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Abstract

There are a number of novel technologies and a broad range of research aimed at the collection and use of data drawn directly from the human brain. Given that this data—neurodata—is data collected from individuals, one area of law which will be of relevance is data protection. The thesis of this paper is that neurodata is a unique form of data and that this will raise questions for the application of data protection law. Issues may arise on two levels. On a legal technical level, it is uncertain whether the definitions and mechanisms used in the data protection framework can be easily applied to neurodata. On a more fundamental level, there may be interests in neurodata, particularly those related to the protection of the mind, the framework was not designed to represent and may be insufficiently equipped, or constructed, to deal with.

Introduction

Neurodata is the description of data directly representing the function of the human brain.¹ Information allowing the possessor to peer into the processes of the human brain would be of significant value in a plurality of contexts where one party seeks influence or knowledge about another—especially when it would allow the more complete understanding and prediction of the actions of one, or a group, of individuals.

Up until now, outside relatively limited medical contexts, there have been significant practical obstructions to the ability to realise the use of neurodata. Firstly, there has not been the level of understanding of brain processes necessary to make the use of neurodata practical. Secondly, there has not been the facility to enable its collection.

¹ There are many forms of data which reflect the processes of the brain. In this article we are specifically considering data coming from the direct monitoring of the function of the brain itself, and refer such as ‘neurodata’.

Owing to two recent developments, we are arriving at a point where we must begin to imagine scenarios in which these are no longer effective obstacles, and in which the processing and use of personal neurodata is a reality in everyday contexts.² Firstly, advances in cognitive science are beginning to provide the requisite knowledge and certainty which would allow practical use of this information. Secondly, there has been a recent expansion of applications—for example brain-computer interfaces—which function through the collection and analysis of information directly from the brain. These applications collect neurodata as a prerequisite for their operation, providing the source and opportunity for its further use.

How will society respond to these developments? How will European law, in particular, respond? As neurodata is data collected from individuals, one area of law which will be key to the regulation of the collection and use of this data will be data protection.

The thesis of this paper is that neurodata displays certain novel characteristics when compared to conventional forms of data. Given that the current European data protection framework was designed around a certain conception of data—predominantly consisting of ascribed social facts rather than data drawn directly from the biological individual (or indeed his or her brain)—the novelties of neurodata may give rise to uncertainties and inadequacies in its application. A similar conceptual and contextual discrepancy was recognised in relation to the difference genetic data and the data protection framework, and led to calls for ‘genetic exceptionalism’. A nascent call for neuro exceptionalism will follow a similar argument (Tovino 2007).

The paper addresses the following issues in turn. 1. What is the state-of-the-art in neurodata processing? 2. What is the European data protection framework, how does it work and what is so special about neurodata in relation to ‘normal data’? 3. Can the formalities of the law—the concepts, definitions and mechanisms of this framework—be applied to neurodata considering its novel qualities? 4. Even if such formalities can be easily applied, might there be more substantive issues with the protection the framework provides?

In section 1, the article begins with a brief consideration of the value of neurodata and the current status of neurodata-based applications, comprising the reality and breadth of their development and the potential scope of neurodata use. The authors particularly consider the diversity of research in areas far apart as medicine and the computer gaming industry.

In section 2, in order to provide the reader with a more practical, and deeper technological, understanding of what exactly neurodata is and how it is gathered, the authors present a case study on brain computer interfaces (BCIs), dealing with exemplary technologies that draw on the collection and processing of neurodata.³

In section 3, the authors offer a brief explanation of the function of the European data protection framework. They consider how data protection functions as a set of rules providing the legitimisation for the processing of personal data. They consider how the informational self-determination of the data subject is only one of a series of interests reflected in the data protection framework and accordingly how the framework provides a form of procedural, rather than substantive, justice for the data subject.

In section 4, the novel characteristics of neurodata (as opposed to the conventional data around which the framework was designed) are considered. Three unique attributes are specifically highlighted. Firstly the

² Ariely and Berns 2010.

³ The case study was part of the EU-funded project PRESCIENT, which aimed at identifying and assessing privacy issues proposed by emerging sciences and technologies, as well as contributing to the development of new instruments for the governance of these sciences and technologies (see e.g. <http://www.prescient-project.eu> and Gutwirth et al. 2011).

depth and form of the connection between neurodata and the individual it represents. Secondly, the ability for neurodata to facilitate the recording of new forms of information about the individual in electronic form. Thirdly, the uncertainty of what is contained in the collected data.

Finally, the novel characteristics of neurodata are considered in light of the questions they may raise for the application of the current European data protection framework. The authors perceive questions to arise on two levels.

Firstly, in section 5, the authors consider that there may be difficulties from a legal technical point of view. Given that the data protection framework will be a relevant legal framework, clarity as to how to apply its concepts, definitions and mechanics will be decisive to effectiveness. The authors consider that, owing to the factors listed in section 4, such application may be difficult. Three examples from the current framework are taken to demonstrate this point; anonymity, accuracy and sensitivity.⁴

Finally, in section 6, the authors take a broader view of substantive protection provided by the framework, and how this relates to neurodata. They consider the possibility that, as neurodata is data representing the mind, and the fact that the mind occupies a unique position in law, and that such data may have a unique sensitivity and privacy value for the individual they represent, that the current standard of protection offered by the European data protection framework may be inadequate.

This article raises, rather than answers questions. Equally, it finds limits in the expertise of the authors, who are social scientists and lawyers rather than neuroscientists (or philosophers). However, whilst this article raises hypotheticals, and relies on certain assumptions, the authors believe that there is value in raising such questions, and in beginning a discussion on this novel theme. As Garland states, with unnerving relevance for the difficulties new technologies pose data protection: ‘If there is a single lesson to be learned about the past century of scientific and technological discovery, it may well be that the unimaginable rapidly becomes the commonplace’ (Garland 2012: 29).

1. The State-of-the-Art Development of Neurodata-Based Applications and the Value of Neurodata

There is significant value in data drawn from the operation of the brain. As cognitive science provides new theories of cognition and comprehension of the brain as a system (or set of systems), it provides templates through which relevance and insight can be extracted from neurodata related to individuals. Accordingly its relevance stretches beyond the confines of being an isolated academic discipline (or an offshoot of medicine) to having relevance for all disciplines and areas of study in which the action of the individual is relevant. As an example of this, one can consider the development of the fields of neuroeconomics and neuromarketing (Camerer et al. 2005).⁵

Initially, the value in neurodata found application in the medical field for diagnoses and in the development of applications with palliative function, however, use perspectives have since expanded and now the potential of neurodata-based applications has begun to be recognised outside the clinical sphere.

⁴ Only three examples are taken due to space considerations. This is by no means an exhaustive list.

⁵ The foundations of economic theory were based on the assumption that the processes of the brain would never be known. As neuroscience aims to comprehend these processes, its findings have significant consequences for economic theory (see also Canli and Amin 2002). Neuromarketing is meant to locate the consumer’s ‘buy buttons’, in order to get closer to opening the ‘black box’ of the consumer’s mind (Nature 2004: 683; Moore 2005: 12). Since it has always been the dream of any company to advertise their products, services or information in a way that a potential buyer is unable to resist while not being aware of the subtle manipulation, neuromarketing is beginning to open up promising opportunities to exploit collected neurodata.

As outlined in table 1, there is a wide range of neuroimaging techniques; such as computed tomography (CT), positron emission tomography (PET), single-photon emission computed tomography (SPECT), functional near-infrared systems (fNIR), diffuse optical tomography (DOT), magnetoencephalography (MEG) and event-related optical signal (EROS). However, most prominent in the medical and neuromarketing fields are functional magnetic resonance imaging (fMRI) and electroencephalography (EEG). The former relies on hemodynamic-based techniques—measuring and deducing brain activity from the brain blood flow. The latter draws on electromagnetic methods—collecting data about the electromagnetic activity of the brain (Horwitz and Poeppel 2002). In order to illustrate what we are dealing with when talking about neurodata, the different data output of the two technologies is displayed in figures 1 and 2 (below).

	Methods and techniques	Measuring	Costs	Portability	Usage	Areas of application	Data quality
EEG	Electromagnetic	Electrical impulses emitted by the brain	Low	Yes	Easy	Medical, marketing, leisure and enhancement: BCI applications: Mental typewriter, Brain2Robot, Mind Walker, BrainDriver	Mediocre
MRI	Hemodynamic	Magnetic properties of atomic nuclei inside the body	High	No	Difficult	Medical and marketing	Good
fMRI	Hemodynamic	Paramagnetic properties of oxygenated and deoxygenated hemoglobin	High	No	Difficult	Medical and marketing	Very good
MEG	Electromagnetic	Magnetic fields produced by the electrical activity of the brain	High	No	Difficult	Medical and marketing	Good
(f)NIR/DOT	Hemodynamic	Optical absorption of haemoglobin	High	No	Difficult	Medical	Mediocre
CT	Hemodynamic	Absorption rate of a series of x-rays	High	No	Difficult	Medical	Poor
PET/SPECT	Hemodynamic	Emissions from radioactively labeled metabolically active chemicals	High	No	Difficult	Medical	Mediocre
EROS	Physical	Changes in the optical scattering properties of brain tissue through infrared light	Low	Yes	Medium	Marketing	Poor

Table 1: Typology of neuroimaging techniques (authors' own research)

As opposed to fMRI, EEG technology is cheap, portable and relatively easy to use. This makes the number of areas in which it could be applied more numerous and, accordingly, the prospect of such data being collected and disseminated more likely.⁶ Considered from the point of view of the data the two technologies collect, another major difference lies in the fact that fMRI aims specifically at the collection of neurodata as a primary purpose (for example in neuromarketing), while EEG can be used for human machine interactions which rely on neurodata for their operations, but whose goal is not specifically the collection of neurodata (Wolpaw and Birnbauer 2006: 603). When data is collected for one purpose, it may still be used for other purposes. Accordingly, EEG technology can have unintended consequences for the user (function creep), breaching his/her reasonable expectation of what happens with the collected

⁶ EEG is probably the most prevalent neuroimaging technique due to its low cost, small size and ease of use as well as the fact that 'electrophysiological features represent the most practical signals for BCI applications today' (McFarland and Wolpaw 2011: 63).

data. In order to better understand the practical implications in collecting neurodata, a case study on EEG neurodata enabling human machine interaction is presented in the following section.⁷

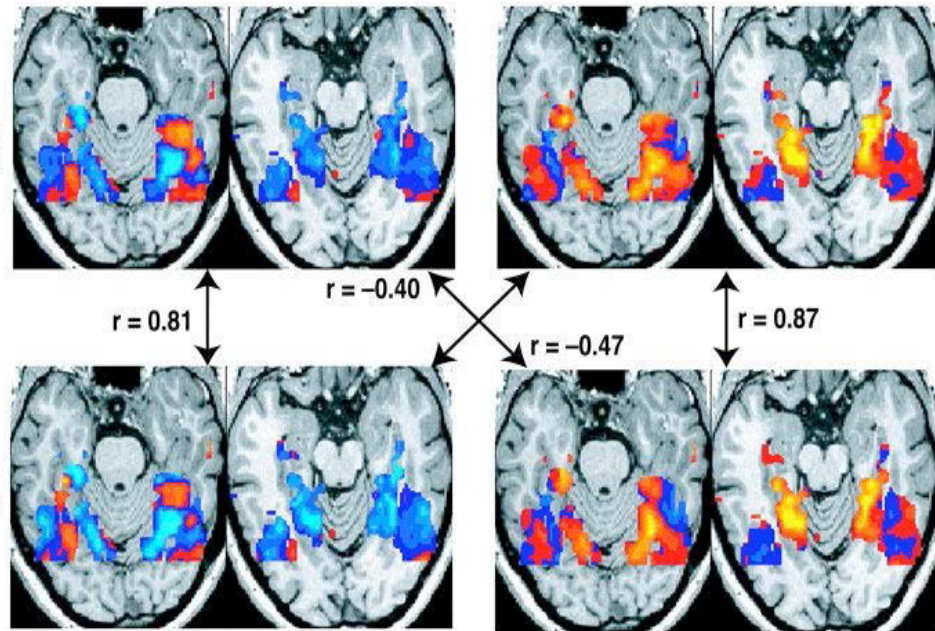


Figure 1: fMRI data output (Haxby et al. 2001: 2427)



Figure 2: EEG data output (Patrizi et al. 2003: 435)

⁷ The authors appreciate the significance of other forms of technique (such as fMRI). However, EEG has been chosen as the focus of the case study as, due to factors such as price, ease of use and the portability of imaging equipment, it seems likely to be the form of neurodata around which brain computer interface design will find most traction.

2. Case Study: Brain Computer Interfaces

The Brain-Computer Interface Project, which was launched in the early 1970s at the University of California by a team of researchers led by Jacques Vidal, marked a new starting point in the field of biocybernetics and human computer interaction. The project was based on the conviction that EEG waves

contain usable concomitances of conscious and unconscious experiences and that the set of continuous electric signals observed does not for the most part consist of random noise as was often suggested, but on the contrary, constitutes a highly complex but significant mixture that reflects underlying neural events.

(Vidal 1973: 164)

Since the brain consists of billions of neurones, which process and transmit information by electrical and chemical signalling, brain activity creates electrical impulses that can be measured. Non-invasive forms of EEG technology draw on electrodes that are placed on the scalp in order to detect these electrical impulses. However, non-invasive forms are prone to rather poor spatial resolution, i.e. determining the precise position of active sources in the brain, as well as artefacts arising from muscle and eye movements (van Gerven et al. 2009: 2).

Invasive forms of EEG technology, e.g. implanting electrodes within the skull directly onto the cortex, provide, on the other hand, a much more precise and effective measurement of electrical impulses. However, such an approach ‘requires surgery and [therefore] carries the risk of infection or brain damage’ (Ortiz Jr. 2007: 17) or even impacting on the carrier’s personality and self-perception, including the fear of losing control.⁸ Thus, invasive methods are rarely used except for urgent medical purposes such as locating and monitoring epilepsy or treating Parkinson’s disease.

Whereas EEG refers only to the technique used to measure brain activity, BCI technology as a whole involves a much wider range of software and hardware to translate the neuronal signals into an image, or commands on a computer (McFarland and Wolpaw 2011: 62). Here we shall focus on practical BCI applications that enable users to exercise control over a computer with their thoughts alone (see figure 3).

Since EEG technology, as pointed out above, does not locate the origin of the electrical impulses perfectly, approximate values have to be constructed in order to link specific actions to particular neuronal signals. Importantly, in some devices, this allocation process is continuously improved by learning, configuring and adjusting on both sides: human and computer. Gerven et al. have called this adaption process between user and the computer, the *BCI cycle*. The cycle is repeated in a loop to improve the desired outcome. Key stages are: measurement, pre-processing, extraction of relevant features, prediction of an outcome (supposed to reflect the user’s intention), output and finally, execution of a task as well as a repeated—often visual—stimulation of the user so that he/she can adjust his/her mental activity to the output of the computer (van Gerven et al. 2009: 2).

⁸ In deep brain stimulation, which is not an EEG technology as it draws on the implantation of impulse-giving electrodes into the malfunctioning region of the brain, changes of personality can be the consequence (Raabe 2011).

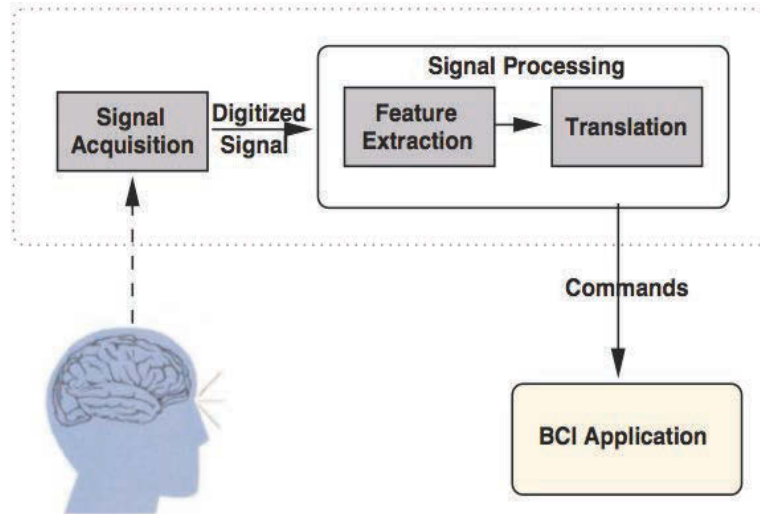


Figure 3: Basic design of a BCI system (Thorpe et al. 2005: 6)

Users are not only obliged to learn to control the neuronal firing rate, i.e. the intensity of brain activity, in order to move, for example, a cursor on a screen (McFarland and Wolpaw 2011: 62), but they also have to be able to activate specific neuronal impulses e.g. by concentrating on a continuous movement of the left hand. The computer, on the other hand, has to identify the user's intention step by step. All of this requires an often time-consuming learning process in which the user has to be trained in order to achieve a precise transfer of his thoughts to the machine.⁹ Normally, control-related BCIs are used for the purpose of communicating or to physically move an object.

The method of transferring commands to a machine without depending on neuromuscular control introduces a variety of new and ground-breaking opportunities. BCI technology allows people to physically interact with the world around them without muscle control, i.e. first and foremost without using their hands or moving their lips. Here the lines between medical and non-therapeutic applications become blurred. Often originally designed for therapeutic purposes in order to help (fully) paralysed people to better manage their lives, BCI technology could be deployed for human enhancement as well.

Classical medical applications involve BCIs which allow amputees to mentally control high-tech prosthesis (Yahud and Osman 2007). However, the idea of a mentally-controlled exoskeleton is also currently being realised by an EU-funded project, named *mind walker*, which primarily aims at conceiving of a system that empowers people with lower limb paralysis to walk again and perform usual daily activities in the most autonomous and natural manner.¹⁰

A further example of BCI applications that is mentioned regularly in the press and in scientific literature is the so-called *mental typewriter* (Krepki et al. 2007). This device provides the trained user with the ability to communicate through a computer screen, typewriting the desired questions, commands or statements without the movement of any part of his/her body. Although the mental typewriter has to be calibrated to the individual brain wave pattern of the user, researchers in the *Berlin BCI* (BBCI) project have succeeded in developing an interface that facilitates and accelerates the otherwise complex and lengthy learning

⁹ The EU-funded project BRAIN (Bcis with Rapid Automated Interfaces for Non-experts) aims to speed and facilitate this learning process so that users with physical impairments can take advantage of BCI technologies. See <http://www.fastuk.org/research/projview.php?id=1449>, last accessed 10.07.2013.

¹⁰ <https://www.mindwalker-project.eu/>, last accessed 01.07.2013.

process on both sides.¹¹ This could revolutionise methods of physical control and communication for severely handicapped, immobile patients, such as people with locked-in syndrome, who are only able to move their eyes, while being totally awake and aware of things happening around them.

Expanding from the medical context, fields such as computer gaming show budding and promising research. For the use of BCI applications in computer games, a short period of training and simplicity in setup are essential requirements. The EEG cap, for example, should not be characterised by lengthy electrode positioning or the need for conductive gel or time-consuming clean-up after a session. Instead, so-called dry caps are being developed.¹² Although skull caps still represent the dominant technology for acquiring neurodata, innovations in miniaturisation and ergonomics have led to more user-friendly designs such as an in-ear EEG (Looney et al. 2012; Rutkin 2013).

According to Nijholt, there are two main areas relevant for the development of BCIs in games and entertainment:

1. to collect information from brain activity that informs us about the cognitive state of the user [...]
2. to develop applications where information derived from brain activity allows us to control an application.

(Nijholt 2009: 225)

The first is particularly interesting in the context of *affective computing*, i.e. adjusting computer processes to the emotional state of the user. That way, a customised adaption of a game or an interface to the user is possible in order to, for instance, raise or decrease the difficulty of a task in a game. The second application area provides the gamer with novel and unique game control opportunities. Due to the highly competitive market, the gaming and entertainment industry welcomes innovative and even seemingly unusual technologies—such as the motion capture technology which successfully entered the mass market with Nintendo's gaming platform *Wii* in 2006.

The first functional BCI applications already exist on the open market. When it comes to control-related BCI technology, applications are mostly characterised by their early stage of development and their potential relevance in the mid- to long-term future. As mentioned in section 1, the deployment of neuro-imaging technologies to simply capture information regarding '*usable concomitances of conscious and unconscious experiences*' is far more advanced and practiced. In that context, EEG-based skull caps and fMRI are widely used by neuromarketing firms, promising clients 'a window into the mind of the consumer', or fMRI lie detection devices are marketed by firms such as nolieMRI, offering the prospects of 'unbiased methods for the detection of deception and other information stored in the brain'.¹³ Behind these frontrunners there is a plethora of significant research being done into potential further use in numerous other fields and contexts. Suggestions include research into image search assistance for law enforcement officials, a form of mental biometric authentication mechanism and a thought control interface for mobile phones. Many further uses have been proposed in fields as diverse as car-safety and computer gaming (Ortiz Jr. 2007; Thorpe et al. 2005).¹⁴

¹¹ The Fraunhofer Institute for Computer Architecture and Software Technology, FIRST, also researched BCI applications aimed at giving control over robots' movements; see for example The Brain2Robot Project; http://cordis.europa.eu/search/index.cfm?fuseaction=news.document&N_RCN=28681, last accessed 15.06.2013.

¹² Fraunhofer FIRST project, 'Speed Cap—Gelfreies EEG' http://brainsignals.de/users/cristian.grozea/articles/poster_speedcap_audiop300_grozea_bbc_i_workshop2009.pdf, last accessed 15.05.2013.

¹³ Website of 'Brain Intelligence' neuromarketers, <http://english.brain-intelligence.com/index-20574.html>, last accessed 30.06.2013; 'nolieMRI' website, <http://noliemri.com/>, last accessed 30.06.2013.

¹⁴ There are also considerable research efforts underway into the use of neurodata for military and national security purposes.

Regardless of the aim of the application, all such technologies would rely on some form of collection of data directly from the brain—neurodata. There are a number of areas of law which may be engaged by the collection and use of this data. Some of the more invasive forms of application, or use contexts, may be governed by specific legislation—for example, some may find regulation under various aspects of medical law. However, as data are collected directly from an identifiable individual, one area of law which will be of general application and significance will be data protection.

3. What is Data Protection and How Does it Work?

Data protection law is the field of law which governs the legitimate use of data relating to an identifiable individual. It draws on a series of legal sources, operating at a series of levels. At its highest level of legal expression, data protection has been enshrined as a fundamental right in the Charter of Fundamental Rights of the European Union. In reality, the piece of legislation giving overarching practical expression to data protection is Directive 95/46. It is around this Directive that analysis in this article will revolve, as the rules laid out in this Directive form the basis of legislation in all European countries (Directive 95/46/EC 1995). The scope of application of this Directive and the principles it lays down is wide. It applies to almost all data which can be connected to an identifiable individual (Article 29 Working Party 2007). Its scope thus stretches to include neurodata as a form of personal data.

On the one hand, the Directive lays down obligations to the data processor for the legitimate processing of data. Generally speaking, the processor is expected to process data only when a legitimate ground for processing exists (as laid out in Article 7), for example, if that processor has received the consent of the data subject (although this is not the only possibility). Further, in the processing of data, the processor is expected to follow a set of rules for fair processing (laid out predominantly in Article 6)—for example, the processor must make sure the data are accurate and up to date, that the purpose of processing is specific and legitimate, and that the data collected is adequate, relevant and not excessive in relation to the purpose for which it was collected. The initial decision as to whether these criteria have been fulfilled lies normally with the data processor, subject to potential subsequent control by a local or national supervisory authority.

On the other hand, the data subject is invested with a series of rights—including the right to be informed about the processing of his or her data and the right to inspect or correct data being processed. However, the data subject does not always have the right to stop processing (Directive 95/46/EC 1995).

These rights and obligations are combined within the Directive to create a system under which data processing is not negatively prevented, nor is the data subject invested with a dominant right to informational self-determination. Rather, it constructs a legal framework according to which individuals' personal data can be processed provided that a certain set of rules and principles are followed. As opposed to, for example, criminal law, which aims at effecting material justice, the data protection framework works on the basis of providing procedural justice. As astutely put by de Hert,

[the data protection framework] relates to procedural justice and to the correct treatment of and explanation to registered citizens with the intention to increase their willingness to accept a system in which others (government agencies, companies, private citizens) have the right to process 'their' data and take decisions that have an impact on their self-determination where information is concerned.

(De Hert. 2009: 17)

4. The Novel Characteristics of Neurodata

The efficacy of a legislative instrument depends on how well it fits the substance and context of regulation. If there is a change in the substance under regulation, it is possible that the instrument of regulation diminishes in application and becomes less suitable to achieve its legislative ends. In the case of the data protection Directive, the substance of regulation was ‘data’.

If one concludes that any specific form of data exhibits novel characteristics, one can equally question whether the framework remains a suitable instrument for the regulation of this form of data. We would argue that neurodata exhibits characteristics which differentiate it from other types of ‘normal’ data. Accordingly, we believe it is worth examining the function of the data protection framework specifically in relation to neurodata.

In order to assume that a form of data represents a change in the substance under regulation (or at least exhibits novel characteristics), one must consider whether it differs substantially from the concept of data around which the framework was constructed.

On the one hand, it is beyond doubt that the idea of data can be broken into a number of sub-classes of data. It is not therefore a monolithic concept. It is also beyond doubt that certain of these sub-classes have been recognised as unique and as embodying different qualities from the ‘traditional’ concept of data around which the Directive was designed. For example, in Article 33 of the Directive, sound and image data are specifically pinpointed as forms of data which may not consist of the same characteristics as normal data (Directive 95/46/EC 1995: Article 33). Equally, the Article 29 Working Party—the primary European body responsible for the interpretation of the Directive—recognises genetic data as ‘data which show within themselves characteristics which make them singular’ (Article 29 Working Party 2004: 4).

On the other hand, these recognitions of novelty are supported by highly disputable argumentation. First, any declaration of novelty must be based on an initial definition, against which the new form of data is ‘novel’. There is no available initial definition of the concept of data either in the Directive, or in any consequent interpretation. Second, any declaration of novelty relies on the drawing of clear lines between classes and characteristics of data. This has proven almost impossible, even in cases when this would seem relatively clear cut. In the case of genetic data, for example, the Article 29 Working Party suggest that genetic data is unique as it can reveal information about groups of people, in particular about relatives. However, it is also the case that both social network data and many forms of health information could also reveal information about relatives.

Where does this uncertainty leave our consideration of neurodata? Can we thus categorically state that neurodata is novel? From a legal perspective, the answer is no. There is no framework, or baseline, from which we can concretely recognise a change in the substance of regulation. The same form of argument we mention above, disputing the exceptionalism of genetic data, can equally be directed at any argument suggesting neurodata as exceptional. It is certainly the case that many prior forms of data which were not considered unique, such as IQ tests and psychometric testing, also aimed essentially at comprehending the processes of the mind, whilst, as will be seen, many of the qualities supposedly marking out neurodata are also shared by genetic data.

The law, however, is a conservative discipline; it is seldom capable of defining in advance which of the assumptions on which it rests will be challenged. In this instance, law often derogates to other disciplines to provide it with the information it needs. Can we find a firm answer in any other discipline dealing with the issue? The answer is once again, no. In the natural sciences, there is significant disagreement between neuroscientists as to what neurodata is and as to whether it allows novel knowledge to be extracted about the individual. In the social sciences, philosophers have been arguing about the nature of thought, and the

function of the brain for thousands of years—current advances in neuroscience have done little to solve these debates.

However, despite the problematic nature of declaring neurodata as unique, the authors would like to suggest that neurodata exhibits a certain set of characteristics which, taken together, do not appear to be mirrored by conventional forms of data, or by other ‘unique’ forms of data. The authors recall that, whilst the threshold for defining data as ‘unique’ is unclear, other forms of data have been seen to reach this threshold. The authors believe that the following characteristics can be taken as the base for the argument that neurodata represents a change in the substance of regulation.

Firstly, the form and proximity of link between neurodata and data subject may be unique. Conventional forms of data have been relatively easy to dissociate from the individual they represent. Once this disconnection had been performed (and the data made anonymous) each piece of data considered individually could be said to have very little so unique that it could belong only to one person. Regardless of what attempts are made to sever the link between neurodata and the individual, certain forms of neurodata may remain unique representations of one single data subject by virtue of its nature as a reflection of that individual’s unique brain function.¹⁵ The Committee on Science and Law state in this regard: ‘brain information is... unique and personal’. Accordingly, ‘[t]he concerns that have been expressed about using genetic information as a means of identification of one individual would apply to brain imaging information as well’ (Committee on Science and Law 2005: 11). In this respect, neurodata also gains unique ‘objective’ quality (not necessarily in relation to the accuracy of interpretation, but in the certainty and directness of connection with the individual—raising further issues about how the data is viewed by those assessing it, regardless of its accuracy).¹⁶

Secondly, neurodata may enable unique depth and form of insight into the individual. Neurodata may reveal information that is not known to the individual or information which may be outside that individual’s control. A sub issue of the above two points is that neurodata could also be used predicatively, to find out characteristics or predispositions that may not only not be known to the individual, but in fact may never even manifest.¹⁷

Neurodata also opens up new potential in the representations of the individual possible through data. It allows the translation into data form of unique, and previously unrecordable, aspects of the individual. In this respect, neurodata may allow insight into ‘real time’ brain processes, allowing the direct recording of processes associated with personality, mood, behaviours, thoughts or feelings. It has also shown potential not only in predicting predispositions to mental and physical illness, but also potentially toward different sorts of behaviour and personality (Farah et al. 2012: 119-20). These features arguably make neurodata intimate in a very different way to other forms of data. Kennedy states, ‘I already don’t want my employer or my insurance company to know my genome. As to my brainome, I don’t want anyone to know it for any purpose whatsoever. It is... my most intimate identity’ (Hamilton 2004).

Finally, the collection of neurodata precludes exact comprehension of what has been collected. Not only are the collection processes limited in their ability to restrict what information might be collected, but further advances in cognitive science—which provides the framework for the interpretation of

¹⁵ The connection between individual and data has been considered in relation to genetic data (see Lunshof et al. 2008). It is also necessary to state that only neurodata of ‘sufficient’ complexity will provide a means of unique identification. However, the threshold of sufficiency will be dependent on the technologies of interpretation used. As technology progresses, we can expect to see a change in the level of sufficiency. Neurodata not judged to be uniquely identifying today, may not be judged so tomorrow.

¹⁶ Genetic data shares these features (although distortion factors differ), see Committee on Science and Law 2005: 10-15. For issues related to interpretation, see Klamming 2011.

¹⁷ This can be compared to the use of genetic data and its predictive characteristics (Committee on Science Law and 2005: 10-15).

neurodata—or further investigation into collected data, may reveal significantly more information than the data controller may initially have wished, or wanted, to collect (Committee on Science and Law 2005).

5. Problems in the Formalities of Law: Possible Difficulties in Applying the Mechanisms of the Current Data Protection Framework to Neurodata

If we can argue that neurodata is unique, we can thus consider the continued applicability of data protection law on a legal technical—formal—level. Can the definitions and mechanisms in the framework still function (in the sense of being formally applied) given that the presumptions as to the nature of data are not necessarily valid? If application is possible, is it sure that the result will match that for which the mechanism was designed?

In a system relying on the function of procedures, lack of clarity as to whether, or how, to apply these procedures can lead to an undermining of the protection these procedures have been designed to provide. Three key concepts employed in the framework are used to demonstrate the potential difficulty in application that may arise: the anonymity of data, the accuracy of data and the sensitivity of data.¹⁸

The data protection framework applies only to ‘personal’ data. If data is found to be anonymous, the framework and the rules it lays out no longer apply (European Parliament and Council 1995: Article 3; Recital 26). The concepts of ‘personal’ and ‘anonymous’ used in the Directive were built around specific presumption as to how the link between subject and data would need to be severed to achieve ‘anonymity’ (Article 29 Working Party 2007: 21). In essence, the Directive foresees that, when data cannot any longer be related to a civil identity, they will be regarded as ‘anonymous’. This concept will not function in the same way in relation to neurodata. While the link neurodata has to an identifiable individual’s civil identity can be severed (in that one could destroy the name at the top of a neurodata file leaving only the raw data), the data still remains a unique representation of that specific individual. Accordingly, neurodata cannot be referred to as ‘anonymised’ in the same way as, for example, travel information, could.¹⁹ The danger of re-identification through supposedly ‘anonymised’ neurodata is thus also altered. The current concept of anonymity is also a product of conceptualisations of personal data as a static substance. The quantity and form of data contained in neurodata is not necessarily static. More information may be possible to extract from neurodata as technology evolves—a temporal element thus emerges in anonymity. What may be anonymous today, may turn out to not be anonymous tomorrow. Whilst, in the consideration of anonymity, technological development ought to be considered, precisely how this is to be done is unclear (Article 29 Working Party 2007: 15).

Article 6 (d) states that ‘data must be: accurate and, where necessary, kept up to date’ (European Parliament and Council 1995: Article 6(d)). Whilst the data processor has the obligation to keep data up to date, this aspect of the framework is essential for the data subject to be able to rely on his subjective rights to verify, and if necessary to correct data regarding him/herself, check the legality of processing and make sure that he/she is not being falsely represented. The term ‘accuracy’ remains an undefined concept in the Directive. The drawing of a line in relation to data accuracy was connected to assumptions as to the simplicity of data and was probably presumed to be a very simple process; the Information Commissioner’s Office in Great Britain, for example, stating, ‘it will usually be obvious whether information is accurate or not’.²⁰ Specific questions and definitions as to exactly what needs to be

¹⁸ This is not an exhaustive list of potentially problematic definitions. Only 3 examples have been chosen due to space constraints.

¹⁹ This is not necessarily true with all data—biometric and genetic data raise issues of anonymisation (Nature 2013: 451; Angrist 2013). See for example, in relation to genetic data, Elger et al. 2006.

²⁰ http://www.ico.gov.uk/for_organisations/data_protection/the_guide/information_standards/principle_4.aspx, last accessed 01.07.2013.

accurate, how accurate this need to be, and what data needs to be accurate in relation to, are not addressed. Neurodata is subject to a series of uncertainties at each stage of the information extraction process which would significantly undermine the assumption of the possibility to allocate an ‘accurate/not accurate’ tag. Firstly, there are a number of inaccuracies and false readings possible in the collection process. Secondly, neurodata would only have relevance after having been analysed in relation to models relating to the working the brain. The readings from the collection device without interpretation would mean nothing—data without information. The ‘accuracy’ of data in relation to the individual would thus depend on the accuracy of these models and the applicability of comparisons to the specific individual. Further, the specifics of the data could also be subject to the specifics of the context in which it was collected. Not only could (and in reality do) brain patterns change based on environmental conditions or even the mood of the person at the time, but the brain itself changes as the individual grows and develops. What was unquestionably correct for one situation, is not necessarily so for any other (Wolpaw and Birnbauer 2006: 603; Greely et al. 2007).

Once data has been defined as ‘personal data’, it is endowed with one of two levels of protection—that of ‘normal’ data, or that of ‘sensitive’ data. Article 8 provides: ‘Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life’ (Directive 95/46/EC 1995: Article 8). The purpose of this category is to provide a heightened standard of protection for types of data whose processing poses a greater risk to the rights of the data subject. *Prima facie*, one could assume neurodata, due to the information it could reveal about the individual, for example about the individual’s mood, would be considered as sensitive data. However, the list of data types understood as ‘sensitive’, despite certain of these groups being extensively defined, is exhaustive and neurodata is not listed. Definition rests on formal criteria and, to be regarded as sensitive, each instance of processing would need to fit into one of the categories. Categorising neurodata could be prohibitively difficult. Firstly, the boundaries and meaning of the categories are not always clear (Article 29 Working Party 2011: 8-11). Secondly, outside obvious instances, data which contain potentially sensitive information may not be counted as sensitive—for example fingerprints may contain information that has been linked to cancer, but are not always considered as sensitive data.²¹ In order to clearly define neurodata as sensitive or not, one would need to be able to evaluate exactly what information was contained in the data and how it relates to each category of sensitive data and then which level of overlap would be significant enough to classify it as being sensitive. Perhaps more worryingly, should a processing operation not into any of the categories of sensitive data, simply because the defining qualities appear absent, the substantive insight offered into the individual—that which defines the *de facto* sensitivity—may remain. Can one really assert that thoughts, or moods, for example, are less sensitive than information about an individual’s health?

The above analysis considers the question as to the definition of neurodata as sensitive in light of the definition employed in the framework. A further but perhaps more searching question is: what if neurodata could be more sensitive than the ‘sensitive’ data listed?

6. Fundamental Inapplicability: What if Neurodata is More Sensitive than ‘Sensitive’ Data?

In the data protection framework, ‘[t]he rationale behind regulating particular categories of data in a different way stems from the presumption that misuse of these data could have more severe consequences on the individual’s fundamental rights, such as the right to privacy and non-discrimination, than misuse of other “normal” personal data’ (Article 29 Working Party 2011: 4). The processing of sensitive data is thus generally prohibited.

²¹ There is a review of European data protection legislation underway at the moment in which the categories of ‘sensitive’ data are being expanded. These changes do not impact the validity of our analysis (European Commission 2012).

We would argue that there are potentially a set of interests in play in the processing of neurodata, which were not perceived as relevant in the construction of the current framework or in its ‘sensitive’/‘non-sensitive’ system.

If we have a physiological reference point for the mind, then it is the brain. Accordingly, an argument could be made that at least some of the processing of data which seek to directly interface, and comprehend, the brain as a system, also open up the possibility to record, in data form, aspects of the mind. The interests an individual (and society) might have in the protection of the sphere of the mind are significant.

The mind, and attendant concepts, such as private thoughts, feelings, mental states and personality are perceived to form the core of the individual’s private sphere (Vermeulen 2010: 7). This core is inseparably connected with the dignity of the individual and concepts of the individual as an autonomous entity. Accordingly, such concepts enjoy a unique standard of protection in fundamental and human rights.

There are legal reference points one can look at to consider the sanctity with which the mind is perceived. One can look at, for example, the concept of the *forum internum*; a layer of the private sphere which describes the inner (mental) world of the individual. In human rights law, the forum internum theoretically enjoys unconditional and absolute protection (Taylor 2005: 115-202).

This level of protection is solely reserved for the forum internum. With certain conditions attached, infringement is permitted into all other aspects of the private sphere. If we make the argument that neurodata touches on the forum internum, we can suggest that neurodata is in fact more sensitive than data which is regarded as ‘sensitive’ in the data protection framework (European Union 2000: Article 7).

However, the argument that the processing of neurodata is the processing of data from the mind, or an interference with the individual’s interests in the mind, is legally difficult and inexact. Firstly, despite the clarity with which protection for the *forum internum* is set out, there is in fact very little clarity as to what it consists of or how to categorise the mind in law—where it begins (and thus ends), or how we could conceive of an interference (Taylor 2005: 115-202). Apart from a recent case at the German Constitutional Court explicitly confirming the existence of a private sphere relating to personality and emotion into which no interference is permitted, there is little other case law on which to rely, nor any statutes (Hornung 2009:117). The reality is that there has been little direct need to rule in the area, as the boundaries of the concept have never needed to be questioned practically (Morse 2011). As Bublitz astutely states: ‘I suspect legal scholars and courts are not too ambitious to get into these questions and rather cling to the belief that freedom of thought is not only legally, but factually inviolable as thoughts and the mind are “intangible” and beyond the reach of interventions’ (Bublitz 2011: 97).

Built upon this fundamental conceptual uncertainty is the consequent uncertainty as to what neurodata really reveals and how to categorise the data in relation to the mind. Can reading electrical signals from certain points on the skull be equated with an interference with the mind? Even if it could in certain cases, not all forms of neurodata processing are the same, or aim at the same level or form of insight into the individual.

It is this uncertainty which reveals potential gaps in the law. If it were possible to unequivocally state that the processing of neurodata was a representation of the mind and its processing constituted interference in the *forum internum*, its status would be easily quantifiable. Until the relationship between neurodata and the mind is clarified, however, neurodata will be treated like any other form of data and accordingly it is the current data protection framework which will be legally relevant.

The question that thus arises is: could the current data protection framework provide appropriate safeguards for the interests potentially at stake, despite these interests not having been considered in the framework's construction? Can the current framework deal with data that have a unique level of sensitivity?

Firstly, this would be no problem if the framework held absolute prohibition on the processing of all sensitive data and we could be sure that neurodata would fall under one of the headings (which, as explained above, we cannot). However, whilst there is *prima facie* a prohibition on the processing of data which falls under a 'sensitive' category, a closer inspection reveals this prohibition is a prohibition in word only. The prohibition is undermined by a broad series of exceptions—laid out in Article 8(2) (Directive 95/46/EC 1995: Article 8(2)). Accordingly, neurodata could be processed under these exceptions.

Nor could one rely on the subjective rights laid out in the framework to ensure self-determination over neurodata. The subjective rights in the current framework generally do not specifically relate to informational self-determination, but to the right to be informed, for data to be accurate and for processing to be transparent. The provision of 'consent' as a legitimising element in processing is referential toward the idea of informational self-determination, but is only one form of legitimation among many others and is not a right (Directive 95/46/EC 1995: Article 7(a)).²²

Finally, the systems of control and redress in current data protection systems would be far too permissive to reflect the intimacy of neurodata. Whilst data protection regimes differ between states, generally speaking the decision as to how to define a processing operation lies with the controller, who should act according to the guidelines laid out in the rules applicable to his area. This is problematic as the interpretation of provisions—whose application to neurodata will initially be very difficult and uncertain—is left with the controller, who will presumably, in cases of uncertainty, act in their own interests. The process of control may then come through *ex post* control by the data protection authority—if at all. Serious infringements on the private sphere of the individual could occur before any control has been applied, and perhaps with no attributed guilt.

It is neither the strength, nor the aim, of data protection to provide absolute prohibitions over data processing or to provide total informational self-determination. The data protection framework aims at providing procedural justice. It is a set of rules for resolving the interest conflicts relating to the processing of an individual's data, and thus for legitimising the situations in which an individual's interest can be overridden. As Vermeulen points out, '[t]he right to data protection...come[s] into play only secondarily, in order to minimize the negative impact of the use of technology on the right to privacy' (Vermeulen 2010: 7). This legal construction works on the assumption that there are legitimate competing interests to resolve in each instance of data processing. In the case of neurodata, the absolute prohibition on any interference with the core of the individual's private sphere would contradict the assumption that competing interests are involved. The only relevant interest would be the individual's right to the inviolability of his/her mind. In order to protect the individual from interference, a completely different construction of law, a construction which acts as a shield around the individual and defines boundaries to external interference—as the right to privacy does—would be required.

²² Even if one could rely on the data subject being asked for consent, a further issue arises in that the concept of consent itself may be problematic in relation to some forms of neurodata processing. The centrality of the mind to our conception of the individual certainly touches on concepts of the dignity of the human. However, human dignity is an elusive and debated concept. On the one hand, it clearly acts to empower the individual, on the other however, it can also be conceived of as a constraint, placing a responsibility on the person not to violate their own dignity and to act in a way which does not violate the vision of human dignity which gives a community its unique character. In this regard an argument could be made along the lines of that made in the famous '*lancer de nain*' case, that one does not possess the right to allow processing of one's own neurodata (Conseil d'État 1995).

Conclusion

Neurodata is data relating to the human brain. Up until recently it was largely not necessary to consider the collection and processing of such data. However, recent developments in cognitive science are providing the requisite knowledge allowing practical use of this information, whilst there has been a recent expansion of applications—for example brain-computer interfaces—which function through the collection and analysis of neurodata. The possibility to collect and use neurodata thus moves out of the realm of fantasy and becomes a theme which deserves genuine consideration.

Given that neurodata is ‘personal data’, one area of law which will be of relevance is data protection. The thesis of this paper is that neurodata is a unique form of data and that this will raise questions for the application of data protection law. Issues may arise on two levels.

Firstly, on a legal technical level, one can question the formal applicability of the definitions and systems of the data protection framework. The functionality of these definitions and systems is based on presumptions as to the characteristics of data the framework was envisaged to be regulating. As neurodata has novel characteristics, these presumptions and the legal tools built upon them are potentially undermined. We demonstrate this by considering the difficulty in applying 3 key mechanisms in the framework to neurodata; anonymity, accuracy and sensitivity.

Secondly, on a more fundamental level, we question the relevance of the current data protection framework considering neurodata as data directly taken from the brain, and thus, data related to the processes of the mind. The mind represents a uniquely sensitive and intimate space in the individual’s private sphere. The current data protection framework is neither equipped, nor constructed, to deal with data of such intimacy.

Whilst the above analysis demonstrates that it may be difficult to apply current European data protection law to neurodata, it is only a theoretical analysis and is by no means definitive. How neurodata processing will interface with data protection law in practice, and the spin-off consequences this will have, will highly depend on the specifics of the development and deployment of neurodata based applications and the jurisprudence that develops around such applications. This, in turn, will provide the framework conditions for any political debate which might take place. The eventual shape of any legislation on neurodata, if it arises, will be the result of this debate and the conclusions we, as a society, come to about the relationship between neurodata and fundamental rights.

However, we can ask the question as to what legal templates might be available should the decision to regulate be taken. Normally, we could conduct a comparative study, and look around jurisdictions for solutions which could be transferrable to the European context. Unfortunately, the dearth of consideration of neurodata’s relationship with European data protection law is mirrored across jurisdictions worldwide. There is not one single instrument of data protection which tackles the issue.

Yet, one potential template could be available closer to home. The problems posed by, and conception of, genetic data in data protection law provides numerous points of similarity with neurodata. Genetic data is also a form of data drawn directly from the biology of the individual, whose properties are not wholly understood and whose relationship with the data subject’s fundamental rights is uncertain. Could approaches currently being pursued in the regulation of genetic data serve as templates for how regulation could approach neurodata?

The authors think so. There is currently a reform of the data protection Directive underway. In the instrument proposed to replace the Directive—the Data Protection Regulation—legislators saw fit to specifically classify and regulate genetic data as ‘sensitive’ data (European Commission 2012: Articles 4

and 9). If the same approach were followed with regard to neurodata, it would address many of the issues highlighted above. First, this would serve to classify and define neurodata—a requisite first step to any functional legislation. Second, the Regulation provides that the processing of ‘sensitive’ would be subject to a heightened level of protection as well as advance oversight and approval. Any fundamental rights implications in the processing of neurodata could be highlighted, before processing went ahead. In the first instance, the processing of neurodata would only be permissible in specific, limited circumstances (European Commission 2012: Article 9). Further, each instance of processing would be subject to reporting requirements and scrutiny for its potential impact on fundamental rights. Any breach of these obligations would result in heavy fines (European Commission 2012: Articles 33, 34). This creates a mechanism which allows a case by case evaluation of the legitimacy and proportionality of processing.

Where the normative position is not clear, it is difficult to justify regulation which places blanket prohibitions (in this case which would prohibit the processing of neurodata). In concrete use scenarios, however, the normative issues at hand will be more certain. The above approach revolves around transparency and advance checking, much more than around prohibition. In this way, necessary and proportionate processing of neurodata—for example for medical purposes—could be allowed to go ahead. Processing which infringed on fundamental rights could be prevented in advance.

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