# Visualising Bodies Within and Beyond Laboratories and Clinics

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**Abstract:** As a response to the spread of biomedical imaging, this conversation explores crucial aspects related to the production, interpretation and use of body images within and beyond laboratories and clinics. Regula Valérie Burri's contribution raises questions about the implications of medical imaging technologies and practices for both medical treatments and patients' identities. Annamaria Carusi explores the intertwined epistemic and ontological roles of visualizations in the field of personalized medicine within two contexts of mediation: that of basic research and biomedical application; and and that of biomedical research and health care systems. Finally, Aikaterini A. Aspradaki discusses the use of body images from a bioethics perspective, focusing on the autonomy of persons and the ethical, economic, legal and social issues raised by the visualizations of bodies.

**Keywords:** visualisation; bodies; biomedical imaging; personalised medicine; bioethics.

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## Pictures, Practices, Paradoxes: Medical Imaging and Modernity

*Regula Valérie Burri*

In this contribution, I argue that medical imaging technologies and practices imply several paradoxes. While, on the one hand, medical imaging opens up a set of new options and possible choices for patients and physicians, it narrows down, on the other hand, the scope of perceptions, agency, and alternatives in certain situations. The new freedom of (diag-

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nostic) choice is contrasted, for example, by the power of the diagnostic facts and the rhetorics of the images on self-perceptions, or the lack of an adequate treatment for several indications. Paradoxes are implied all along the imaging trajectory – from the construction of the images and their interpretation to the ways they are used and deployed in (biomedical) practices within and beyond the labs and clinics. Paradoxes are thus implied in the whole process, which should be studied in the context of social studies of scientific imaging and visualization (SIV): production, engagement, and deployment (Burri and Dumit 2008), in other words, the production, interpretation, and use of images (Burri 2008, 2012).

This contribution explores the paradoxes and unintended dilemmas related to medical imaging. It raises questions about their implications for medical treatments and patients' identities, and finally discusses the findings in the context of the modern societies we live in.

## 1. Blackboxing the Apparatus: The Technology Paradox

The first paradox relates to medical technology. Imaging apparatuses such as computed tomography (CT) and magnetic resonance imaging (MRI) scanners are very complex machines. However, their output – the image – does not reveal the complexity of the apparatus that was used to produce it. The technology is blackboxed and made invisible in a body scan. A medical image thus appears to be a photorealistic depiction of nature instead of a sociotechnically constructed representation in many situations. "It's almost a photograph of the brain", said a neuroscientist during my fieldwork in imaging centers of large university hospitals, and a professor of neuroradiology held that through these pictures, you can look directly into someone's head (see also Dumit 2004; Joyce 2005; Burri 2008, 2013).

Whereas in the early days of imaging technology, CT and MRI body scans were not able to display any clear contours of body parts, today's images are high in resolution and contrast, thus making the sophisticated technology 'transparent' and able to disappear behind the image (Borck 2001; Burri 2008). The technology paradox thus implies that the better developed and more complex an imaging technology is, the more likely people are to forget about it once they look at the images.

## 2. Flood of Images: The Selection Paradox

Once images are interpreted, a further antagonism comes into play. The process of understanding the images and making up a diagnosis includes a selection paradox. Physicians appreciate the advantage of images to provide information on the inside of the body in a noninvasive manner. Visual screening makes surgery often unnecessary. Physicians also say

that images allow them to perceive information at once, just by looking at one image, whereas it would take them much more time to read the information provided by an accompanying report. Such "visual value" (Burri 2012, 49) allows people to perceive visual information simultaneously.

In order to make this one glance possible, a lot of images have to be produced. Even if the number of images constructed depends on the patient, the examination, the physician, and the local routines, there are usually several dozens of images produced in one imaging examination. An MRI examination of a person's head, for example, may include two series of 24 images each with a contrast agent (which enables the visualization of the blood vessels) and three series of 24 images each without applying a contrast agent, thus fabricating 120 brain scans in total. In some centers, these images are printed out on film and the whole examination results in several films, each of them containing 12-20 images. Other centers do not print out digital scans at all.

To make sense of an imaging examination, a radiologist does not consider all fabricated images. Usually, the medical technologist in charge picks a selection of a few images, which she or he presents to the radiologist for interpretation. The final diagnosis is thus based on only one or a few images, although a large amount of images had to be produced to make this one glance possible.

## 3. Increasing Uncertainty: The Epistemic Paradox

After their production, the images have to be interpreted to get more insight into the human body. The increased knowledge that is gained through the new digital possibilities of looking inside a patient's body, however, is often accompanied with an epistemologically nondefined situation. In other words, the certainty gained through the visualization of the body may at the same time imply an increase of uncertain knowledge. For example, when someone is examined with MRI because she or he suffers from a headache, diffuse changes of brain regions may accidentally be detected on a scan. In some cases it is not clear what such changes mean – they may be a symptom of a tumor or may not be pathological at all. The further course of a detected change often remains unclear. The interpretation of such images may thus increase both the unknowns and the epistemic uncertainty of a situation instead of gaining in-depth medical knowledge and achieving certainty about the course of an illness.

## 4. Lack of Treatments: The Option Paradox

Although in most cases the interpretation of images does contribute to

the diagnosis of an illness (or helps to exclude the existence of such), such stabilized medical knowledge may include an option paradox. While, on the one hand, the diagnostic advantages of MRI are widely recognized today, and diagnostic skills have increased in recent decades, there is not always an adequate therapy at hand to treat the diagnosed illness. The gap between the diagnostic possibilities and the available treatment for certain indications is growing.

For example, medical imaging is widely used in the evaluation of Alzheimer's disease. This debilitating disease affects approximately 5 million, mostly elderly people in the United States, and 50-70 percent of an estimated 7.3 million Europeans who suffer from different types of dementias[1]. Although Alzheimer's disease was first described 100 years ago, the causes of the disease are complex and not yet fully understood. Up to this day, there is no adequate treatment to heal Alzheimer's but only treatments aimed primarily at slowing progression of the disease rather than halting it completely or reversing its progression. This produces the paradoxical situation that, on the one hand, the diagnostic tools (including MRI) are very advanced but, on the other hand, this new freedom of diagnostic choice contrasts with the limitations of available treatments.

Another example is the diagnosis of brain aneuyrisms. By the use of imaging technologies such as magnetic resonance angiography, a brain aneurysm, which is a localized, blood-filled bulge in a blood vessel of a brain, can be quite easily detected. Today, elaborated techniques for treatment called *surgical clipping* and *coiling* are available, and less invasive methods such as endovascular management have been developed in recent years. Nevertheless, there is a lack of adequate treatments for some patients. In several online forums, patients report that because of the size or location of their aneurysm, it can't be treated. A user called newtons63, for example, recounts that: "doctors are watching and waiting as it is in a [too] dangerous area for coiling procedure"[2] and another patient with two aneurysms holds: "The smaller one could not be operated on because they didn't have anything small enough to stint it"[3]. Similarly, the user peaches217 claims that: "the surgeons say that my aneurysm is inoperable"[4]. In cases when aneurysms have not yet ruptured – and may never do so – physicians are very cautious about invasive procedures. While treatments of brain aneurysms have advanced over recent years, the gap between diagnostic and available therapeutic methods is thus increasing.

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[1] US National Institutes of Health (2012) and http://ec.europa.eu/health/major_chronic_diseases/diseases/alzheimer/index_en.htm#fragment1 (retrieved May 10, 2014). The data refer to the year 2006; see also introduction section.
[2] See http://neurotalk.psychcentral.com/thread52715.html (retrieved March 18, 2014).
[3] See http://www.bafound.org/survivor-stories-2 (retrieved March 18, 2014).
[4] See http://neurotalk.psychcentral.com/thread52715-2.html (retrieved March 18, 2014).

## 5. Forcing Decisions: The Agency Paradox

Once medical images are interpreted, they force physicians and patients into decision situations that may be difficult to cope with. Despite the uncertainty of the further course of a detected and only potentially dangerous disease, patients have to decide whether to get special treatments such as surgery or not. A discovered aneurysm may remain stable and not rupture at all during a patient's life course. This is recalled in patient forums, for example, by a neurosurgery physician assistant called Mike: "Remember, most people with aneurysms die with them… unruptured"[5]. It is thus a mere potential risk that a patient is confronted with. Nevertheless, once an unruptured aneurysm is diagnosed, patients and doctors have to deal with the situation and are forced to decide whether to opt for an intervention (i.e. to clip or coil the aneurysm, or treat it by endovascular management) or refrain from taking any activities and just monitor the cerebral abnormality.

Taking a decision may be especially difficult in cases of accidental diagnostic findings when the detected abnormality is not causing any pain, like in the case of a patient called Raglet, who reports that she or he did not have any symptoms and thus did not know about having any medical problems at all.[6] Patient Anna's story illustrates the difficulties of decision making regarding choice of treatment. Being concerned about a pain in the side of her face, the 40-year-old schoolteacher went to see a doctor who sent her for a CT scan and an MRI. She was diagnosed with two brain aneurysms. Anna reports: "As a family, we had to make very serious decisions… Should we do nothing and hope [the aneurysms] never burst or should we risk two invasive operations?"[7]. After having several consultations with a top neurosurgeon, weighing all the factors, and calculating the odds, Anna and her family finally opted to go for the clipping surgeries.

Within families, such decisions may be controversial, as a female patient recounts, who agreed to the surgery but whose husband "was totally against" her decision[8]. In such situations, patients have to trade off two forms of risks – the risk that the aneurysms may rupture, and the risk of a complex neurosurgical intervention. These decisions are very difficult to make, given the uncertainty of the situation: "They said I could live to be 70 or die in my sleep tonight", peaches217 notes in her forum contribution, and seeks advice from other patients by asking them: "Did you get it

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[5] See http://neurotalk.psychcentral.com/thread152664-2.html (retrieved April 4, 2014).

[6] See http://neurotalk.psychcentral.com/thread52715.html (retrieved April 4, 2014).

[7] See http://www.bafound.org/annas-story (retrieved March 18, 2014).

[8] See http://www.bafound.org/survivor-stories-2 (retrieved March 18, 2014).

fixed?"[9].

Mostly, decisions are not the result of mere medical assessments or simple rational calculations but rather the outcomes of complex considerations that include psychological and social aspects. For some patients, it is simply no option to live with the knowledge of having a bulge in their brain that may rupture at any time. Mike, the above-mentioned forum user, explains: "What may eat [yo]u up psychologically is thinking you have a 'ticking time bomb' in your head"[10]. Such patients may take the risk of surgery even if there is a certain chance that their aneurysm will never burst.

Medical imaging thus forces patients and doctors into situations to decide for or against certain activities. The new options and possibilities that imaging technologies and practices open up – the new freedom of choice – go along with the obligation to indeed make a choice. Other medical technologies and diagnostic methods, such as genetic testing, result in a similar agency paradox. Nevertheless, medical images allow people to see abnormalties with their own eyes. Images are thus visually more persuasive than genetic testing results, as patients confirmed during my fieldwork, and may thus make a greater imposition on one's self-perception (Burri 2008).

## 6. Shaping Self-Perception: The Identity Paradox

Such "visual persuasiveness" (Burri 2012, 52) involves the next antagonism: the identity paradox. The new freedom of diagnostic choice enabled by medical imaging is in contrast to the shaping power of the images regarding self-perception. If a person, for example, gets a brain scan that shows no abnormality in medical terms, this person knows that this finding is evaluated as a biological fact, and that she or he will thus be considered as normal by both physicians and society. A 'normal' finding – in which a neurologist can't see any major differences when comparing a brain scan with a so-called normal or average brain image – is considered as a confirmation that this person legitimately feels good. If, however, she or he rather experiences being ill, a 'normal' finding makes an imposition on him or her: because of the lack of any medical indications, this person is expected to feel well. A normal finding, and thus the absence of any medically classifiable disease, can otherwise be a great relief to persons who suffer, for instance, from an enduring headache. Based on an imaging examination, an illness such as brain tumor can be excluded. On the contrary, if the finding is abnormal, the person is assigned a legitimation

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[9] See http://neurotalk.psychcentral.com/thread52715-2.html (retrieved March 18, 2014).
[10] See http://neurotalk.psychcentral.com/thread152664-2.html (retrieved April 4, 2014).

for his or her possible pain and is thus stigmatized as being in a problematic condition even if she or he subjectively feels healthy.

Although historians have shown that boundaries of what is socially considered normal and abnormal (Canguilhem [1966] 2007; Foucault [1963] 1973, [1975] 1995), or objective and non-objective (Daston and Galison 1992), are contingent and change over time, patients know that images are mostly considered as evidence by both physicians and the public. Any knowledge based on a person's medical images will thus shape the way this person perceives him or herself (Dumit 2004). The evidence of medical images thus includes an identity paradox, that is, an antagonism between the new freedom of choice and the shaping power of the images for people's self-perception and identities.

## 7. Conclusions

The paradoxes related to medical imaging correspond to the ambiguous feature of contemporary societies described by Beck *et al.* (1994, 76), who have pointed out the characteristic of reflexive modernity to offer new choices to individuals: "choice has become obligatory. This is a substantive thesis about everyday life today," the authors note. At the same time, they state that people constantly have to opt for one of the offered choices. Drawing on this analysis of the contemporary modern society, medical imaging can be interpreted in a wider context. On the one hand, it offers a set of new diagnostic choices for physicians and patients, yet, on the other hand, it limits the agency and alternatives in certain situations, for example through fashioning the ways people feel and see themselves. Medical imaging technologies and practices open up spaces while at the same time restricting them. They offer new choices but force people into steady processes of decision making – a situation that is enforced by cutting-edge biomedical and other emerging technologies. Just like these complex technologies, medical imaging may increase unknowns and non-knowledge, which have been termed by Ulrich Beck and Peter Wehling (2012) as further characteristics of contemporary society. In this understanding, medical imaging technologies and practices can be seen as a characteristic feature and expression of modern technosocieties.

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## Personalised Medicine: Visions and Visualisations

*Annamaria Carusi*

The new generation of computational life sciences that is bound up with 'big data' and all its associated forms of data gathering, processing, modelling, simulating and visualising are currently positioning themselves for 'translation' into personalised medicine, or what has become known as P4 medicine (preventive, predictive, personalised and participatory medicine). Currently the ground is being prepared for this 'translation' in a raft of position papers, funding calls and medical science and health care strategies[11]. No doubt social, cultural and political actors will play a role alongside science, and will be co-responsible for the forms of personalised medicine that may be actualised.

The notion of translation is not an especially good one to describe the process of bringing science to application as it does not capture the extent to which both science and application shift and mutate along the way (Löwy 1996). The formation of a personalised medicine informed by systems biology (which from now on I'll refer to as systems personalised medicine) will occur through the co-evolution of the technoscience of computational systems biology with experiences and understandings of personalised medicine. While 'personalised medicine' is generally understood as 'tailoring diagnosis and treatment to particular individual patients', the meaning of each of the terms in that statement ('diagnosis', 'treatment', 'individual patients') is still indeterminate in many ways. Scholars have raised questions about the definition of individuality in a genomically informed personalised medicine, which is closer to a statistical ensemble than to anything in which a particular person may recognise themselves (Jones 2013). Even though proposing a different approach[12], a systems biology informed mode of personalised medicine will come up against similar issues: how will the personal be carved out of the systems of the science and research?

In the process of forming the systems personalised medicine, the various visualisations that permeate computational systems biology (as they do any form of computational science) will play a key role. Information visualisations (for example, that visualise large quantities of data so that patterns become evident in them), network visualisations (that visualise the output of network modelling) and computational science visualisa-

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[11] See for example Auffray *et al.* (2010); Wolkenhauer *et al.* (2013); Kyriakopoulou and Mulligan (2010); Hunter *et al.* (2013); Hood and Flores (2012); European Commission (2011).

[12] See Carusi *et al.* (2013) for an in-depth discussion of an example of computational systems biology, and Wolkenhauer (2014) for an overview of different modes of systems biology.

tions (that are the material output of the computational simulation of a dynamical process), are just some of the variants used. In computational science (as in many other forms of science), they are hybrid visual artefacts, with complex causal-computational etiologies (Carusi 2012). These visualisations are an integral part of the scientific process, playing a central role in the construction of the experimental phenomenon: that is, what is observed as the outcome of the experiment, and what this can be taken to be evidence for. They play a crucial role in materialising the biological process under investigation as a system, and in making that system something that can be considered real, or something that can engage with as real. By 'the real' I do not mean anything particularly philosophically burdensome. In using it, I am echoing the practices of the scientists in the domain, for whom what is real in their own and others' experimental practices is a constant preoccupation. My use of it indicates what experimenters, researchers, and ultimately individuals who will encounter personalised medicine in the health care systems, take to be real, experience as real, and interact with as real. This might be the experimental phenomenon or research context, or the way people, individual and collective, experience the personal as real in the personalised health care system. This use of 'real' does not imply a pre-existing, pre-formed real, but precisely something that is negotiated over, struggled over, formed and transformed.

Visualisations do not do this on their own but as part of a experimental system where, however, they play a role that cannot be reduced simply to showing the output of the prior computation (Carusi 2011 and 2012; Spencer 2012; Chandrasekharan and Nersessian 2011). In their role of making the outputs of simulations and other forms of computations materially available for observation, manipulation and interaction, they have intertwined epistemic and ontological roles: the mode in which they provide evidence for the process as a system also has ontological consequences for defining both what is 'realistic' in the visualisation and what is real in the experimental system. They also have ontological consequences for the disciplinary and other social groupings that are brought into contact, and need to cooperate or participate in order to realise the vision of systems personalised medicine. Because they have this epistemo-ontological role in virtue of being material artefacts, that can be shown, displayed, interacted with, discussed, and so on, they are also sites of mediation between the different spaces of systems biology research, and the different modes of collaboration that are required for it. Elsewhere I have discussed the role of visualisations in mediating the context of forging new collaborations between wetlab and drylab (Carusi 2008, 2011). Here I shall discuss two other contexts of mediation: between basic and applied biomedical research, and between research and health care each of these in turn. As in Carusi (2011), I continue here the approach of tracking visualisations that are emerging, are not entrenched and over which there is disagreement, as in these cases it becomes more evident what

might be ontologically at stake in contexts of mediation[13].

## 1. Between Basic and Applied Biomedical Research[14]

This context of mediation can occur in places where academic researchers interact with clinicians, or in other contexts such as pharmaceutical companies or drug regulatory institutes. The example I discuss is taken from an initiative to show that computational cardiac modelling can be useful for clinical research, in that it can propose new hypotheses that are not readily available using widespread clinical cardiological techniques. It is an example of the mode of systems biology that constructs models of dynamic processes in order to investigate the mechanisms that give rise to them. Obtaining data that are relevant for modelling and simulation is a driver for establishing collaborations in this context too; however, the shift to the clinic or other biomedical context also brings an engagement with experimental systems geared towards clinical research questions and concerns. There are many routes to showing the role of the visualisations in making this crossover into applied biomedical contexts such as the clinic. Here I shall discuss just one example episode involving the work of a computational systems biologist, a mathematician by background, who – in a collaborative team that included a 'converted' clinician who had contributed clinical data from in vivo human hearts – had used modelling and simulation to show that there may be factors that give rise to arrhythmias (irregular heartbeat) that have not yet been considered by clinicians. Getting clinicians' interest more broadly would be beneficial because it may result in access to more clinicians' data, or even to experiments targeted to the hypothesis explored by the model, and therefore to a contribution to the development of the model. The particular research reported on focused on the tissue level of electrical activity in the heart; in this case, the systems approach is evident in the interest in the interactions between sub-cellular, cellular and tissue levels, and ultimately with other electro-physiological levels of the 'whole heart'. In our conversations the researcher stressed that in the simulations, the aim is to achieve *a correspondence with what happens in the real heart*. Since the pattern of electrical activity is a dynamic process, the only way it can be seen is through a movie as the visualised output of the simulation. This visible pattern is a crucial aspect of the evidence for the claim being made. However, the production of the visible pattern necessitates a change in the parameter space of the data (fast speeds are made faster and slow speeds are made slower) – and in this respect, there is not an

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[13] For a discussion of the mediating role of images see also Carusi and Hoel (2014); and Hoel and Lindseth (2014).
[14] 'Basic' is of course always relative. By 'basic' here I mean science that is not targeting a specific application.

exact correspondence with the 'real heart'. The researcher was very concerned to make this clear to viewers of the visualisations.
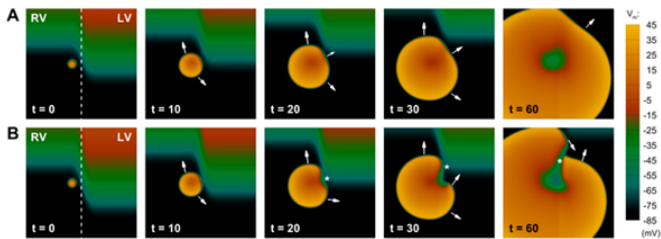


Figure 1 – The visualisation of mathematically modelled and computationally simulated action potential re-entry at tissue level[15]

The work was presented at conferences through presentation and posters, particularly targeting clinicians. Presentations included figures that were similar to the electrocardiagrams that clinicians are used to, as well as an extremely striking visualisation in the form of a flow of swirls of colours to show patterns of Action Potential Duration Reentry (the form in which electrical activity of the heart is salient to experiment) [see Figure 1]. However, clinicians tended to respond sceptically to that visualisation. Their response, as reported by the researcher, was: *"this is not what is happening in real hearts"*[16] – not because they object to the distortion of parameter space of the data (which they do not remark upon). Rather there is a lack of correspondence between what is shown in the visualisation of these mathematically modelled and simulated patterns of arrhythmia at tissue level, and what they see in their own research. The computational visualisation is of a localised bit of *mathematically modelled* tissue showing up relationships between ion channels; it is not of a whole heart and it is not generated by an automated connection with physical hearts. Clinicians, instead, deal in visualisations with a very different logic, that is visual output in the form of tracings made by automated connections via electrocardiagrams, catheters and needles, attached to or inserted into human research subjects. The visual output of these experimental settings – an example of which is found in Figure 2 – is interpreted as being of 'real hearts' against the background of these settings. Their reservations about the visualisation are not elicited by distortions of the parameter space, but by the fact that the visualisation does not map onto these experimental settings. Not only is its smooth, swirling pattern formally (or we could say aesthetically) very different from the jagged tracings of an electrocardiogram, but how these visual features are

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[15] Availble at http://www.plosone.org/article/info:doi/10.1371/journal.pone.0052 234 (retrieved May 14, 2014).
[16] Fieldwork notes.

related to 'real hearts' is not evident to them; they have no implicit setting against which to interpret these mathematical visual objects.
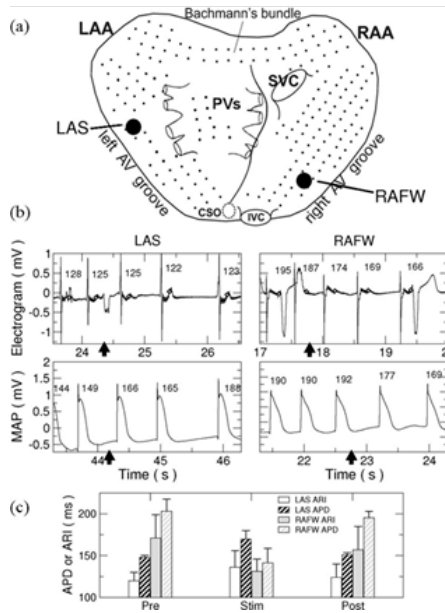


Figure 2: Typical visualisations used for cardiac electrophysiology using electrograms[17]

Considering that these cardiac clinicians consider ECGs in the context of 'whole hearts', the researcher reflected that perhaps if he had tried visually to contextualise the tissue in the whole heart, "maybe then they would see it happening in real hearts, but then it would look as though this is a 3D model, and this is not a 3D model"[18]. However, the context that seems to be missing is the link to the experimental setting that makes it, for clinicians, of a real heart. What is at issue in the ability to see the visualisations as evidence providing is a tension over what counts as a 'real heart'. For the systems biologists, reality depends upon the way that data are obtained (from which experiments) and from the ability of the mathematical model to fit the data thus derived. It is this fitting that makes the model 'realistic'. But clinicians fail to recognise these patterns

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[17] Reprinted with permission from Vigmond and colleagues (2009). Available at http://ieeexplore.ieee.org/xpl/login.jsp?tp=&arnumber=4785512&url=http%3A%2F%2Fieeexplore.ieee.org%2Fxpls%2Fabs_all.jsp%3Farnumber%3D4785512 (retrieved May 14, 2014).

[18] Fieldwork notes.

as occurring in real hearts: the mathematical model with which they are presented cannot be contextualised in anything they recognise as a 'real heart' – and the modeller's attempts to contextualise it for them runs the risk of misleading them as to the nature of the model.

## 2. Between Research and Health Care System

Big data approaches to systems biology are predicated upon technological capabilities to collect and process large quantities of data, yet those data do not always already exist. In the case of the vision of personalised medicine that issues from the big data mode of systems biology, there is a reliance on users of the health care system to be data producers, and many of its rhetorical efforts are geared to this end. Because this part of the vision of personalised medicine is still programmatic and future oriented, my research has focused on the documents and other public engagement output that attempt to gain support for this vision, or to show what concrete form it could take. This vision of systems personalised medicine stresses the participatory aspect of P4 medicine. For example:

> "Patients and consumers will be a major driver in the realizaton of P4 medicine through their participation in medically oriented social networks directed at improving their own healthcare."
>
> (Hood and Flores 2012)

The 'big data' mode of systems personalised medicine in fact depends on data acquired from large populations. Scientists in this domain talk of a 'data cloud' for any individual of trillions of data points, from the genomic to the social level and everything in between (Hood and Flores 2012). Data can be acquired through a myriad different encounters with the health care system; but importantly, to be really effective, it needs active participation from health care users, for example, through self-monitoring via social media and through their willingness to use a whole new range of devices to gather data. This kind of participation entails non-trivial social, economic and political transformations of health care, which are impossible to broach in this article (see Prainsack 2014). I shall focus on a representational issue. Like vaccination programmes, the benefits to any particular individual of this mode of personalised medicine, depend on the participation of very large numbers of people. There are different rhetorical arguments that can be made for participation, but one is to appeal to the stake that any individual has in this massive data gathering exercise. This is the tactic that is sometimes used. For example, 'The Digital Patient' is a project funded under the auspices of the Virtual Physiological Human Network of Excellence, with the aim of describing how computational systems biology can be transformed into personalised medicine. Computational systems biology aims to construct models of the

organs and physiological processes of the human body and the digital patient is envisaged as a model of each individual patient:

> "The Digital Patient is a vision of a coherent digital representation of each patient that is used to provide an integrative framework for personalized, predictive, and integrative medicine."
>
> (Hunter *et al.* 2013)

The website of the project has a more patient directed version of this:

> "The Digital Patient is an envisaged super-sophisticated computer program that will be capable of generating a virtual living version of yourself. When this is achieved, it will be possible to run 'simulations' of health and disease processes on the virtual or 'digital' you, and use the results to make predictions about your real health. It will also be possible to determine the best treatment specifically for you. This is termed 'personalised medicine', and is intended to be the future of healthcare."[19]

The project's exploration of the digital patient includes an in-depth consideration of the visualisations that would be used in the patient-doctor encounter. The highly detailed account of what would be required of these visualisations is in itself a good indicator of how significant they are in the interface between the patient and the systems mode of personalised medicine. There is much to say about this, but here too, for the sake of brevity I shall focus on just one detail. From the patient's perspective, their 'corresponding' digital patient will be an avatar. Included in a draft of the Digital Patient roadmap is the following statement:

> Avatar lookalike.
> Develop rapid, automatic and low-cost strategies to individualise the physical appearance of the Avatar to that of the patient. This provides emotional intensification, as used in Microsoft's Xbox Live Service or Nintendo's Mii, which can affect individual behaviour, including healthy behaviour.
>
> (Digital Patient Project, undated)

In a short animated movie,[20] that is a kind of scenario of what such a consultation might be like, a patient is shown an avatar, which is at first of a generic human that (in the patient's voice) is described as "breathing and moving its eyes", and when made to jog, "started to sweat". We hear the patient say that he does not understand what this has to do with his check up, but he is then asked to stand on a platform and is scanned by a

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[19] Available at http://www.digital-patient.net (retrieved May 10, 2014).
[20] Available at http://www.youtube.com/watch?v=JijSCaVrYhw (retrieved May 10, 2014).

laser, and "suddenly the model on the screen changed and it was me… it even had my face", down to "all my skin blemishes". Two of these blemishes are picked out on the avatar, and "a robotic arm came and found them on me". The movie then goes on to describe other forms of interaction between this highly personalised avatar and the patient. In this whole consultation scenario, the line between what is personal to the patient, via those trillions of data in 'his' data cloud, and what is personal to him, via the avatar, is blurred: in fact the 'emotional involvement' depends on this blurring.

It must be stressed that this has not been developed, and interestingly, this visual strategy does not appear as such in the final roadmap. However, it is telling that this visual strategy of getting patients to recognise themselves in the generic mass of data that systems personalised medicine actually is, could even be considered as part of the roadmap. It points to a fissure in this vision of otherwise seamless all inclusive data, a fissure between data for systems biology and the personal in any way that 'personal' is actually experienced. It will take work to knit together the ends of this fissure, a work that we might expect, will result in a new form of personal, bridging experience and data. For this very reason, it is of social, cultural and political importance how this new personal is forged.

## 3. Conclusions

Just as in contexts of mediation between wetlab and drylab, visualisations figure in multiple ways in mediations between basic research and biomedical application, and between biomedical application and health care system. They are part of observation and evidence of experimental systems; but they are also depended upon to communicate with researchers who do not share the same experimental system, to policy makers who must be convinced of the viability of this vision of personalised medicine, and eventually, to act as an interface between the personalised health care system, doctors and patients. At each of these junctures, the visualisations show slippages in what is taken to be 'real'. These examples have in common that they are not, or not yet, entrenched. They are visualisations that are questioned, of which the communicative intent is not smoothly accepted, or which are programmatic and futuristic rather than actualised. At these points, before the gaps are closed, we have the opportunity to see the slippages, misunderstandings, and struggles over how to realise systems personalised medicine. The visualisations that are deployed and crafted in this process are crucial to the formation of these new realities. As such, they are also sites around which participation and activism can occur in the emerging modes of personalised medicine.

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# Bioethical Issues on Autonomy of Persons in Visualizing Bodies

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## 1. Introduction

The research on the "increasingly sophisticated visualization tools" (Perrotta 2012) in science and technology and their implications – with emphasis on visualizing bodies by biomedical imaging and body picturing in a broader sense – is an area of growing interest at the intersection of the fields of science and technology studies (STS) and bioethics.

In this context, scholars in the social studies of scientific imaging and visualization (SIV), for example, have emphasized on a research agenda including the epistemic status of images in the knowledge generation process and the impacts that images and imaging technologies have on social organization and research communities (Burri and Dumit 2008, 307-308). Special research interest has been drawn to the "labor- and capital- intensive" nature of imaging and visualization and the related identification of "hype" in bioinformatics, computer-generated imaging and nanotechnologies. This hype has been partly attributed to the visual persuasiveness of scientific imaging, as "a crucial part of contemporary scientific authority" (ivi, 308-309). Moreover, scientific images of humans have been highly correlated to issues on the deployment of persuasion because of their special character of being images of "our own bodies and lives", our "educated" bodies as well as our thoughts and actions regarding an "ideal and fit person" (ivi, 306). In addition, due to the deeply personal character that medical images have in picturing ourselves, scientific images of humans are considered to be not only persuasive but also "entangling", many times in a special relation with our human personhood (ivi, 307).

At the same time, scholars in bioethics have emphasized on the research work required on the epistemological status of results from imaging studies in sciences. As an example, epistemological considerations on neuroimaging as a "prerequisite" for the neuroethics have been strongly discussed (Huber and Huber 2009). The discussion has been illustrated by the widely used method of functional magnetic resonance imaging (fMRI) for analyzing brain structure. More concretely, in a common framing for neuroimaging methods in neuroscience, philosophy of science and sociology of science into the elaboration of neuroethics discourse, the concept of objectivity has been challenged in its use to guarantee methodological quality in current neuroscience (ivi, 341-343). Two arguments have been mainly discussed. The first develops the hypothesis of technological construction of scientific objects detected by neuroimaging and concludes that: "the artificial environment of the laboratory situation will remain an epistemological problem" (ivi, 344). The second considers the

interdependence of theories and data (hypothesis-driven/data-driven approaches) in neuroimaging research and highlights the problems in the interpretation of controversially defined cultural and philosophical concepts such as the concepts of self, well-being, and empathy. Finally, a probability of hypotheses to generate their own phenomena as objects of research in neuroscience is supported (ivi, 345). Something like that would be extremely crucial and would raise ethical, legal and social implications in the case of extremely debated concepts such as the concepts of racism and proneness to mental illness. In particular, neuroimaging research, especially racism research, is referred to have the possibility to create new diagnostic entities, such as the pertaining to unconscious attitudes and, to provide the potential for discrimination and for legal, financial and privacy issues (ivi, 347).

In parallel, scholars in sociological studies of health and illness have emphasized on a number of problems raised by body picturing visual methods, including video and photography, in the research methodology of social life, health and health care (Harrison 2002). More specifically, four considerations have been suggested to social researchers (ivi, 859-860). The first is the relationship of visual data with the research questions and the need of visual data to be used, since it would possible that the same data would be provided through words or/and that the visual dimension would be provided without visual display. The second consideration is the "conventionality" of visual methods, such as everyday photographic practices, if, for example, the responders would be asked to produce a visual diary of their illness progress, since such photographic records would encompass only selected social occasions, particular people and places and would be framed by particular aesthetic principles. The third is about the technologies of visual production, since the developments in camera technologies, audio/video recording, multi-media software and internet have crucially determined, by also opening new questions, the provided opportunities for both the access to resources of visual data and the development of skills required by researchers and participants to use them. Finally, the fourth consideration is the ethical issues of anonymity, confidentiality and privacy raised by the use of health-related visual materials, since, due to their very nature, much more personal information can be available to a "public gaze" during investigation process.

Taking into consideration all the aforementioned issues raised by visualizing bodies, a very central area of bioethics, namely the issues regarding the bioethical principle of the respect for the autonomy of persons, is coming to the fore. It is widely accepted that autonomy has gained a prominent thesis as a key principle in the field of bioethics. Already in the ancient Greek philosophy, the term "prohairesis" in the Aristotelian ethics has usually been translated as choice, decision, purpose, will, intentional choice, free choice and, in Epicteus' Discourses, as moral purpose, choice and free will (Dragona-Monachou 1978-1979, 309). The word "au-

tonomy" derived from the Greek words "*autos*" ("self") and "*nomos*" ("rule", "governance", "law"). Referring originally to the self-rule or self-governance of independent city-states, it has been extended to individuals acquiring a great number of "diverse" meanings, such as "self-governance, liberty rights, privacy, individual choice, freedom of the will, causing one's own behavior, and being one's own person" (Beauchamp and Childress 2001, 57-58). In contemporary moral and political philosophy, the concept of autonomy has been used in an "exceedingly broad fashion" (Dworkin 1988). In particular, autonomy has been equated with "dignity, integrity, individuality, independence, responsibility, and self-knowledge", and identified "with qualities of self-assertion, with critical reflection, with freedom of obligation, with absence of external causation, with knowledge of one's own interests" and also to be related to "actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts and to principles" (ivi, 6).

In this paper I aim to open a discussion on this principle in the field of the applications of the visualizing bodies technologies in biomedical imaging and body picturing in a broader sense, by posing three questions. First, could the applications of these technologies enable individuals to take a more proactive role in the maintenance of their health and help society improve health and reduce health costs? Second, what about public participation in scientific and technological developments in contemporary democracies? Third, what about the understanding and interpretation of the principle of the autonomy of persons in contemporary applications of these visualizing bodies' technologies? I will answer to these questions and discuss the related bioethical concerns in the next three sections.

## 2. Individuality, Resource Allocation and Regulation Issues in Biomedical Imaging

Researchers in bioethics have worked on the ethical implications for the "autonomous and relational dimensions of the person" raised by the use of home-based self-testing diagnostic devices, including biomedical imaging like computer assisted tomography (Kearns *et al.* 2010). It is worth mentioning that these ethical implications have been considered to be fully understandable long after their initial applications, due to the "pace of discovery within the biomedical world and its subsequent interface with technological developments" (ivi, 200). Moreover, despite the suggested potential for such biomedical diagnostic self-testing technologies to benefit both individuals in taking a more proactive role for their health and society in improving health and reducing health costs, the possibility to "push health care away from its relational basis and further into an individualistic paradigm" has been importantly heightened (ivi, 207). Then, in a climate of "new pressures" by such offered diagnostic tools,

"isolated individuals" are considered to be forced to decide on their own whether to use them, how to interpret their results and how to face with difficult situations coming from the resulting health knowledge for themselves and their families (Kearns *et al*. 2010).

Furthermore, there is an emphasis in bioethics on the ethical and social implications of the fostering a "consumerist" approach to healthcare and health-related services by the use of direct-to-consumer body imaging services, including computerized tomography (CT), magnetic resonance imaging (MRI) and ultrasound (Nuffield Council on Bioethics 2010). In particular, in such a consumerist approach, which puts individuals in the position of a customer in the marketplace, conflicts have been importantly reported. These conflicts are considered to arise between the ethical values of individuals "being able to pursue their own interests" and those of state actions in order to "reduce harm, safeguarding private information, fair and efficient use of public resources and possibly social solidarity" (ivi, 166). At the same time, body imaging services have been widely advertised and sold directly to asymptomatic individuals by commercial companies as a form of their "health check-up" in a highly suggested health "responsible behavior". However, the lack of regulatory frameworks for these private providers to "ensure services are meeting established standards of quality and safety" has been importantly pointed out (ivi, 174-178). Appropriate legally constituted regulator schemes have been then highly recommended (ivi, 178).

## 3. Health-related Bioethics Oriented Social Movements and Body Picturing

While it is widely accepted that the fetus' ultrasound photos are coming to be crucial in discussing issues of women's autonomy (Seavilleklein 2009), there has been a tremendous influence of coma patients' photos, as body picturing in a broader sense, in discussing issues of dying patients' autonomy too. The latter could be interestingly illustrated by the world-famous Quinlan Case and the subsequent constitution of a right to privacy (liberty) in "letting die".

In particular, in January 1976, after 2 months of deliberation, the New Jersey Supreme Court in the United States ruled unanimously in favor of Karen Quinlan's parents allowing "the family of a dying incompetent patient to decide to let that patient die by disconnecting her life support" (Pence 2004, 38). Doing so, the New Jersey Court was the first to apply the right to privacy in a case of "letting die", as the Supreme Court of the United States had not made a comparable decision until that time (ivi, 38).

Taking coma Karen's photos, with the "new" "oppressive" medical technologies of nasogastric feeding tube and big respirator "unnaturally"

prolonging her dying, has been importantly determined by the respect for her autonomy and dignity in the reported her parents' refusal for their coma daughter having a photography taken to be published in a tabloid. More specifically, it has been written that:

> A hired security force vigilantly kept Karen from being photographed, thus never allowing her condition to penetrate public consciousness. During the wait for the later court verdict, a national tabloid offered the Quinlans $10,000 for just one picture. They refused because they wanted their daughter to be remembered as she had lived rather than as a coma patient. Ignorant artists even portrayed her in newspapers and magazines as a normal girl resting peacefully so that most people never understood the horrible nature of her deterioration.
>
> (Pence 2004, 32)

Furthermore, on the basis of concerns regarding the justification of the bioethical principles of autonomy and dignity in cases such as that of the Quinlan Case, scholars in social movements in bioethics have emphasized on the constitution of the end-of-life social movements as health-related bioethics oriented social movements (Aspradaki 2008). It is well accepted that "contentious politics consists of a wide range of portrayals of concerted social actions aiming to overcome deeply rooted structural obstacles" (Kousis 2004, 275). In such a context, end-of-life social movements, going beyond the typologies of health social movements (Brown *et al.* 2004; Brown and Zavestoski 2004; Epstein 2008), demand institutional (public) support for legal reforms supporting the "right to die" while simultaneously changing the relationships between patients, doctors and the state. They also play a crucial role in the development and strengthening of the public in view of the omnipotence of biotechnologies, the negotiability of death and more generally the medicalization of life and death (Aspradaki 2008). More generally, issues of public participation in scientific and technological developments in contemporary democracies have been highly correlated to deliberative procedural arrangements based on substantive commitments to autonomy "for the essential establishment of the equal moral and political value of collectively acting individuals" (Aspradaki 2013, 13).

## 4. On the Understanding and Interpretation of the Principle of Autonomy of Persons

A minimalist interpretation of individual or personal autonomy often amounts simply to a right to choose or refuse medical treatments on offer and to the corresponding obligations of practitioners not proceeding without patients' consent. This interpretation has been in accordance

with an extremely ethically problematic "consumer view of autonomy" and a highly problematic consumeristic view of justification in bioethics and beyond (O' Neill 2002). Alternatively, autonomy, against such "atomistic reductions to individual preferential choice" (Tsinorema 2006), should be interpreted as a "principled autonomy" that is "expressed in action whose principle could be adopted by all others" (O' Neill 2002, 85).

Moreover, in the aforementioned case of coma patients, the bioethical principle of autonomy is extremely difficult to enact in the sense of individual self-determination and self-expression, if it is not grounded on the Kantian approach, in other words, on human obligations to respect human persons and protect their inviolability and integrity (Aspradaki 2008). In this way autonomy is interpreted in terms of human dignity.

## 5. Conclusions

Respect for the autonomy of persons seems to be in high relevance to visualizing bodies. A further investigation in biomedical imaging and body picturing in both the fields of science and technology studies and bioethics normative inquiry of moral, social and political challenges resulting from the rapid developments in the life sciences and biotechnologies, would be very valuable. At the same time, evolving global economic, social and political crisis makes this need extremely urgent.

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