks to assess the degree of sensitivity of the personal data at issue from an objective point of view. The assessment from the data subjects' prospective may likely be different, since they would judge subjectively those personal data they deem to be more important not to share for personal reasons.

<sup>&</sup>lt;sup>173</sup> For instance the collection of genetic data where, by means of a syringe or other instruments, it is necessary to literally "aspirate out" of the body the required fluid sample.

<sup>&</sup>lt;sup>174</sup> Genetic data, in particular, are able to provide detailed and personal information about the data subject. For instance, they can disclose information about relatives and family, and, because of their predictive quality, to foresee behaviours, abilities or even diseases.

<sup>&</sup>lt;sup>175</sup> Article 29 Working Party, 'Working Document on Genetic Data' ('WP91'), 17 March 2004, 4-5.

<sup>&</sup>lt;sup>176</sup> The Committee on Science and Law, (n. 32), 11.

taken into account the eight categories of sensitive data mentioned by Article 9 of the GDPR, <sup>177</sup> the quantitative approach to "sensitivity" considers more sensitive those kinds of personal data which provide information related to the higher number of categories listed. Therefore, for instance, those personal data able to provide information related to both the sexual orientation of an individual (8<sup>th</sup> category of sensitive data mentioned by Article 9 of the GDPR) and their political beliefs (2<sup>nd</sup> category of sensitive data mentioned by Article 9), covering two of the eight categories listed in the law, under a quantitative approach, are more sensitive than those personal data capable of disclosing information only related to, for instance, the trade-union membership of that individual (4<sup>th</sup> category of sensitive data). The amount of sensitive information provided, thus, becomes the benchmark to define the degree of sensitivity of a specific piece of information. The higher the potential to disclose a larger amount of sensitive information is, the more sensitive the personal data are from a quantitative point of view.

In consideration of these distinct approaches, it is now possible to evaluate the degree of sensitivity of the information extrapolated from the human brain by taking into consideration also its more complex status when further interpreted and analysed. It will then become clear that different applications of raw brain data for different purposes, may achieve a different degree of sensitivity to the extent of crossing the current boundaries set by the legal framework. In particular, it is demonstrated that in each context taken into consideration hereunder, raw brain data will achieve a new piece of sensitivity that makes them more sensitive than in the previous level, both in a qualitative way (because of the intrusion into the individuals' private sphere) and in a quantitative way (because of the amount of sensitive information that they are capable of disclosing).

# 4.4. Different levels of "sensitivity"

#### 4.4.1. The second level of sensitivity: biometric data

One of the novelties introduced by the GDPR is the addition of biometric data within the list of the special categories of personal data provided by Article 9 of the GDPR. According to the GDPR, biometric data are "personal data resulting from specific technical processing relating to the physical, physiological or behavioural characteristics of a natural person, which allow or confirm the unique identification of that natural person, such as facial images or dactyloscopic data". These data are sensitive when processed "for the purpose of uniquely identifying a natural person". Biometric data, in fact, relying on their constant

<sup>&</sup>lt;sup>177</sup> Namely, information revealing i) racial and ethnic origin, ii) political opinions, iii) religious or philosophical beliefs, iv) trade-union membership, v) genetic data, vi) biometric data, vii) health data and viii) sex life or sexual orientation.

<sup>&</sup>lt;sup>178</sup> Article 4 (14) of the GDPR.

<sup>&</sup>lt;sup>179</sup> Article 9 (1) of the GDPR.

link with the individual, permits a match "between a live digital image of the body and a previously recorded image of the same part". 180

In recent years, several conventional biometric authentication or identification systems were built on both physiological-based applications and behavioural-based applications which alternatively measure the physiological characteristics of a person or their behaviour, and include fingerprint verification, retina analysis, iris recognition, ear shape recognition, voice recognition, DNA pattern analysis, but also hand-written signature verification, keystroke analysis, etc.<sup>181</sup> However, an increasing interest has been recently invested in new physical identifiers like brain signals. In fact, because of their particular relation with the individual's genetic information and their unique link to the subject, brain signals would be more reliable and secure sources for biometric identification and authentication systems,<sup>182</sup> overcoming the security issues of the traditional biometric methods.<sup>183</sup> Different studies and researches have shown that brain signals, especially EEG-based brainwaves, can well be used for identification and authentication of individuals and, moreover, they would provide several advantages because they are inherently difficult to imitate.<sup>184</sup>

However, in current times these methods are still in their "infancy", especially because of the difficulty in achieving the required level of accuracy of the extrapolated data. Nevertheless, in consideration of the significant benefits that brain data may bring to this field in terms of security, researches and studies will likely progress to the extent that, in a close future, they will probably become biometric data processed "for the purpose of uniquely identifying a natural person". This is particularly true with regard to EEG-based brain data which are being frequently used in this sector. 187

On that ground, it can be said that raw brain data, besides the inherently sensitive nature related to the health information they contain and the information associated to the racial and ethnic origin they may provide (if certain regions of the brain are involved), in combination

<sup>&</sup>lt;sup>180</sup> A. Sprokkereef, P. De Hert, 'Ethical Practice in the Use of Biometric Identifiers within the EU', (2007), Volume 3, Law, Science and Policy, 178, available at <www.vub.ac.be/LSTS/pub/Dehert/200.pdf> last accessed 12 April 2018.

<sup>&</sup>lt;sup>181</sup> Article 29 Working Party, 'Working document on biometrics', ('WP80'), 1 August 2003, 3.

<sup>&</sup>lt;sup>182</sup> N., Shashank, C. R., Rashmi, 'EEG Based Person Identification and Authentication Using BCI', (2016), Volume 5, Issue 12, International Journal of Engineering and Computer Science, 1, available at <a href="http://ijecs.in/index.php/ijecs/article/view/3242">http://ijecs.in/index.php/ijecs/article/view/3242</a> last accessed 12 April 2018.

<sup>&</sup>lt;sup>183</sup> W. Liang, L. Cheng, M. Tang, 'Identity Recognition Using Biological Electroencephalogram Sensors', (2016), Journal of Sensors, 8, available at <a href="https://www.hindawi.com/journals/js/2016/1831742/">https://www.hindawi.com/journals/js/2016/1831742/</a> last accessed 12 April 2018.

<sup>&</sup>lt;sup>184</sup> S. Marcel, J. del R. Millan, 'Person Authentication Using Brainwaves (EEG) And Maximum A Posteriori Model Adaptation', (2007), Volume 29, Issue 4, IEEE Transactions on Pattern Analysis and Machine Intelligence, 743, available at <a href="https://ieeexplore.ieee.org/document/4107576/">https://ieeexplore.ieee.org/document/4107576/</a> last accessed 25 June 2018. <sup>185</sup> Ibid., 745.

<sup>&</sup>lt;sup>186</sup> Article 9 (1) of the GDPR.

<sup>&</sup>lt;sup>187</sup> The majority of the experiments and studies are focused on EEG signals. The interest in fMRI signals for biometric purposes is very scarce because of the characteristics of the fMRI machine which appears to be not suitable from a practical point of view considering the big size of the machine.

with other technologies or matching systems, can acquire an additional level of sensitivity because of their use as biometric data. Therefore, whenever used outside the medical field for authentication and identification purposes, data extracted from the human brain will have two different levels of sensitivity: the first enshrined in their raw status, which cannot be eliminated because of their biomedical origin, and the second related to their use as biometric data. Albeit the raw values are used as biometrics, the health information they embed and, possibly, the information about the race or the ethnic group, is still there and could be extracted at will whenever there is the intention to. This second additional level makes brain data more sensitive both in a qualitative and in a quantitative way. With regard to the former, biometric data, by enabling the precise identification of the person, offer a deeper insight in the individual private life than health data or information related to the racial and ethnic origin. With regard to the latter, a third category of sensitive information is additionally disclosed together with the two categories already mentioned (i) health data and ii) racial and ethnic origin data). In both scenarios, they fall within the definition of sensitive data provided by the EU data protection legal framework.

Having concluded that raw brain data will likely become biometric data, a further reflection should be made. A typical characteristic of biometric data is that they generally contain more information than the ones necessary for the sole identification/authentication purposes. <sup>189</sup> This is even more so with regard to raw brain data which, having a predictive quality even stronger than the one of genetic data, <sup>190</sup> and being inherently dynamic, <sup>191</sup> may reveal not only future diseases or predispositions to them, but also behaviours and, if connected with proper technologies or specific algorithms, even emotions, moods, thoughts, and intentions. <sup>192</sup> Here comes the third level of sensitivity that raw brain data may potentially achieve, being the unique point of access to the human mind.

#### 4.4.2. The third level of sensitivity: access key to the human mind

In 2005, Professor Yukiyasu Kamitani from the ATR Computational Neuroscience Laboratories in Kyoto was able to decode human dreams starting from an analysis of the under-sleep brain activity registered with an fMRI machine.<sup>193</sup> Even if, according to the

<sup>&</sup>lt;sup>188</sup> As it has been highlighted in the previous sections, information related to the racial and ethnic origins can be disclosed only by specific regions of the brain. Therefore, there could be the case where raw brain data are not capable of revealing such kind of information. In those cases, only health data will be, thus, disclosed. Nevertheless, for the scope of this analysis, it has been deemed appropriate and more useful to consider the riskiest scenario, the one where the regions of the brain the raw brain data originate from, are the ones which allow the disclosure of both health data and information about racial and ethnic origins.

<sup>&</sup>lt;sup>189</sup> Article 29 Working Party, (n. 181), 7.

<sup>&</sup>lt;sup>190</sup> See Chapter 3, para 3.3.3.

<sup>&</sup>lt;sup>191</sup> See Chapter 3, para 3.3.1.

<sup>&</sup>lt;sup>192</sup> The Committee on Science and Law, (n. 32), 10-11.

<sup>&</sup>lt;sup>193</sup> Y. Kamitani, F. Tong, 'Decoding the visual and subjective contents of the human brain', Nature Neuroscience, (2005), Volume 8, Issue 5, 679-685, available at < http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=1&sid=a7f2df83-414b-4ae2-a431-e90d86cdc6bd%40sessionmgr120>, last accessed 15 April 2018.

authors, the dreams reading was 60% accurate, <sup>194</sup> it represents a significant example of the kind of insight that neuroscience can achieve starting from physiological signals related to the humans' brain activity. In the same years, at the other side of the ocean, Jack Gallant and his team from Berkeley University of California, were able to reconstruct what an individual was seeing starting from the fMRI brain signals captured during the process. <sup>195</sup> Using a particular algorithm, they have been able to translate fMRI signals into complex images similar to the ones seen by the individual participating in the experiment. <sup>196</sup>

Brain information, being inherently able to tell something more about the individuals compared to other kinds of personal data, in combination with innovative technologies can offer a particular intrusive insight into the individuals. Due to their dynamic nature, <sup>197</sup> when used outside the healthcare system, they can be the access key to human emotions, thoughts, memories, intentions, and even dreams. Furthermore, the current state-of-the-art is making said technologies more affordable and easy to use even without specific expertise. Emotiv is a "bioinformatics company" founded in 2011 and aiming to "track cognitive performance, monitor emotions, and control both virtual and physical objects via machine learning of trained mental commands" through BCI technologies. <sup>198</sup> Thanks to a variety of different portable EEG headsets, Emotiv can offer several services dependent on the customers' needs. "MyEmotiv", for instance, is a software able to interpret the brain waves by providing a "real time detection of cognitive and emotional states", while "Insight" is a wireless EEG headset which records brain waves and "translates them into meaningful data" understandable to everyone. <sup>199</sup> In both cases, EEG signals are processed with the aim to decode emotions, intentions, or other intimate information of the individual who uses those tools.

Going deeply into the technical explanation of the recent techniques used to decode brain data into emotions, thoughts, intentions, and even dreams is out of the scope of this thesis. However, these examples highlight the hidden qualities of the data directly extrapolated by EEG and fMRI neurotechnologies and their current use. When raw brain data are used for mind-reading purposes and translated into what has been defined as 'mind data', a unique level of sensitivity comes to existence, not present in other kinds of personal data but undoubtedly worthy of consideration because of the important implications for the individuals' fundamental rights.

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<sup>&</sup>lt;sup>194</sup> T. Horikawa, M. Tamaki, Y. Miyawaki, Y. Kamitani, 'Neural Decoding of Visual Imagery During Sleep', Science, (2013), Volume 340, Issue 6132, 639-642, available at < http://science.sciencemag.org/content/340/6132/639.full>, last accessed 15 April 2018.

<sup>&</sup>lt;sup>195</sup> See K. Smith, 'Brain decoding: Reading minds', Nature, (2013), Volume 502, Issue 7472, available at <www.nature.com/news/brain-decoding-reading-minds-1.13989#/ref-link-5>, last accessed 15 April 2018.

The video showing the images reconstructed with the study is available at <www.youtube.com/watch?v=nsjDnYxJ0bo>

<sup>&</sup>lt;sup>197</sup> See Chapter 3, section 3.3.1.

<sup>&</sup>lt;sup>198</sup> Emotiv official website, 'About Emotiv', available at <www.emotiv.com/about-emotiv/>, last accessed 25 June 2018.

<sup>&</sup>lt;sup>199</sup> Emotiv official website, 'Products', available at <www.emotiv.com/insight/>, last accessed 25 June 2018.

The current EU data protection law lacks a specific disposition able to properly address this singular degree of sensitivity. Therefore, currently, mind data seem to not be adequately protected. Although raw brain data can partly find protection in Article 9 of the GDPR, the special categories of personal data explicitly covered by this provision lack the peculiarities of the raw brain values when translated into mind data. Again, raw brain data can be the key to access personal emotions, thoughts, mental states, intentions, dreams, memories, the "core of the individual's private sphere". By studying the mental reaction of an individual to a movie, a song, a poetry it could be possible to disclose their political opinion, trade-union membership, sexual orientation, religious or philosophical beliefs and even more. As a result, not only, from a quantitative perspective, mind data would be able to enclose all the eight categories of sensitive data listed in Article 9 of the GDPR, but, from a qualitative one, they would also be able to go further in terms of intrusiveness in the private mental sphere. With the addition of this peculiar third level of sensitivity, mind data appear to exceed the boundaries of the data protection law, being even more sensitive than the sensitive data considered by the current EU legal framework.<sup>201</sup>

#### 4.5. A portrayal of a dynamic multi-layered sensitivity

If brain information was treated as any other type of sensitive data, then a traditional and static concept of sensitivity would be applied. Accordingly, there would be no difference between raw brain data, brain data, and mind data. All these different typologies and status of information extracted from the human brain, albeit entailing different implications and risks for the individuals, will be regulated and treated in the same way. Mind data, most probably, would be added to the current list of the special categories of personal data at the moment in which the mind-reading technologies will become more reliable and available. However, this static concept of sensitivity would hardly allow a proper appreciation and treatment of the peculiar nature of brain information. Consequently, it is not capable of properly protecting the higher risks arising from the processing of the information extrapolated by the EEG and fMRI neurotechnologies.

By contrast, a dynamic, tailor-made, multi-layered categorisation of sensitivity will be able to better address its unique characteristics as well as its inner dynamic nature. Chapter 2 has shown how the information that EEG and fMRI neurotechnologies are able to capture from the human brain (defined as raw brain data), can be further interpreted and processed to disclose more intimate and sensitive information of the data subjects they originate from. <sup>202</sup> By doing so, the dividing line between brain-reading and mind-reading can easily be crossed. The inherent potentiality of raw brain data of being translated into mind data able to reveal human thoughts, emotions, intentions, and memories deserves an enhanced protection which the current legal framework is not equipped to fully provide. However, the same level of

<sup>&</sup>lt;sup>200</sup> D. Hallinan, M. Friedewald, P. Schütz, P. De Hert, (n. 11), 68.

<sup>&</sup>lt;sup>201</sup> Ibid., 67-69.

<sup>&</sup>lt;sup>202</sup> See Chapter 2, para. 2.4.

protection may not be required when dealing with less complex status of brain information, such as raw brain data. Even though, also when dealing with less complex status of brain information, it should be borne in mind the inner potentiality of being exploited to disclose more intimate information of the data subjects. For this reason, the dynamic nature of this kind of information needs to be carefully considered and regulated in different ways for different contexts.

With these considerations in mind, Figure 3 below has been designed to show the correlation between the classified three levels of sensitivity and the different degrees of interpretation. Specifically, depending on the way in which raw brain values captured by neurotechnologies as EEG or fMRI are interpreted, it is possible to define three different typologies of brain information, namely i) raw brain data, ii) brain data and iii) mind data, each placed in a different "area of sensitivity" in the graph. Raw brain data are located in the area where no interpretation is required, yet they still involve the first level of sensitivity because of the health information and the data related to the racial and ethnic origin they embody. Brain data, being the scientific interpretation of the raw values by experts and scientists, belong to the area of the graph where an interpretation is required, yet they result in the same level of sensitivity than raw brain data. By contrast, raw signals used as biometrics and, even more, mind data, both require a higher level of interpretation than the one associated to brain data. In this case, the term 'advanced interpretation' is used to identify the further processing of raw values by means of innovative technologies or computational techniques. The more the raw data are interpreted and translated into mind data, the higher the degree of sensitivity is.

This advanced interpretation, when dealing with mind data, crosses the boundaries of the sole brain-reading process (as is portrayed in Fig. 3 by the black dotted line) until reaching a deeper insight in the human mind to investigate thoughts, emotions, memories, intentions, and even dreams. In that specific area, where the sensitivity reaches the third level, higher risks are involved for the individuals concerned, and accordingly, stricter rules should be required which are not yet designed. The grey dotted line, in fact, symbolically represents the boundaries of the static concept of sensitivity currently provided by the GDPR, which is not equipped to adequately protect such a special category of sensitive data as mind data. The lack of a proper legal protection for the most sensitive status of the information extrapolated from the human brain may dangerously lead to its exploitation at the expense of the data subjects. As a result, all the ethical and social concerns stated in the previous Chapter may likely become reality. Fundamental rights and principles such as human dignity, freedom to self-determination, right to identity, privacy of thought and feelings, and principle of equality will then be realistically threatened.

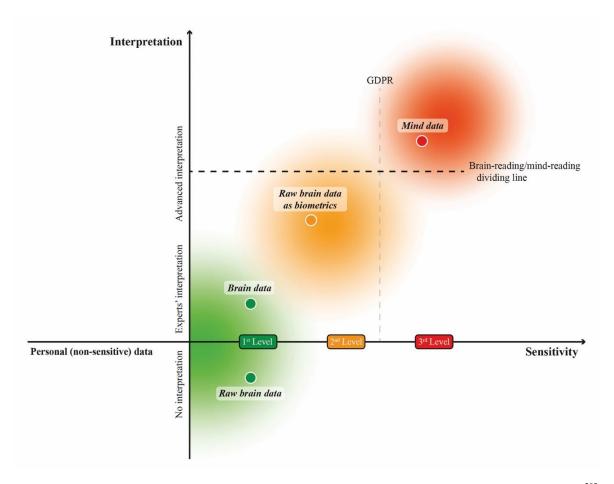


Figure 3: relation between degree of interpretation and level of sensitivity with regard to brain information<sup>203</sup>

Being aware of the dynamic nature of raw brain data by considering the different levels of sensitivity they may involve when further processed, can be particularly beneficial for the data subjects' safeguard. Depending on the context, the purpose of processing (e.g. healthcare, authentication/identification, mind-reading, etc.) and the degree of interpretation (e.g. no interpretation, experts' interpretation, advanced interpretation involving mind-reading technologies, etc.), it would be possible to determine which typology of brain information is processed, whether i) raw brain data, ii) brain data, or iii) mind data. Accordingly, different levels of risks for the individuals' lives could be identified and specifically addressed whenever dealing with different typologies or status of brain information. Consequently, different legal rules should be designed: when mind data are involved, a distinct legal framework consisting of stricter rules and more severe sanctions should be in place.

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<sup>&</sup>lt;sup>203</sup> The graph showing the relation between the degree of interpretation and the level of sensitivity has been designed by the author.

Even if the current technologies are not yet completely capable of reliably translating raw brain data into meaningful mind data, they may likely be in a close future. <sup>204</sup> In this regard, the current EU data protection legal framework does not seem to be future-proof. Moreover, it should be stressed that the mind-reading technologies, which will become spread and widely available in the close future, will likely be able to also trigger the raw brain data collected today, or even the ones collected in the past, and, thus, to reveal the intimate information hidden therein. For that reason, a proactive approach is essential by starting a proper discussion in order to design a more suitable regulation which considers the peculiar nature belonging to this typology of personal data.

#### 4.6. Conclusions

This Chapter aimed to offer an in-depth analysis of the sensitive nature of brain information in light of the current EU data protection law, the GDPR. Provided the nature of personal data of the information directly extracted from the brain by means of modern neurotechnologies, it showed that said raw data can also be considered as a special category of personal data. However, it also highlighted that the current legal framework can offer only partial protection to brain information which, because of its dynamic nature, is capable of providing a deeper insight into the human mind if combined with innovative technologies. In the light of this, it has been argued that raw brain data, when translated into mind data, are characterised by a third unique level of sensitivity which makes them even more sensitive than the sensitive data considered in the current legal framework. This extra degree of sensitivity seems to cross the boundaries of the current legal system which seems to not be capable of fully addressing it yet.

Albeit the state-of-the-art is still far from fully and reliably read the human mind by translating raw values into mind data, the rapid technological progress makes it reasonable to believe that in a close future it will be possible to easily do so. Considering the risks for the human fundamental rights and principles, it has been suggested that a proactive approach built on the awareness of the deep implications hidden inside raw brain data, should lead the future discussion and bring to a proper and adequate legal protection. With this aim in mind, a dynamic multi-layered and tailor-made concept of sensitivity has been proposed as a useful tool able to distinguish between the different risks arising from the different status of brain information and, thus, capable of better addressing its dynamic nature and the related concerns.

<sup>&</sup>lt;sup>204</sup> K. Evers and M. Sigman, 'Possibilities and limits of mind-reading: A neurophilosophical perspective', Consciousness and Cognition, issue 22, 2013, 895, available at <a href="https://www.sciencedirect.com/science/article/pii/S1053810013000822">www.sciencedirect.com/science/article/pii/S1053810013000822</a>, last accessed 18 June 2018.

# CHAPTER 5

# **CONCLUSIONS**

This thesis aims to answer the following question: 'How can the concepts of the EU data protection legal framework be adapted to better approach the peculiarities of brain information and address their legal, ethical, and social implications?'. The description of the technical functioning of EEG and fMRI neurotechnologies allowed an understanding of the underlying measurements related to the electrical activity of the neurons inside the brain or the level of oxygenated blood flow within it. However, it has been said that these raw values have no meaning without a proper interpretation by scientists and experts. This scientific interpretation, in fact, permits the reading of the brain's functioning and, consequently, the identification of brain diseases, abnormalities, or disorders as well as the predisposition to acquire them in the future. In the light of this, two main components have been identified: the raw values recorded by the neurotechnologies and their scientific interpretation. Together they represent the process of brain-reading. Accordingly, two different typologies of brain information have been defined: i) raw brain data, and ii) brain data.

Nevertheless, a basic distinction of brain and mind, as well as brain-reading and mind reading, has shown that modern technologies and innovative techniques are being increasingly applied to raw brain data in order to investigate the human mind. Raw values are currently used as a starting point to disclose human thoughts, memories, emotions, intentions, and dreams. For this reason, a third typology of brain information has been defined: mind data, understood as the further potential status of raw brain data, whenever combined with innovative techniques and computational methods of interpretation ('advanced interpretation'). Whenever dealing with mind data, the dividing line between brain-reading and mind-reading is crossed in favour of the latter.

Notwithstanding this classification of brain information, the wide scope of the EU data protection law, in combination with the *argumentum a fortiori*, has been used to conclude that all the three categories fall within the definition of personal data as provided by Article 4 (1) of the GDPR. However, four main peculiarities have been identified: i) the dynamic nature (related to the capacity of raw brain values to be translated into other status and typologies of brain information); ii) the predictive quality (related to the capacity of brain information to disclose diseases or disorders as well as the likelihood of developing them in the future); iii) the uncontrollable nature (related to the incapacity of the individuals the brain information originate from to control the inner functioning of their brain and the outcome of the further advanced interpretation of their raw values); and iv) the unique and direct link with the individual (related to the capacity of brain information to uniquely and directly identify the data subject).

In addition, these four peculiarities have been used as the starting point to analyse the possible implications that the processing of brain information may have for society. While the legal concerns in terms of applicability of the EU data protection legal framework have been already addressed by the existent literature, this thesis has acknowledged them and has further developed the ethical and social concerns. Accordingly, several threats and risks have been identified. From an ethical perspective, the main qualities of brain information, if not adequately understood and regulated, not only could undermine the human dignity by leading to a process of commodification of individuals, but they could also negatively affect the freedom to self-determination and the right to identity. Similarly, from a social perspective, they may have significant implications for the privacy of thoughts and feelings and the principle of equality.

In order to offer an adequate protection to individuals against the actual occurrence of these risks, the legal instruments characterising the EU data protection law come into play. Article 9 of the GDPR provide an enhanced protection for certain special categories of personal data which, by their nature, can have a significant impact on the data subjects' lives. The information extrapolated from the human brain by EEG and fMRI do fall within the definition of sensitive data. However, it has been claimed that a traditional and static concept of sensitivity does not allow a proper understanding of the peculiar nature and potentialities of this information. Therefore, a different approach has been suggested: A dynamic multilayered notion of sensitivity able to identify different levels of sensitivity for different types of brain information depending on the data that can be disclosed from the raw values recorded from the brain. This dynamic concept would better address the different concerns and risks related to the distinct status the brain information can entail.

In conclusion, thus, the following answer can be provided to complete the present research: the legal, social, and ethical concerns arising from the particular qualities of brain information can be addressed through a dynamic, multi-layered concept of sensitivity able to include different levels therein. This new notion, in fact, is capable of approaching the different risks originating from the various status that brain information can entail. In particular, a dynamic concept of sensitivity shows that different status of brain information ( raw brain data, brain data, raw brain data used as biometrics, mind data) require different treatments and different rules. Since mind data are able to disclose more intimate and sensitive information of the individuals and, hence, imply higher risks for the data subjects, whenever dealing with them more severe rules and sanctions should be designed. This, without neglecting the specific protection that brain information deserves also in its raw status because of its latent potentialities which could be further exploited.

This thesis has aimed to raise awareness to the hidden potentialities of raw brain data which, combined with the fast progress in technologies, may allow the access and the further exploitation of personal information previously unachievable. Although it is out of the scope of this thesis to suggest a specific regulation of this kind of information, a few important

seeds to lead the future discussion and trigger further researches have been planted. Notwithstanding the current limitations for an effective and fully reliable mind-reading process, raw brain data are already commonly recorded by modern neurotechnologies and could be further interpreted in a close future. Accordingly, a proactive approach appears to be the most advisable way to offer an adequate protection for the individuals' fundamental rights by designing tailor-made rules which take into account all the meaningful potentialities of brain information.

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