





FROM SOLIDARITY TO THE MARKET. THE  
HUMAN BODY AND BIOTECHNOLOGICAL  
COMMERCE



MARÍA CASADO GONZÁLEZ  
*(Editor)*

FROM SOLIDARITY TO THE  
MARKET. THE HUMAN BODY  
AND BIOTECHNOLOGICAL  
COMMERCE

CIVITAS



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# Introduction

This book is the result of the joint work that the authors of their respective chapters have been doing as part of the activities carried out at the Bioethics and Law Observatory and the UNESCO Chair in Bioethics<sup>1</sup> of the University of Barcelona, and which is currently focused on the commercialization of the trafficking of the human body and its constituent parts.

From different theoretical and practical perspectives, jurists, philosophers, doctors and geneticists are trying to unravel, from a bioethical point of view, how it can be possible for the principles of global justice and respect for acknowledged human rights to continue to be declared valid, while at the same time the commercialization of the human body, its parts and its components is increasingly accepted.

The growing trend that recommends the application of criteria prioritizing business relationships not just for the economy but also for society, and which disdains the social while basing itself on “the societal”, abandons areas to the tyranny of the market that the law once reserved for non-remuneration and solidarity among people. It was always said that money could buy everything. Another matter altogether is that this proposition should be acceptable. This is the core issue on which this book pivots, as does the research project, the results of which these articles are a part<sup>2,3</sup>.

1. The Bioethics and Law Observatory (1995) is a research centre of the University of Barcelona that works in the analysis of the ethical, legal and social implications of biotechnologies from the perspective of the acknowledged human rights; it has the backing of the consolidated research group “Bioethics, Law and Society”, of the Generalitat de Catalunya (2005) and it constitutes the basis of the University of Barcelona’s UNESCO Chair of Bioethics (2007).
2. Research project “BODYBYLAW: Transferencias de material biológico de origen humano: aspectos sociales, jurídicos y bioéticos” (MINECO DER 2014-57167-P).
3. The previous debates were held in February 2016 as part of the 10th Seminar on the Universal Declaration on Bioethics and Human Rights, by UNESCO, dedicated to

Throughout the chapters in this book, facts and arguments are presented that will enable readers to support their own approaches and contribute to the informed social debate, and thus promote public policies in keeping with the democratically agreed model.

After this introduction, the coordinator of the book, Dr María Casado (Full Professor of Philosophy of Law. Director of the Bioethics and Law Observatory and of the Master's degree in Bioethics and Law, holder of the UNESCO Chair of Bioethics, and member of the University of Barcelona Bioethics Committee)<sup>4</sup> considers, in her chapter "Free or at a Price? Concerning the Human Body as a Resource", the issue of whether the human body and its parts ought to be the object of financial gain, and she points out examples that are evidence of the contradiction between the facts and the laws that regulate them and the collision between the two coexisting models of analysis. In the chapter "The Right to One's Own Body and its Consequences", Dr Manuel Atienza (Full Professor of Philosophy of Law at the University of Alicante, editor of the journal *Doxa* and director of the Legal Argumentation Observatory for the Spanish-speaking world. Professor of the Master's in Bioethics and Law at the University of Barcelona)<sup>5</sup> analyses the different ways of understanding the right that an individual has over their own body and the consequences involved in subscribing to certain ideas of human dignity. Next, Dr Ana Rubio (Full Professor of Philosophy of Law at the University of Granada and president of the Spanish Society of Legal and Political Philosophy. Member of the Bioethics and Law Observatory, University of Barcelona)<sup>6</sup>, in her chapter "Subject, Body and Market: a Complex Relationship", supplies the context in which the concepts operate and shows that not only has the reduction to bodies for the market –or for the reproduction that liberal modernity carried out– not disappeared, but it has been reinforced as a consequence of the process of objectification and commercialization of all human bodies. Following that, Dr Albert Royes (Retired Professor of Medical Ethics in the Faculty of Medicine of the University of Barcelona. Member of the Bioethics and Law Observatory and secretary of the University of Barcelona

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commenting on article 21: "Cross-border practices. The human body in the global market", a seminar in which all the authors in the book took part.

4. See <http://www.bioeticayderecho.ub.edu/es/dra-maria-casado>.

5. See [https://es.wikipedia.org/wiki/Manuel\\_Atienza\\_Rodr%C3%ADguez](https://es.wikipedia.org/wiki/Manuel_Atienza_Rodr%C3%ADguez).

6. See [http://directorio.ugr.es/static/PersonalUGR/\\*/show/b2c41aaac9e31559e16dac0db3101bb](http://directorio.ugr.es/static/PersonalUGR/*/show/b2c41aaac9e31559e16dac0db3101bb).

Bioethics Committee)<sup>7</sup>, faced with the question “Is there Anything that Money Can’t Buy?” proposes arguments that distinguish the factual from the prescriptive. Dr Ricardo García Manrique (Full Professor in Philosophy of Law at the University of Barcelona. Member of the Bioethics and Law Observatory and lecturer on the Master’s in Bioethics and Law, University of Barcelona)<sup>8</sup>, in his contribution “Is My Body Mine? Concerning the Private Ownership of the Human Body”, reviews the constant expansion of the sphere of commerce, of what can be owned and exchanged for a price, and he points out how, more and more, the human body is threatened with colonization by the market. He is followed by the chapter “Between Property and Person: the Disposal of Body Parts and Products. An Analysis from the Perspective of Civil Law”, by Dr Esther Arroyo (Full Professor of Civil Law and holder of the Jean Monnet Chair of European Private Law at the University of Barcelona. Professor on the Master’s in Bioethics and Law, University of Barcelona)<sup>9</sup>, who with an approach that focuses on civil law and goes beyond it, discusses whether everything that is not a subject of law can be the object of a real right as long as it serves to be used by human beings, or whether, on the contrary, the separate parts of the body still belong to the subject and must consequently be considered *res extra commercium*. The following chapter, “Notes on the Human Body and its Parts in the Market”, by Dr Salvador Darío Bergel (Holder of the Chair of Bioethics and Emeritus Professor of Business Law, University of Buenos Aires)<sup>10</sup>, tackles the issue from an approach doubly rooted in bioethics and business law, who comes from the other side of the Atlantic Ocean to uphold the idea that is based on the major declarations of human rights and the principles of universal justice.

After this first part of the book, theoretical and argument-based, part two is devoted to explaining how facts and situations actually occur, in which the decision must not be put off for another day, nor must we look the other way. Dr Esther Farnós (Professor of Civil Law at Pompeu Fabra University, Barcelona)<sup>11</sup> devotes her chapter to pointing out the need to adopt a normative decision in a subject that arouses local and global discussions, in “Should Surrogacy Be Permitted in Spain? The State of the Question and Some Considerations”. Next, Dr Chloë

7. See <http://www.bioeticayderecho.ub.edu/es/albert-royes-i-qui>.

8. See [http://www.ub.edu/dptscs/filodret/?page\\_id=113](http://www.ub.edu/dptscs/filodret/?page_id=113).

9. See <http://www.ub.edu/dret/professor/cas/earroyo.ub.edu.html>.

10. See <http://www.bergelmartinez.com.ar/consultor.html>.

11. See <https://www.upf.edu/dretcivil/professorat/farnos.html>.

Ballesté (Professor, Department of Surgery and Surgical Specialities in the Faculty of Medicine, University of Barcelona, and International Cooperation and Development Director of the Transplant Procurement Management Foundation – Donation and Transplantation Institute)<sup>12</sup> develops one of the most classic and endlessly interesting themes, “Organ and Tissue Donation and Transplantation: Altruism or Business?” There follow the reflections and data supplied by Dr Carme Barrot (Associate Professor of Legal and Forensic Medicine, Faculty of Medicine, University of Barcelona, and head of the Forensic Genetics Laboratory)<sup>13</sup> in “The Commercialization of Genetics”. In her chapter “Emergent Research and Markets: Websites, Apps, Big Data, Biological Samples and Genetic Information”, Dr Míriam Méndez (Lawyer in the Hospital Clínic of Barcelona Legal Services, and member of the Clinical Research Ethics Committee, Hospital Clínic of Barcelona) talks about the problems research ethics committees face when performing their multiple functions in extremely complex contexts that go into emergent markets. To end with, Dr Itziar de Lecuona (Professor in the Department of Public Health, Faculty of Medicine, University of Barcelona, member of the Bioethics Committee of Catalonia, of the Research Ethics Committee of the Hospital Clínic of Barcelona, and of the Bioethics Committee, University of Barcelona. Professor on the Master’s in Bioethics and Law, University of Barcelona)<sup>14</sup>, in her chapter “The Trend Towards the Commercialization of Human Body Parts and of Privacy in Research with Biological Samples and Data (Big and Small)”, reviews the situation of research with respect to the dilemma, or compatibility, between altruism and financial gain that arises with rare force in these fields, which constitute a very interesting area for research and for the market.

I thank all of these authors for their generosity when giving us the benefit of their knowledge and for their involvement in the making of this book. At the same time, I wish to thank Editorial Fontamara for its generosity and the facilities for joint publication with Edicions de la Universitat de Barcelona, which has worked with its habitual adaptability and professionalism. It is my hope and wish that readers will appreciate the value of contributions such as those in each of the chapters, since the information contained in them is not easy to find or to supply. Nevertheless, pooling all this analysis and reflection is necessary for a

12. See <http://wp2.eulivingdonor.eu/expo-speakers/chloe-balleste/>.

13. See <http://www.ub.edu/spublica/equip.html>.

14. See <http://www.bioeticayderecho.ub.edu/es/itziar-de-lecuona>.

## INTRODUCTION

dialogue to be possible that, starting with the facts, makes it possible to hierarchize the values and update the laws, and to reach an agreement that does not disdain the requirements of universal dignity on which human rights are based.

MARÍA CASADO

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# Part one



# Free or at a Price? Concerning the Human Body as a Resource\*

MARÍA CASADO

Who owns the body? The person concerned, his or her relatives, a god who has given it to us, Mother Nature, who wishes it to be inviolable, a social power that takes possession of it in a thousand ways, a doctor or a judge who determines its fate? And what body are we talking about?

These questions refer to ancient narratives, but which are constantly renewed, with old and new subjects that fight over their mortal remains. In the meantime, the object in question multiplies and decomposes, seeks unity and fragments. They seem like giddy games of mirrors in which various bodies –physical and electronic, material and virtual, biological and political– confront one another. The body is increasingly coming to be understood as a series of separate parts that takes us back to the hypothesis of the *homme machine*.

Stefano Rodotà, “The Body”, in *La vida y las reglas*<sup>1</sup>

## 1. INTRODUCTION

In a period when “the new gospel is consumption and the only acknowledged rite is selling and buying”<sup>2</sup>, we should be asking ourselves what is the role of the law and what is the place of bioethics, and whether –with the excuse of exercising free will– it is acceptable to trade with fundamental rights and with the human body itself. Human rights are non-negotiable,

\* Research project “BODYBIOLAW: Social, legal and bioethical implications of the transfers of biological material of human origin:” (MINECO Der2014-57167-P).

1. See the magnificent book by S. Rodotà (2010), *La vida y las reglas*, Trotta, Madrid, an essential work for this subject. The quote is from p. 93.
2. Rodotà, *La vida y las reglas*, p. 15 Op. Cit.

and dignity and freedom are off-limits to the market because the law must not be a copy of mercantile ideology, since belonging to the civilized world brings with it the obligation to uphold the principles that have gradually marked its development<sup>3</sup>. This has inescapable consequences in the sphere of health and for the consideration afforded the human body and its components in a context of increasing privatization. Just as the person is no mere economic subject identified by making decisions according to his or her patrimonial capacity, nor are laws the mere management of everyday interests. As a guarantee of shared interests, they come somewhere between morality and politics, which should not be mere administration *à la carte*, nor permit “bioethical tourism” that sidesteps the legal barriers, using those most favourable for the fulfilment of the wishes of privileged groups. “The market, a new agent that has joined in the debate –playing an essential leading role– is governed by rules and principles that have nothing to do with either ethics or bioethics and which exert a very often crucial influence over the powers of the State”<sup>4</sup>.

## 2. THE DISTANCE BETWEEN PRESCRIPTIONS AND PRACTICES

The national and international legal framework places transactions with the human body and its parts under a general mantle of non-remuneration and solidarity. In theory it may be said that, invoking human dignity, only things can have a price and therefore the human body and its parts are beyond the reach of the market. But this point of departure, which is generally accepted, clearly clashes with the reality of the practices that are carried out in the sphere of health and research; this is the case in Spain and elsewhere. So much so that, even on a theoretical level, analyses are being made that reformulate the established norms in order to accept making a profit in this sphere too.

From my point of view the fact that such a distance exists between the facts and their regulation is serious, and I therefore consider it necessary for bioethics to encourage careful reflection on the values underlying the various contrasting options, to help to stimulate an informed debate in society about the model, and to point public policies in the right direction.

Article 2 of the Council of Europe’s Convention on Human Rights and Biomedicine establishes the primacy of the human being, pointing out that “the interests and welfare of the human being shall prevail over

3. Rodotà, *La vida y las reglas*, pp. 44-51.

4. Bergel, S. (2007), “Bioética, cuerpo y mercado”, *Revista Colombiana de Bioética*, vol. 2, N.º 1, Jan-Jun, p. 136.

the sole interest of society or science” and, unequivocally, in article 21 it institutes the prohibition of financial gain: “the human body and its parts shall not, as such, give rise to financial gain”. Furthermore, article 22, referring to the use of parts taken from the human body, envisages that “when in the course of an intervention any part of the human body is removed, it may be stored and used for a purpose other than that for which it was removed, only if this is done in conformity with appropriate information and consent procedures”. The Council of Europe has been reiterating the non-trading principle over the years in different pronouncements. Examples are the Council of Europe’s Convention on Action Against Trafficking in Human Beings<sup>5</sup> and the Statement on the prohibition of any form of commercialization of human organs, of 2014<sup>6</sup>. The international institutions urge States to penalize organ trafficking<sup>7</sup>. At the same time, it is important to mention that the European Union’s Charter of Fundamental Rights also establishes in article 3.c the prohibition of the human body and its parts being made a source of financial gain. Moreover, the United Nations Organization for Education, Science and Culture (UNESCO)’s Universal Declaration of Human Rights and Bioethics points out in article 21.5, concerning transnational practices, that “States should take appropriate measures, both at the national and international levels, to combat ... illicit traffic in organs, tissues, samples, genetic resources and genetic-related materials”<sup>8</sup>. Also, UNESCO’s Universal Declaration on the Genome and Human Rights, protecting Human Rights with respect to new possibilities of the genetic technologies, advocates that the genome is the heritage of humanity, and in article 4 it establishes that the genome, in its natural state, shall not give rise to financial gain. It furthermore attempts to provide incentives for scientific cooperation in order to allow developing countries to gain access to the benefits of biotechnology.

5. It should be pointed out that the Convention was signed in Santiago de Compostela. See <http://www.msssi.gob.es/gabinete/notasPrensa.do?id=3415>. Furthermore, in Spain, Organic Law 5/2010, 22 June, adds to the Law Code (article 156 bis) the crime of illegal human organ trafficking, intended to respond to both domestic trafficking (especially via Internet) and to “transplant tourism” in clinics in other countries.
6. The Declaration states in paragraph three “... *les organes humains ne doivent pas faire l’objet d’un commerce, ni être source de profit ou d’avantages comparables pour la personne sur laquelle ils ont été prélevés ou pour un tiers*”. See <Déclaration relative à l’interdiction de toute forme de commercialisation d’organes humains>.
7. For example, Resolution 63.22, 21 May 2010, of the World Health Organization (WHO), which establishes the guiding principles on transplants of human cells, tissues and organs.
8. Casado, M. (coord.) (2009), *Sobre la dignidad y los principios. Análisis de la Declaración Universal sobre Bioética y ddhh de la Unesco*, Civitas, Cizur Menor.

In the European Union, community legislation closely associates concern over voluntary non-remunerated donation with the quality of the donations. Directive 2004/23/EC<sup>9</sup> establishes in article 12.1 that Member States must submit reports to the Commission every three years on the existing situation in relation to the said principle; based on them, the Commission must inform the Parliament and the Council of any additional measure that it deems necessary in relation to the said donations. The report submitted on 21 April 2016 reveals in section 3.4<sup>10</sup> that, even though States comply with the adoption of measures to guarantee voluntary non-remunerated donation, it is difficult to assess their compliance exhaustively. Furthermore, it warns that some practices that are considered compensation in one country may be seen as payment in another, due to the differences in purchasing power in each of the Member States. The report confirms the difficulties arising from the dissimilar monitoring and control of the registers, and insists that non-remuneration is a guarantee of safety to protect human health, since if donors were allowed to be paid they might feel tempted to conceal important health data. It is interesting to note the data of the Eurobarometer, according to which only 13% of citizens consider it right to receive money for donation<sup>11</sup>.

In Spanish legislation, non-remuneration for human organ and tissue donation is an established ethical principle and it is considered contrary to human dignity to trade with body parts. The law advocates the general principles of non-remuneration and altruism for the donation of organs, cells and biological samples; the specific regulation established for the various fields –for example egg donation– is based on the same consideration. What is questionable is that, once this principle has been established, “other possibilities” are accepted, and the principles that seemed solidly established are gradually watered down in practice and are even downgraded in the development regulation itself. Hence the confirmation that once again the legislation operates as a screen concealing, or at least embellishing, the reality. This also occurs in other areas, such as the theoretical equality between men and women, but the one that interests us here is the creeping, almost imperceptible paradigm shift gradually being legitimized which entails very profound cultural consequences.

9. See <https://www.boe.es/buscar/doc.php?id=DOUE-L-2004-80731>.

10. Report of the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, relative to the application of Directives 2004/23/EC and 2006/86/EC which establish safety and quality standards for human cells and tissues, Brussels, 21 April 2016. In particular, see, pp. 13-16.

11. Report of the Commission to the European Parliament..., p. 15.

## EGG DONATION

Examples illustrating what I wish to make clear can be seen just by looking at the posters on the walls of any university faculty in Spain appealing for human egg<sup>12</sup> or semen donors. Designed to make the greatest impact, they stress the idea that donating eggs is donating life, while at the same time revealing the existence of “compensation” that currently stands at about 1,300 euros. This approach is common to almost every assisted reproduction centre, the only difference being the more or less aggressive nature of their advertising campaigns<sup>13</sup>. Adverts like this are received –via mobile telephone too– by women within the target age range and profile, something that questions the commercial use of personal data, and especially health data that are sensitive and require special protection.

To begin with, there are two issues here: firstly, advertising to boost donations is prohibited and it is clearly established that campaigns to encourage them must be informative and not commercial; secondly, in a period of crisis and unemployment such as the present one, isn't this compensation a surreptitious payment? Initially, the authorities set the amount of the compensation taking into account travel, expenses, and so on, but clinics have been raising the amount they offer, since they acknowledge that it has to be “a little bit enticing” to obtain “donors”. We should remember that, as the previously mentioned Directive 2004/23/EC warns about tissue donation, the payment of a large sum might corrupt the consent of the young women who agree to donate, since the desire for financial gain could lead them to underestimate the physical and psychological risks of ovarian stimulation and egg retrieval<sup>14</sup>. Moreover, the globalization of the practices and the lack of donor registers, updated and inter-connected<sup>15</sup>, may give rise to the existence of

12. See Casado, M. and Egozcue, J. (coords.) (2000), “Documento sobre donación de ovocitos”, Opinion Group of the Bioethics and Law Observatory, University of Barcelona, [www.bioeticayderecho.ub.edu/documentos](http://www.bioeticayderecho.ub.edu/documentos).
13. See some of the centres' webpages, which are generally more careful in their content than the advertisements in the street, as they are designed to comply with the law and at the same time imply the rest: [www.institutomarques.com/donantes-ovulos.php](http://www.institutomarques.com/donantes-ovulos.php); <https://ivi.es/donantes/>; <http://www.dexeus.com/donante-ovulos>; <http://www.icinfertilidad.com/>.
14. In 1998, the National Assisted Reproduction Committee assessed compensation as a sum equivalent to about 600 euros, and now about 900 euros is recommended; nonetheless, this amount has in practice been increasing, with some divergences between the different autonomous communities; variations are also seen between private clinics and public hospitals. For more information see Alkorta, I. (2003), *Regulación jurídica de la medicina reproductiva*, Aranzadi.
15. Although mandatory in Spain since 1988.

“professional donors” who may even come from other countries with lower income levels<sup>16</sup>.

## SURROGATE MOTHERHOOD

Another of the discussions that generate a high degree of controversy in this field refers to the possibility of legalizing surrogate motherhood contracts. This debate concerns not only the price, but brings into play the idea of what it means to be a mother and how such bonds are constructed – or broken.

There is currently strong pressure in favour of legalizing surrogate motherhood by both assisted reproduction clinics and male homosexual couples who, after the legalization of gay marriage, argue that this is the only way for one of them at least to become biological parents. Although its defenders claim that surrogates offer to perform this service voluntarily and altruistically, there is in fact a great deal of evidence to the contrary<sup>17</sup>. Even if the woman is only paid in the form of compensation, the existing commercial network associated with it is extremely lucrative; something that leaves up in the air the considerable debate of whether or not it is acceptable for everyone except the surrogate to make money<sup>18</sup>.

Those pushing for the law to accept surrogate motherhood contracts claim that it is better to regulate a situation that “occurs unavoidably in the globalized world”, a maxim that strangely is not invoked for other activities such as drug trafficking, for example. Nevertheless, it continues to be one of the arguments that is most forcefully put forward by supporters of authorization along with the theory that, if there is no law, the surrogate is defenceless against the clients, since depending on her ability to deal with pressure and her knowledge she will either be in a situation of vulnerability or at the other extreme she will be paid six-figure sums or more.

Some also argue that the prohibition of surrogate motherhood contracts is paternalistic towards women who decide “freely” about their body. But, as I see it, an attempt should be made first to determine precisely what requirements have to be taken into account to describe a decision as

16. In 2005, complaints by different countries (Great Britain, Spain...) gave rise to a resolution of the European Parliament that condemned trading in human eggs.

17. See, for example, <http://californiafertilitypartners.com/spanish/infertility-treatment-options/gestational-surrogacy/>.

18. From my point of view, also very interesting is the social acceptance of intermediaries' agencies, which are a key element for identifying “low-cost” and “high-cost” surrogates.

free. The same argument for free decision is the one used by the defenders of sales of human organs, tissues or services associated with the body. It is not acceptable to appeal to the autonomy of decision-making in conditions of extreme poverty, as we know is usually the case in relation to the sale of organs; in such circumstances there are no alternatives, nor information about options, nor a fair price for the “donor”. And we do not even have to look at other countries, since despite the much publicized and successful Spanish transplantation model, here also attempts to perpetrate these acts have been detected that it has apparently been possible to thwart. In Bergel’s opinion, “...someone who goes to the market offering body parts or products is in a situation of inferiority in relation to the possible purchaser, an inferiority that increases depending on the kind of offer (offering blood or sperm –naturally renewable products– on the market is not the same as offering a cornea or a kidney). In every case the vulnerability of the person offering parts or products of their body is exploited, which makes the transaction doubly reprehensible, since in addition to the affront to human dignity there is the exploitation of a state of need, which in some circumstances subjects the seller to an inhuman mutilation. In a world characterized by multiple imbalances with regard to the distribution of wealth and the individual’s possibilities for fulfilment, the matter takes on a larger dimension since no one is unaware of the state of extreme poverty in which huge masses of the world’s population find themselves”<sup>19</sup>.

## ORGAN DONATION

I mentioned earlier that we only have to walk around and read posters in university faculties –or on the streets– and we begin to doubt the non-remunerated status of trafficking with the human body; if we take a step further and read certain newspapers or we search on the Internet, we shall discover offers to buy and sell kidneys, eggs, bone marrow and parts of the liver at varying prices, which depend on the place of origin or whether the donor has a good advisor and is capable of “negotiating”. The issue of living donor transplant trafficking is one of the most archetypal and terrifying since, even though it is penalized by the law and prohibited by international conventions, it is obvious that organ selling is a reality<sup>20</sup>. What is more, some justify its acceptance, with certain provisos;

19. S. Bergel, “Bioética, cuerpo y mercado” ..., pp. 149-150.

20. See [http://elpais.com/diario/2012/01/17/sociedad/1326754803\\_850215.html](http://elpais.com/diario/2012/01/17/sociedad/1326754803_850215.html), <http://www.rtv.es/noticias/20120119/sanidad-creara-registro-unico-publico-donantes-medula-osea/490901.shtml> and [http://sociedad.elpais.com/sociedad/2012/01/16/actualidad/1326745598\\_760215.html](http://sociedad.elpais.com/sociedad/2012/01/16/actualidad/1326745598_760215.html).

according to this idea, market and propertarian logic once again legitimates these “rational choices”.

The moral issues raised by living donor organ transplants are associated with the values of justice and solidarity and with the fact of social and economic inequality; furthermore, they pose specific problems that affect the autonomy, safety, health, quality of life and privacy of donors. The sale of organs, a phenomenon that is spreading rapidly around the world, is one of the greatest expressions of the inequality of resources and living conditions<sup>21</sup>. Therefore, the spread of organ donation and transplantation must be accompanied by increased measures to prevent the covert sale of organs. In this respect, the Opinion Group of the Bioethics and Law Observatory, which I direct, issued a statement in which it warned of the dangers of covert commercialization in living donor transplantation. Additionally, the statement pointed out that the sale of organs is a practice that “infringes human dignity because it turns the person of the vendor (their body, their health and even their life) into a means at the service of the purchaser; and also that, given the current inequality of resources between people (at a local level, but above all at a global level), it represents a particularly hateful version of the exploitation of some people by others”<sup>22</sup>. I abide by it.

## BLOOD DONATION

Another example one cannot avoid mentioning is that of blood, whose non-remunerated donation was considered a hallmark of solidarity in Spain and other countries, which made it possible to overcome historical situations of extreme poverty and exploitation –the so-called vampires, the queues of people in need selling their blood that Victor Hugo wrote about. Nevertheless, the managing director of the Grifols pharmaceutical company, the most important in Spain specializing in blood plasma– which is quoted on the stock exchange and which has been designated by the Wikileaks papers as a point of strategic interest for the USA – has allowed himself to propose the purchasing of blood from unemployed people in order to thus supply the needs of his company

21. See <http://www.abc.es/20120615/espana/abci-delitos-internet-venta-organos-201206141937.html>, [http://sociedad.elpais.com/sociedad/2014/03/12/actualidad/1394632795\\_283474.html](http://sociedad.elpais.com/sociedad/2014/03/12/actualidad/1394632795_283474.html) and <http://www.larazon.es/historico/vendo-rinon-por-50-000-eur-el-negocio-de-la-donacion-de-organos> FLLA\_RAZON\_124686.
22. Buisan, L.; García Manrique, R.; Mautone, M. and Navarro, M. (coords.) (2011), *Documento sobre trasplante de órganos a partir de donante vivo*, drafted by the Opinion Group of the Bioethics and Law Observatory, Barcelona, see [www.bioeticayderecho.ub.edu/documentos](http://www.bioeticayderecho.ub.edu/documentos).

and, furthermore, to “benefit them”, so that by “donating periodically, they can make ends meet”<sup>23</sup>.

## RESEARCH WITH HUMAN BEINGS, BIOLOGICAL SAMPLES AND HEALTH DATA

Although the sale of organs is illegal and the channels of access are semi-clandestine, other instances of the commercialization of human body parts take place in plain sight<sup>24</sup>. There are examples of such practices associated with banks of umbilical cords, bone marrow and stem cells, or human subject research. It is interesting to note that the communication systems used by students of medicine and health sciences, faculty information boards included, include advertisements aimed at recruiting healthy volunteers for clinical trials that mention the “compensation” on offer<sup>25</sup>, something that casts doubt on the principle of non-remuneration, and even free and informed decision-making.

If we broaden the scope and turn our gaze to the donation of biological samples of human origin, knowing full well that altruistic donation implies waiving exploitation rights<sup>26</sup>, we shall also find a market. To the monetary value that the biological sample of human origin acquires, we must add that of the associated personal data, depending on the context in which it is wished to use the samples and data; this is something that generally occurs without the source subject knowing. Biomedical research and genetic testing enable us to broadly appreciate that human body trafficking is not free of charge and supportive. The so-called “triad of researchers, patients and laboratories” is seen

23. These declarations were widely reported by the audio-visual and written media. See examples: *El País*, 17 April 2012: [http://ccaa.elpais.com/ccaa/2012/04/17/catalunya/1334651946\\_436308.html](http://ccaa.elpais.com/ccaa/2012/04/17/catalunya/1334651946_436308.html), and also [http://sociedad.elpais.com/sociedad/2012/04/30/actualidad/1335812150\\_848890.html](http://sociedad.elpais.com/sociedad/2012/04/30/actualidad/1335812150_848890.html).

24. See <https://www.23andme.com/en-int/>, <http://www.clinicamenorca.com/test-genetico-vitagenes> and <http://www.elle.es/belleza/cara-cuerpo/news/a503353/rejuvenecimiento-facial-con-celulas-madre/>.

25. They are invited to take part in trials with a variable remuneration that may be 450 euros for four days a week, which may also include full board.

26. “Article 7. Non-remuneration. The donation and use of human biological samples will not be remunerated, whatever their specific origin, and under no circumstances shall the compensations envisaged in this law be lucrative or commercial”. Donation implies, furthermore, the waiving by donors of any economic right, or of any other kind, over the results that may be derived directly or indirectly from the research carried out with the said biological samples. Law 14/2007, 3 July, of biomedical research, retrieved from <https://www.boe.es/buscar/act.php?id=BOE-A-2007-12945>.

necessarily to overlap, but without sharing interests or expectations, or even assessment guidelines, because while research pursues innovation, patients wish to obtain benefits in therapies and wellbeing, and businesses seek greater financial gains in the short, medium and long term<sup>27</sup>.

But if we still have any doubts about the change that is taking place, we can focus our attention on the sale of health data contained in computerized medical records. This is based on the reuse of data that is in turn based on their anonymization. Given that it is now beyond all doubt that re-identification is technically possible, it is obvious that invoking anonymization as protection for personal data is yet another respectable front.

### 3. TWO CONFLICTING MODELS: DIGNITY AND RIGHTS V MARKET SOCIETY

The treatment of the human body, its parts and components, is a core theme for bioethics. Historically, it has been a question of the utmost interest for medicine, anthropology, ethics and legal philosophy. In different cultures, the consideration given to the human body is diverse, and although the distinction between body and matter –with their different names– may now be considered outdated, it must be acknowledged that it continues to imbue many of the most common ideas, and underlies numerous bioethical discussions on the subject<sup>28</sup>. The idea that the human body has a “special dignity” is usually thought to refer to its totality; the notions of unity and integrity are associated with the dignity of the human body, since it is the human being –one and indivisible– that has dignity and is priceless<sup>29</sup>. But when its separate components and parts are referred to, that peaceful agreement disappears and the status of the various body parts is subject to discussion.

In the current context of unbridled neoliberal globalization, the market sets a price and objectifies, and science and technology become essential operators. The twofold onslaught of the market and of science and

27. Cardozo de Martínez, Carmen A.; Sorokin, Patricia D. and Sotomayor, María Angélica (2015), “Bioética y derecho a decidir sobre el propio cuerpo, sus extensiones, productos y derivados: el discutible caso de las células HeLa”, in *Medicina & Laboratorio*, vol. 21, nos 11-12.

28. For example, see <http://comitebioetica.cat/wp-content/uploads/2012/03/pocbc.pdf>.

29. Kant, I. (1990), *Fundamentación de la metafísica de las costumbres*, Ariel, Barcelona.

technology divides and cuts up organs, tissues, cells and genes, so speaking about the dignity of the parts of the human body is problematic to say the least<sup>30</sup>.

In this context two trends have been outlined with respect to the consideration merited by the human body and its parts: the continental and the Anglo-American. Although the former option was initially the dominant one, it has gradually lost ground to the latter one. In 2000, Hottois<sup>31</sup> revealed the existence of two opposing models that he called “Euro-French” and “Anglo-American” and, along the lines of the studies of the Council of Europe, he defended the priority of the former, then very much a part of continental European and Latin American bioethics. He considered the human body to be out of bounds to commerce, based on the notion of human dignity, at the same time condemning the European Union’s mercantilist drift. This approach is opposed to leaving the human body and its parts at the mercy of a market dominated by money, technology and individual wishes. This would mean renouncing a long and valuable tradition whose cornerstone is the prohibition of the exploitation of others and the consideration that the use by a third party of a human body part is the result of a “gift”, a gratuitous act of solidarity<sup>32</sup>. It is therefore the State –and not technology, the market or money– which must mediate in these exchanges, ensuring that the agreements are transparent and that they take into account “public order” at all times. On the contrary, the Anglo-American approach is based on a particular interpretation of Locke’s thinking, as it has been developed by the libertarians who start with the idea that individuals have inalienable rights and that ownership is the most important of them; something that would also apply to the human body that –thus appropriated– becomes an asset of free exchange. This Anglo-American individualist tradition, like its contractualist concept of medical practice, has eventually penetrated even our ways of thinking. Moreover, individual freedom and wishes –elevated to the status of rights– are mixed up and confused, frequently determined by everybody’s personal context. At the same time, “... the ideology of economic liberalism turns out to be the law of the strongest and social Darwinism, which has turned society into a market that –destroying social ties and solidarity– abandons social cohesion to techno-structures frequently manipulated by private interests”<sup>33</sup>.

30. Hottois, G. H. (2001), “Corps humain”, in Hottois, G. H. and Missa, N., *Nouvelle encyclopédie de bioéthique*, Ed. de Boek Université, Brussels, pp. 243ff.

31. Hottois, “Corps humain”..., pp. 248-249.

32. Rodotà, “El don”, *La vida y las reglas...*, pp. 139ff.

33. The opposition between these two trends that affects bio-law and bio-politics –closely related to bio-economics– has been outlined intriguingly by Hottois

To sum up, the regulation of trading with the products of the human body depends on the way in which the human body is perceived –object body/subject body– and it looks different according to the idea that each society has of freedom, free will, and responsibility. If one considers that the body is a property of the subject, freedom is limited by the product’s possibility of regeneration, and information is required for valid consent. But, if one starts from a relationship of identification between body and subject, even the separate parts of the human body deserve to be considered differently, making it necessary to take the notion of non-remuneration seriously. Of course, biomedical technologies have turned the human body and its parts into raw materials for industry, but this must not imply a new source of discrimination and exploitation. Although it is not reasonable to place the parts on an equal footing with the whole body, it is neither desirable to legally turn them into mere “things”. It may be a good idea to establish specific regimes for “products of human origin” which, according to their different symbolic characteristics, would not fit in a single concept either<sup>34</sup>.

In 2000 it could still be maintained that there were two paths before us; by 2016 it was clear that development had brought with it a tendency to the “reification” of the human body through technology and, even more so, the market, a “divine entity” that now regulates not only the economy but also human relationships and society itself<sup>35</sup>. A paradigm shift has gradually been taking place through financial incitements, the education –persuasion– of advertising, or due to a utilitarian rationalization of research and the idea of “taking advantage” of what is not used (for example, with the “reuse” of the health data in the hands of the authorities by public/private third parties, and the establishment of “presumed consent”). It can be seen that the mercantilist concept of the human body –and the law– is winning the contest. This is obvious not only because of the proliferation of deplorable events that we hear about every day, but also the philosophical foundations on which it is based and which, pragmatically, are shifting from facts to prescriptions, and from “it is” they are moving towards “it must be”, committing an elementary naturalistic fallacy.

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(“Corps humain” ..., pp. 212-213), saying that the American citizen is the owner of his body, while the French citizen is merely the occupant of a body that belongs to the State.

34. Hermitte, M. A. (2001), “Commercialisation du corps et de ses produits”, in Hottois, G. H. and Missa, N., *Nouvelle encyclopédie de bioéthique*, Ed. de Boek Université, Brussels, pp. 207ff.
35. Sandel, M. (2013), *Lo que el dinero no puede comprar. Los límites morales del mercado*, Debate, Barcelona.

#### 4. SOME THOUGHTS ABOUT JUSTICE AND THE CONSIDERATION OF THE BODY AS A RESOURCE

If dignity is (or should it be was?) the greatest of values, competitiveness, profitability and financial gain can neither surpass it nor replace it. In this respect, as Felber points out, one must maximize the common good, going one better than capitalism in its current market society version, because if the supreme good is oneself and we deceive everybody else in everything, we are losing our dignity<sup>36</sup>. No society can prosper or be happy if the majority of its members are poor and unhappy<sup>37</sup>. The symptoms of collective impoverishment are visible all around us because private wealth and public poverty are made explicit. In the last 20 years the welfare state has been left by the wayside and the inequality gap has been growing constantly, not only between countries, but also within countries<sup>38</sup>.

Laws reflect social agreements expressing them in legal terms. In other words, if the system is truly democratic, they express the consensus reached over what is considered just and fair in each society, for each specific field. Beyond the rules of positive law, it is necessary to state that the conceptual development of human rights represents in itself a theory of justice, applicable to the distribution of goods and values as far as health is concerned<sup>39</sup>, since it is what must be demanded and it concerns fair distribution in the global and local world.

The reference to justice is crucial in the distribution of assets and especially when there is a problem of scarcity, as is the case with the availability of human organs and tissues. The core idea of the debate requires the place of individual responsibility –said to be lost– and of collective responsibility to be clarified, and for it to be determined whether it means a loss of autonomy and of the personal project, as the libertarians suggest, or rather it is the consequence of the social nature of human beings<sup>40</sup>. Thus, it is wholly relevant to answer the question of what it is we owe one another and what are the State's obligations with regard to the availability and the allocation of healthcare resources, bearing in mind that they include parts and components of the body.

36. Felber, C. (2012), *La economía del bien común*, Deusto, Barcelona.

37. Smith, A. (2011), *La riqueza de las naciones*, Alianza, Madrid.

38. Judt, T. (2011), *Algo va mal*, Taurus, Madrid.

39. Martínez Bullée-Goyri, Víctor (2013), "Sobre los derechos humanos y la justicia", in González, Juliana and Linares, Jorge (coords.), *Diálogos de bioética. Nuevos saberes y valores de la vida*, FCE / UNaM, Mexico City.

40. See the interesting polemic by Schmidt, D. and Goodin, R. (2000), *El bienestar social y la responsabilidad individual*, Cambridge University Press, Madrid.

Public ethics is linked to a particular policy and refers to a series of anthropological suppositions about human nature and to other –sociological– suppositions about action. We are witnessing a sort of twilight of duty in which the language of virtue and of the common good has been replaced by the language of individual happiness and the supportive citizen’s good conscience. Neoliberalism suppresses the notion of the ethical State, considering as a preferable option that of the minimal State which regards politics as instrumental, and in which ethics is relegated to the internal sphere of the sovereign individual’s project and his or her freedom<sup>41</sup>.

According to Daniels’s classic<sup>42</sup> there are three main criteria for allocating health resources: market, rights and needs. For those who uphold the first of them, goods –including medical services– must be distributed in accordance with supply and demand, because since individuals are the main actors in this model, they will seek the suitable means for achieving their goals. The second model, the one in the constitution of Spain, the European Union and many other culturally close countries<sup>43</sup>, is faced with the problem of cuts and the breakdown of social and economic rights in the current global crisis<sup>44</sup>. The third criterion focuses on the subject of the so-called basic necessities, about which there has been a great deal of debate in philosophical, legal and economic circles in recent decades. They have even been used as the basis for human rights, because if these needs are not met it is impossible for people to achieve any personal or social goals in life<sup>45</sup>.

The economic crisis has led to a quickening process of privatization of the public domain and of increased inequality in such a way that States, instead of protecting their citizens, surrender to the private financial systems that control the global economy. In countries where there used to be a good public health service, like Spain, the process of the growing privatization of medicine is an attempt by private interests to take possession of public resources that has had a notable effect on inequality. It has also affected values because commercialization –the market– has the effect

41. Rodríguez Alba, J. (2010), “Ideología y política en la ética pública. La cuestión del Estado ético”, in Peña, L. and Ausin, T. (coords.), *Ética y servicio público*, Plaza y Valdés / Dilemata, Madrid, p. 273.

42. Daniels, N. (1995), *Just Health Care*, Cambridge University Press, Cambridge.

43. For example Mexico, well explained in the chapter by Paulette Dieterlem (2013), “Bioética y justicia distributiva”, in González, Juliana and Linares, Jorge (coords.), *Diálogos de bioética. Nuevos saberes y valores de la vida*, FCE / UNaM, Mexico City.

44. See García Manrique, R. (2014), *La libertad de todos. Una defensa de los derechos sociales*, El Viejo Topo, Barcelona.

45. Dieterlem, “Bioética y justicia distributiva” ..., pp. 365-367.

of “corrupting” certain values and practices, a central strand of Sandel’s thinking on this issue<sup>46</sup>.

The fundamental moral duty not to harm people is related to equal consideration of the interests of each and every one, to justice in other words. This implies determining whether trafficking with the human body should or should not be non-remunerated and on what reasons our decision is based. I consider that it is worth taking the necessary steps to start a real debate that does not gloss over an issue in which there is profound disagreement. And that –in view of the current disagreement– it should contrast the arguments in a fair debate that once again makes it feasible to establish agreements based what we do have in common. But a debate is rather more than affirmations with which to sympathize or to abhor: it is necessary to take the trouble to argue. If the culture of debating ideas fails, it is necessary to construct it, as without it democracy cannot enjoy good health and citizens cannot enjoy good lives.

If divisions run deep in a society and there is no real debate about what is happening, democracy becomes the tyranny of the number; to avoid this, it is necessary to find shared principles substantial enough to shape a bioethical and political debate that is beneficial<sup>47</sup>. As Dworkin points out, common principles have to do with the value and the responsibilities of human life and they concern the two basic principles of human dignity: that all life is intrinsically and equally valuable, and that every person is individually and inalienably responsible for identifying and fulfilling the value of his or her own life. These principles can serve as a common basis for any bioethical and philosophical and political argument.

If every life has equal intrinsic importance, we cannot treat the life of any human being as if it were a trivial affair; if we do that, we degrade ourselves as much as it. The State must satisfy certain moral conditions to enjoy political legitimacy and exercise authority and coercive power; for that it must treat all its citizens with equal consideration – not just with consideration<sup>48</sup>. Therefore, the gap between rich and poor and the existence of extreme poverty are indefensible, and a “market society” must not be accepted, nor a State of minimums that simply guarantees transactions, nor a State at the service of powerful private interests that dictate its rules in a context of the commercialization of life, in which inequality shows no signs of being halted and which in matters of health is particularly odious.

46. Sandel, *Lo que el dinero no puede comprar...*

47. Dworkin, R. (2008), *La democracia posible. Principios para un nuevo debate político*, Paidós, Barcelona. Along similar lines, see his work, *El dominio de la vida* (1996), Ariel, Barcelona, key for reasoning in bioethics.

48. Dworkin, *La democracia posible...*



## The Right to One's Own Body (Bodily Integrity) and its Consequences

MANUEL ATIENZA

### 1

Most of the problems that are discussed in bioethics –and therefore the answers to them– have to do with the way an individual's right to their own body is understood. It is not that nobody is discussing the existence of that right, but there seem to be many ways of understanding it, and each of them also leads to a different answer to the very varied moral and legal questions that are posed with regard to abortion, euthanasia, the use of human assisted reproduction techniques, organ transplants, and surrogate motherhood. It is therefore worthwhile pausing for a moment to try to clarify a concept that is perhaps less simple than it might seem at first sight.

To start with, many jurists still think that the category to which the right to one's own body would belong (rights of the personality) is somewhat illogical, given that in them the person is considered at one and the same time the subject and the object of a legal relationship, which, apparently, would be an impossible situation or, at least, an obstacle to be overcome. Hence, some have begun to talk of "assets", instead of "rights" of the personality; or others may have thought that we ought to construct the object of that right so that it is not identified with the subject (nor –for obvious reasons– with things in the material sense) (on this point, see Puig Brutau, 1979<sup>1</sup>; Gordillo, 1987<sup>2</sup> and Lacruz Berdejo, 2012<sup>3</sup>). In other

1. Puig Brutau, José (1979), *Fundamentos de Derecho civil* (book I, vol. I, part one. General part: Sujeto y objeto del Derecho por Luis Puig Ferriol), Bosch, Barcelona.
2. Gordillo, Antonio (1987), *Trasplantes de órganos: "pietas" familiar y solidaridad humana*, Civitas, Madrid.
3. Lacruz Berdejo, José Luis (2012), *Elementos de Derecho civil*, I-2, 5th ed., Dykinson, Madrid.

words, what civil lawyers find strange is due to the fact that their notion of subjective right (which in turn has been the theoretical framework of that of “fundamental right”) has been constructed on the basis of property rights that are usually subdivided into personal (over persons) and real (over things). In the case of personal rights or rights of credit it is usually said that the creditor (as a consequence, for example, of making a contract) has the power to demand from the debtor a certain provision; and it is obvious that one cannot be both a creditor and a debtor of oneself. Nobody can make a contract with him or herself. So the right over one’s own body would have to be constructed as a real right (the prototype is the right of ownership); and then the difficulty that we saw emerges (the identification between the subject and the object of the right) and which, analysed more carefully, might perhaps be resolved thus: if the body –our body– were (in whatever way) a material thing that could be separated from the personality, then this problem would not exist, as subject and object would cease to coincide. But, of course, this is no great help either. It would allow us to speak perhaps of rights of ownership over our teeth, our hair, our fingernails or (in a limited fashion) our blood, our sperm, our eggs, which we can see as separable parts of our bodies without this meaning that we cease to be ourselves; but not of a right of ownership over our life, our limbs or our vital organs. Consider however, that the objection of civil lawyers (the objection that I am talking about) would not in principle affect the possibility of a man having a real right (of ownership) over another man or over parts of that man (his organs), since this confusion between subject and object of law would no longer arise. Or, rather, it does not affect it insofar as some men are not considered to be people, but things. Roman law recognized three types of objects over which ownership could be exercised: things, animals and slaves. And it seems that the phrase that appears in the *Digest*<sup>4</sup> and which was very often used later to uphold the idea that the Romans denied the right to one’s own body, in the sense that they could not dispose of its limbs, must be understood in reference to the free man: he did not possess the right of ownership over his body, but he could possess it over the bodies of his slaves (who were things, *rei*); so the appeal to this Roman formula by medieval theologians (*homo non est dominus membrorum suorum*) presupposed having dispensed with the earlier distinction, between free man and servant (Hervada, 1975: 201<sup>5</sup>).

4. “*Liber homo suo nomine utilem Aquiliae habet actionem: directam enim non habet, quoniam dominus membrorum suorum nemo videtur*” (Hervada, 1975: 201). The text is from Ulpian: D.X, 2,13.
5. Hervada, Javier (1975), “Los trasplantes de órganos y el derecho a disponer del propio cuerpo”, *Persona y Derecho*, n.º 2.

## 2. THE RIGHT TO ONE'S OWN BODY (BODILY INTEGRITY) AND ITS CONSEQUENCES

However, in the end, this “technical” difficulty to which jurists refer is actually very easy to get round. One only has to bear in mind the criticism that Hans Kelsen made many decades ago of the division of rights into personal (*ius in personam*) and real (*ius in rem*), in the sense that real rights are also rights with respect to people; they do not consist, basically, of a relationship between a person and a thing, but of a relationship between people<sup>6</sup>. Thus, the right of ownership over a thing would result in the obligation that all other individuals have to agree to the acts of disposal performed by the owner. And, similarly, it could be said that an individual's right over their own body would result in the obligation of everyone else to agree to the acts of disposal that he or she (the owner) made over their own body (over it, above all, or parts of it).

### 2

But with this, the basic difficulty entailed in the category of the rights of personality is of course not overcome; a category that –we must not forget– is very recent: it is not present, for example, in Spain's Civil Law Code, which dates from the late nineteenth century. And it is not overcome because what is at stake in it is very closely associated with no less than three of the most difficult and the most basic concepts of legal and moral philosophy since the Early Modern period: of rights, of the person and of dignity. In order to explain them and show how they are connected to one another, I shall begin by pointing out how a great contemporary jurist, Luigi Ferrajoli, understands them, and I shall then proceed to add some extra elements in order to obtain, as an end result, a satisfactory view of them.

### 2.1

Ferrajoli constructs his notion of basic rights based on that of subjective right and he does so moreover in purely formal terms. He tells us that, “‘Basic rights’ are all the subjective rights that correspond universally to ‘all’ human beings endowed with the *status* of people, of citizens, or of persons with the capacity to act” (Ferrajoli, 1999: 37). And he immediately explains that by subjective right he understands “any expectation,

6. Kelsen ascribes an ideological motivation to this consideration: disguising the exploitation, the control, over man represented by the capitalist right of property: see Kelsen, 1975: 143-145.
7. Ferrajoli, Luigi (1999), *Derechos y garantías. La ley del más débil* (foreword by P. Andrés Ibáñez), Trotta, Madrid.

positive (of benefits) or negative (of not suffering injury), ascribed to a subject by a law", and by *status*, "the condition of a subject, envisaged by a positive law, as the presupposition of his or her suitability to be the possessor of legal situations and/or the author of the acts by which they are exercised" (Ferrajoli, 1999, 37). To this we must add that the word "universally" has for him a purely logical and evaluative meaning. In other words, it is simply a question of the law that establishes the right in question being formulated in such a way that it includes all the individuals in the class of subjects that are possessors of the rights (people, citizens, or persons with the capacity to act). For example: "Everyone [all persons] has the right to life (although 'everyone' does not include the unborn)" (article 10, Spanish Constitution); or "All Spaniards are equal [they have the right to be treated equally – or not to be discriminated against in relation to certain circumstances: sex, race, etc.] before the law" (article 14, Spanish Constitution). But as this requirement of universality is purely formal, from it a conclusion also follows that might seem counterintuitive: "If an absolutely futile right were established as universal", says Ferrajoli, "such as, for example, the right to be greeted in the street by one's acquaintances, or the right to smoke, it would be a basic right" (Ferrajoli, 1999: 38).

From here, Ferrajoli devises a classification of basic rights as a result of the combination of two major divisions: on the one hand, between rights of the personality (which correspond to all) and rights of citizenship (which correspond only to citizens); and on the other hand, between primary rights (or substantial rights: they correspond to everyone) and secondary rights (instrumental or of autonomy: they correspond only to people with the capacity to act). We would have, in the end, four classes of basic rights: human rights, which are people's primary rights and concern all human beings without distinction; public rights, which are the primary rights acknowledged for citizens only; civil rights, which are secondary rights ascribed to all human beings with the capacity to act; and political rights, the secondary rights reserved only for citizens with the capacity to act.

One aspect that in Ferrajoli's exposition is very interesting, and which directly affects this subject, is the difference he makes between basic rights and property rights. From the point of view of their form or structure, these differences are specified in the following four characteristics: 1) Basic rights are universal rights in the sense –logical, formal– that we have seen, while those of property are singular. In other words, for each of those rights there is a possessor to the exclusion of all others; so the former

“are acknowledged to all their possessors in equal form and measure”, while the latter “belong to everyone differently, in both quantity and quality” (Ferrajoli, 1999: 46). Here it is important to be clear that one thing is “the right to be a proprietor and to have one’s own rights of ownership” (a right extensible –according to Ferrajoli– to the class of civil rights), and another, the specific right of ownership over this or that commodity (the latter is what is exclusive and is at the heart of legal inequality). 2) Basic rights (unlike property ones) are non-disposable, inalienable, inviolable, non-transferable and very personal. 3) Property rights are liable to be established, modified or extinguished by legal acts, while basic rights have their title immediately in the law (habitually constitutional). Or, to put it another way, “while basic rights *are laws*, property rights are *pre-disposed by laws*” (for example, the ownership of the computer on which I am writing this is not disposed, but predisposed by laws in the Civil Code that enabled me to purchase it through a contract of sale, but my freedom to express myself freely in this text is disposed in an article of the Spanish Constitution). 4) Property rights are horizontal, and fundamental ones, vertical; this basically means that the former belong to the private sphere (corresponding to property right –in real rights– is the generic prohibition to others to do harm or –in the case of personal rights of credit– the duty to perform a service by the person obliged), while the latter, basic rights, are part of the state-level public sphere, in other words, the limits and bonds established for their tutelage are (basically) prohibitions and obligations by the State.

If we transfer the above analysis to the right to one’s own body (in which we could include the right to life, to health, to bodily integrity and perhaps also to personal freedom) they constitute what are occasionally called [Puig Brutau, 1979] “rights of the personality in the physical sphere”. They are compared to “rights of the personality in the moral sphere” (the right to one’s name, to honour, to privacy). It seems obvious that they would belong to the category of human rights: those that correspond to all, to everybody. Although it might be thought that those rights (or the exercise of them) also involve characteristic elements of civil rights, rights of autonomy, as only those who enjoy the capacity to act (they can give their consent) may also make decisions about their own body. But what is no longer so clear is if those basic rights do not also have some element characteristic of property rights. More precisely, it seems that this could occur in relation to the characteristic of universality, which is one of the traits that, according to Ferrajoli, separate basic rights from property rights. It is indeed a fact that the right to one’s own body corresponds in principle to everyone “in equal form and measure” (as does the right to be a proprietor that Ferrajoli considers –remember– to be one of the civil

rights, and a right that is different to the right of ownership over this or that asset). But just as the specific right of ownership over certain assets is exclusive and may mean condemning others to poverty (seeing as wealth [assets] is something limited), the same could also be the case in relation to the right one has over one's own body and over its organs. In other words, given the conditions of scarcity (there are fewer organs available to be transplanted than are needed), the exercise of that right over one's own body does seem to have exclusionary effects on others (those who might need a vital organ). And that difficulty could also arise in relation to another of the characteristics of basic rights: their non-disposability. Because if I decide to donate one of my lungs so that it can be transplanted to someone who needs it, am I not disposing of it? Or can we only speak of disposal if that cession is not completely disinterested? But can I not dispose of an asset that I own (a car, a house) completely disinterestedly? And would I therefore cease (if I act disinterestedly) to exercise a property right? And, after all, if the rights to one's own body are not property rights but basic rights, does that mean that someone receiving compensation (for example, a sum of money) for having donated an organ to another person could never be accepted? Nor if that compensation does not benefit anyone in particular but, upon being paid –let's say– by the public health system of a particular country, it goes towards there being a larger number of organs available? And could not a woman dispose of her own body (would it not be morally licit), in the sense of offering to go ahead with a pregnancy, in exchange for a sum of money? Why not? In short, is the characterization that Ferrajoli makes of basic rights appropriate for the category of rights that we are looking at here?

## 2.2

These and other problems that the rights to one's own body pose, cannot be solved in the context of a theory of rights such as Ferrajoli's, precisely because, as we saw, it is purely formal and restricted to positive law: to the positive law of a State or to international law. It is useful for us as a point of departure, but the answers to questions like those above demand that we take into consideration, as well as formal and structural elements, others that are inevitably substantive and of an unequivocally moral nature. This is so for two sets of reasons. On one hand, because one could consider not just the question of what Spanish or international law says about human rights on the subject of transplants, the right to life, the use of human assisted reproduction techniques, etc., but also what a legal system would be morally justified in establishing in this respect, even though it did not in fact do so. One must not forget that we very often speak of human rights or

basic rights to contrast them with actual legal rights; human rights, in their most radical sense, are moral entities. And, on the other hand, because even if we accepted that the rights to one's own body must be understood precisely and exclusively in the sense in which they have been established in certain legal texts (for example, in UNESCO's Universal Declaration on Bioethics and Human Rights), the identification and interpretation of those rights cannot be made outside of a moral theory. More specifically, rights are rather more than normative positions (positive and negative expectations, in Ferrajoli's terminology) in which certain subjects are situated: they are also –above all– the assets and the values that this normative structure attempts to satisfy. In the case of the rights of the personality, it is obviously a question of the value that we usually call dignity, so we now need to analyse those concepts: of the person and of dignity.

And speaking of the person and dignity necessarily means referring to Kant, to the second formulation of the categorical imperative (the duty to treat others and ourselves as ends in themselves and not as mere instruments) and to the characterization of people, as opposed to things, as entities endowed with dignity (things have a price and can be swapped for one another or exchanged for money, but people –or rational beings– possess an absolute, unconditional value, and therefore deserve respect). There is an interpretation of the Kantian concept in this respect that links up very directly with what we are considering here. In effect, according to Manuel Jiménez Redondo, the idea of the person comes to Kant through his legal training and it has its origins in the *Institutions*, one of the works that make up the *Corpus Iuris Civilis*, with which Kant would have been familiar. In the *Institutions*, the supreme division of the law of persons arises due to the contrast between the state of freedom and that of servitude (but in this didactic work there is no definition of the person). And in relation to the law of things (the other branch of property law), the basic division that appears in *Institutions* is made between the things that are or could be owned by us (one of those things would be slaves) and those which are not nor could be. In turn, within this second group there are certain things that cannot be the object of appropriation because they are *essentially* things that belong to all people (the air, the sea) or to the group (stadia or theatres), but which do not belong to anybody. They are the sacred, religious and holy things.

*Sacred things* are things consecrated to God in accordance with the rites of pontiffs, such as temples and offerings. Sacred things cannot be founded by our own authority, since if anyone became something sacred by his own authority, he would not be sacred but profane. *Religious things* are those that have to do with death, chiefly tombs; these are the symbol that human existence, in its possession

of itself, is held in usufruct, not in ownership; it is the property of the gods and they, when the time comes, will appear to claim what is theirs as owners of it. *Holy things*, such as the walls and the gates of the city, are those that signal the limit within which a structured and supportive existence and coexistence are possible, based on the sacred and the religious, and beyond which begins disintegration, strangeness, chaos, which for existence is not a measure but the lack of it (Jiménez Redondo, 2013: 26<sup>8</sup>).

Kant's notion of the person, as something that is *an end in itself*, would have been constructed precisely from that category of things that belong to no one.

We could then say that, just as ancient existence is based on a transfer from the right of persons to the right of things, whereby a class of people are converted into things in the sense of things that may essentially be owned by us. On the contrary, modern existence is based on a transfer from the right of things to that of persons, whereby the person, and *necessarily every person*, is understood in accordance with a category of things, the *things that essentially belong to nobody*, which are the sacred, religious and holy things, and by the way the only sacred, religious and holy thing (Jiménez Redondo, 2013: 26).

That strange transfer of meaning also leads Kant to understand the person (and their dignity) in terms that ought to be classed as extremely radical: "Man, in Kant's words, has no *price* because essentially he cannot be anyone's property or remain as anyone's property, either individual or collective, and he cannot even belong to himself". (Jiménez Redondo, 2013: 28). To properly understand this notion of the person, it is worth pausing for a moment to see with what other notions of the person –the human individual– it is compared.

Of course, it is compared with the ancient notion, not just because there were human beings in Greece or Rome whose status as persons was not acknowledged, but because individuals that are people (if you will, the citizens of the *polis*) are not seen either (I am referring to the predominant concept in Greek thinking), or at least not completely, as ends in themselves and for themselves. The Greek or Roman citizen does not belong to himself, he belongs to (is part of) the *polis*, the city. This explains, for example, that when in *Nicomachean Ethics* (Aristotle, 1981: v. 9<sup>9</sup>) Aristotle wonders why suicide is unlawful, his reasoning is the following. Whoever voluntarily takes his or her life acts unjustly, but against whom, he wonders. It is not possible, in his opinion, to be unjust to oneself because "justice and injustice necessarily require more

8. Jiménez Redondo, Manuel (2013), "El hombre como fin en sí: una aproximación kantiana a la idea de persona", *Teoría y Derecho*, n.º 14.

9. Aristotle (1981), *Ética a Nicómaco* (edition by Araujo, M. and Marías, J.), Centro de Estudios Constitucionales, Madrid.

than one person", and hence his conclusion that someone committing suicide acts unjustly, not against him or herself, but against the city. And the same could be said in relation to mutilations. In short, man, in this concept, is not the complete master of himself or of his limbs.

He is also opposed to Christianity's idea of the person. Now, inchoately at least, all men would be persons and would be endowed with the same dignity as children of God; but we already know that in societies inspired by Christianity these considerations did not have the consequences that might have been foreseen: Christian societies were perfectly compatible with servitude and slavery. In any case, according to this religious idea of existence, man is not an end in himself, or he is only in a limited way. As Javier Hervada points out, "man is only an end in himself relatively, not completely". Man "is a person through participation and, consequently, the human person only partakes finitely and limitedly of the personal being, whose plenitude –analogously– we find only in God". (Hervada, 1975: 222). This author gives the following explanation (which in reality is derived from the idea that life is a gift from God) of why man is not the master of himself or of his limbs, or he does not exercise absolute control over his own body:

The moralists' expression –*homo non est dominus membrorum suorum*– is supposed to mean that, on the moral plane, man is not an absolute being, left to his free judgment as the only criterion of good and evil. In other words, it means on one hand the principle of finality and, on the other, the existence of natural law, which influences life, health and physical integrity, in such a way that these three assets –which are summarized in life, health or vitality, and bodily integrity– are not left to the arbitrary nature of man or to his free disposal. Control, real but finite and dependent, is a control for some ends and in accordance with some rules (Hervada, 1975: 224).

From this it is derived that "the primary thing that appears with respect to life, health and physical integrity is a duty: the duty to preserve them" (Hervada, 1975: 224). And that "legally, the right that man has over his life, his health and his limbs is not a right of ownership, but a right of another kind: it is a *natural and basic right* to exist and to preserve in full his faculties, the right to be and to live" (Hervada, 1975: 226).

Put another way, man is not free to dispose of his life or his own body, because he does not belong to himself. Nor does he belong to the community. He belongs to God; he is one of His children.

In the end, Kant's notion of the person also differs from that of a liberal such as Locke. In the *Second Treatise on Civil Government*, Locke associates the idea of freedom with that of ownership and claims that "every man has a property in his own person. This nobody has a right to but himself"

(Locke, 1981: 5<sup>10</sup>). So his notion of the person implies the idea of freedom and equality (all persons are free and equal; equally free). Locke however does not see man as an end in himself, but as an end for himself. Jiménez Redondo presents it thus:

According to these explanations by Locke [...] man is not something that another may dispose of as a thing, as he is not there for another thing or another man, and therefore, in this sense he is not a means, or he is not just a means that another man may make use of, but he is an end or always also an end, not a relative end but an absolute one. However, he has the *ownership of himself*. Therefore, being merely an end, or being always also an end with respect to other people and with respect to any other thing, he is, nevertheless, an end with the right to dispose of himself as the owner of himself. Man, therefore, is an end who as an end doubles as an end and a means, and is an end solely for himself in the sense of being able to be a complete means for himself, of which he could dispose wholly as he wishes. *He is an end for himself* (Jiménez Redondo, 2013: 19)<sup>11</sup>.

### 3

I believe it is very important to realize the difference between the purely liberal concept of the person and the Kantian concept. Both are alternatives to the religious view (or the communitarian view), but it is not the same to think that everyone is the master of their own body and can therefore use it as they think fit (with the limit that would be the equivalent of what we usually associate with freedom: that it must be compatible with the exercise of those rights by others). Or that no one is, and that, therefore, the individual cannot use his body –or, of course, that of others– as he wishes: he has to treat himself as a person, as an end in himself (not as a mere instrument), just as he must also, naturally, treat others in that way: “act that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end and never merely as a means” (Kant, 1973: 84). And that is why Kant considered suicide to

10. Locke, John (1981), *Ensayo sobre el gobierno civil* (translated by A. Lázaro Ros; int. by L. Rodríguez Aranda), Aguilar, Madrid.

11. It is useful to clarify, in any case, that although Locke states that the individual is the owner of his body, he nevertheless also maintains that “no one possesses absolute arbitrary power over himself” (Locke, 1981: 135). A state of freedom is not, Locke adds, the same as a state of license: “although man may have in such a state [of nature] an unlimited freedom to dispose of his own person and his properties, that freedom does not confer upon him the right to destroy himself” (Locke, 1981: 6). And the reason is that, “since men are the work of an omnipotent Maker”, “they are the property of that Maker and Lord” (Locke, 1981: 7). But it seems obvious that liberalism, once it is freed of these religious bonds, carries in its internal logic the consequence that the individual is the complete master of his own body.

be morally illegitimate, although I feel that one could, subscribing centrally to Kantian moral philosophy, disagree with this thesis. But, in any case, Kant's argument was that the person who commits suicide (who, for example, takes his own life to avoid terrible suffering) would not treat himself as an end, but as an instrument<sup>12</sup>. He would not be committing an unjust act against himself (as he is not the owner of his body), or against the community, or against God, but against the very idea of humanity, of morality; he who commits suicide treats himself contemptibly, but the offence has a dimension that goes beyond the individual, because he would be denying, in his person, the possibility of morality.

A very important consequence of the latter is that, understood this way, dignity cannot be reduced to autonomy. This is, precisely, one of the main themes that can be found in different studies on dignity appearing in the book coordinated some years ago by María Casado: *Sobre la dignidad y los principios. Análisis de la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO*<sup>13</sup> (Civitas, 2009). As opposed to the ideas of authors such as Macklin, Pinker or Mosterín, who had suggested dispensing with the "intractable" concept of dignity and replacing it with that of autonomy (taking it to mean, approximately, the duty to respect the decisions of individuals, at least as long as they do not harm another person), almost all of the writers in this book about dignity maintain that this thesis is a mistake, although they do acknowledge that dignity is not exactly an easy concept to define and that, in some ways, dignity and autonomy are concepts necessarily associated with one another. Thus, for example, Ricardo García Manrique, upon proposing a reconfiguration of dignity in the sphere of bioethics, starts from the fact that "the basis of human dignity is human beings' capacity for moral autonomy", but that capacity would only be valuable to the extent that it could be "exercised to get close to the human ideal", an ideal that goes "beyond the autonomous". Furthermore, dignity means, in his opinion, a limit (a substantive, not simply formal, limit) to autonomy not just on an individual level, but also in the collective exercise of autonomy; this is how he interprets article 12 of UNESCO's Universal Declaration on Bioethics and Human Rights, when it establishes that "The importance of cultural diversity and

12. Although this statement can be qualified. Thus, concerning a passage from *The Metaphysics of Morals*, Rawls writes the following: "I do not interpret this passage in the sense that suicide is always bad. Rather, it says that it always needs a moral authorization, which cannot be granted by the ends desired through natural inclination. The casuistical questions Kant lists in this section imply that such a title can be given by conflicting grounds of obligation" (Rawls, 2007: 246).

13. Casado, María (coord.) (2009), *Sobre la dignidad y los principios. Análisis de la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO*, Civitas-Thomson Reuters.

pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope" (García Manrique, 2009: 55-56, 60<sup>14</sup>). In other words, dignity is also a limit for democracy.

So, to continue with the Kantian, and not merely liberal, idea of the person and dignity, it seems that it would not be acceptable, for example, for someone to put forward a reason such as "my body is mine and I shall do with it what I want" to justify actions that could involve taking one's own life, mutilating oneself, having an abortion, donating an organ, taking certain types of drugs, and so on. Pablo de Lora and Marina Gascón, in relation to the problem of organ transplants, include words spoken by Bernat Soria, the Spanish minister for Health in September 2008 (in reference to euthanasia, but applicable to many other things): "There is a basic principle that separates two ways of thinking: those who think that the owner of someone's body is that person, and those who think that it is someone else, a church, an institution or a political party. The Socialist Party says 'You are the owner of your body'". To which De Lora and Gascón add this comment: "The Socialist Party and the vast majority of individuals say this. It was asserted as an axiom a while back by the rationalist iusnaturalist school under Samuel Pufendorf and Hugo Grocio". (De Lora and Gascón, 2008: 189<sup>15</sup>). Which may well be very true, but one must insist that this opinion is in direct contradiction not only to religious or totalitarian ideas about the person, as the minister pointed out, but also to the Kantian notion of dignity.

One of the examples Kant gives of what would be against the categorical imperative (he brings it up due to the different formulations of the categorical imperative, given that, for him, they are three formulations of the same moral law) is that of the individual who "prefers to indulge in pleasure rather than to take pains in enlarging and improving his happy natural capacities" (Kant, 1973: 75<sup>16</sup>). In other words, not only people who take their own life or cause themselves physical harm, but also those who do not do everything possible to develop their natural gifts, their capabilities, would not be treating themselves with the dignity that corresponds to a rational being. Put another way, the free development of the

14. García Manrique, Ricardo (2009), "La dignidad y sus menciones en la Declaración", in Casado, María (coord.), *Sobre la dignidad y los principios. Análisis de la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO*, Civitas-Thomson Reuters.
15. De Lora, Pablo and Gascón, Marina (2008), *Bioética. Principios, desafíos, debates*, Alianza, Madrid.
16. Kant, Immanuel (1973), *Fundamentación de la metafísica de las costumbres* (4th ed.; translated by M. García Morente), Austral, Madrid.

personality would not simply be a right, but a duty of the individual<sup>17</sup>. However, this danger of moral perfectionism that one might see in the Kantian concept of dignity is, in my opinion, cancelled out, when the following three circumstances are considered that would perhaps make it possible to arrive, from Kantian moral presuppositions, at consequences surely not very different to those that would be derived from the classic liberal scheme.

The first one is the distinction between law and morality established by Kant and which does not allow us to go from judging that such an action (the one previously indicated or other similar ones) is contrary to morality, to upholding that, therefore, this conduct must also be stipulated as a legally illicit act. It is just the opposite in fact. As Jiménez Redondo also points out (interpreting Kant's thesis of the distinction between law and morality):

[T]he [l]aw releases those who are subject to it from the need to be virtuous, precisely out of consideration for everyone else's right; that is, to the exercise of equal freedom. The [l]aw, therefore, is thus wholly detached from morality precisely by virtue of the fact that man must never be treated simply as a means but also always as an end in himself [...] precisely by virtue of the fact that the *person* is a *sacred* thing, the [l]aw is not there to be converted into a tool of either Kantian morality or of any other type of morality (Jiménez Redondo, 2013: 30<sup>18</sup>).

And although I do not subscribe wholly to the Kantian way of understanding the relationships between the law and morality, there is one point of the theory that to me seems irrefutable: the fact that there may be reasons for describing a form of behaviour as immoral –or it may be justified– does not mean that it should therefore be considered unlawful. Moreover, not being punished (that coercion is not used against someone) simply because one's behaviour is not a moral behaviour is even a human right, a basic right: not everything immoral is (must be) unlawful, nor is everything lawful moral.

The second consideration refers to the Kantian notion of dignity, taken in normative terms, as essentially one of a limit or denial; it is not purely formal, it contains a substantive element, but one that rather takes a negative form. Javier Muguerza has insisted at length on this: what the imperative of ends means above all is the exigency to say no, to disagree even with the decisions of the majority; it supplies a basis for disobeying, but not for imposing a decision on others. Hence he even sees in dissent the

17. And a duty to oneself and to others: we are forced to do whatever is possible so that others (any other) can develop personally.

18. Jiménez Redondo, Manuel (2013), "El hombre como fin en sí: una aproximación kantiana a la idea de persona", *Teoría y Derecho*, n.º 14.

basis of human rights and proposes this formulation in negative terms of the imperative of ends: “it does not exactly tell us ‘what’ we must do, but rather what we ‘must not’, namely, we must not treat ourselves, or treat anyone, exclusively as an instrument” (Muguerza, 1998: 64<sup>19</sup>). Furthermore, this would more likely be addressed to the individual and not the institutions. Once again, the radical nature of Kant’s message would seemingly have to be restricted fundamentally to the sphere of individual ethics.

And finally, the third consideration that sets a limit on this danger of moral perfectionism derives from the need to interpret Kant’s notion of the person (and of dignity) in a functional sense, whether or not this was the philosopher’s intention. Here Jiménez Redondo’s reading that we saw earlier is once again very useful. Just as the function of the things that essentially belong to nobody is that of setting certain limits that make civilized life possible in the *polis*, the function of the notion of the person is to make it possible for a person to lead a morally satisfactory life, to develop his or her personality freely. Therefore, when that possibility ceases to exist, we should not think that someone who decides to end their physical life is also infringing their dignity. That is why I said earlier that suicide (rather, suicide in certain circumstances) did not have to be seen as an infringement of the categorical imperative.

#### 4

We shall now examine the consequences that an idea of the rights over one’s own body based on the Kantian notions of the person and dignity have in relation to bioethics. To do so, please allow me to briefly summarize the ideas that I put forward in a study that was published over 20 years ago (Atienza, 1996<sup>20</sup>) in which I made a methodological proposal about how to tackle the problems of bioethics.

In my opinion, if the “principles of bioethics” were carefully examined, one might reach the conclusion that they set out to offer an answer, basically, to these four general problems, against the backdrop of people’s lives, health and integrity: 1) Who should decide (the sick person, the doctor, the relatives, the researcher)? 2) What harm and what benefit can (or should) be caused? 3) How should an individual be treated in relation to others? 4) What should be said, and to whom? And I also thought that these four problems formed a sort of concretion (in a particular field) of the general question of ethics: what should I do (what should be done)?

19. Muguerza, Javier (1998), *Ética, disenso y derechos humanos. En conversación con Ernesto Garzón Valdés*, Argés, Madrid.

20. Atienza, Manuel (1996), “Juridificar la bioética”, *Claves de Razón Práctica*, n.º 61.

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The answer would then have to agree with the principles of *tout court* ethics and I was trying to show that the principles of bioethics were, effectively, specifications of the four formulations that Kant ascribed to the categorical imperative, that is, of the principles of autonomy, dignity, universality (equality) and publicity that, in turn, were linked to the traits that characterize people: nobody can decide for us, if we can do it; we are not used, we are respected; we are not treated worse than others; we can learn to be able to decide. I thus formulated what I called “primary principles of bioethics”:

- Principle of autonomy: every individual has the right to decide about what affects them (here, in particular, about their life and health).
- Principle of dignity. No human being can be treated as a simple means.
- Principle of universality (or equality): those who are in the same conditions must be treated equally.
- Principle of information: every individual has the right to know what affects them (here, what affects their health).

These four principles are all we need to resolve what could be called –resorting to legal terminology– easy cases. But there are times –the difficult cases– when these principles are insufficient. For example, what to do if the person affected is unable to make decisions due to their young age or because they are unconscious? Is an inter vivos transplant a case of treating one person as a simple means for the benefit of another? Do transplant lists respect (for example, taking into consideration a person’s age or lifestyle habits) the principle of equality? The shortcomings of the above principles for answering these last questions are not derived from the fact that we might think there are cases in which those principles cannot be respected. We should not have to accept that there are times when it may be lawful to infringe autonomy, dignity, etc., but rather that these principles are formulated very openly, in such a way that certain sets of circumstances may arise that justify making a decision without having the affected person’s consent, performing an action that means harming a person, establishing a certain difference in the way two people are treated, or not telling someone the truth. What serves as justification for what in that study I called “secondary principles” (in other words, the establishment of exceptions to the primary ones) must be respect for autonomy, dignity and equality<sup>21</sup>. For example, a paternalistic decision is justified

21. Information (the right to know) could be considered a condition for being able to decide and, naturally, it ceases to make sense if one is not in a position to decide.

because it is the way of allowing someone to become autonomous, for them not to be used, etc.; the harm that it may be justified to inflict on a person must not mean dispensing degrading or arbitrary treatment; a similar action must not mean treating one person with less consideration and respect than another, and so on. This kind of connection between the primary and secondary principles is what also led me to establish in the practical discourse a priority in favour of the former that could take the form of a rule of the burden of proof: whoever hopes to use, for the resolution of a case, one of these secondary principles must prove that, in effect, the circumstances arise of applying one or several of these principles. To be precise, my construction of the four secondary principles corresponding to the previous ones (they are not, then, the negation, but a complement or a specification of them), was as follows:

*Principle of justified paternalism:* it is legitimate to make a decision that affects the life or the health of another if: 1) they are in a situation of basic incompetence; 2) the measure represents an objective benefit for them; and 3) it may be rationally presumed that they would consent if the situation of incompetence were to cease.

*Principle of restricted utilitarianism:* it is legitimate to undertake an action that does not represent a benefit for a person (or which harms them) if with it: 1) there is (or it is rational to think there might be) an appreciable benefit for one or more others; 2) you have the consent of the person affected (or it may be rationally presumed that they would consent); 3) it is not a humiliating measure.

*Principle of difference:* it is legitimate to treat one person differently to another if: 1) the different treatment is based on a circumstance that may be universalizable; 2) it produces an appreciable benefit in one or more others; 3) it may be rationally presumed that the affected person would consent if they could decide in circumstances of impartiality.

*Principle of secrecy:* it is legitimate to keep from a person information that affects their health if with it: 1) their personality is respected; or 2) an investigation is made possible to which they have given their consent.

However, all these principles, and even accepting that the formulations I have just proposed are agreed to, do not always allow us to resolve, without further help, the variety of difficult cases that may arise in bioethics. On the one hand, because there may be other circumstances not taken into account and which could lead to the formulation of new principles. And on the other, because even if we confined ourselves to the previous ones, they need to be specified in the form of rules. What does basic incompetence mean? How far can the risk for one person and the benefit for another

stretch? The conclusion to which all this led me (and which I presented in the form of a “table of bioethics”) was to consider that the basic problem of bioethics is that of going from the level of principles to that of rules, or:

Constructing, based on the above principles –which, with the odd variation, enjoy a broad consensus– a set of specific guidelines that are consistent with them and which make it possible to solve the practical problems that arise and for which there is in theory no consensus. Bioethics would have to give us, so to speak, the satisfaction of confirming that our practical problems can be resolved (at least in a large number of cases) without us ceasing to be true to our principles (Atienza, 1996: 72).

## 5

Now the moment has come to check whether it is effectively so by looking at a series of cases that seem to involve above all the issue of limits in relation to the rights over one's own body (what is the interaction, then, between the principle of dignity and that of restricted utilitarianism) that have lately been the subject of various polemics.

### 5.1

A strange case but one that, precisely because of its strangeness, it seems a good idea to discuss is that of the wannabes who want to be mutilated in order to feel complete. In an interesting article on this subject, Macario Alemany says that he has doubts about the legitimacy of the behaviour of the surgeons who perform these interventions, but in the end he seems to choose to give a cautiously affirmative reply: “the legitimacy of voluntary amputations cannot be ruled out for some extraordinary cases” (Alemany, 2014: 245).

His reasoning for reaching that conclusion starts with the presupposition that a doctor would be allowed to apply a measure that might mean physical and/or mental harm if these two conditions are both present: “(1) That the measure should be suitable and necessary to avoid greater physical or mental harm to the person who is being operated on, and (2) that individual autonomy should be respected. The first condition”, he adds, “I shall call the condition of medical responsibility, and the second, the condition of respect for autonomy” (Alemany, 2014: 234<sup>22</sup>). As we see, it is the principle that I called “restricted utilitarianism”, but with

22. Alemany, Macario (2014), “Las fronteras de la autonomía en el ámbito clínico: El caso de los *wannabe*”, AFDUAM, n.º 18.

the exception that he does not include the condition that it must not be a humiliating measure. It might be thought that, in this way, what Alemany is doing is avoiding the issue of dignity. But perhaps that is not the whole story; this last notion would simply be included in that of harm. Let us see.

One way of interpreting Alemany's ideas would be, in effect, to consider that he starts from the liberal notion of the person, and not from the Kantian notion, associated with the idea of dignity. This explains why his reasoning is focused on discussing the conditions under which it must be said that consent has been given autonomously, and on how the notion of harm should be understood and, in particular, if in those suppositions it can be said (given certain conditions) that with the amputation of a limb serious psychological harm can be avoided. Alemany considers that his presupposition (the two conditions mentioned above) operates in his reasoning as the "guarantee", as Toulmin<sup>23</sup> would have it. However, that guarantee has (to continue with Toulmin's terminology) an implicit "endorsement", which would be the liberal notion of the person. In other words, his complete reasoning would be: "given that each individual is the owner of their own body, if X irrefutably expresses his wish to have a limb amputated and if the amputation will save him from serious psychological harm (there are good reasons for believing it to be so), Y's action, consisting of performing the amputation, is a morally legitimate action".

The criticism that could then be made of him is that this reasoning would have to be very different if we were to change the endorsement, in the sense of replacing the liberal notion of the person with the Kantian one. For what would now happen is that, by introducing a new ingredient, there would also at least be a displacement with regard to the importance to be given to the premises: the important thing would no longer be so much (or only) the autonomy of the individual (who has given their consent in suitable conditions), but also whether the measure in question is humiliating, whether it infringes the individual's dignity or not.

Of course, Alemany could reply by saying that, although he has not referred explicitly to dignity, it does appear in some ways, contained in his concept of harm. Which may be acceptable, although it forces us to interpret "harm" in a very broad sense that would not be limited to physical and psychological damage. As we saw above, the Kantian notion of the person is that of an entity that is not (nor can be) anyone's "property", in such a way that one could cause personal harm (infringing an individual's dignity)

23. Toulmin, Stephen E. (1958), *The Uses of Argument*, Cambridge University Press, Cambridge.

even though one had that individual's full consent, that is, even though the person harmed does not perceive it as such, psychologically speaking.

If we consider the question of the legitimacy of these conducts (the amputation of a limb) from the perspective of the Kantian notion of the person, I believe that we would come to the same conclusion as Alemany does, or at least a very similar one: under certain rather exceptional circumstances, the moral legitimacy of these behaviours could be accepted. But, as I was saying, the emphasis would now have to be placed on the idea that showing respect for people does not simply mean taking their wishes into consideration. One would have to give reasons that endorse the fact that performing the amputation contributes to –or at least does not hinder– the development of the amputee's personality. To defend that this may indeed be the case, the argument by analogy, in relation to sex-change operations that Alemany introduces in his text, is very relevant. If a sex-change operation is not considered an infringement of a person's physical integrity, it must be because it is understood that with it, the idea is to promote the values of respect for and protection of human dignity and the development of the personality, not just in the sense that this development is free, but that it should embody a valuable life project. Here we once again come up against the risk of moral perfectionism, but we could find the solution in the same factors mentioned above. Particularly, in the need to distinguish moral from legal judgment: it makes sense to morally question an individual's actions that are incompatible with a good life (which means total respect for their dignity as a person), but it would be wrong to pretend that this morality deficit is reason enough to also uphold the illegitimacy of that behaviour.

## 5.2

One of the fundamental ethical problems posed by the transplantation of organs is that of the criteria to be used in their allocation (for example, see De Lora and Gascón, 2008: ch. 4; Veatch and Ross, 2015<sup>24</sup>), given the scarcity of organs in relation to the number of sick people who need them. It is a situation in which it is impossible to give to each according to their needs.

Years ago there was a scandal when a Dutch television channel announced that it would be broadcasting a reality show in which a woman, terminally ill with cancer, would donate (in life) one of her kidneys to one of the three contestants who would compete for it: each of

24. Veatch, Robert M. and Ross, Lainie F. (2015), *Transplantation Ethics*, 2nd ed., Georgetown University Press, Washington.

them had to try and convince her to donate it to them<sup>25</sup>. The programme was broadcast and watched by a huge audience, but at the last moment, before the winner was announced, the presenter explained that it was all a stunt aimed at raising awareness among the public and that there would be no donation.

If one were to ask whether, had it not been a stunt, the kind of action that the donor, the recipients and the people in charge of the channel would have undertaken could be described as moral or not, I think that many people, the majority probably, would say yes, it is immoral and it does infringe people's dignity. To clarify what this means, a comparative argument could be used: people who have to compete for an organ are in a position similar to that of the gladiators in the Roman circus: all of them are forced to fight for their life, for their survival, because they have been placed –without wishing to be– in a sort of state of need for the sole purpose of creating a spectacle. Of course, there is a difference, as in the case of the gladiators this situation would have been created by voluntary actions of other human beings, while in the case of the organ donation, in part at least, the situation of need is rather a product of chance. But what seems important is that in this second case too this situation could have been avoided, that there is a way of obtaining and distributing organs that does not consist of making the possible recipients compete with one another. It is indecent to place a person in a situation of extreme need, if the person in question does not wish to find him or herself in such a situation, and it is possible to find an alternative.

However, it seems obvious that an organization in relation to organ transplants such as that in force in Spain largely avoids this kind of situation. It does this because the allocation of organs does not depend on any circumstance that the recipient can or has been able to control (the kind of life they have led, whether or not they agree to be a donor, etc.); the only things taken into account are data such as their age, medical condition, where they live. And the allocation criteria are public and everything suggests (with the odd rare exception) that they have been applied uniformly, completely free of bias. So, instead of making those in need of an organ compete against one another, the governing principle seems to be that of equality in relation to needs, modulated for reasons of efficiency. The question that should still be asked is: by making sure that fewer individuals were affected by the scarcity of vital organs would a situation be possible that also ought to be considered respectful of people's dignity to a greater extent? The answer is that it probably would. If a system could be set up in which the public authorities compensated donors or their families (the

25. I dealt with this subject in Atienza, 2007. The following is a summary of that study.

criterion of equal treatment of recipients would thus be guaranteed) with the consequence that more organs would be available, and without this being an incentive for donors to place their life or health (significantly) at risk, then not only would this system (in which donations ceased to be free) not be immoral, but for moral reasons (of respect for people's dignity) it would be necessary to try to introduce it. The criterion obviously appeals to causal relationships that might not arise. Still, that (empirical) problem must be distinguished from the normative and moral problem. That is, the moral duty that has just been established is determined by these empirical circumstances arising (or it is reasonable to think that they will arise).

### 5.3

The last case that I wish to discuss here is quite a bit simpler than the previous ones. Rather, there are two: one is saviour sibling (so-called by the Catholic Church), and the other is surrogate motherhood. Those opposed to these two practices usually brandish the argument that both of them are contrary to the respect due to human dignity, but I feel that in both cases a totally inadequate concept is used of what human dignity is. The error –quite crude– is the same in both cases.

The first of these practices consists in making use of human assisted reproduction techniques to select embryos whose tissues are compatible with those of sick relatives, so that the future baby may contribute (via transplantation) to saving the life –or curing a serious illness, for example– of an already born sibling. To think that this practice (which does not represent any appreciable risk for the baby; Spanish law, as is known, authorizes it) is contrary to human dignity seems particularly unreasonable and it is not difficult to realize why this is. It turns out that those who defend this thesis (insofar as they do not produce purely religious arguments, based on dogma) seem to think that the principle of human dignity is limited to prohibiting a human being from being used as an instrument for another, when what it establishes (which is clear from the Kantian formulation) is the prohibition that they be used *only* as a means and not always at the same time as an end – something (a purely instrumental use) that it is absurd to think is going to occur with the babies born in these conditions.

Surrogate motherhood is a rather more complex problem, but one that comes down to the same thing: the solution is the same one as for saviour siblings.

In recent years in Spain there has been a rather long-winded debate over a lawsuit that got as far as the Supreme Court and which can briefly

be expounded thus (see Atienza, 2016<sup>26</sup>). Years ago, the person in charge of the Consular Civil Register in Los Angeles, California, gave a ruling in which he refused the request of two Spanish citizens (both men) to enter the births of their two children, born via surrogate motherhood. The two of them later lodged an appeal with the General Directorate of Registers and Notaries, which accepted it and entered it. The resolution was appealed, however, by the public prosecutor before court number 15 of first instance in Valencia, which ruled that the entry made was null and void, on the basic understanding that the application of the Spanish law that prohibited [*sic*] surrogate motherhood could not be overlooked. The reasoning was assumed by section 10 of the Provincial Court (*Audiència*) of Valencia, which ratified the court's decision when it rejected the appeal lodged by the parents of the children. And finally, after an appeal of cassation was lodged with the Supreme Court, the plenary session of the civil court (Sentence 06/02/2014) ratified the criterion of the court and the *Audiència* (although not unanimously) with a set of reasons in which the argument that surrogate motherhood is prohibited in Spain, and is contrary to Spanish public order, is repeated again and again. "Contrary to Spanish public order" means contrary to some basic principle or value of the legal system (human dignity, to be precise), the reason why the Supreme Court understood that this birth could not be entered on the Register.

These decisions are, in my opinion, doubly wrong. The first error consists of interpreting that surrogate motherhood is prohibited in Spanish law, when it is not. What the law says is that this kind of contract is "null and void", but from that it cannot be inferred that it is therefore prohibited. In other words, the concept of nullity is not the same as that of sanction. A punishment must be preceded by a forbidden, illegal act, but the Law of Human Assisted Reproduction in fact establishes no sanction for the case of someone making a surrogate motherhood contract. The precedent for a law that establishes the nullity of an act is not –or not necessarily– that of having done something that is prohibited. The second mistake, linked to the first one, is that of interpreting that the cause of the "prohibition" is the infringement of dignity represented by this kind of contract. In the sentence of 6 February 2014, the Supreme Court states as a necessary truth, in several of its legal grounds, that surrogate motherhood violates "the dignity of the surrogate and the baby". It does not take too much of an effort to clarify for us what its reasoning was to reach that conclusion, most probably because the majority of the Court think it is an obvious thesis. I fear that what lies behind all of this is a lack of understanding

26. Atienza, Manuel (2016), "Gestación por sustitución y prejuicios ideológicos", *El Notario del Siglo XXI*, n.º 65.

of the concept of dignity. If the prohibition to exploit a human being, the obligation to respect their dignity, is understood as it should be (not that it is forbidden to treat another person or oneself as a means, but *only* as a means), it can be understood that surrogate motherhood does not in itself represent any infringement of dignity. Of course, it is possible that in the context of these practices –as occurs in the context, let's say, of a work contract– someone might treat another without respecting their dignity, as a means only; but that has nothing to do with this issue. There are, doubtlessly, good reasons to oppose considering everything that technological progress makes possible as being in conformity with morality. It is also important to be alert in order to avoid considering what are none other than the normative expression of ideological prejudices to be ethically (and legally) justified prohibitions.

## 6

The context of the right to one's own body and its consequences is established by the idea of human dignity. I shall therefore dare, as a conclusion to all the above analyses, to give a formulation of the principle of human dignity, surely the most basic concept of morality and, for this reason too, the most difficult. Even at the risk of simplifying (or not sufficiently specifying, I would say) that the core of this principle (the core of ethics) lies in the right and the obligation that every individual has to develop as a person (a development that can obviously take a variety of forms, or ways of life, but from there it does not follow that any way of life is acceptable), and, at the same time, the obligation in relation to others, to each and every human individual, of contributing to their free (and equal) development. It ought to be said then that the ultimate basis of morality lies in human dignity, but this is due to the fact that the other two main principles of morality, equality and autonomy, are also contained in that notion. For that reason also, there would be no problem with constructing morality on the basis of either of these last two principles, but provided they were formulated in such a way that each of them also contained the other two.

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# Subject, Body and Market: A Complex Relationship

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## 1. INTRODUCTION

This paper<sup>1</sup> aims to answer some questions that have been troubling me for years: how can the sexual and reproductive rights so closely associated with the body-subject, rights that are so important for the protection of personal integrity, autonomy and freedom, still be the subject of controversy and contempt? Why does legal culture find it so difficult to acknowledge the body and the human heterogeneity of subjects with rights? How should we respond globally as one to the issue of the commercialization of human biomaterial (organs, tissues, cells, genetic information) and to the presence of financial gain in these transactions? These questions are impossible to answer if we do not analyse the representations of what it means to be human and the value of the body in modern legal and political culture in Europe.

To understand the difficult relationship that the law has with the bodies of subjects with rights, we have to say that the first pattern of hegemonic power in the world was constructed around a global representation of the world as a system, made possible due to racist coloniality, capitalism and Eurocentrism (Quijano, 2005<sup>2</sup>). It was a pattern of systemic global control into which a modernized patriarchal order<sup>3</sup>

1. This article has been written as part of the project: *Tradición y constitución: problemas constituyentes de la España Constitucional*. Der 2014-56291-C3-3-P.
2. Quijano, A. (2005), "Colonialidad del poder, eurocentrismo y América Latina", in Lander, Edgardo (comp.), *La colonialidad del saber: eurocentrismo y ciencias sociales. Perspectivas latinoamericanas*, FLACSO, Buenos Aires.
3. Although, as Kate Millett states, patriarchy predates racist coloniality as a system of control, I consider that the latter's influence over the power of patriarchal control

and the human distinction between body and non-body (reason) were inserted. The introduction to modern societies of these three axes of the rationalization of human difference means that we are unable to understand how each of them works separately and the logic behind them, and it explains the title of the paper: "Subject, Body and Market: a Complex Relationship". In this essay I shall try to show that not only has the reduction to bodies for the market, or for reproduction, carried out by liberal modernity to prevent some social groups from gaining access to subjectivity and to citizenship, not disappeared with the development of the liberal State and the globalization of the economy, but it has been reinforced as a consequence of the process of objectification and commercialization of all human bodies. This process made it possible to devalue human corporality and to reduce a large number of human beings (women, ethnic groups treated as inferior, minors, servants) to an existence close to, or like, that of an animal. At the present time, the hierarchization and the devaluation of humans (poor workers especially) is being reinforced by the market. Protected by the brilliance of science and technology, everything seems to be for sale: women's wombs, the organs of poor people or prisoners (China used its prison population for organ transplants), the tissues of cadavers, the freezing of eggs as an incentive for female employees (offered by tech companies such as Facebook and Apple)<sup>4</sup> to guarantee their loyalty during their most productive years, and the international adoption of children à la carte, among other possible examples.

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systemically intensified the subordination and inferiorization of women. About the complexity entailed in patriarchy, I wish to quote these words by Millet: "[the] subordination of women represents not just an economic or political fact, but an entire social and psychological phenomenon, a way of life that Engels (whose psychology is less fine and specific than Mill's, based as it is on collective states) describes as a class struggle" (Millet, 1995: 226). It is essential to explain from the beginning the complexity entailed in the power of patriarchal control and its impact on all levels of life when it comes to assessing, morally and politically, surrogate motherhood, the regulation of prostitution, companies offering to freeze female employees' eggs, the sale of organs, etc.

4. With the slogan "Delaying motherhood has its reward", tech companies Facebook and Apple told TV channel NBC how interested they were in female employees, something that had led them to pay for the process of freezing and keeping their eggs. "According to Brigitte Adams, the founder of Eggsurance.com, the company that both firms turned to in order to offer the incentive, each ovarian stimulation cycle for taking samples costs \$10,000 (€7,900), plus an additional \$500 (€394) per year for storing the eggs. Facebook was already offering €3,159 (\$4,000) for expenses for the birth of a child. This new perk is aimed at delaying women's pregnancy. Eggsurance and Extend Fertility are two of the companies that have for some time been providing the same service to consultancies". Retrieved from [http://tecnologia.elpais.com/tecnologia/2014/10/15/actuali-dad/1413333970\\_087854.html](http://tecnologia.elpais.com/tecnologia/2014/10/15/actuali-dad/1413333970_087854.html), consulted on 17 March 2016.

In order to form an opinion about whether or not practices like these are advisable, and to discuss the ethical and legal nature of their commercialization, I think it right to analyse the socioeconomic and political context in which these practices are created and developed, and their impact on the lives and rights of the people affected, firstly, and of every citizen, secondly. If we do not take this complexity into account and we isolate each particular story, we will not get the whole picture.

One of the mistakes made by Western culture has been to see scientific knowledge as a process whose mission is to dissipate the complexity of social phenomena, so as to theoretically construct an order that is clear, tidy and as simple as possible. The complexity of the analyses is perceived as a lack of rigour or classed as cognitive dispersion. From this perspective, one-dimensional theorizations –highly specialized, clear and limited in their object– are understood to be of greater quality. Nevertheless, I maintain that reductionist pretensions introduce more obscurity than clarity to the analysis of social phenomena such as this one. For this reason, far from avoiding, or eliminating, the complexity entailed in the relationship between subject, body and market, I have attempted to explain it. There is no philosophical, epistemological or wholly legitimate scientific legacy behind complex thinking; on the contrary, it suffers, as Edgar Morin says, from a heavy semantic burden by having been traditionally associated with the ideas of confusion, uncertainty and disorder. Nor should complexity be confused with “completeness”<sup>5</sup>. Complete knowledge is impossible. Totality is, in the words of Adorno, the non-truth. This means acknowledging that in any scientific analysis uncertainty, lack of plenitude and falsifiability always exist. The recognition of these limits in the work that they are presented with does not invalidate the effort made to show the logics and the interactions that exist between the legal and political and the economic discourse, and between subjects and non-subjects (individuals reduced to commercialized and fragmented bodies).

## 2. THE MODERN LEGAL AND POLITICAL DISCOURSE AND CAPITAL/THE MARKET

We cannot understand the close relationship between the economy, politics and the law in modern societies without looking back to the past and analysing the presuppositions out of which the socioeconomic order was shaped and the power of subjects with rights was legitimized.

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5. I use the expression that Morin uses in his study of complex thought (Morin, 2009).

1. Racist coloniality constructed a hierarchized representation and classification of human beings, which was consolidated in the modern European legal and political order, and which survives to this day (Europe's attitude to refugees reflects this representation, as does the way in which it regulates migration or prostitution). The peculiar thing about this model of power is not its naturalization and rationalization, but the way in which it expands "as a universal representation of the human condition, transcending borders, cultural peculiarities" and challenging to this day the discourses about human rights (Quijano, 2005).
2. In "the historical process of the constitution of America, all the forms of control and exploitation of work and of the production-appropriation-distribution of products, were structured around the relationship between capital/salaries and the world market. Slavery, servitude, small mercantile production, reciprocity and salaries were regulated under this system" (Quijano, 2005). From a historical and sociological point of view, this produced a new socioeconomic reality, in which all forms of production and work were structured under a pattern of common power. This model of power linked race to the division of labour, both elements being structurally united and mutually reinforced in the establishment of relationships of control and oppression, despite the fact that neither of the two elements was dependent on the other to exist or to develop. Thus was created "a systematic racial division of labour", that legitimated paid work as a "privilege of the whites", while black human beings were subjected to slavery and the gratuitous appropriation of their labour, resources and production, and native Americans were subjected to relationships of servitude (Quijano, 2005). It is not hard nowadays to find socioeconomic attitudes and relationships in Spain, and in Europe, that reflect this type of hierarchized human differentiation and the illegitimate appropriation of labour, or working relationships based on socioeconomic and emotional exploitation (Young, 2000<sup>6</sup>). Examples of it are the working conditions experienced in the grape picking season and in the greenhouses of western Andalusia (the sub-Saharan Africans work closer to the ground, while the North Africans do other jobs that allow them to stand up straight more); in roadside prostitution, where the subjugation and exploitation of foreign women is very similar to slavery; the domestic work done in houses by immigrant women

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6. Young, I. M. (2000), *La justicia y la política de la diferencia*, Cátedra, Madrid.

in the big cities, or the market for organs or wombs for hire<sup>7</sup> in developing countries.

The modern social and political order in Europe is then, the result of the convergence of two constituent historical processes. On the one hand, the codification of differences between dominators and dominated, based on the idea of race and gender as a distinguishing biological structure between them, which legitimates the whites' control over, and inferiorization of, blacks and native Americans, and that of men over women. And on the other, the design of new individual and social relationships and identities (Indians, blacks and those with multiple racial backgrounds), and the redefinition of other already existing ones. "Thus, terms such as Spanish and Portuguese, and later European, which up to then had only indicated geographical provenance or country of origin, became references for the new identities, a racial connotation that transcends geographical origin". The reality that emerges from this systemic pattern of power cannot be compared with other previously known ones. In old medieval servitude and in slavery, the lord or the master had certain responsibilities towards those in his power, responsibilities that the new system of power does away with. Racial coloniality and capital/the market, together with the sex/gender system, design "a new way of legitimating the already ancient ideas, and practices of superiority/inferiority between the dominated and the dominant", which are acknowledged as being universal (Quijano, 2005; 199-200, 208).

3. In addition to these structures there was a new myth: the idea of Europe as the cradle of civilization and the geographical centre of human cultural evolution. Europe, as an ideal, brings together all the foundation myths of the new model of economic, political and social power, by representing at the same time capital, the white race and culture. As we all know, the real story is nothing like the

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7. I prefer to use the expression "wombs for hire", to stress that bought motherhood reduces women to reproductive receptacles. The recently coined expression "surrogate motherhood" plays with the language to create an idealized image of bought motherhood. It is striking that whenever this practice is mentioned, biological motherhood, the value of the wishes of whoever is buying, and the personal freedom of those offering their bodies are all extolled, ignoring the physiological and emotional process that pregnancy holds for every pregnant woman, or the use to which women who are poor or in need are put, in order to satisfy the wishes of others. On top of all this there is the business. The Surrogate Motherhood Convention is advertised for 7 and 8 May 2016, where information and advice is offered about its use in the USA and Canada, with the slogan "Do you dream of having a child?".

one made up about the conquest of America and the civilizing hegemony of Europe. As Aníbal Quijano rightly argues, this view of the world “only makes sense as the expression of the exacerbated ethnocentrism of a recently established Europe, due to its dominant central place in modern worldwide colonial capitalism, the validity of mythified ideas of humanity and progress, products of the Enlightenment, and the validity of the idea of race as the basic criterion of the universal social classification of the world’s population” (Quijano, 2005: 214, 216).

Consequently, Eurocentrism produced:

- A. A representation of historical experience, in which we go from a hypothetical state of nature (pre-capitalist, non-European, primitive, traditional) to a modern European society as a result of agreement and political pacts between equal subjects, the only ones with natural and sacred rights. The high point of this narrative came with the birth of the State and modern constitutionalism. What this discourse concealed was the subordination and the oppression that shaped it. For this reason the ideal of justice is linked to legal equality, and not to the absence of oppression.
  - B. The naturalization of the cultural and biological differences between human groups through the codification of the idea or representation of “race” and gender.
  - C. A distorted temporal relocation of everything that existed prior to the process of domination and conquest of America. In this narrative the European way of life is presented as progress, culture and civilization, while the non-European is the past, savagery, and the absence of culture. This account hides the fact that there was no “Europe” prior to the birth of America. The objective of the narratives constructed around both geographical realities was to present history as an upward, one-way, evolutionary process, in which Europe represents the end of history. But the reality was very different. European economic progress and its subsequent scientific and technological development was due to the process of appropriation by European colonists and traders of the labour, resources and production of the different American peoples, both intellectually and materially (Quijano, 2005).
4. Over these economic and social power structures, European modernity laid other, older ones, between men and women, or gender

relationships<sup>8</sup>, adapting the old patriarchy and the family model of Roman law to the new demands for rationality and equality imposed by the Enlightened legal and political discourse (this can be clearly seen in Hobbes, Locke, and above all Rousseau). The interaction between racist coloniality and the patriarchy, reformulated to allow all men to gain access to subjectivity and to citizenship (a male universalization that previously did not exist), makes it possible to rationalize the exclusion of women from basic personal categories (individual, subject of law, citizen). This political exclusion, pre-State and pre-legal, can still be felt today. Never before in history had there been a universal and global exclusion and inferiorization of women because of their sex, something that surprised the aristocratic and bourgeois ladies of pre-revolutionary France.

5. In addition to all the above there was a new representation of the human condition marked by the distinction between the body and the non-body. Powerful individuals would be associated with non-corporality, rationality, while inferiorized human beings would be reduced to mere bodies (Quijano, 2005: 221-223).

### 3. WHAT STRUCTURAL CHANGES SHOULD LEGAL AND POLITICAL CULTURE UNDERTAKE IN ORDER TO OVERCOME ORIGINS-BASED OPPRESSION?

In the first place, it is essential to irrationalize any kind of hierarchized differentiation of humanity on the basis of biology. And to achieve this, race and sex must be deconstructed as elements of hierarchized differentiation and as forms of the symbolic representation of the human condition. Overcoming these essentialist bases in political and legal culture moreover demands that we critically review and deconstruct the pairing “body, non-body” consolidated and reinforced by liberal modernity.

Although the differentiation between body and non-body is present in cultures and in historical periods prior to modernity<sup>9</sup>, the specific thing

8. Research has recently been carried out analysing coloniality and gender together, while proposals for decoloniality have been made (Mignolo, 2014). Of these studies, I would like to mention the one by María Lugones, for the criticism she makes of Quijano's ideas, and for her interesting analysis of coloniality and gender (Lugones, 2014).
9. Although it was during the “repressive culture of Christianity –as a result of the conflict with Muslims and Jews in the fifteenth and sixteenth centuries, at the height of the Inquisition– that the primacy of the soul was emphasized, exasperated perhaps”, and the body was turned into a “basic object of repression” by the soul, it was

about modernity is the way in which both elements are related to one another. The non-body –where the soul or reason is– gets confused with the essence of what it is to be human while the body is abandoned to the laws of nature (the only reality for women and inferiorized races) or subjected to the control or observation of the soul or reason. After Descartes, reason was to become a new form of human identity and the core idea that shaped the subject, while the body would be the object of knowledge and of observation by rational subjects and science.

Inferiorization continues. The way in which we now treat minors as people unfit for any labour or work increases their vulnerability, hinders the development of their skills and diminishes their capabilities. The aim of this representation of minors is to legitimate and maintain adults' superiority and control over them, and the natural and rational human classification between rational and non-rational beings. There is no such thing as a rational and a non-rational human being, there are only different stages of human evolution and development. To complement this reasoning we should mention the struggle of many minors in the world to have their right to work and decent working conditions recognized, as a means for their subsistence and that of their families. Although there is a shortage of empirical studies about the work experiences of boys and girls and their associative movements, given the existing legislative prohibition of child labour, the fact is that they are real citizens, who acquire meaning and significance as a self-organized practice, interacting with adults and other supportive social movements, which makes them citizens shaped from below and not just formally recognized (Liebel, 2015: 43-61<sup>10</sup>; Cordero, 2015, 87-127<sup>11</sup>).

The objectification of the body makes it possible to deny subjectivity to all the human beings who are reduced to simple stereotyped bodies, as their soul or reason is denied by subjects of law-citizens. We are talking about women, servants, slaves and minors. These human beings are deprived, as non-persons, of the value of their work and subjected to the will of others, excluded from the discourse of rights and politics, and expelled from the world of knowledge and science.

When the historical idea of the category “individual-subject of law” in modern European culture is analysed, it can be seen that it was

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Descartes who culminated the process of radical separation between reason-subject and body (Quijano, 2005; Descartes, 1977: 61-75).

10. Liebel, M. (2015), “Sobre el interés superior de los niños y la evolución de las facultades”, *Anales de la Cátedra Francisco Suárez*, n.º 49.
11. Cordero Arce, M. (2015), “El derecho de las niñas y los niños al trabajo: un derecho secuestrado por el adultismo y el capitalismo hegemónico”, *Anales de la Cátedra Francisco Suárez*, n.º 49.

institutionalized by removing it from the economy and dissociating it from family and social power structures. Hobbes and Locke both separated political power and the law from other pre-existing social authority, that of the father over his children, the master over the servant (in Locke the servant is the worker), the husband over the wife and the owner over the slave. This is a distinction between the private and public spheres that enables us to make the natural hierarchization of humanity compatible with the principles and values of the new legal and political order (Clavero, 1997: 16, 18, 20<sup>12</sup>). But who is this person who becomes a subject? What potential does this acknowledgement confer?

The person who becomes a subject, in law, represents a particular social and procedural position. "Person" was, therefore, an individual's particular human quality or capacity. Hobbes was the first theorist to rework this term to refer with it to the individual that is, in him or herself, conceived as a subject of law. We have to wait until the middle of the eighteenth century to find the term "person" used, by jurists, "not as something that is possessed, but which is". And in Locke, in the *Second Treatise on the Legal and Political System*, we find the first joint ideation of the constitutional individual and State. In Locke there is already "a more elaborate idea of the individual as a subject of law, a possessor and agent of freedoms", and of the State "as an institution that endorses and guarantees the individual's position as a subject". Locke is therefore a point of reference when we ask ourselves about the constitutional effects of the individual-subject of laws (Clavero, 1997: 16, 18, 20). For Locke the status of subject of law implies "the property of one's own person. This proprietary right is above all the right to oneself, the person's right of self-disposal, a radical right of freedom" (Clavero, 1997: 21). This implies that the constitutional individual is affirmed as a form of freedom that produces internal discrimination (women, minors and servants are excluded) and external segregation (all non-citizens are excluded from the discourse of rights and the acknowledgement of equality) (Clavero, 1997: 23). We are thus faced with a category that only acknowledges a few human beings as holding the status of subject and citizen. The abandonment by modern legal and political culture of a large part of the population (internally and externally) is justified by the existence of human beings who by nature are little more than animals (women's reproductive nature, their dimension as females, is stressed) or simply are animals (blacks, slaves). This inferiorization makes it possible to reduce white women and individuals of inferiorized races to bodies-commodities and to stereotyped bodies (in the case of women, highly sexualized bodies).

12. Clavero, B. (1997), *Happy Constitution*, Trotta, Barcelona.

We might think that none of this has anything to do with the present. However, people trafficking, organ trafficking, the buying and selling of wombs for hire, the medical and legal controls that transsexual people are forced to undergo<sup>13</sup>, moral and political indifference to refugees, the living and working conditions of millions of people outside Europe, tell us a totally different story. The burden of stereotypes regarding corporality can be felt in the law and in society.

Like Rodotà, I think that, in its process of institutionalization and legal codification, the legal category of subject has been too abstract, something that distances it from the human reality that it ought to identify and recognize (Rodotà, 2014<sup>14</sup>). The abstraction that every legal category must have in order to conceal privilege and inequality cannot be used. Both the category of subject of law and the principle of legal equality must admit human diversity and legally relevant differences for the equal application of the law. Otherwise, we shall turn legal equality and the subject of law into idealized representations that get in the way of understanding what is real. When basic personal categories (individual, subject of law, citizen) and legal principles break the points of connection with the social and political reality that they speak to and represent, legal forms become structures that prevent the development of just law.

Insofar as the law and public policies are forced, under pressure from citizens and the development of democracy, to challenge structural inequality and violence, new, apparently non-coercive resources become more prominent, such as advertising, the media and new fashions, which reproduce human differentiation and inferiorization. One only has to analyse some of the best-known television series in the world (among others, *Borgen*, *Madam Secretary*, *Scandal*, *Castle*, *The Good Wife*, *Body of Proof*, *Damages*) to see how a process of cultural assimilation is being implemented (through a radical homogenization of the way the various professionals

13. Let's look at the example of Alexa. She is 13 and she has an unbreakable desire to live as she is. "She has always been this little girl", says Ches Cordero, Alexa's mother. This transsexual minor and her family have been strong and courageous enough to break down the barriers that society has placed in their way and Alexa has reached adolescence overwhelmingly certain about her gender. Nevertheless, she has now come up against a complicated obstacle. In a month's time she will be 14 and at that age she has to have her National Identity Card to go abroad to enter sporting events. A year ago they asked for her name to be legally changed on the document, but the court has refused to do this until she is 18. Most of the time the courts are sensitive and favourable to this kind of request, but 25% are still refused. The ruling has not taken into consideration the fact that the minor at school and in sport is a girl. Retrieved from <http://www.diariodesevilla.es/article/andalucia/2214661/deniegan/cambio/nombre/dni/una/m>, consulted on 8 February 2016.

14. Rodotà, S. (2014), *El derecho a tener derechos*, Trotta, Barcelona.

dress and act, regardless of their culture or geographical origins), and the radicalization of femininity. Successful professional women appear on television wearing the “uniform” of the tube skirt, 15-centimetre heels and tight-fitting dresses, a form of dress that leaves no room for imperfection, or bodily diversity. These forms of cultural and aesthetic homogenization are effective disciplinary systems, which regulate the bodies and minds of those who are subjected to them<sup>15</sup> – and in the specific case of women, excessive physical exposure (another way of reducing them to sexualized bodies)<sup>16</sup>.

To the regulation of bodies one must add their commercialization and excessive sexuality, of young women especially, encouraging their objectification and fragmentation. Women (preferably white) appear in adverts as people who are sick or in need of constant physical improvement (among others, urinary incontinence, deafness, herpes, cellulitis, wrinkles, being overweight, capillary problems). Non-whites, on the other hand, appear as vulnerable, passive people, constantly asking for help. Television always shows immigrants or refugees sitting, inactive, waiting for humanitarian aid. Only humanitarian Non-Governmental Organizations (NGOs) show us creative, productive and active beings. In both cases we do not see subjects, only helpless or imperfect bodies, which paradoxically do not generate empathy or solidarity, only bewilderment.

15. The other day, on a well-known television programme the Spanish actor Arturo Fernández said that one thing was being elegant, which had more to do with how the person lives life and how they relate to others, and something else altogether was dressing well. This distinction is neither new nor original, but it does allow us to reflect on why we wish to dress well, what dressing well brings us, and those who most need to do so. I think the answers to these questions are closely linked to everything described with respect to the foundations of the pattern of economic, cultural and global control, which interweaves social and political life. The wish to dress well expresses the wish to be recognized, to be accepted as a non-intrusive person, to be an equal. Remember the mockery to which some female ministers in Spain were subjected for their dress or their appearance (they were only seen as a body).
16. María Luz Esteban and Rosa Cobo claim that, “the growing process of the sexualization of women is deeply rooted in the symbolic structures that define women as nature, biology and sex”. What women have learned with regard to looking after their bodies is chiefly intended to reinforce their social role as reproductive and seductive beings (pornography, prostitution). Cobo says that “sexualization is a device that control systems apply to members of oppressed groups with the aim of removing them from the sphere of rationality and politics”, which leads her to claim that women’s bodies have been used as a support for inequality. Along with this process of objectification there is also “another alternative and critical idea of female subjectivity promoted by feminism”, Women are at the crossroads of both ideas (Esteban, 2004: 73; Cobo, 2015: 9-10, 14-15).

Science also collaborates in the process of stereotyped human differentiation. It is not hard to repeatedly find neurological studies in the press that attempt to demonstrate the different size and functioning of the brains of men and women, blacks and whites, despite the fact that human genome studies have shown that there are no important differences between the various human phenotypes, and between the human and the non-human. Just one example: for more than a decade we have known that our species has only about 30,000 more genes than a worm. But the best is yet to come. The genome of the mouse, which was presented in 2002 in the journal *Nature*, revealed that this tiny rodent shares 99% of its genes with humans. Our species' astonishing brainpower is therefore not due to the evolutionary "invention" of new genetic strategies, but to subtle modulations in the activation of some genes that, essentially, we share with all mammals. Allen Bradley of the Sanger Institute said in *Nature*: "Although anatomical differences between mice and human beings are spectacular, they do not usually reflect anything other than alterations in shape and size. Detailed analysis of organs, tissues and cells reveals many similarities, which extend to complete organic systems, physiological functions, reproduction, behaviour and diseases"<sup>17</sup>.

Why, in spite of scientific progress, does a stereotyped differentiation of humans persist, which experience and much of science has shown to be erroneous? What political function does it fulfil? If a particular corporality (genotypic, genital and heterosexual) determines which people become subjects of law, then it is not rationality that identifies the subject of law, but a stereotyped body. For this reason, medicine will have the job of determining what is normal and pathological in human bodies, shifting "the concept of truth –truth about the body and sexuality– towards empirical, objective and scientific regimes" (García, 2015: 52). There is no readiness for human nature to oppose the normative male/female pairing, hence intersex people are subjected to operations and mutilation, either when they are born or during childhood. When in 2006 the agreed conclusions of a group of experts were published in the San Francisco Report *Human Rights Commission (Medical "Normalization" of Intersex People)*, it was said that the term by which these people ought to be identified was "persons suffering from anomalies of sexual development or anomalies of sexual differentiation". With this expression the aim is to avoid terms such as intersex, hermaphrodite or pseudo-hermaphrodite – and

17. *El País*, Thursday 5 December 2002, retrieved from <http://webcache.googleusercontent.com/search?q=cache:u7PsjxuXx6gJ:elpais.com/diario/2>, consulted on 28 January 2016.

most importantly, to posit as a scientific truth what is a political option. This allows us to maintain that a person's gender and sex are cultural constructs (Butler, 2006: 148).

What has to change for the legal concept "subject of law" to recognize every individual without discrimination? The answer to the first question has already been given, although I shall discuss it in greater detail below. With regard to the second question, we have to say that a person becomes a subject, a subject of law, through a long process that lasts from childhood to adulthood. To integrate in the category of subject of law and in the principle of equality, plurality and dynamism, we need new narratives about human rights<sup>18</sup>, in which new symbolic representations of what it means to be human appear, as happened in Europe in the eighteenth century, so that they may encourage and be conducive to a change of thinking<sup>19</sup> and a perception of equal and different others<sup>20</sup>. We must develop new attitudes and aptitudes of comprehensive respect for human beings and the community, from which to promote different and plural ways of being in the world; and also common places from which to construct, translate and agree. We must transform consciences to transform realities (Herrera, 2005: 30<sup>21</sup>).

18. As Joaquín Herrera pointed out, human rights, as a cultural product, belong to the context in which they emerge and for which they function as categories legitimating or opposing the idea of a decent life in a particular social group. This leads us to maintain that the discourse of human rights, with its expansive and globalizing vocation, only imposed one world economy and a world ideology based on the idea of universal enlightened reason that is absolutely superior to any other way of acting and perceiving, and this is the Western one. This means that we are looking at a way, like another, of fighting for human dignity against relationships of control and oppression. Consequently, when what is real speaks to us and asks us to explain why the human rights of real people, not of idealized subjects, are not observed, we cannot theorize outside of reality, ignoring social practices. (Herrera Flores, 2005: 20-25).
19. Changes to the law are difficult due to the epistemological obstacles in the scientific practice of jurists and to the restraints placed on legal theorizing due to its proximity to the exercise of power. A critical analysis of the law cannot now be reduced to pointing out the repressive role of the State through the law, it must account for the functions of subordination and oppression that the legal system promotes and endorses. Society cannot be covered in all its complexity exclusively by the law; nor can the human dimension be reduced to the status of subject of law-citizen. For this reason we must broaden the approaches, the views. The legal discourse is part of the discourses of government, but its centrality has now been usurped by science and the market.
20. Lynn Hunt, in her book *The Invention of Human Rights*, takes a historical look at the narratives that managed to change ideas about violence and human beings in pre-revolutionary France (Hunt, 2009).
21. Herrera Flores, J. (2005), *Los derechos humanos como productos culturales. Crítica del humanismo abstracto*, Catarata, Madrid.

#### 4. THE POLITICAL AND ETHICAL VALUE OF THE MODERN DISCOURSE

The fact that women and many men were not part of the process of constructing the discourse on rights or the development of the State and modern constitutionalism has been considered irrelevant from the moral or political point of view. The arguments put forward to support the moral and political value of the modern legal and political discourse have been that “the rational subjects” who laid the intellectual foundations of legal and political culture and the basic personal categories (individual, subject of law, citizen) did so impartially, seeking universality – a myth that extended from the liberal State to the welfare State.

If there are significant differences of power and in access to resources, between the different classes, groups or interests, impartial decision-making procedures –in the sense of allowing everybody to formally have equal opportunities in order to campaign for their interests– will normally produce results that benefit the interests of the most powerful. Moreover, impartiality is, for those who make bureaucratic decisions, just as impossible as it is for other moral agents. It is simply impossible for flesh-and-blood people, whether in government or not, to adopt the point of view of transcendental reason when they make decisions, separating their own person from the affiliations and compromises that constitute their identity and give them a perspective with respect to social life (Young, 2000: 193-194<sup>22</sup>).

Consequently, if human knowledge is a (corporally and politically) positioned knowledge, then masculine rationality –the author and actor of the narratives about human rights, the State and constitutionalism– cannot be presented as “universal reason”, with the ideals of equality, justice and truth linked to it. Nor does having used the scientific method guarantee the goodness of what is decided. Adorno criticized the limits of the scientific method and the importance of the social position of the subject who knows, claiming that the “method threatens to both fetishize what is studied and to degenerate into a fetish” (Adorno, 2001: 23, 28). The criticisms made are not aimed at disdaining all that has been constructed; on the contrary, they are intended to show the deviations, the grey areas and the limits of the basic legal categories and of liberal constitutionalism, showing the need to resignify the discourse on human rights and the basic category of person-subject of law<sup>23</sup>, opening them up to human reality and cultural diversity.

22. Young, I. M. (2000), *La justicia y la política de la diferencia*, Cátedra, Madrid.

23. There is an extensive wide-ranging bibliography on the subject, in which subjectivity is approached from multiple points of view. In the majority of them, however, the presence of the body is confirmed, whether for analysing relationships of control over it or pressure on it, or presenting it as a place for constructing the self and of liberation. Despite everything that has been written and discussed, the notion of “body-subject”

The purpose of analysing the limits of the foundations of European legal and political culture and its structural violence is, in the first place, to understand the current phase of globalization and, secondly, to show that capital/the market's controlling power has increased in recent decades, affecting the category of subject with rights and its corporality. Inferiorization and social subordination have spread to poor people with jobs<sup>24</sup>, and human bodies have been reduced to bodies for the market. This means that colonial, racial and patriarchal capitalism is being reinforced from one of its axes, the exploitation of the working classes and the appropriation of the value of labour. This turns the working classes into another form of merchandise (a process aided by human objectification). This merchandise is unusual, because unlike the traditional kind that has been able to circulate freely, unhindered by tariffs or frontiers since the World Trade Organization (WTO) was set up on 1 January 1995, this kind is trapped in the local sphere, as a result of the immigration laws and the limits to mobility that Europe imposes on its citizens and on nationals of other countries (Rubio and Moya, 2011: 183-227). What level of concentration of power by capital and the global market will be sustainable on a human and environmental level? It is a question to which we have no answer. But the facts do not allow us to foresee a positive turn of events.

## 5. THE COMMERCIALIZATION AND FRAGMENTATION OF BODIES

Walder maintains that when the American photographer Spencer Tunick<sup>25</sup> got together 7,000 volunteers in 2005, posing naked in Avenida

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must be rethought, to make the different levels and forms of subject and subjectivity visible. There is no consensus in feminism, which has reflected a great deal on corporality and the monolithic nature of the subject, with regard to body-subject unity. There are many interesting debates, however, especially in Simone de Beauvoir, Luce Irigaray and Judith Butler. Some of these debates have been collected by Luisa Femenias in her thoughts about subject and gender (Femenias, 2000). In line with what I uphold in this article, it is interesting to point out the analysis by Iris Marion Young, in her work *Justice and the Politics of Difference*, and Marian Martínez's thoughts about this author and her idea of the body, from the perspective of political theory (Martínez Ramírez, 2009).

24. The right to a salary to guarantee subsistence and a certain degree of autonomy is no longer a privilege of all white men, but only some of them, those that are over-qualified and belong to certain classes. Therefore, not all formal subject-citizens are addressed or recognized by the political or economic discourse at this moment. The legal and political system is only interested in the individual-citizens who are useful as consumers or producers of talent; the rest are abandoned, if not blamed, for their lack of value and productivity. The old concept of servant is valid today for all working people, and that of outcast for poor workers (Bauman, 2015).
25. Tunick did his first nude session with 30 people in New York in 1994, and they all ended up in jail.

María Cristina in Barcelona<sup>26</sup>; 450 naked people in Buenos Aires in 2001; or he did his performance in Caracas (Venezuela) in front of a statue of Simón Bolívar, or on the banks of the Thames in London for the opening of the Saatchi Gallery of Contemporary Art, his intention was to criticize the commercialization to which human bodies are subjected. Through nudity he aims to show the truth of the human condition, its diversity –old and young bodies, with different harmonies and shapes– and to allow us to think about what we are, how others see us, and what we lack. Exposing the weakness of the individual body and at the same time its strength, in so many bodies together, was a way of rebelling against the market and the canons of beauty it imposes. The wish is to go beyond the limits of the normative, making the performance an act of provocation, but also of freedom, as each individual, regardless of what their body looks like, regains control of him or herself, against those whose intention is to reduce human beings to bodies for the market. During the performance bodies lose their exchange value and become art, beauty; one only has to look at Tunick’s photographs. For a few minutes, human bodies acknowledged one another, outside the control of the market, as an asset in themselves, free of appropriations, contracts and impositions. Human beings formed a single global body, made up of thousands of limbs and subtle differences, detached from competition and mass consumption. The importance of these gatherings is that human bodies were in, and occupied, the global, public and political arena<sup>27</sup>. In other words, in themselves they shaped possible new significances and meanings of what it is to be human.

The only refuge for nudity<sup>28</sup> –against structural and institutional tedium– was the company and the nakedness of others. Reciprocal recognition is constructed by the confirmation of vulnerability and dependence, not by fear or independence. With this metaphor, Tunick tries to highlight the importance of the group, to be able to construct sense and meaning of life on an individual and collective level. To show, as Walder says, that “many singularities made up a whole, the naked social body, as an observation and as a linguistic figure. Bodies freed of their economic,

26. Retrieved from [http://webcache.googleusercontent.com/search?q=cache:LvsG88StroJ:www.eltiempo.com/Multimedia/galeria\\_fotos/cultyentre6/GALERIAFOTOS-WEB-PLANTILLA\\_GALERIA\\_FOTOS13130338.html+&cd=1&hl=es&ct=clnk&gl=es](http://webcache.googleusercontent.com/search?q=cache:LvsG88StroJ:www.eltiempo.com/Multimedia/galeria_fotos/cultyentre6/GALERIAFOTOS-WEB-PLANTILLA_GALERIA_FOTOS13130338.html+&cd=1&hl=es&ct=clnk&gl=es).

27. It is no coincidence that the photographer looks for public places where he will have an audience, and announces sessions in public places where art, culture, beauty and politics are concentrated, the most typical human endeavours.

28. Nudity represents, as I understand it at least, the truth without obstacles, without artifice, naked.

social, statutory, ethnic condition; in collective nakedness there were no differences, only similarities” (Walder, 2012<sup>29</sup>).

In pre-modern societies individuals were acknowledged by the place they occupied in society as a whole; modernity on the other hand represents the self alone, dissociated, unlimited, or rather, with no limits other than those imposed on it by the freedom and rights of others. For this reason it must accept certain coercive rules, guaranteeing individual freedom and sociability free of violence and chaos. In the modern social and political order it is not the individual-subject who changes its nature, but society and political power, in order to guarantee the structural and institutional conditions that make the development of individuality possible (only of those recognized as persons-subjects), and of the rights ascribed to it. This explains why liberal thinking limits the intervention of the State in private life to the creation of laws conducive to the free circulation of people, goods and ideas, and does not pass any moral judgment on individual conduct except when behaviours endanger public life. These days, something else has occurred. When neo-liberalism restricts social matters to the market, “many obsessions of modernity, law, order, duty are broken up” (Walder, 2012). But returning to those old ideals requires a new act of faith<sup>30</sup> and new narratives to adapt them to reality.

Jon Beasley-Murray claimed in his book *Posthegemony* that power is half coercion and half legitimacy. The State maintains its control through consensus and the acceptance of those it controls, as a result of the acceptance of the principles that legitimate it. This means that the power of the State is maintained because people keep believing in the ideas and utopias that shaped it. That is, the State retains its power of persuasion, conviction and seduction – seduction that has recently been articulated as much by fear as by the old, more or less radical, longing or desire for change. As the author puts it:

29. Walder, P. (2012), “El cuerpo fragmentado”, *Polis* [Online], 7 | 2004, published on 10 September 2012, retrieved from <http://polis.revues.org/6278>, consulted on 16 January 2016.

30. “It is difficult to say exactly what human rights are because their definition, their very existence, depends on the emotions and on reason. The pretension of evidence is ultimately based on an emotional attraction [...] it is convincing if it strikes a chord in everyone. Moreover, we are almost sure that it is a human right when we feel horrified by its violation”. Human rights represent red lines, what is no longer admissible. Diderot said as much in 1755, when he claimed: “I do not have any other truly inalienable natural rights than those of humanity”. Without the feeling of belonging to the human race it is difficult to defend and guarantee human rights on a local and global level (Hunt, 2009: 25).

Feeling is a gateway to the immanence of politics (and to a politics of immanence). Affect, then, is an index of power, which is itself a function of its affective capacity or receptivity. Affect marks the passage whereby one body *becomes* another body, either joyfully or sorrowfully; in this respect affect always takes place *between* bodies, at the mobile threshold between affective states as bodies either coalesce or uniting or disintegrate as they become other to themselves [...] affect in general constitutes an immanent and unbounded “field of emergence” or “pure capacity”, prior to the imposition of order and subjectivity. It is only as affect is delimited and captured that bodies are fixed and subjectivity and transcendence emerge.

But insofar as this occurs, affect itself is transformed and with it the subjectivity and order that it establishes (Beasley-Murray, 2008). What I have said up to now enables me to conclude that capital/the market has extended its pattern of control over the bodies of all individuals –men and women– to the extent of confining subjectivity to the limited space of the body on the market. For this reason the deterioration of corporality is experienced with great anguish, given that it symbolizes social exclusion and expulsion from the market. This explains the horror of ageing and the need to artificially seek youth through surgical operations or pharmacology. “Physical wear and tear is the metaphor of the extinction of life. The darkening of the body is the evidence of death, of the subject’s finitude” (Walder, 2012). What is paradoxical about this situation is that human life is presented as a life without transcendence, and the subject as an amputee, as they have been deprived of their capacity and potential for transcendence, just when body-subjects are experiencing a “biomechanical prolongation” as a consequence of the interaction between bodies and new technologies (cyborg), and individuals can develop, through the social networks, multiple identities and developments of their subjectivity. How can we prevent the subject from being turned into a commercialized body?

To eradicate from our societies the relationships of exploitation, control and inferiorization suffered by discriminated social groups, and to free body-subjects from the limitations imposed by the market, we must:

1. Deconstruct and rework the intellectual foundations on which modern legal and political culture and the capitalist economic system are based. Limits must be placed on the commercialization and objectification of human beings. Personal freedom and the market cannot simply legitimate the buying and selling of bodies or organs. And if this were permitted, we ought to establish strict anti-discrimination controls –red lines– to prevent the human body

from being converted into dehumanized material, or a new dehumanizing market niche<sup>31</sup>.

2. Irrationalize the symbolic representations of human beings that science and moral philosophy constructed, and still do, generating new narratives, in which the heterogeneity of the human condition is revealed as that which is truly natural and rational, and where body-subjects can see one another and be seen, but also dream to be. It would ultimately be a question of freeing bodies and desires from the control imposed on them by the market. Categories such as women, men, transsexuals, hermaphrodites, Europeans, Latin Americans, should refer only to the diversity and heterogeneity of human beings, not to identities. Others such as whites, blacks, Mestizo Indians, should be eradicated from the language, as they produce an absolutely misleading mental image of humans. To achieve these goals we must go beyond the traditional separation between body and non-body, given that a subject does not exist outside a body, nor is there a body without subjectivity. We must rebalance the relationship between labour and capital, and redefine the concept of labour so that all work is acknowledged as such: commercialized work and caring, child-raising and domestic work; and lastly, we must develop new foundations for the discourse on human rights, so that we are horrified by the violation that the market perpetrates by reducing a human being to merchandise for production or to a source of spare organs to be bought and sold<sup>32</sup>.

## 6. BODY-SUBJECTS AND CITIZENSHIP

Bodies are not just simple receptacles of a higher spirituality that must be protected, but the space from where each self is, exists and relates to

31. At the inaugural session of Cumbre Sur, in Havana on 12 April 2000, Fidel Castro denounced the position of poor countries: "financial gain prevails over needs in private research, intellectual property rights exclude under-developed countries from knowledge, and patent law does not recognize either knowledge or traditional ownership systems, so important in the South. Private research concentrates on the needs of rich consumers. Vaccines are the most efficient technologies in relation to health care costs, as they are capable of preventing disease with a dose that is administered just once, but they produce small profits and they are relegated with respect to medicines that require repeated applications and generate larger profits. New medicines, the best seeds and in general the best technologies, converted into commodities, have a price" only affordable by rich countries. Retrieved from <http://www.g77.org/summit/ceniai.inf.cu/f120400e.html>, consulted on 10 March.
32. Sexual and reproductive rights must be constitutionalized, and the systems guaranteeing social rights to guarantee the full value of human beings must be improved.

other body-subjects. If the body is the space from which the self shapes its identity and develops its personal autonomy and subjectivity, then it makes no sense to differentiate between body and non-body, nor should a human being be reduced to a body. For all these reasons I feel it is more appropriate to use the notion of person, once it has been purged of its age-old residues, so that it can act as the notion and the red line that establishes the sacred unitary nature of every human being.

Person is a term that has a long history in law, functioning today as a device (Foucault), whose success and excess of rash significance is surprising. Its use after the end of the Second World War, in the Declaration of Human Rights of 1948, is due to the wish to re-establish the connection between body and reason, to give pride of place to value and the dignity of the human person, and to reconnect rights with life. But, in principle, the notion of "person is not suitable to make up for the extraordinary hiatus between life and law, *nomos* and *bios*, because it is actually what produced it". This, in the words of Esposito, obliges us to reveal the hidden residue, of violence, that the foundational tales associating the origins of civilization with a conflict between blood relatives conceal when they speak of the person. The limit that this category presents for its use today is that it contains a unity "constituted by a separation", "which unites in itself, without confusing them, two states or natures" that "are not equitably equivalent" in Christian culture. For this reason, it could be used to distinguish between subject and object, making it possible to create subjectivity "through a procedure of subjugation or objectification. Person is what keeps a part of the body subject to the other insofar as it makes the latter the subject of the former". "It subjects the living being to itself". Based on this, Roman law developed the term granting it the meaning of representation of what is human, and the prism that makes it possible at the same time to distinguish between different classes of men (*servi* and *liberi*, *ingenui* and *liberti*) and to contain the highest human status and the lowest, the slave (*res*). The category of subject seemed to transcend this human classification, but what it did was expel it from the law and conceal its social and political existence. For this reason we must resignify the notion and make the notion of person describe the body-subject, the human being that is and has, through "a transverse relationship that decomposes, and then superimposes", obliging us to see what is hidden and to go beyond the idea of appropriation that underlies the notion of person, to give it another meaning, which states that the human person, the human being, is sacred in its unity. Taking sacred to mean untouchable, that which must be respected by everybody, because it protects the human condition (Esposito, 2011: 56-60, 62, 63, 65, 67, 68, 74, 90<sup>33</sup>).

33. Esposito, R. (2011), *El dispositivo de la persona*, Buenos Aires.

The device “person” possesses a sufficient degree of abstraction to account for the diversity of human body-subjects, and sufficient concreteness to prevent the category “subject” from moving too far away from what is real, from life. This line of reasoning, taken to the economic and political and legal level, implies the absolute prohibition to dominate, exploit or take possession of the labour, resources or intellectual or material production of body-subjects, but also to objectify and commercialize human bodies<sup>34</sup>. This is why I consider that any mercantile cession related to human corporality must be seen as a possible danger for human unity and equality. And, consequently, it must be subjected to strict controls, to prevent any form of discrimination. We are talking about prohibiting the market from using the law of supply and demand to reinforce and maintain a devalued image of women and inferiorized ethnic groups, neutralizing the discourse on human rights, humanitarian and anti-discriminatory law, through the fragmentation and commercialization of their bodies. The law of the market cannot legitimate human differentiation, reproduce discrimination, through the price of surrogate motherhood, the buying and selling of an organ, tissue or any other biomaterial.

The structural problems or violence mentioned make it impossible to point to guilty parties, legally speaking, although they no doubt exist, nor to establish a close logical connection (without a shadow of a doubt) between action and discriminatory effect, given the complex and diffuse group nature of its causes, actions and impacts. For this reason citizens must take political responsibility on an individual and collective level (Young, 2011), and overcome the temptation to exonerate ourselves from all blame. In democracy, the struggle against discrimination and dehumanization is the responsibility of each and every one of us.

When body-subjects do not perceive social discrimination or oppression it is because they have internalized the established rules and the value systems that support them, because they have identified as their own the points of view of the hegemonic and controlling social groups. To break this alienation one must develop critical awareness, moral education and the ability for reflection in individuals. Freedom is not a natural quality; it is developed or constrained in the framework of social relationships allowed by structures and institutions. The body-subject is not born free, it becomes free as a collateral effect of its capacity for thought, choice and action, in the interaction with other

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34. All this leads me to state that surrogate motherhood or prostitution are not activities that should be accepted socially and regulated as the mere hiring out or cession of one’s body, which in no way affect subjectivity and equality. Body and non-body, in my opinion, are indissociable when legally safeguarding subjects and their rights.

body-subjects with whom it lives and is. To minimize the differences between those who are acknowledged by the market as subjects and those who are reduced to stereotyped and occupied bodies is to hide the fact that true equality is only possible in reciprocity, equivalence and the mutual recognition of equal value and dignity<sup>35</sup>, in both the law and the market.

Although technology has enabled the authorities and the market to act and develop in a delocated way, human beings cannot live like that. Individuals live in bodies, integrated in family and social structures, and in cities. In other words, human life is and develops in a particular –corporeal and social– territory and in coordinates of temporality and sociability. The reason for transferring the function of mediation between the authorities and society, previously occupied by politics and the law, to families and businesses, is in order to create weakened State models, whose functions are reduced to those of local gendarme and the institutional maintenance of spaces for meetings, negotiations and decision-making between individuals (singly and corporatized) and the market. The deregulation of important social and economic sectors, the loss of control of politics and the lack of alternative political discourses, are serving to dismantle welfare states and to introduce other new ones, which are presented<sup>36</sup> as more efficient and participative. The privatization of politics and the delocation of the economy bring back a highly corporate model of society, in which together with the old human hierarchies other new ones surface, as we have tried to show, which strip the working classes of subjectivity and citizenship, reducing them to commercialized bodies, a process of dehumanization that affects the whole of society and the discourse of human rights in particular.

## 7. WHAT MISTAKES HAVE WE MADE AND ARE WE STILL MAKING?

1. Believing that access to rights and basic freedoms on a formally equal footing would be sufficient guarantee for the exercise of citizenship

35. I understand dignity in the descriptive and normative sense. Normatively, that is, as the ultimate basis of human rights, it represents a red line with regard to what we find unbearable, inadmissible. A statement that is not averse to considering the complex nature of dignity in its interaction with equality in rights, pluralism and the social context, which enables us to speak about flexible and minimal consensuses (Atienza, 2009: 92; Lucas, 2009: 319-321).
36. In this new context of the privatization of politics and the relocation of production a highly corporate social model returns, which once again hierarchizes human beings according to their technical and intellectual skills and their origins, configuring new, apparently voluntary servitudes, (Rubio and Moya, 2011).

and access to all rights, without the need to make institutional or structural changes to eradicate origins-based discrimination represented by the hegemonic pattern of control by capital/the market/racism/gender. Ignoring or not properly valuing the myths constructed around modernity<sup>37</sup>.

2. Thinking that the public policies developed from the principle of equal opportunities, in education, employment or politics, would make up for the lack of formal equality and would manage to eradicate social discrimination and subordination, unaware of the group nature –not individual– of these.

3. Understanding that the legal and political categories that shaped political culture and the discourse of rights, once their partiality and lack of universality had been confirmed, could be used, once they had been broadened, to promote the effective equality of men and women and the development of an inclusive democracy.

## 8. UNEXPECTED PROBLEMS AND FUTURE CHALLENGES

1. A particular area of feminism and some social movements have criticized institutional tutelage and public equality policies, on the basis that they neglect or do not pay enough attention to relationships of control and subordination in the private domestic sphere. It is an approach that places the debate about social justice in the reduction or elimination of oppressive controlling relationships, in both the private and the public sphere.

2. The model of distributive justice has been questioned, on which the development of the principle of equal opportunities and anti-discriminatory laws was based, claiming that it reproduces an image of oppressed social groups as victims and does not act on the structural causes of discrimination.

3. Two models, the basis for legislative changes, have been criticized and questioned. They are the democratic model and the model of the subject (for which multiple and open subjectivities have been proposed). This is because it is understood that they did not take into account the necessary global nature that politics and citizenship must have today, as does the category of subject.

4. The prevailing picture of disorder in Spanish and European society seems to have made all utopian references worthless, making the idea of a

37. People are now talking about trans-modernity, as a means of overcoming the myth of modernity and making denied otherness visible (Dussel, 2005: 55).

controlled and controllable social reality disappear. The world seems to be “a field of scattered and unequal forces that crystallize in places difficult to foresee and gain a momentum that in truth no one knows how to stop” (Bauman, 2015: 79<sup>38</sup>). In this context only the market seems to have any meaning and logic, hence what is common and social is reduced to it. The effect on the subject we are discussing here is to think that the commercialization of bodies and organs is morally and politically unimportant, given that personal freedom should prevail in this context. But as in every social practice, the context is important for its evaluation and regulation, and the individual and collective effects of such practices as well.

5. Nobody seems to be able to speak on behalf of humanity, nor knows how to do it (even if it were possible). The apparent destruction of everything known on a theoretical and practical level, together with the image of confusion generated by the creation of new dangers and uncertainties, plunges human beings into dismay and confusion. This paralysis undermines our confidence in ourselves, as a collective political subject for action and the control of power. But this loss of confidence in ourselves makes no sense. If local and global citizens really did not have the power to control and act, the rise in the discourse of fear promoted by executives, the discrediting of politics, and the efforts to reduce the common general interest to what the market establishes and regulates, would not exist.

6. Due to this reality, the only task that the market demands of States is that they keep the deficit and the budget under control, suppressing all local civic expressions in favour of greater intervention in the market and the institutions (Bauman, 2015: 91). But, as we have been saying, it is essential to control the market through politics and the law.

7. Disdain for local affairs, social cohesion and the State may make sense and be logical for the powerful, but not at all for the working classes who live in specific places, and are not, nor could be, cosmopolitan. Ricardo Petrella claimed that, “globalization drags economies towards the production of the ephemeral, the volatile (through a massive and widespread reduction of people’s useful working lives, products and services), and towards the precarious (temporary, flexible, part-time jobs)”. This kind of production and consumption marks people’s way of life, plunging them into immediacy, superficiality and mass consumption, disconnecting us from what is necessary and making us prisoners of unlimited desires; or, even worse, seeking refuge in what is “mine”, in biology (Petrella, 1997: 17<sup>39</sup>). But the body-subject with rights is only protected when, on a local

38. Bauman, Z. (2015), *La globalización, consecuencias humanas*, FCE, Spain.

39. Petrella, R. (1997), “Une machine infernale”, *Le Monde diplomatique*, June.

level, “we” are too. Controlling the commercialization to which human beings are subjected and putting it to the test of human rights is the only possible way to oppose dehumanization.

8. The effects of the reduction of subjects to bodies for the market are by now self-evident. Human beings live immersed in an existential void that makes them constantly question what they are and what they have achieved. And it is in these times of uncertainty when the value of the biological –blood ties– makes its reappearance. There is talk of our people, my country, what is mine, seeking a projection of oneself, the value or the meaning of life, through biological paternity or maternity (and if it is not possible, taking the body of a woman), which is surprising. For a long time we stressed that the important things were affection and care and not the biological origins of paternity or maternity. But everything that was discussed seems to have paled into insignificance in the face of the desire to have one’s own children, whatever the human and financial cost. The question we must ask ourselves is: why does experiencing fatherhood or motherhood require a child of one’s own? Is adoption unsatisfactory? Are all our wishes needs?

9. The fact that nowadays the organ or womb of a Caucasian (white) person has a higher price than that of a different phenotype, or from certain places in the world, is and will be a new form of racial coloniality and the sex-gender system. We must prevent human bodies from being valued differently in the market according to their phenotypic, sexual traits or origins. If we are going to compensate inter vivos donations, let us standardize the costs, let us prevent human inferiorization from being encouraged, disguised as free trade, and the bodies of women and poor young people from being new speculative market niches. If financial compensations are established for inter vivos donations to mitigate the health and personal problems involved in donation, let us make sure they go directly to the donor, avoiding the unfair enrichment of corporations and intermediaries.

10. Without dismissing everything that science and technology offer us, and acknowledging the impossibility of returning to a non-globalized world, we must look again at the red lines, the limits of power/the market, the act of faith implied in acknowledging human rights as sacred, inalienable, inviolable rights of the body-subject. We must return to “we humans”, to the person with rights, to placing the market and the State under the control of (local and global) citizens and the law. We must recover our faith in ourselves (all humans), in utopia, in the new narratives about human rights. Without this act of faith human beings run the risk of continuing to be dehumanized, which will end with us being reduced to occupied and stereotyped bodies.

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## Is There Anything Money Can't Buy?<sup>1</sup>

ALBERT ROYES

In relation to the subject to which the title of this text refers, one must begin by asking oneself two questions, similar but different, like two sides of the same coin. Firstly, is there really anything that money cannot buy (directly or indirectly) in the world today? And secondly, is there anything that money ought not to be able to buy, because it should not be for sale?

My answer to the first question is no, if we are referring to actions, behaviours, wishes and decisions. Everything that comprises our emotions, feelings, thoughts, desires, dreams and hopes would therefore be outside the scope of what can be bought. In short, everything we refer to as our intimacy (not privacy, terms that should not be confused). As to the second question, in this case my answer is yes, and how to justify this answer with specific arguments is precisely what I consider interesting to debate.

I shall begin by explaining why I generally say no to the first question. As is well known, in the late eighteenth century, in *The Wealth of Nations* Adam Smith described the basic components and mechanisms of the market economy, appealing to “the markets” as the invisible hand that regulates and controls everything. He was talking about England, already a fairly industrialized society and the possessor of a vast empire that enabled it to set in motion the first globalization, the prelude to and the portent of the present one. In this it differed from continental Europe, made up basically of rentier societies where the highest incomes were on average about fifty times larger than those of the general population. That situation essentially lasted until after the two world wars of the twentieth

1. This text was written after reading the book by Michael Sandel (2012), *What Money Can't Buy: The Moral Limits of Markets*, Farrar, Straus and Giroux, New York. Spanish translation: *Lo que el dinero no puede comprar*, Debate, Barcelona, 2013.

century. As a consequence of the resulting socio-political situation, what has been called the Social or Welfare State came about in Europe (from 1946 to the mid 1980s). It was characterized by a significant cap on profits and incomes of all kinds (through progressive taxation), increased equal opportunities (through public education and training), and therefore, a reduction of inequalities, besides local reinvestment policies, strong trades unions and a highly regulated banking and finance system. In short, the kind of policies promoted for years by European social democracy.

All this began to change (forever?) between the mid-1980s and the Great Recession of 2008, which is where we still are: banking and financial deregulation, lower progressive taxes and higher indirect or proportional ones (VAT), no limit to profits, a sharp drop in salaries, job insecurity, scant local investment (more relocations), heavy disinvestment in the previous Welfare State, a gradually globalized world, and so on. To sum up, a scenario of greater inequality, greater globalization of capital and less equality of opportunities. A globalized market society, in which, in the words of Joseph Stiglitz (a good exponent of American social democracy), “politics has conditioned the market with the aim of it benefitting the wealthiest (the 1% of the population and, above all, the 0.1%) at the expense of the people down below”<sup>2</sup>. The American tycoon Warren Buffet said it clearly in 2006 in a burst of sincerity: “There’s been class warfare going on for the last 20 years, and my class [that of the wealthiest] has won”.

Is anyone surprised, then, that a market economy has generated a market society, and moreover globalized? Surely it was just a matter of time (and the consolidation of the almost total hegemony of a certain kind of economic policy called neoconservative) before this process proved to be successful. Has the cause of all this been the unlimited greed of a few? Not completely. An important role in this process was also played by the expansion of the market economy (and the ideology that goes with it, of course) towards areas of life where it should perhaps never have prevailed; that is, towards the introduction of a market society.

As I see it, what has happened is that this process I have very briefly described does not have much to do with morality or ethics, just as the capitalist economic system has never had anything to do with morality or ethics. Hence it is at the very least odd that Michael Sandel should be surprised when he writes, in the book cited above, that “mercantile reasoning empties public life of moral arguments” and that the only “moral argument” that capitalism uses (because it suits it, naturally) is the moral hazard: if we subsidize the unemployed we are removing the incentive to

2. Stiglitz, J. (2012), *El precio de la desigualdad*, Taurus, Madrid.

look for work; if we pay for universal public healthcare people will not need to save up to pay for their health insurance, and so on. On the other hand, however, if banks are “too important (or too big) to be allowed to fail”, their managers may feel highly incentivized to grab everything they can, because when all is said and done it is the taxpayers who will pick up the bill! And capitalism and its financial acolytes apparently see absolutely no “moral risk” in this at all.

Thinking of the “absence of morality” of Wall St. and its managers, Sandel says in his book, is the first thing that comes into your head. But he then advises us to generalize “rethinking the role of the markets in the lives of everyone”: a good tactic for making the very specific, abstract, in order to thus defuse it (we are all guilty in part, or at least complicit, etc.). If we compare it to the detailed and concrete analyses offered, for example, by Stiglitz in *Freefall*<sup>3</sup>, when he directly studies the utterly unethical behaviours of the Wall St. raiders, Sandel’s argument is the closest thing to a fairy tale. Indeed, when in the last part of his book Stiglitz analyses the moral crisis of capitalism, crystal clear since 2008, he describes “the moral depravation, the exploitation of poor and middle-class Americans by financial capitalism” as a well-documented fact. Stiglitz concludes by saying, “if earning money is the ultimate purpose in life, then there is no limit to acceptable behaviour” (for example, financing slavery, as the first Morgan banker did; financing apartheid in South Africa, as City-Bank did, etc.).

To better understand the world we live in, it is a good idea to reread the classics from time to time. Let’s look at some examples.

If everything does indeed have an (explicit or implicit) price, and everything is increasingly governed by the fundamental law of the market –supply and demand– it may be interesting to reread *Das Kapital*, by Marx, and what he writes in the first ten pages of the first chapter about “commodity fetishism”. The difference today is that in the globalized market society any thing, object, person, organ or tissue is just another commodity, which as such has a price and can be sold if buyers appear anywhere in the globally interconnected world, in which information on available goods travels at the speed of internet. Even more so, because now in this global market not only is it possible to sell commodities, but ideas too, especially the ideas on which policies and therefore the economy itself are based.

3. Stiglitz, J. (2010), *Freefall: America, Free Markets, and the Sinking of the World Economy*. W. W. Norton. Spanish translation: *Caída libre: el libre mercado y el hundimiento de la economía mundial*, Taurus, Madrid, 2010.

As I said, right at the start of his book, Marx describes the capitalist system as an economic system based on the continuous and massive transformation of the value of use of objects (or of assets in general, including people's intellectual skills and capabilities) into exchange value, commodities that can be bought and sold in some kind of market. This is precisely the basis of the market economy (for example, diamonds have enormous "exchange value", far greater than their possible value of use in industrial processes, because they are rare and require a huge human and technological effort to mine, cut and polish them).

Speaking of diamonds, and citing another very different classic book, when many years ago I first read *The Vanished Diamond (The Southern Star)* by Jules Verne, I began to sense, with surprise, some of the paradoxical situations of the market economy: Verne explains that a German chemist (he had to be German!) arrives in the diamond mines that British and Dutch colonialism possessed in South Africa. He easily manages to create an artificial diamond with the same properties for use in industry as natural diamonds, but without the necessary terrible effort to extract them and the high price in fatal accidents with which they were, and still are, obtained. However, when he reveals his discovery, much to his surprise it is met with hostility by the colonists looking for diamonds, because they rightly think that his discovery will cause the price of this product (i.e., its exchange value) to drop like a stone in the markets, and they obviously do not like that at all.

As we are remembering the classics it is also interesting to read Balzac, especially *Le père Goriot* and the famous speech by Vautrin that begins the novel's central chapter. In it, Balzac comes out with a terrible sentence that could almost certainly apply to many young people nowadays: "social success through studying, merit and work is a mere illusion". You'd be better off (Vautrin advises the young Rastignac, an arriviste who, like D'Artagnan, comes up from Gascony to Paris to make his fortune anyway he can) seducing a young heiress, marrying her and living comfortably off her money. In other words, following Balzac's logic many people will seek other ways (legal or not) simply to get by and survive, or in some cases to prosper.

The important question for this subject is, in my view, the following: that which has been generated by nature (the human body and its parts, non-human animals, the environment) may also become a commodity; that is, it is also liable to acquire exchange value in the different markets. And in this dynamic (globalized, moreover) there are no caps, no limits to the implacable logic of commodity fetishism as Marx said. Or, at least, there are no limits in a market economy and society. As Marx wrote,

many years ago: “the dominant social relation is the relation between men as possessors of commodities [of any kind, I would add], which, as they have exchange value, are expressed in the form of money”. In my opinion, nothing has changed.

In this socioeconomic context the academic legal debate about the ownership of the body, concerning the possible uses of it and the protection it merits by the law runs the risk of turning into a debate increasingly disconnected from the circumstances and the specific situations in which much of the world’s globalized population tries to survive, in extreme cases at any price. Let us now discuss the second question: is there anything that money ought not to be able to buy, because it should not be for sale? The debate about what money can or cannot buy (a hypothesis that, as I have already said, I find inconsistent in the globalized economic context in which we move) is focused on two points, which refer to:

- Justice or fairness (the inequality generated by the market society in addition to the lack of equal opportunities).
- Corruption (the term by which we refer to the attitudes and laws that trading relationships may infringe or directly destroy).

If, for example, this model is applied to the buying and selling of kidneys of living people the result is obvious: it is a question of taking advantage of poverty and of promoting a denigrating concept of the human being understood as a set of biological spare parts (organs and tissues). Applied to prostitution, I do not think the corruption argument is so evident, if this practice is truly a matter of choice and freely consented, because the working conditions in many relocated companies are surely much worse, and against them people have neither choice nor protection. The hackneyed reference to the issue of dignity<sup>4</sup>, the affirmation that it is indecent to buy or sell people’s bodies or parts of them, is, in my opinion, an example of simple moralizing. We do not really know what we mean by dignity, but we certainly can know (and see it, if we want to look) what indignity is, now globalized as well: poverty, malnutrition, lack of hygiene, gender violence (or any other kind), being homeless because it has been impossible to repay an excessive and often unfair debt to a bank, being jobless, no matter how hard you look, and, if you find one, having to work in virtually slave-like conditions (without protection, rights or security), being unable to decide freely about almost anything, and so on.

4. For the debate, see Macklin, R. (2003), “Dignity Is a Useless Concept”, *British Medical Journal*, 327 (7429): 1419-1420 and Pinker, S. (2008), “The Stupidity of Dignity”, *The New Republic*, May.

In this context of moral misery (and material in too many cases), can we reasonably ask people who live in appalling conditions to behave “with dignity” and not to play the market game by contributing the little they have to offer? It is perhaps more worthwhile to focus the question on the side of those who buy because they can, because they are on the *good* side of inequality. And buyers of course do not think about issues of dignity, only about their own profit and interest.

The interesting question here is what do we have left? Well, bioethics and law, as always. But only if we approach things from a certain type of bioethics that prioritizes the ethical duty of non-maleficence can we argue and maintain that removing kidneys in exchange for money, or anything else, is clearly maleficent; it is causing absolutely avoidable harm, and the important thing is to eliminate or at least sufficiently minimize the appalling conditions that the globalized market generates and which lead some people to make this kind of decision, which may under no circumstances be considered free, voluntary and altruistic (as is required for inter vivos organ donations), but as a last resort in conditions of poverty.

As in the other suppositions on which it reflects, on this subject bioethics can influence legislation with its contributions, so that:

- No one lives in such appalling conditions that selling their body or parts of it is seen as an alternative, and not the worst.
- In a globalized market society, what is really needed is to attack indignity at source and not just to intervene in the end market. Meanwhile, however, one must put all possible obstacles in the way so that in our rich societies the maleficent behaviours I have mentioned cannot be conducted in any way, shape or form. That is the role of the law.
- The law for this purpose must be severe enough so that no one will consider collaborating, participating or being complicit in maleficent acts; if they do, they will be severely punished. Obviously, this law must not be merely local or regional but universal –assumed by international bodies with executive power– and, moreover, participation or collaboration in this kind of action must be part of the cases punishable by a court of law with international jurisdiction.
- Along with this, international Human Rights protection bodies must incorporate, as a core element of their interventions and declarations, the defence and protection of the most vulnerable; that is, those most liable to finding themselves forced to enter –as a commodity– this global market.

#### 4. IS THERE ANYTHING MONEY CAN'T BUY?

In this subject as in so many others, one can so easily be utterly sceptical in the face of so much nonsense. But bioethics must not fall into this intellectual temptation. On the contrary, and although it may sound utopian, it must offer and uphold a scale of values in which submission to the commodity fetishism that I was talking about is not the dominant value in our real world.



# Is My Body Mine? Concerning the Private Ownership of the Human Body

RICARDO GARCÍA MANRIQUE

## 1. THE HUMAN BODY, TEMPTED BY THE MARKET

Two powerful forces have united to tempt our bodies with the materialization of a dream that has long been occupying our thoughts: the complete domination of nature. I am not referring to the nature that surrounds us, but to our own, our corporeal, vital, animal and human nature, which enslaves us from within, and limits and determines our freedom, or what we imagine to be our freedom.

One of these forces is the ever more rapid development of biotechnologies, which has enlarged the circle of what is no longer just a dream but something realizable, a little more each day, quicker even than we can assimilate. Others will do it more fully. Reproduction is not what it was, and nor is the fight for good health and the prolongation of life. Their basic concepts are changing, and with them the guidelines that we have to follow when in one way or another we take care of our body, either to preserve it, or to project it on to others. And what we can already do allows us to catch a glimpse of what we will be able to do soon. We can feel our natural corset being loosened and how freely we can breathe.

The other tempting force, formally unconnected to the previous one, but a contributory factor when it is set in motion, is the indisputable hegemony of liberal ideas and capitalist practices, resulting in a constant expansion of the mercantile sphere, of what can be owned and exchanged for a price, of what is perishable, therefore. Hitherto essentially immune to it, largely depatrimonialized or at least not commodified, the body is now threatened by the colonization of the market, which can smell business. I say threatened, because not everything in the market is attractive,

and who knows, it might even be a malevolent force, but earlier I said tempted because we know how powerful this force is, how it has transformed the world in a very short period of time, and we are tempted to think, although morbidly, about what might happen when it takes possession of our bodies.

Both forces are indeed identified as separate, but it does not occur to us that they could be acting separately because we have become accustomed to thinking, rightly or wrongly, that the profit motive is what drives the world forwards, what pulls the cart, above all in sophisticated fields such as biotechnology. That the results of the progress made are later made available to everyone in conditions of civic equality, to some extent at least, is not denied on principle; but nor is it that this progress requires what is known as private enterprise, which seems to be nothing without a market and grows at the same rate as the market.

Moreover, in a society defined by consumption, hierarchized by it, the majority finds its place according to its purchasing and accumulative power and devotes its greatest efforts to increasing this. In this case, how are we not also going to want the body and its parts, so dear to us and so tempting, to likewise be consumed? How are we not going to want, if we are above all else consumers, to be able to buy and sell our body, or its parts? Of course we would want it all for everyone, if it were one of those resources –so abundant– whose distribution, according to Hume, Marx and Rawls, does not require justice; requiring it, for being more or less scarce, the justice of the market seems the most appropriate to us: we are not prepared to share if that levels us down, instead of up, with everyone else. The double temptation, of biotechnology and the market, would however run the risk of failing in its endeavour were it not for the fact that it has an unexpected ally: the demystification of the body. They say that the body was sacred once and we can well believe it if we remember how priests, overseers of the sacred, defined the rules of the body that guided our sexual, reproductive, aesthetic and health care practices. It is less and less sacred today and no one pays any heed to priests – there are no longer any priests to listen to. The result is that sex, reproduction, aesthetics and health care have been liberated, and everybody does what they like, because, in short, my body is mine and I do what I want with it.

Of course, it is a valuable ally, because without this demystification it would be difficult to regard as tempting, let alone legitimate, everything that the biotechnologies are in a position to offer, from another woman giving birth to our baby, or our child having someone else's genes, to us deciding to change our nose because we prefer it straighter, and because, as yet another consumer item, the new one will also be ours. And there

is an ever more varied supply of surrogate mothers, other people's genes and false noses, so varied in fact that it contains things with meanings as different as that of the three examples, chosen at random except for that very diversity and without wishing to be frivolous. I am no one to venture a hypothesis about the profound causes of this process of bodily secularization. It may perhaps be the logical correlation, in its field, of the general secularization of the world. However, I do believe that there is a cause that should be called indirect, because it was not seeking the effect, and it is relevant. We wanted to liberate ourselves from the control of others, from the control of priests, to take it in our own hands. That my body was mine meant, more than anything, that it was not theirs; but in order to snatch that control away from them it was necessary to argue against the traditional narrative, which after being demolished has not been replaced by another one. The unwanted result, at least indirectly, is the end of bodily mystique: the body loses the value it once had and has not acquired any other. It has remained in the sphere of the profane and the pathways for its manipulation are open.

In the same way, just because the body has lost its old value without gaining a new one, just because we give it merely instrumental value, we can easily imagine it in the space of what can be owned, accumulated and exchanged, subject to price. Because something that is priceless, that money cannot buy, possesses a specific, non-disposable value of its own. Without it, there are no reasons to prevent it from becoming just another object, one of many: the logic of the supermarket and the credit card will prevail. Thus, the demystification of the body predisposes us to the joyful acceptance of biotechnological products and the mercantile invasion of bodies.

This demystification, is it really an unexpected ally, as I have called it? It depends. I think it is, bearing in mind that the demand for control over our own bodies, which encouraged it, in part at least, was made with a desire for liberation, and on the other hand it could end up giving rise to new forms of oppression; hence it is unexpected or paradoxical. Of course my impression is due to the fact that I am convinced that the mercantile regime is dangerous and may lead to, in this sphere as in others, considerable losses of freedom for many, perhaps the majority, maybe for everyone. In many walks of life, I believe that freedom (or self-determination, or autonomy) is actually better safeguarded the other way round, by the prohibition of accumulation, with the intention of ensuring an equal share-out of resources, in this case those concerning the body. On the other hand, the mercantile regime necessarily involves this accumulation and, therefore, the very real possibility that some may end up

having more than one body and others none, so to speak. Wishing to free ourselves from the oppression of priests, we could end up subjected to that of our peers, or that of ourselves, and so everyone is oppressed, even those who accumulate and oppress: because not knowing the true value of things (things?) means living according to inappropriate models, alien to our way of being, and that alienation, even though it is self-induced, is oppression. That this is paradoxical depends, of course, on the idea that one has of the relationship between the market and freedom, and those who think it is a directly proportional relationship will see no paradox whatsoever in all this. Moreover, we can easily trace a conceptual sequence that is not completely illogical, apparently at least, and which leads from the assertion that my body is mine to the justification of its commercialization, via the notions of ownership and free disposal. It might not be so paradoxical after all.

In this article I wish to discuss one of the links in this chain, the first one of all, the one that makes it possible to go from the concept of 'it's mine' to that of ownership, because I feel it is the weakest link. Indeed, once the ownership of my body, or of its separate parts, is asserted, it is simpler, although not totally obvious, to claim the right of free disposal, and from there to justify commercialization. On the contrary, if the ownership of one's body or of its parts cannot be claimed, the possibility of its commercialization cannot be either – because only if I am the owner of an asset am I in a position to alienate it for a price, to put it on the market. It is not a good enough condition, because contemporary ownership is compatible with all kinds of limitations, even those that might hinder free disposal; nevertheless, it *is* a necessary condition. Of course, we can have non-patrimonial rights over our body, as is the case with some basic rights (the right to physical integrity, to start with, although we could think of others, like the right to sexual freedom or the right to reproductive self-determination); but the basic rights are precisely non-patrimonial rights, that is, rights by definition neither disposable nor alienable (Ferrajoli, 45-50<sup>1</sup>).

We are therefore witnessing a general commercialization of life together with, on the one hand, the multiple possibilities that the biotechnologies offer us, and which include that of detaching parts of our body and transferring them to others; and, on the other hand, the relaxation of the traditional respect for the body. It is true that, up to now, the human body and its parts have remained outside the market, but the temptation is growing, and falling into it is justified by resorting to the intuition that my body is mine; and if it is mine, why can't I do business with it? If my organs, tissues, blood and reproductive cells are transferrable, why can't

1. Ferrajoli, L. (1999), *Derechos y garantías: la ley del más débil*, Trotta, Madrid.

I sell them? For what reason can I not freely use and dispose of my body and its parts and put them on the market? Am I not entitled to dispose of my own body? Isn't the prohibition to do business with the body an unjustified restriction of individual freedom? Against the argument that is implicit in these questions, the issue is whether or not we are in a position to put together a counter-argument to oppose it and contribute to the protection of the human body against commercial piracy. One way of trying to do it, and thus to answer these questions, is to attempt to answer 'no' to another question: Can I be the owner of my body? This is what I propose to discuss below. The other key question, whether or not I can be the owner of the detached parts of my body or of other bodies, will be left for another occasion.

It is important to clarify, before continuing, that these are questions of a philosophical, legal and, if you will, anticipatory nature. They are not questions about the current legal regulation of the body and its parts, but about what that regulation should be in the future, something that will of course in turn imply a value judgment about the current regulation. Concerning this, it should be pointed out that a long legal tradition going back to Roman law and surviving to this day has established that neither one's own body nor its vital parts may be a property; it is true that the legal debate is being opened up about the possibility of owning the separate parts of the body, but there is still agreement to leave the actual body out of the patrimonial sphere. This is true for the legal systems of the English-speaking world, or common law systems (Hardcastle, 2007; 15 *et seq.*<sup>2</sup>), and for the European and Latin American, or civil law, systems (Arnoux, 1994; 28, 150, 236<sup>3</sup>; Reid, 2015: 10<sup>4</sup>). In Spain, one of our great civil lawyers wrote some time ago that no real subjective right is possessed over the so-called "assets of personhood", given that the person "lacks the power to dispose of them", since "they are outside the commerce of men". In other words, they are "non-patrimonial assets" (De Castro, 1972: 10, 45<sup>5</sup>), and it must be understood that the body would be one of these assets. Nevertheless, De Castro warned then of the growing patrimonialization of civil law (De Castro, 1972: 8<sup>6</sup>), which could particularly affect these assets of personhood, as could be seen some years later in relation to

2. Hardcastle, R. (2007), *Law and the Human Body. Property Rights, Ownership and Control*, Hart, Oxford.
3. Arnoux, R. (1994), *Les droits de l'être humain sur son corps*, Presses Universitaires de Bordeaux, Bordeaux.
4. Reid, K. G. C. (2015), "Body, Parts and Property", *Research Paper Series*, no. 2015/25, University of Edinburgh School of Law.
5. De Castro, F. (1972), *Temas de Derecho Civil*, sin editorial, Madrid.
6. De Castro, F. (1972), *Temas de Derecho Civil*, sin editorial, Madrid.

honour, privacy and one's own image (Carrasco, 1988: 37<sup>7</sup>). In short: the human body remains excluded from the sphere of the patrimonial and the commercial, but this sphere is expanding relentlessly and threatening it.

## 2. MY BODY IS MINE

### OWNERSHIP

The Spanish Civil Code establishes in article 348 that “ownership is the right to enjoy and dispose of something with no limitations other than those established by law”. It is a very similar precept to the one contained in other European and Latin American civil codes, all of them more or less direct descendants of the French Civil Code of 1804, a product of the Revolution known as the *Code Napoléon* in honour of the man who gave it its last and definitive boost. Article 544, in effect, defines ownership as *le droit de jouir et disposer des choses de la manière la plus absolue, pourvu qu'on n'en fasse pas un usage prohibé par les lois ou par les règlements* (Ownership is the right to enjoy and dispose of things in the most absolute way, provided no use is made that is prohibited by the laws or by the regulations). Ownership is therefore the most extensive patrimonial right that one can have over a thing, and not only the most extensive but also the most characteristic and definitive of legal-real relationships. Indeed, the other real rights (over things) are classed as “limited” real rights and they are usually constructed on the basis of the right of ownership, through the conferral of one or various powers on a holder other than the owner (thus, leasing, usufruct or mortgage, which allow their holders to carry out certain activities with respect to the thing, but not all of them).

It is true that the extent of a right of ownership depends on those “limitations established by law”, of which there may be many, above all when they are “special” ownerships, or of a particular kind of assets (thus, waters, mines, or intellectual creations protected by copyright or patents). Nevertheless, the essence of ownership is constituted by these two generic powers in the abovementioned articles: that of enjoying the thing (using it or enjoying it) and that of disposing of the thing (transmitting it in some way, either whole or in part; sold for a price or given away, through donation; *inter vivos* or *mortis causa*, as in the case of inheritance; the destruction of the thing is also an act of disposal, although not the most habitual). These two basic powers can also be restricted by law to some extent, but not completely annulled, because in that case the right

7. Carrasco Perera, Á. (1988), *El Derecho Civil: señas, imágenes y paradojas*, Tecnos, Madrid.

of ownership would lose its essence: it would not make much sense to continue talking about “ownership” if one is unable to enjoy or dispose of the thing in some significant way.

It therefore seems obvious that if we were the proprietors of our own bodies we would have to have these powers over it: the one that permits a generic use of it and the one that allows it to be transmitted. We shall see below that this is very problematic with respect to the body, but I shall now take the opportunity here to express my surprise about the fact that some people, in recent years and above all in the English-speaking world, have been proposing the possibility of establishing rights of ownership with respect to the separate parts of the body (for example, an organ or reproductive cells), claiming in support of their idea that such rights of ownership would not necessarily imply an unlimited use or the possibility of disposing of such parts for financial gain, a possibility that opens the doors to a body parts market. In mercantile societies such as ours, the most characteristic way of disposing of or transmitting a thing is selling it, and therefore the possibility of doing this is what, I believe, best defines modern ownership, so ascribing the status of appropriable things to the separate parts of the body without enabling us to freely dispose of them is at the very least surprising.

## MY BODY IS MINE AND NOT YOURS

A good basis for the articulation of a right of ownership over one’s own body is this idea that “my body is mine”. Words like these must sound attractive to the ears of modern man and far more so to those of modern woman. However basic and intuitive the idea that they express may be, they are by no means trivial words. If they have been said over and over again, if they have been hoisted like a standard, it has been as the assertion of our individual autonomy, as a reaction against those who for centuries have tried to organize the way in which we can use our body in the name of the opposite idea, that of “your body is not yours” (whose is it then? God’s, for example).

Indeed, our individual autonomy has suffered multiple humiliations because of this doctrine of the ownership of our bodies by someone else, especially when it has been accompanied by a negative consideration of the body, or at least certain carnal appetites, as in the case of the Christian doctrine that has been dominant in the West for so long (on the other hand, what might be considered another form of otherness, upholding that the individual belongs to the community, after Aristotle, does not seem to have been so rigorous in the regulation of the body).

In one way or another we can associate historical phenomena with this doctrine, such as the restriction of sexual freedom, a restriction suffered especially by all women and by homosexual men, but which has affected all of us; the prohibition of contraceptives; women's relative lack of legal protection against male sexual violence; the punishment of all forms of abortion; or the obstacles in the way of performing sex-change operations.

Therefore, it is no surprise that the contemporary demand for bodily autonomy should have been made, crying "my body is mine!", the most direct and categorical way of refuting that our body belongs to others or can be controlled by others. There can be no doubt that asserting the ownership of one's body is a good way of opposing all the restrictions that have affected everyday lives so much and which can be so hurtful for those who have decided that individual freedom constitutes the supreme ideal of life. Nevertheless, this claim that "my body is mine" is not without its problems, and, of course, in itself it is not enough to justify the existence of a supposed right of ownership over one's body.

### IS MY BODY MINE?

The possessive pronoun "mine" indicates some kind of possession, provided we ascribe a very broad meaning to possession, or several meanings. My life is mine, and so is my property; my wife is mine too, as are my children and my parents. My country is mine and my God is mine. My thoughts are mine, along with my poor handwriting. The books I have written are mine, but so are those that I have on my shelves. "My fear is my concern" is Lawrence of Arabia's reply to the Arab who asks him, "Have you no fear, English?" Also, in this broad sense, in some of these senses, my body is mine. So far, I have no objections, but nothing else either to derive with regard to the justification of a right of ownership. Because the possessions implied in all these "mines" are not all the same kind and, above all, no one would be willing to claim that everyone justifies the appearance of a corresponding right of ownership. What is more, the claim that my body is mine does not even justify that it should be me who decides how it is used or how it is disposed of. It is not even useful for rationally opposing those who hope to control, from elsewhere, this use or disposal, even though its rhetorical power is obvious. There can thus be no doubt that in one sense my body is mine, but what does this mean? And, above all, what normative consequences follow from it?

### 3. MY BODY AND I: DO I HAVE A BODY OR AM I A BODY?

Regardless of how much it is “mine”, the possibility of “appropriating” my body presents an obvious difficulty: that of the possible identity of the subject who possesses and the object that is possessed. To say “my body is mine” seems to suppose that there is a self (me the subject) who possesses a body (the object); what is important to point out now is not so much the idea of possession but the idea of duality, the existence of two entities, one of which is me and the other is my body. However, it is not the least bit clear that such a distinction can be established between my body and I, because, am I actually something else other than my body? Am I something more than my body? Do I *have* a body or *am I* a body?

To claim the duality between the self and the body requires identifying the self with something different to the body, the soul, the spirit or the mind, and it is therefore necessary to adhere to some variation on the doctrine of the “ghost in the machine”, the name given in 1949 by Gilbert Ryle to the doctrine that is usually associated with Descartes (Ryle, 2005 [1949]: 29<sup>8</sup>), according to which my body is a material reality (*res extensa*) governed by an immaterial mind (*res cogitans*). However, one of the great undertakings of modern philosophical thinking would have consisted in “understanding man naturally, understanding him from his body” and, at this point, Descartes, “at times so modern, was not modern when he conceived of man, as he continued to conceive of him Ptolomeically and metaphysically through the Soul” (Rodríguez Camarero, 2002: 120, 135<sup>9</sup>). Even so, a purely corporal consideration, let us say, of the human condition could also be glimpsed in Descartes’ last writings (Rodríguez Camarero, 2002 and 2012<sup>10</sup>) and it would make its way, via Spinoza, through the Enlightenment, or the “century of the body” as Rodríguez Camarero puts it. This can be seen in Voltaire’s *Philosophical Letters*; in the thirteenth dedicated to Locke, he wrote “I am a body, and I think: that’s all I know of the matter”; or in Hume’s *Treatise on Human Nature*; or in the work of Diderot, for whom “thought” is a “faculty of matter” and it is nonsense to place it outside of it (Scotto, 2014: 111-113<sup>11</sup>). A symbol of this enlightened improvement on Cartesian dualism is the significant title of

8. Ryle, G. (2005 [1949]), *El concepto de lo mental*, Paidós, Barcelona.
9. Rodríguez Camarero, L. (2002), “La novela del alma: la comprensión natural del hombre en la ilustración inglesa y francesa”, *O legado das Luces*, Universidad de Santiago de Compostela.
10. Rodríguez Camarero, L. (2012), “El valor y la génesis de las pasiones humanas en el último Descartes y en Spinoza”, *Cauriensia*, VII.
11. Scotto Benito, P. (2014), “Naturaleza humana y política en Denis Diderot”, *Oxímora*, 5.

the book that La Mettrie published in 1748: *Man a Machine*. For Descartes, animals are machines; for enlightened scholars, men are too.

But we already know that reason advances slowly through the fields of the collective imagination, especially when it contradicts deeply rooted beliefs, no matter how irrational they may be; in the late nineteenth century Nietzsche still considered it necessary, in his *Thus Spake Zarathustra*, to shake the “despisers of the body” with a famous diatribe:

But the awakened, the enlightened man says: “I am only body and nothing more; and soul is merely a word for something in the body”. The body is a great intelligence, a multiplicity with one sense, a war and a peace, a flock and a shepherd. [...] A tool of your body is your lesser intelligence, my brother, which you call “spirit” –a little instrument and plaything of your great intelligence. [...] Behind your thoughts and feelings, my brother, there stands a mighty commander, an unknown wise man– he is called Self. He lives in your body, he is your body. [...] There is more reason in your body than in your best wisdom. [...] Your Self laughs at your ego and its proud leaps. “What are these leaps and flights of fancy to me?” It says to itself. “A detour to my purpose. I am the leading reins of the I and the prompter of its conceptions”. (Nietzsche, 2005 [1892]: 93<sup>12</sup>).

Thus, and taking notice of Merleau-Ponty, the contemporary philosopher of the body, only in the twentieth century was body-mind dualism discredited, at least in philosophical and scientific circles, and in large measure also in popular awareness: “Our century [the 20th] has erased the dividing line between the ‘body’ and the ‘spirit’, and it sees human life as spiritual and corporal at one and the same time, always based on the body, always interested even in its most carnal customs [...]. For many philosophers, in the late nineteenth century, the body was a piece of matter, a bundle of mechanisms. The twentieth century has restored and deepened the notion of the flesh; that is, of the animated body” (in Martínez Rodríguez, 1995: 84<sup>13</sup>).

Whether this suppression of the dividing line between the body and the spirit has given rise to a coherent view of the body is another matter. In other words, mind-body dualism, although expressly rejected, may perhaps continue to act unconsciously within many of us, and perhaps the way in which we see ourselves still depends on this dualism that we find hard to shake off. What is more, it could be that the rapid development of biotechnology (and the fantasies due to progress in artificial intelligence) are the basis for the emergence of a new version of it, according to which we could clearly distinguish between our brain and the rest of

12. Nietzsche, F. (2005 [1892]), *Así habló Zaratustra*, Valdemar, Madrid.

13. Martínez Rodríguez, F. (1995), *Merleau-Ponty*, Ediciones del Orto, Madrid.

our body, and ascribe to the former the role of the *res cogitans* of which Descartes spoke, or that of Ryle's ghost. This is because the boom in biotechnology leads us to harbour the hope that one day in the not too distant future we might be able to replace any part of our body, or our entire body, keeping our brain and, thus, our identity, because we understand that one's "self" or conscience resides in that grey matter. If I may be permitted a cinematic simile, in reference to the dream that I mentioned at the beginning of this article, the triumph over our own nature. We do not see it reflected in the now classic replicants in *Blade Runner*, which aspire to be more human than humans, because they delve into their essence, but in Ava, the robot in the recent film *Ex Machina*, which changes an arm or its skin as it would a jacket. It could even change its whole body while retaining its identity, residing in that sort of viscous plastic brain, an Ava that is no longer human but in fact a robot (García Manrique, 2006<sup>14</sup> and 2016<sup>15</sup>). Therefore, I am not very sure that this way of thinking about ourselves is truly human, but rather transhuman. One would perhaps have to turn to neuroscience to know if it makes sense to think about ourselves that way. One could initially turn to the memoirs of Henry Marsh (2016<sup>16</sup>). It is not a book about neuroscience proper, but it *was* written by a prestigious brain surgeon; reading it will rather incline us to think the opposite: that it can't be easy to transplant a body to a brain (or is it a brain to a body?) and cautiously accepting the idea that our identity lies only in our brain.

Whatever the case, until that possible future arrives, it seems sensible to accept the improvement on body-mind dualism and, therefore, to assume that we cannot establish a difference between the subject "me" and the object "body", because we do not *have* a body, we *are* a body. If this is so, then the idea that we possess a body is nonsense; and if this idea is nonsense, so is the pretension of formulating a right of ownership over an object called the body, no matter how much it belongs to us.

## THE PARTS OF MY BODY AND I

On the other hand, what we *can* imagine is the separate existence of parts of our body: a litre of blood that is in a bag next to us but outside of us, an egg or a sperm sample kept in the fridge in an assisted reproduction clinic, a kidney that we have had removed and which is in a portable

14. García Manrique, R. (2006), "*Blade Runner* o la pregunta por la dignidad humana", *Revista de Bioética y Derecho*, 6.

15. García Manrique, R. (2016), "*Ex Machina* o sobre la dimensión corporal de lo humano", *Revista de Bioética y Derecho*, 37.

16. Marsh, H. (2016), *Ante todo no hagas daño*, Salamandra, Barcelona.

fridge. In these cases, subject-object dualism does not seem to present problems, or not the same problems as in the case of the body, because we can clearly distinguish between the existence of a subject and an object, and because we can advocate a relationship of possession of the latter by the former. It is true that there are those who speak of the “disseminated body” to refer to this separate existence of parts of our body, and they maintain the need to consider it a functional unit despite its dissemination (Rodotà, 2008: 304 *et seq.*<sup>17</sup>). This consideration may well be necessary, but I understand that it is a normative, not a factitious, consideration. Because the fact is that I (my body) am here, my kidney is there, and over there is my sperm sample; separation is a fact, and the notion of the disseminated but still unitary body points to the normative treatment merited by the separate parts of the body. What interests us now is to realize that the issue of whether it should be possible to be the owner of these biomaterials that come from my body deserves to be treated differently from the issue that we are discussing here –whether it should be possible to be the owner of one’s body– in spite of the fact that both issues are obviously linked. I therefore believe that it is better to tackle them separately.

#### 4. THE OWNERSHIP OF ONESELF, OR SELF-OWNERSHIP

A first way to justify the ownership of one’s own body has been discarded, provided we have renounced body-mind dualism or other equivalents. However, a second path opens up if we reformulate our question in these terms: can we be the owners of ourselves? That is, we cannot be the owners of our own body conceived as an object different to ourselves, but perhaps we can, reflexively, be our own masters. The obvious difference is that, in this case, there is no dualism whatsoever: subject and object coincide; the owner subject and the owned object are one and the same entity.

#### NOZICK AND SELF-OWNERSHIP

The question of self-ownership was raised in contemporary political philosophy as a result of the publication in 1974 of *Anarchy, State and Utopia*, the book by Robert Nozick that quickly became the bible of what was called libertarianism, a sort of extreme liberalism that was attempting to oppose egalitarian liberalism as it had been formulated by John Rawls

17. Rodotà, S. (2008), “Aventuras del cuerpo”; in Silveira, H. (ed.), *El derecho ante la biotecnología*, Icaria, Barcelona.

in his *Theory of Justice* in 1971 (Nozick, 1974<sup>18</sup>; Rawls, 1973 [1971]<sup>19</sup>). The thesis upheld by Nozick is that we are masters of ourselves; here we are interested in this thesis as such, although one must bear in mind that its principal function is to sustain a framework of consequences relative to the organization of the political community, the core or foundation stone of his theory (Domènech, 2009: 27<sup>20</sup>; Mundó, 2004: 189<sup>21</sup>). It thus helped to lay the foundations of the conservative neoliberalism that has prevailed in subsequent decades, especially in the English-speaking world, and whose core idea is that of a minimal state, whose functions do not include limiting the inequality generated by the free market – this, in turn, is hopefully as large as possible.

What it *is* worth pointing out beforehand, so that one can get an idea of the scope of Nozick's thesis, is that, given that a person is the owner of him or herself, they must have the right to sell themselves to another as a slave (Nozick, 1974: 331<sup>22</sup>). I point this out because it is strange to say the least that the founding text of libertarianism, a doctrine that aspires to maximize individual freedom, should consider that slavery is legitimate, provided it is voluntary. It remains to be seen in what circumstances one would wish to sell oneself as a slave to another, and if in them one could speak of genuine willingness, but we'll leave that for another time. On the other hand, due perhaps to the year when the book was published, virtually nothing is said in it, specifically at least, about the possibility of selling parts of one's own body, although we ought to suppose that it would also be legitimate, just as it would be legitimate for someone to take possession, for any purpose and with consent, of a large number of other people's body parts (as well as surrounding themselves with a few slaves).

Nozick's ideas about self-ownership have aroused a heated academic debate, in which Gerald A. Cohen's monographic book on the issue stands out: *Self-Ownership, Freedom and Equality* (1995). Here I shall merely try to explain why I believe Nozick's thesis does not make it possible to justify a right of ownership over one's own body, where ownership is understood in the civil law and patrimonial sense mentioned above, in which asserting ownership means asserting, in principle at least, free disposal (in this case, of the body, and thus, for example, enslaving it in return for

18. Nozick, R. (1974), *Anarchy, State and Utopia*, Blackwell, Oxford.
19. Rawls, J. (1973 [1971]), *A Theory of Justice*, Oxford University Press, Oxford.
20. Domènech, A. (2009), "¿Qué fue del 'marxismo analítico'? (En la muerte de Gerald Cohen)", retrieved from [www.sinpermiso.info](http://www.sinpermiso.info).
21. Mundó, J. (2004), "Autopropiedad, derechos y libertad (¿Debería estar permitido que uno pudiera tratarse a sí mismo como esclavo?)", in Bertomeu, M. J.; Domènech, A. and De Francisco, A. (eds.), *Republicanism y democracia*, Miño y Dávila, Buenos Aires.
22. Nozick, R. (1974), *Anarchy, State and Utopia*, Blackwell, Oxford.

payment). I am supposing, as will be shown later, that ownership must be understood in another sense, one that is neither civil law nor patrimonial, in which free disposal is not implied.

In short, I shall argue as follows: when Nozick says that we are the proprietors of ourselves, he may mean two different things. One is that we are autonomous and we must have the possibility to govern our lives freely through the exercise of our individual rights. If this is what he means, I believe he is right, but from this it does not follow that we can have a patrimonial right over our body. The other is, precisely, that we do have this patrimonial right. If this is what he means, then he is wrong.

In actual fact, Nozick's references to self-ownership are scattered and rudimentary. They are rather, and as Cohen calls them, "invocations" to something that seems to be taken for granted (Cohen, 1995: 67<sup>23</sup>), which Nozick attributes to liberal tradition, going back to the work of Locke (in fact, the idea of ownership of oneself is developed far more in Cohen's own book). The concept appears in the thread of the discussion about the legitimacy of taxes and the redistributive state. As Nozick understands it, this means that everyone else owns a part of us and our actions and work, and this represents "a change from the classic liberal notion of self-ownership to the notion of (partial) rights of ownership over other people" (Nozick, 1974: 172<sup>24</sup>).

Incidentally, calling Locke a "liberal", as Nozick does in accordance with the interpretation of Locke's work that was still the majority one in his day, is anachronistic to say the least (Domènech, 2009: 27<sup>25</sup>), since liberalism must be understood rather as an ideological phenomenon whose date of birth must be placed in the nineteenth century (that of course is the moment when the word began to be used with the political meaning that we give it today). On the other hand, there are reasons for describing Locke as a "republican" rather than a "liberal" *avant la lettre*, and this is how some have interpreted his work recently, as Víctor Méndez explains in his wonderful contextual study of the *Second Treatise on Civil Government* (Méndez Baiges, 2010, 258 *et seq.*<sup>26</sup>). In any case, what is important now is not to pin one label or the other on him,

23. Cohen, G. A. (1995), *Self-ownership, Freedom and Equality*, Cambridge University Press, Cambridge.

24. Nozick, R. (1974), *Anarchy, State and Utopia*, Blackwell, Oxford.

25. Domènech, A. (2009), "¿Qué fue del 'marxismo analítico'? (En la muerte de Gerald Cohen)", retrieved from [www.sinpermiso.info](http://www.sinpermiso.info).

26. Méndez Baiges, V. (2010), "Apelando a los cielos: el *Segundo tratado* en la historia del pensamiento político moderno", in Locke, J., *Segundo tratado sobre el gobierno civil*, Tecnos, Madrid.

although it may be illustrative, but to know what Locke meant when he maintained that we are masters of ourselves. This is the important thing if we agree that Nozick is not proposing a new notion, but assuming a far older one that he attributes, I repeat, to classical liberalism and, within it, to Locke; later we shall see if Nozick has interpreted Locke's idea correctly.

## WHAT LOCKE SAYS

In his *Treatise*, Locke uses the term "property" in two ways that can be clearly distinguished:

- 1) A generic sense, according to which our property would be composed of our life, liberty and estate (or assets), namely, the three basic natural rights (life, liberty and ownership of things). This sense appears here: "man [...] has by nature a power not only to preserve his property – that is, his life, liberty, and estate ..." (Locke, 2010 [1690]: Sect. 87<sup>27</sup>); and here also; "[man] is willing to join in society with others, who are already united, or who have a mind to unite, for the mutual preservation of their lives, liberties and estates, which I call by the general name 'property'" (Locke, 2010 [1690]: Sect. 123). With regard to the reason for this generic use of the term, it seems it was not uncommon in that period, but it has also been considered to be significant of the importance that Locke attaches to patrimonial property, which would in principle be only one part of that whole (Laslett, 1988: 102-104<sup>28</sup>); on the other hand, other interpreters, even if they share the opinion that patrimonial property plays a central role in Locke's political theory, do not regard this generic use of the term as being particularly important (Macpherson, 1979 [1962]: 172, 190<sup>29</sup>).
- 2) A specific meaning, according to which what is referred to is a patrimonial right that is exercised over things. It is, as I said, one of the three basic natural rights, along with life and liberty. Its justification and development are to be found in the famous chapter V of the *Second Treatise*, where it becomes obvious that Locke is referring to authority over things.

27. Locke, J. (2010 [1690]), *Segundo tratado sobre el gobierno civil*, Tecnos, Madrid.

28. Laslett, P. (1988), "Introduction", in Locke, J., *Two Treatises on Civil Government*, Cambridge University Press, Cambridge.

29. MacPherson, B. (1979 [1962]), *La teoría política del individualismo posesivo*, Fontanella, Barcelona.

And what about ownership of oneself? Locke, in effect, asserts it in at least two passages of the *Second Treatise*, in sections 27 and 44:

Though the earth, and all inferior creatures, be common to all men, yet every man has a property in his own person: this no body has any right to but himself. The labour of his body, and the work of his hands, we may say, are properly his (Locke, 2010 [1690]: Sect. 27).

Man, by being master of himself, and proprietor of his own person, and the actions or labour of it, had still in himself the great foundation of property (Locke, 2010 [1690]: Sect. 44).

So, when Locke states in these passages that we are proprietors of ourselves, in which of the two senses that we examined does he do so? In my opinion, in neither of them, but in a third one, according to which “property” (of oneself) means “personhood” or “being an autonomous subject” who has his own interests and may not be placed at the service of the interests of another, a personhood from which the individual rights would derive: life, liberty and ownership of *things*. In this sense, the ownership of oneself would play the same role that the concept of “dignity” currently does, or, as Jordi Mundó aptly points out, the same role as the Roman concept of *sui iuris*, according to which one has one’s own legal personhood and is therefore susceptible to be the possessor of rights (Mundó, 2004: 203<sup>30</sup>). In actual fact, this sense of ownership as personhood may be similar to what, above, we described as the generic sense of the term, although it is hard to identify them, perhaps due to the fact that Locke does not use the term very precisely (or maybe because the term is not univocal and may mean several things). An additional argument in this respect is that, apart from everything that has been said already, Locke also states that God is our proprietor (“All mankind are the property of the Creator, whose workmanship they are, made to last during his, not one another’s pleasure” Locke, 2010, [1690]: Sect. 6); and it is difficult to reconcile the claim that we are God’s property with the one that we are the property of ourselves, if we attach the same meaning to the term “property” in both statements. Therefore, it should come as no surprise that we confer a different meaning –to the two previous ones– on the expression “property” (of oneself).

On the other hand, what does seem clearer, and for our purposes is more interesting, is that ownership of oneself is not ownership in the specific sense of a patrimonial right over things. We do not have over our

30. Mundó, J. (2004), “Autopropiedad, derechos y libertad (¿Debería estar permitido que uno pudiera tratarse a sí mismo como esclavo?)”, in Bertomeu, M. J.; Domènech, A. and De Francisco, A. (eds.), *Republicanism y democracia*, Miño y Dávila, Buenos Aires.

body (over our person, if you wish) a right equivalent to the one we can have over a thing, a right that would allow us to freely use and dispose of our body. There are at least two reasons for this. The first is that, in sections 27 and 44, self-ownership acts as the basis of the right of ownership over things (or over the fruits of labour), so it is something different, and different in nature (I repeat: “personhood”). The second reason is that throughout the *Second Treatise* it is clear that individual rights are limited, and that the way in which they are compromises the possibility of claiming some kind of patrimonial right over oneself. Let’s look at it.

In effect, the right to life is not without limits, since man “has not liberty to destroy himself” and “he is bound to preserve himself”; for the same reason, “ought he, as much as he can, to preserve the rest of mankind” and “there cannot be supposed any such subordination among us, that may authorize us to destroy one another, as if we were made for one another’s uses” (all this in Locke, 2010 [1690]: Sect. 6).

Nor is liberty without its limits, but:

Freedom of men under government is, to have a standing rule to live by [...]; a liberty to follow my own will in all things, where the rule prescribes not; and not to be subject to the inconstant, uncertain, unknown, arbitrary will of another man: as freedom of nature is, to be under no other restraint but the law of nature (Locke, 2010 [1690]: Sect. 22).

Law, in its true notion, is not so much the limitation as the direction of a free and intelligent agent to his proper interest (Locke, 2010 [1690]: Sect. 57).

The specific consequence of this limitation of the rights to life and liberty is that, in the chapter dedicated to slavery, Locke expressly denies that someone can be enslaved voluntarily:

This freedom from absolute, arbitrary power, is so necessary to, and closely joined with a man’s preservation, that he cannot part with it, but by what forfeits his preservation and life together: for a man, not having the power of his own life, cannot, by compact, or his own consent, enslave himself to any one, nor put himself under the absolute, arbitrary power of another, to take away his life, when he pleases (Locke, 2010 [1690]: Sect. 23).

It seems obvious, then, that individual rights are heavily limited by their function, which is that of allowing their possessors to live as independent and autonomous subjects and thus (it must be added now) be capable of performing the duties that the law of nature imposes on them,

a concept that appears constantly throughout the *Treatise* and which, incidentally, sounds quite illiberal (that our rights are at the service of the performance of duties imposed by a law greater than our own will). Within this picture, it is not plausible to formulate a right to the patrimonial ownership of oneself, when it turns out that we are unable to dispose of our life or our liberty. What is more, the description that we could give to all of Locke's rights (ownership of things excepted) is "non-disposable" or "inalienable". Whereby these rights are closer to the modern concept of basic rights than to that of patrimonial rights (to which we could link only that of the ownership of things).

In this way, the conclusion we reach at this point is the following: when Locke claims that we are masters of ourselves, what he is saying is that we are autonomous subjects, endowed with our own personhood, which makes us possessors of individual rights.

#### IS NOZICK WRONG?

With all due respect, I think he is, since his notion of self-ownership is derived from Locke's (or from the "classical liberal notion of self-ownership"), but he confers on it a patrimonial nature that we have already seen it does not have, either in Locke's work or, as far as I am concerned, in that of any other classical author who could be called liberal. By conferring this nature on it, he also confers on it the traits typical of patrimonial rights (among which are free disposability or alienability), deriving normative consequences that go to the extreme of legitimizing slavery when it is freely consented (specifically disagreeing with what Locke maintains). Nevertheless, we cannot attach any validity to what has been derived on the basis of a false premise. Therefore, one must conclude that Nozick has misinterpreted Locke's notion of self-ownership, whether it is a liberal notion or not; and that he has not shown that we ought to have a (patrimonial) right of ownership over our own body.

#### IS COHEN WRONG?

To add weight to this conclusion, let us see how G. A. Cohen tackles Nozick's idea, even if only because, as I mentioned earlier, Nozick's idea (or Nozick's interpretation of Locke's idea) has been developed far more by Cohen than by Nozick himself – who, by the way, and as Antoni Domènech tells us, never replied to the studies that Cohen published on the subject and which are collected in his book *Self-ownership, Freedom*

and *Equality* (Domènech, 2009: 27). Cohen maintains that Nozick is right (Cohen, 1995; chs. 9 and 10). His analysis is in two parts: in the first one he judges whether the *concept* of “ownership of oneself” is coherent, reaching the conclusion that it is, despite its reflexivity; in the second, he judges whether the *thesis* that we are proprietors of ourselves is correct, and he also concludes that it is. However, this is not a case of Cohen (a confirmed socialist) supporting Nozick’s political theory. What he tries to show in other parts of his book is that the political and legal consequences that Nozick believes do not follow from the idea of self-ownership. Therefore the importance of this idea, no matter how true or correct it may be, is much diminished, and the idea loses its attractiveness (Cohen, 1995: 230).

Consequences aside, why does Cohen believe that Nozick is right? In my opinion because, like him, he uses the concept of “ownership” with less care than he should. Cohen writes:

What is there in the content of the concepts of ownership and personhood that could disqualify the concept of self-ownership? People and their powers can be controlled by, among others, themselves, and, with respect to anything that may be controlled, there is certainly always an answer to the question: who has the right to control it? Even if the answer is ‘no one’. The idea of self-ownership says that the answer to all these questions about people and their powers is ‘the person’. Why should this answer be deemed incoherent? (Cohen, 1995: 210).

Indeed, this answer ought not to be deemed incoherent; it is just that this is not the answer that Nozick offers. If Nozick or his idea of self-ownership had merely stated that, there would no incoherence whatsoever in it; what is more, we could gladly accept it. As we may infer from the passage, Cohen believes that “ownership”, applied to people, consists of the faculty to control themselves and their powers; but the faculty to control ourselves and decide how we are going to use our powers, that is, the ability to govern our lives in accordance with our judgments, seems very different from the power that we have over a thing that we own. Cohen gives the impression that he is referring to both faculties at once, or at least he gives no clues to suggest that he is distinguishing them. In fact, that faculty to govern ourselves is protected by constitutional legal systems, but never through the right of ownership, or by any other patrimonial right, but through the basic rights, whose nature, we know, is very different.

That same impression of carelessness in the handling of the concept of ownership can also be perceived when, later on, Cohen tackles, with critical

intent, a passage by Kant in which the German philosopher argues against the coherence of the concept of self-ownership. The passage is this one:

Man cannot dispose over himself because he is not a thing; he is not his own property; to say that he is would be self-contradictory; for insofar as he is a person he is a Subject in whom the ownership of things can be vested, and if he were his own property, he would be a thing over which he could have ownership. But a person cannot be a property and so cannot be a thing that can be owned, for it is impossible to be a person and a thing, the proprietor and the property (Kant, 2002 [1785?]: 2052).

And this is so, although a few pages before that, he writes –but as I understand it conferring a different meaning on the term “belong”– that “our body belongs to us and it also concerns the universal laws of liberty from which our duties are derived”.

The key to Kant’s argument is that ownership is held over things and that people are not things (you cannot be a person and a thing at the same time). Therefore, one cannot be the owner of a person or, consequently, the owner of oneself. As Cohen sees it, (1995: 212), here Kant commits the fallacy of begging the question, because the crux of the matter is precisely knowing whether one can be the proprietor of oneself (i.e., of “a person”), and, if we claim that one can only be the owner of things and not of persons, we are considering the matter to be settled in advance. The issue is precisely this: whether we can be the owners of persons (even though it is only our own person); and we have already seen that Cohen believes we can.

What is demonstrated by the passage by Kant and the way Cohen analyses it? Cohen uses a non-legal concept of ownership, in contrast to Kant’s. The legal concept of ownership, at least in the Roman law tradition that we have inherited in continental Europe (but, I would say, also present in common law) is, precisely, that of a right over things; this is why in the *Digest* we read that *dominus membrorum suorum nemo videtur* (man is “not the owner of his own members”, those of his body, we understand, D. 9, 2, 13). In turn, the idea of a right over things is supposing that distinction between people and things to which Kant resorts. One cannot be a person and a thing at the same time, precisely because the definition of person is “that which is not a thing”. Kant’s presentation of the argument might not be as clear as it should be (the humble Prussian professor is even accused by the arrogant Oxford professor of “pulling a normative rabbit out of a conceptual top hat”, because, based on that argument, Kant deduces that it is unacceptable to sell parts of one’s own body or to prostitute oneself). It is also true that the Canadian-born Oxford professor

could have based himself on a book published in Kant's lifetime and not on some notes compiled by his students and published long after his death. I believe, however, that this is no obstacle to an understanding of the meaning of Kant's argument: ownership of a person is a contradiction in terms because ownership is, by definition, a right over things; and the invocation of those legal systems, such as Roman law, that have permitted the ownership of slaves is irrelevant here, because slaves were in fact considered things and not people (which is precisely, remember, what Locke tries to avoid when he says that we are the proprietors of ourselves). Savigny, one of the great jurists of the nineteenth century, put it very well:

Thus another person may be, like a thing, subject to the dominion of our will and to our power; if this dominion is absolute, the other person loses their freedom and personhood, so in actual fact we do not exercise dominion over a person, but over a thing [...]. But if we wish to represent for ourselves a legal relationship that establishes our dominion over a person without destroying their liberty, a right that resembles ownership, and which, nevertheless, is different from it, it is necessary for this dominion not to embrace the entirety of the person, but only one of their acts [...]. However, the legal relationships by virtue of which we exercise dominion over a specific act by another person are called "obligation" [and not ownership] (Savigny, 1878 [1840]: 227<sup>31</sup>).

On the other hand Cohen, as can be clearly seen in the passage transcribed above, uses a concept of ownership that does not seem to be the legal one, and which could well be equivalent to that of "personhood" or "autonomy", as I have already suggested when reading Locke. In actual fact, Cohen specifically refuses to accept that "self-ownership" and "autonomy" both refer to the same concept in Nozick's work because, as he rightly says, we would then not find there any arguments in favour of self-ownership as a concept separate from autonomy (Cohen, 1995: 236, n. 6). Even so, and despite the fact that Cohen does his best to interpret Nozick, I do not think that the idea of self-ownership can be interpreted any other way, only as "personhood" or "dignity", if these concepts must be distinguished from "autonomy". If I am right, what we can observe now is that it was not a question of arguing in favour of every person being their own master in the sense that their personhood must be respected, and, with that, their autonomy, but being in favour of every person having a patrimonial right of ownership over him or herself, and Cohen does not achieve this. In fact, he does not even try to because he does not use the legal-patrimonial concept of ownership. In short, if what Cohen

31. Savigny, F. K. von (1878 [1840]), *Sistema del Derecho romano actual*, Tomo i, F. Góngora y compañía, Madrid.

pretends, by accepting the idea of self-ownership, is to justify that people must be masters of themselves in the sense of ultimately being the ones who decide how to live or how to use their faculties or powers, I have no objection, with the proviso that, in this case, what is not fully understood is his determination to distinguish “autonomy” from “self-ownership”. On the other hand, if we were to interpret his words as meaning that people have over themselves the particular right that appears in European civil codes, and in common law, which we shall call “ownership”, then we would say that those words are not accurate, due to his not having understood the meaning that has traditionally been given, and still is, to the right of ownership.

It is worth insisting that the right of ownership is an instrument devised to enable people to have control over things, in order to guarantee their liberty, bearing in mind that people’s freedom depends on –among other factors– ensuring their welfare or material survival, via ownership or other ways. Therefore, one of the two powers of the right of ownership is the use of things. Of course, one could resort to the term “use” to refer to what one decides to do in life and with one’s life, although it would be strange, linguistically speaking. Even so, the meaning of the term “use” would be very different in each case: “using a thing” is very different to “making decisions about my life”. The other power of the right of ownership is that of disposing of things, which, let us remember, means above all transmitting them (destroying them too, but this is a particular case that we can ignore, in order not to complicate things here with the problem of suicide, which would merit a separate analysis). However, the idea of transmitting oneself to oneself is nonsense precisely because it means turning oneself into an object owned by someone else; in other words, into a thing, and “thing” is precisely what people are not. Therefore, the idea of disposing of oneself, in the sense of transmitting oneself to another person and becoming part of their estate, is absurd, given that the right of ownership, I repeat, has been designed to guarantee people’s liberty or autonomy, and allowing this right to be used for the opposite end (to lose liberty or autonomy) denaturalizes it. Locke clearly understood it this way. On this point, not at all original but indebted to a tradition that, I would say, rather than liberal could well be called modern iusnaturalist, he is preceded by Grotius and Hobbes, for example (Blanco Echaury, 2003: 117-120<sup>32</sup>). For all of them, asserting that human beings are a property of themselves means asserting that human beings are endowed with a personhood of their own and they cannot be fully subjected to the discretion of others.

32. Blanco Echaury, J. (2003), “Las concepciones del *ius naturale* o los fundamentos de la política en Grocio, Hobbes y Espinosa”, *Agora. Papeles de Filosofía*, 22.

As it is, and ignoring the different language in which it is expressed, I believe that Kant's concept of the person is not too far away from Locke's, or not as much as, basing himself on a study by Jiménez Redondo, Manuel Atienza suggests in this book (Atienza, 2016<sup>33</sup>). Atienza attributes the limits that Locke places on the disposal of oneself to "religious bonds" (and he quotes the passage from Section 6 of the *Second Treatise* in which Locke conceives of human beings as the "property" of God), and he continues by saying that "liberalism, once it has been freed of these religious bonds, carries in its internal logic the consequence that the individual is the complete master of their own body". Leaving to one side the matter of whether Locke truly is an exponent of "liberalism", I would say that these bonds are better understood as rational rather than religious (and in this sense they are very similar to Kant's), and that they would continue to be even after applying the tenets of secularization to Locke (or Grotius or Hobbes), if they had not already done so themselves. It is in that same section, number 6, where Locke writes "the state of Nature has a law of Nature to govern it, which obliges every one: and Reason, which is that law, teaches all Mankind, who will but consult it, that being all equal and independent, no one ought to harm another in his Life, Health, Liberty, or Possessions". A secular reading of Locke, and the tradition of which he is part, should not produce an interpretation different to the one I am putting forward here, an interpretation of the idea of the ownership of oneself that does not differ much from Kant's concept of the person as an autonomous being and an end in him or herself.

In short: the concept of "ownership of oneself" is nonsense if "ownership" is understood in the usual legal sense as the right to use and dispose of a thing. Therefore, the idea that one is the master of oneself is also nonsense. Another thing altogether is that we may wish to express our condition as free or autonomous beings differently. If this is so, the ownership of oneself would be more or less equivalent –or it would have a similar function– to the concept of legal personhood or the concept of human dignity. But this is a rather imprecise and uninteresting meaning of the term "ownership" and, of course, it tells us nothing about whether we have the right to use and freely dispose of our body (and above all, for a price).

## 5. MY BODY IS NOBODY'S

Sheltered from commerce for many years, the human body is now being tempted by the market. Biotechnological progress, the commercial

33. Atienza, M. (2016), "El derecho sobre el propio cuerpo y sus consecuencias". Chapter 2 of this book.

invasion of life, and the demystification of the body and its parts have formed an alliance that threatens to turn our flesh into something to be bought and sold. In this process, a key milestone must be the consideration of the body or its parts as things liable to be appropriated, and this consideration, in turn, is based on the fundamental idea that we are the proprietors of our own bodies and so we are therefore in a position to freely dispose of them. Against this drift, one way of reacting is to warn that this idea is erroneous, despite the fact that it is linked to a very popular intuition, that of “my body is mine”. The argument goes like this: my body is mine; if my body is mine, my body is my property; if my body is my property, I can dispose of it; if I can dispose of it, I have the right to commercialize it.

The error that invalidates this reasoning lies in the erroneous use of the term “property”. There is, on one hand, a use of the term by a tradition of modern philosophy that some have called “liberal”, anachronistically in my opinion, and which passes through Grotius, Hobbes and Locke. According to this usage, we are “proprietors” of our body in the sense that we have our own personhood and nobody can deprive us of it; but from this it does not follow that we may freely dispose of our body, just the opposite in fact. This usage must not be confused with the one that is more typical of our times, the legal-patrimonial, according to which, to be the “proprietor” of our body is to possess it as if it were a thing. In this second sense, we are not the proprietors of our bodies, because the body (while it is alive, at least) is not a thing; free disposal of it does not follow from this either.

Therefore, words like those of Bernat Soria, at the time the Spanish Minister of Health, and which Manuel Atienza quotes in the article to which I have just referred, may be confusing. The minister said, “There is a basic principle that separates two schools of thought: those who think that the proprietor of the body is oneself and those who think it is someone, a church, an institution or a political party. The Socialist Party says, ‘You are the proprietor of your body. You are the one who makes decisions’”.

This statement is confused, or simply wrong, because it poses an erroneous dilemma: our body is either our property or someone else’s. The error lies in the exhaustive nature of the dilemma, in the exclusion of a third possibility, that of our body being nobody’s property, as it is not an object that can be appropriated. And if this is the case, it follows that we are not free to decide what to do with it. This free disposal, of course, is not “socialist ideology”, as the minister maintained, nor should it be derived from the rationalist iusnaturalist tradition, for which, it is true, the ownership of one’s own body constituted an axiom (remembered as such by De

Lora and Gascón, in the study quoted by Atienza) but in the sense already indicated: as an unconditional assertion of the personhood or dignity of all humans. Of course, it is not a question of it being others who have to decide for us in matters concerning our body, but that, simply, there are decisions that must not be made –and the legal system must not allow them to be made– such as treating oneself as a tool to be used by others.

The clearly dominant use of the term “ownership” is now the legal and patrimonial. Therefore, if Bernat Soria was still the Minister of Health, which he is not, I would dare to suggest to him that, in order not to confuse people, he should not refer to individual autonomy in bodily matters (about which he must have been thinking) in proprietorial terms. It would be terrible if, in our attempts to stand up for everyone’s control over their own body and thus avoid illegitimate intrusions by others, we end up giving arguments to those hoping to make it an object of commerce – who, of course, do not seem to be guided by the socialist ideology that the minister invoked.

We are not, then, the owner of our body, but no one is. We cannot dispose freely of our body, but that does not mean that others can, or that somebody can tell us how we must “use” it. The law has instruments to protect our body and the sexual and reproductive use we make of it; but these instruments do not imply free disposal, which would pave the way for the commercialization of the body and its parts, and with it a new form of oppression. This commercialization implies the potential control by others of our bodies, of us. The apparent freedom given us by the right to dispose of our body could become, in the not too distant future, a new form of slavery. On the contrary, we will be freer provided our body remains outside the sphere of what is appropriable.

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# Between Property and Personality: The Right to Dispose of Parts and Products of the Body from a Civil Law Perspective

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## 1. INTRODUCTION

Social and technological change, in the context of biomedicine, poses great challenges. One of them is knowing whether or not it is possible to speak of a right of ownership over the separable parts of the human body and its fluids and products. The intense debates taking place particularly in Anglo-American legal circles are proof of this. The aim of this article is to clarify whether everything that is not a subject of law can be the object of a property right, as long as it can be used by human beings, or whether, on the contrary, the separate parts of the body still belong to the subject and, consequently, must be considered *res extra commercium*. I shall just say here that there is no univocal response in the different legal systems, and not even among jurists belonging to the same legal system is there consensus. Sometimes the issue is approached from a strictly patrimonial perspective, and at others, conversely, the notion of personality transcends the logic of *ius ad rem*<sup>1</sup>. There is not even a perfect division

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1. For the approach, see Von Bar, Christian (2015), *Gemeineuropäisches Sachenrecht*, I, Beck, Munich, pp. 135-136; Godt, Christine (2013), "The Functional Comparative Method in European Property Law", *European Review of Contract Law* (= ERCL), 2 (1)

of opinion, since dealing with the body is not the same as dealing with one of its parts. Which parts they are is also important, as is, of course, whether they are organs, tissues or fluids, not to mention the differences that may exist depending on whether they come from a living person or a cadaver. Since the question of whether it is tolerable to talk in terms of the “right of ownership” requires us to be sure that the material that might be the object of it is being traded, it is necessary to know in what conditions this takes place. Therefore, the article also discusses the non-remuneration that governs this issue and its more than proven exceptions. Some final considerations, halfway between a summary and a conclusion, will serve to show to what extent it is futile to try to impose categories, at least in view of the difficult cases analysed in this article, and how the traditional categories need to be reconsidered, precisely in view of the social changes.

## 2. BETWEEN THE RIGHT OF OWNERSHIP AND THE RIGHT OF PERSONALITY

From the legal point of view, any patient has the last word about the control of their body<sup>2</sup>. Furthermore, the law also agrees that it should be they who decide to have medical treatment or not<sup>3</sup>. However, does this right to dispose of one’s own body go any further? And is it unlimited? The debate has an ethical and moral component that inevitably determines the legal discourse, which it is impossible to reproduce in full here<sup>4</sup>. Therefore, just a few basic ideas will enable us to frame the terms of the controversy.

### 2.1. OWNERSHIP OF THE BODY OR OF ITS SEPARATE PARTS?

The initial hypothesis could be that if the person is also a body, the body belongs to the person. Intuitively, from that it could be derived

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[pp. 73-89], pp. 79, 85. The dichotomy is also considered, even if only to explain the state of the question in Italian law, by Zatti, Paolo and Klesta, Laurence (2012), “Le statut juridique du corps humain en Italie”, in *Travaux de l’Association Henry Capitant. Journées suisses* (2009), vol. LIX, Bruyland/LB2V, Brussels [pp. 153-187], p. 159.

2. Art. 212-7 of Book II of the Civil Code of Catalonia (= CCCAT) (L. 25/2010, 29 July, of Book Two of the Civil Code of Catalonia, relative to the person and the family; DOGC n.º 5686, 5 August).
3. See chapter II (Autonomy of the Person in the field of health), of title I (The physical person), of Book II CCCAT; L. 21/2000, 29 December, on the rights to information concerning the patient’s health and autonomy, and clinical documentation (DOGC n.º 3303, 11 January 2001).
4. In detail, Bergel, Salvador Darío (2007), “Bioética, cuerpo y mercado”, *Revista Colombiana de Bioética*, 2 (1), pp. 133-164.

that the person is the owner of their body and, as a result, they ought to be able to decide what to do with it, or with parts or products of it. It might seem that this is in fact what happens when a patient's functions improve due to undergoing different interventions, on the many occasions when implants are inserted, or when they undergo different voluntary or self-satisfying medical operations, and even when they decide to have piercings and tattoos<sup>5</sup>. Nevertheless, traditionally the answer is that free disposal is not possible because there are ethical and moral principles that have to do with the dignity of the person, that demand respect for the human body. In this respect, it is common to claim that no trade must be carried out with it, not even with separate parts of it, because that could give rise to exploitation and it entails the potential danger of harm being done to the person<sup>6</sup>. This is partly what is already happening in countries such as Thailand, Cambodia, the Philippines, Myanmar, Pakistan, Bangladesh and Ukraine, where it has been said graphically that, "the poor sell their bodies so that the rich can live"<sup>7</sup>.

In Europe the laws meticulously regulate the donation of organs (lungs, kidneys), tissues (cornea, bones, skin, bone marrow) and cells (eggs, semen), and they establish the limit of what is tolerable and the conditions in which donation must take place. In particular, for cases of organ donation *inter vivos*, they establish the need to give consent before the judge (or equivalent authority) so that he or she can see that the decision

5. Berlioz, Pierre (2007), *La notion de bien*, LGDJ, Paris, p. 125. Rodotà, Stefano (2008) speaks about "modelable raw material" in "Aventuras del cuerpo", in Silveira Gorsky, Héctor C. (ed.), *El Derecho ante la biotecnología. Estudios sobre la nueva legislación española en biomedicina*, University of Lleida-Icaria, Barcelona [pp. 291-307], p. 305, to demand new control guarantees.
6. On the ideas that preach freedom to sell parts of the human body and its consequences, see Sandel, Michael, J. (2013), *Justicia ¿Hacemos lo que debemos?*, DeBolsillo, Barcelona, 4th ed. (transl. Juan Pedro Campos Gómez), pp. 85-87. Extensively, Bergel, "Bioética...", esp. pp. 151-154. On these lines, Hernández Plasencia, José Ulises (2006), "Sistema de aceptación de donantes vivos: análisis comparativo", in Rodés Teixidor, Juan (ed.), *Trasplante de órganos y células. Dimensiones éticas regulatorias*, Fundación BBVA, Bilbao [pp. 465-484], pp. 472-473, who nevertheless shows himself to be in agreement with a system of incentives for donation. On this subject, see below, heading 3 ss.
7. See the interview between Ima Sanchís and Jean-Daniel Rainhorn, a doctor specializing in international health, in the section "La Contra", in the newspaper *La Vanguardia*, 15 July 2016 (back page): "[I]n India 83% of the people who have had an organ removed are women, the poorest of the poor"; "[An] article should be added to the Declaration of Human Rights to include that human beings must not be traded, in line with the model of the abolition of slavery. In slavery the trade was in people's muscles, now it is with parts of their body". The interviewee has co-coordinated a book with a provocative title: (2015), *New Cannibal Markets. Globalization and Commodification of the Human Body*, Éditions de la Maison des sciences de l'homme, Paris.

is freely made and that the donor understands its scope exactly<sup>8</sup>. Such precautions merely confirm that donation is perfectly legal –although not in all cases– but only when it serves an altruistic or supportive purpose, namely, when it helps to save or improve other people’s lives. One must bear in mind also that disposing of self-regenerating parts of the body or fluids (blood, semen, nails, hair, urine), or which are easy to replace (teeth), cannot be the same as disposing of organs that cannot be replaced or regenerated once they have been removed from the body, and whose removal might be a possible cause of the person’s death or at least the deterioration of their life (liver, kidneys, lungs, heart)<sup>9</sup>. Apart from that, the practice demonstrates that numerous transactions with body parts take place every day: the trade in wigs made with natural hair is legal, there are private banks that hold umbilical cord stem cells, and, to give one last example, the donation of genetic material is not at all uncommon. These are, then, assets *intra commercium* of which the owner can freely dispose. Consequently, if the subject has an indisputable power of decision, why shouldn’t their ownership of these parts, removed from their body, be acknowledged? Many jurists in Germany, Scotland, Austria, Italy, Greece and Hungary would answer that question by saying that it should<sup>10</sup>. The views of English judges on this subject are also well known<sup>11</sup>. When I refer

8. Article 19.2 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Convention relative to human rights and biomedicine), signed in Oviedo on 4 April 1997: “[C]onsent [...] must be given expressly and specifically, either in writing or before an authority”. In Spain, see Instrument of Ratification (BOE n.º 251, 20 October 1999). Furthermore, article 4 letter *c* L. 30/1979, 27 October, on Organ Removal and Transplantation (BOE n.º 266, 6 November 1979) and Ch. X, arts. 78-80 L. 15/2015, 2 July, of Voluntary Jurisdiction (BOE n.º 158, 3 July 2015). In Italy, article 2 of L. of 26 June 1967 n.º 458, *Trapianto del rene tra persone viventi* (*Gazzetta Ufficiale* 27 June, n.º 160, special edition).
9. This matter is governed by the medical principle of *primum non nocere*, see Hernández, “Sistema...”, in Rodés (ed.), *Trasplante...*, pp. 469-470. This is also established by the legislation. For example, in Spain, see article 8.1 letter *b* of Royal Decree 1723/2012, 28 December, regulating the activities of obtainment, clinical use and territorial coordination of human organs used for transplantation, and establishing quality and safety standards (BOE n.º 313, 29 December 2012). In Portugal, see article 6.7 of Law n.º 12/93, 22 April, *colheita e transplante de órgãos*.
10. See the references in Von Bar, *Gemeineuropäisches...*, pp. 135-136.
11. *English Court of Appeal R v. Kelly* (1998) 3 All E.R. 741. Usually cited also is the influence of the decision of the Australian High Court in *Doodeward v. Spencer* (1908) 6 CLR 406. For a succinct account, Forster, Charles (2013), *Medical Law: A Very Short Introduction*, Oxford University Press, Oxford, pp. 114-118. In detail, Mason, J. Kenyon and Laurie, Graeme T. (2013), *Mason & McCall Smith’s Law & Medical Ethics*, Oxford University Press, Oxford, 9th ed., pp. 480 *et seq.*; Skene, Loane (2014), “The current approach of the courts”, *Journal of Medical Ethics*, 40, pp. 10-13. References also in Von Bar, *Gemeineuropäisches...*, p. 137, note 89.

to ownership I am not alluding to intellectual ownership over the material that has been transformed thanks to the work of others, because it is clear that, in such a case, ownership by the institutions, researchers or companies working with those tissues *is* acknowledged and moreover protected in the form of patents. No one, by the way, would say that the latter are not driven by the desire for financial gain<sup>12</sup>.

## 2.2. OR A RIGHT OF PERSONALITY AND SELF-DETERMINATION?

The answer to whether or not it is tolerable to talk in terms of a “right of ownership” over body parts, fluids or tissues is largely determined by the debate about the admissibility of trading with parts or products of the human body<sup>13</sup>. As this is generally prohibited, jurists tend to argue in terms of “rights of personality” when admitting the lawfulness of the disposal of these parts or products<sup>14</sup>. The language of ownership or of “patrimonial rights” seems to treat the person as an item of merchandise and it generally generates rejection. That seems to be the point of view of the French legislators, who, by virtue of the Law of 29 July 1994, have introduced new provisions in the Civil Code concerning the integrity of the human body (articles 16 and 16-1 to 9 *Code*) that prescribe the impossibility of it, or its parts or products, being the object of trade<sup>15</sup>. If the body is not an object, but a subject of law, the fact that the owner must consent to the disposal of it, or to the use made of parts of it or its genetic material,

12. In Spain, article 7.2 of L. 14/2007, 3 July, of Biomedical Research (BOE n.º 159, 4 July 2007) is categorical: “[D]onation implies, furthermore, the waiving by donors of any right of an economic nature, or of any other kind, to the results that may be derived directly or indirectly from the research carried out with the said biological samples”. Well known is the case of *Moore v. Regents of the University of California* (1990), of the California Supreme Court, which refused the plaintiff, ill with leukaemia, the right to share in the financial results of the patent to which the cell line created by the researchers from his semen and without his prior consent gave rise. The court refused the sick man the right to own the cells and, as a result, it was unable to find the doctor guilty of a tort of conversion. See Mason & Laurie, *Mason & McCall Smith’s Law...*, pp. 480-481. See now S. 32 (9) (c) *Human Tissue Act* 2004.
13. On the subject, see below, heading 3 ss.
14. For a succinct summary of the problem, Von Bar, *Gemeineuropäisches...*, pp. 137-138. More extensively, Bergel, Salvador Darío (2011), “Aportes para un estatuto de las partes separadas del cuerpo”, *Revista de Derecho y Genoma Humano*, 35 [pp. 65-100], pp. 79-87. For a recent approach to the concept of “rights of personhood”, see García Rubio, M.ª Paz (2013), “Los derechos de la personalidad”, in Gete-Alonso, M.ª Carmen (dir.) and Solé Resina, Judith (coord.), *Tratado de derecho de la persona física*, Civitas-Thomson Reuters, Cizur Menor (Navarre), pp. 595-631.
15. Article 3 of L. n.º 94-653, 29 July 1994 (JORF 30 July 1994). In particular, see articles 16-1.3, 16-5, 16-6.

should mean nothing in terms of “ownership” for either the person donating them or the recipient. It seems that regarding decisions about one’s own body in terms of dignity and self-determination, and from the point of view of inalienable rights (for example life, health, integrity and privacy), adapts better to the idea that the parts of the body are considered *rei extra commercium*. That perspective, which continues to be a majority one in Spain, situates the issue within the coordinates of the *subject* of the right and distances it from the *object* of it and the resulting commodification<sup>16</sup>. It is still disgusting to reduce a person to the status of a thing and, in the opinion of this legal doctrine, that is exactly what would happen if the human body or parts or products of it were treated as the object of a patrimonial right. In the current Spanish handbooks, it is common to address this problem when dealing with the explanation of the rights of the personality and, more specifically, the right to physical integrity<sup>17</sup>.

### 2.3. SOME DIFFICULT CASES

Although there are plenty of jurists in Spain who acknowledge the possibility of disposing of detached parts of the body and regenerative substances (breast milk, blood or bone marrow), those same jurists express their misgivings with regard to the disposal of germ cells (semen, eggs and pre-embryos)<sup>18</sup>. Once again, the problem consists of determining whether it can be said that there is a donation or any other contract when the subject disposes of these “things” that are considered off-limits to human commerce (article 1.271 CC) or whether such acts are rather manifestations of the person’s right to self-determination<sup>19</sup>. The courts have

16. García Rubio associates dignity with rights over the body and human tissues, in “Los derechos...”, in Gete-Alonso (dir.), *Tratado...*, p. 612. Clearly in favour of this approach, Gordillo Cañas, Antonio (1987), *Trasplantes de órganos: “pietas” familiar y solidaridad humana*, Cuadernos Cívitas, Madrid, pp. 39-41; Navas Navarro, Susana, “Le statut juridique du corps humain en Droit espagnol”, in *Travaux...* [pp. 119-131], p. 121. In relation to biological samples, Gómez-Salvago Sánchez, Cecilia (2014), “Marco jurídico privado del material biológico de origen humano en la actividad investigadora”, *Anuario de Derecho Civil*, 1 [pp. 11-79], pp. 45-49. The same perspective would be the one observed by some jurists in Portugal (but not unanimously) and in Poland, according to Von Bar, *Gemeineuropäisches...*, p. 138, note 93.
17. As an example, see Lacruz Berdejo, José Luis *et al.* (1999), *Elementos de Derecho Civil*, I, Dyckinson, Madrid, p. 72; Hualde Sánchez, José Javier (1995), in Puig Ferriol, Lluís *et al.*, *Manual de Derecho Civil*, I, Marcial Pons, Madrid, pp. 363-365.
18. Gil Rodríguez, Jacinto (2011), “Comentario al artículo 333 CC”, in De Pablo Contreras, Pedro and Valpuesta Fernández, Rosario (coords.), *Comentario al Código Civil*, Civitas-Thomson, Madrid [pp. 1353-1356], p. 1355.
19. In favour of this, Soto Díez, Carlos (2007), “Comentario al artículo 5”, in Lledó Yagüe, Francisco *et al.* (dirs.), *Comentarios científico-jurídicos. Ley 14/2006, del 26 de mayo, sobre técnicas de reproducción humana asistida*, Dyckinson, Madrid [pp. 88-97], p. 90.

also had their say in this controversy. They are all difficult cases, which clearly show the impossibility of establishing general rules.

### 2.3.1. The destruction of male genetic material

That semen, once it is expelled from the body, may be the object of ownership is something generally admitted by the law in countries such as Germany, Hungary, the United Kingdom and the Netherlands<sup>20</sup>. In some, the courts have had to deal with this issue, because of the lawsuits filed due to the negligent destruction of semen by the clinic that should have cryopreserved it. In answer to the plaintiff's claim for compensation for the psychological damage arising from the loss of the opportunity to procreate (*solatium* or *pretium doloris*), the United Kingdom Court of Appeal's judgment 'Yearworth and others v. North Bristol NHS Trust'<sup>21</sup> acknowledged a right of ownership over the genetic material. The court declared the defendant responsible by reason of damage to the ownership of the semen that the hospital was preserving in bailment; it could no longer return it and that was the same as saying that the plaintiff's ownership had been damaged, namely, the right to use the sperm and to control the use that was made of it. Hence, he could demand compensation for psychological and psychiatric damages, provided that such suffering was a foreseeable consequence arising from the defendant's breach of duties and that this could be proved. The court expressly denied that there had been a lesion of the body, contrary to what the judges in Germany had decided some years earlier. In effect, the judgment of the Bundesgerichtshof of 9 November 1993<sup>22</sup> considered that although the sperm had been wholly separated from the body and was no longer a part of it, its function was what it would be if it were still inside the human body, that of fertilizing an egg and procreating. Consequently, the court understood that there was damage to the body and agreed the compensation arising from the frustration of the only opportunity left to the plaintiff to become a father<sup>23</sup>. In Scotland, the law had reacted to the solution proposed in 'Yearworth', proclaiming the need to protect the right to procreate through the protection of people's right of personality or their dignity<sup>24</sup>. Nor, it would seem,

20. References in Von Bar, *Gemeineuropäisches...*, pp. 137-138.

21. (2009), EWCA CIV 37.

22. BGH of 9 November 1993 – VI ZR 62/93 (BHZ 124, 52-57; JZ 1994, 464-465). An extract of the sentence in English is retrieved from <http://germanlawarchive.iuscomp.org/?p=157>, consulted on 26 July 2016.

23. See Banert, Christian (2011), "Die Vernichtung von eingefrorenem Sperma als Rechtsproblem", *European Review of Private Law* [ERPL], 2 [pp. 283-290], pp. 287-288.

24. See Farran, Sue (2011), "Storing Sperm in Scotland: A Risky Business?", *ERPL*, 2 [pp. 258-273], pp. 271-272; Harmon, Shawn (2011), "Yearworth v. North Bristol NHS

in the recent judgment ‘Holdich v. Lothian Health Board’, did the Scottish judges give clear support to the theory of ownership<sup>25</sup>.

Common to all three cases is the need to acknowledge the control of the use made of the material separated from the body, so the judges seek solutions within the limits of the legal system. It is important to point out that when the German judgment was issued, the BGB did not recognize the existence of moral damages when the asset damaged was ownership. And that if, on the contrary, the English judge had not acknowledged the ownership of the semen, the breach of a contract of deposit or any compensation could never have been declared, in view of the English court’s description of the German judges’ arguments as “fiction”.

### 2.3.2. The disposal of gametes and embryos

The Spanish Constitutional Court has twice had occasion to explain that donating embryos is not the same as patrimonializing or commodifying the person. First it was the judgment (=JCC) 212/1996, issued against the (now repealed) Law 42/1988, 28 December, on the donation and use of human embryos and foetuses or their cells, tissues or organs, which, despite having a dissenting opinion stating that living embryos cannot be the object of a contract, expressed the following idea<sup>26</sup>:

Both in relation to article 1 and to other successive ones (articles 2, 3.2, 7 and first additional regulation), the law is reproached for its use of a concept, that of donation, of precise meaning, they maintain, in our law and which they deem to be incompatible with the dignity of the person insofar as it means the patrimonialization of human beings, whatever their degree of development. Having clarified, nevertheless, that the law envisages only the donation of dead or, in any case, unviable foetuses or embryos (or of biological structures

Trust: A property/medical case of uncertain significance” *Working Paper Series*, n.º 32, University of Edinburgh School of Law, pp. 12-15, retrieved from <http://ssrn.com/abstract=1948099>, consulted on 26 July 2016.

25. [2013] CSOH 197, 2014 SLT 495. See Reid, Kenneth G. C. (2015), “Body Parts and Property”, *Research Paper Series*, n.º 2015/25, University of Edinburgh School of Law, pp. 1-18.

26. The judgment was issued in response to the constitutional challenge moved by Federico Trillo-Figueroa y Martínez-Conde, commissioned by 78 deputies of the Popular Party Parliamentary Group. The law was challenged in its entirety and subsidiarily against articles 1, 2, 3, sections 2 and 3, 5 section 1, 5 section 3, 7, 8, 9 and First Additional Provision, sections d) and e), for contradicting articles 9, 10, 15, 25, 53 and 81 of the Spanish Constitution (BOE n.º 19, 22 January 1997). The dissenting vote corresponds to magistrate José Gabaldón López.

coming from those whose death has already been confirmed, article 6), such a reproach lacks all foundation from the moment when this singular “donation”, like that of human organs regulated in Law 30/79, or even that of the cadaver of a person, does not in any way imply “patrimonialization”, which is pretended of the person, which would of course be incompatible with their dignity (article 10.1 EC), but, in fact, the exclusion of any lucrative or remunerative cause, expressly prohibited by article 2 d) of the law: “That the donation and subsequent use must never be lucrative or commercial in nature” (§ 8).

Shortly afterwards came JCC 116/1999, 17 June, issued as a result of the constitutional challenge against the (now repealed) Law 35/1988, 22 November, of assisted reproduction techniques, reads thus<sup>27</sup>:

“It must be remembered that neither non-implanted pre-embryos nor, a fortiori, simple gametes, are, for these purposes, a ‘human person’, whereby the fact of remaining at the disposal of the banks after a certain amount of time has passed can hardly be contrary to the law [...] to human dignity (article 10.1 EC), as the appellants nevertheless maintain. For its part, article 5.1 is challenged insofar as it allows for the donation of gametes and pre-embryos, because, as is stated in the appeal, this ‘patrimonializes and turns an individual who is the result of conception into a human object’, which is incompatible with art. 15 EC. However, as was stated in JCC 212/1996 (8th legal basis), in relation to certain precepts of Law 42/1988, this singular donation ‘does not in any way imply the ‘patrimonialization’ of the person, which is pretended, which would of course be incompatible with their dignity (article 10.1 EC), but in fact the exclusion of any lucrative or remunerative cause, expressly prohibited’; a prohibition that, in this case, is to be found in article 5.3 of the law that we are now judging. In short, the object pursued by article 5.1 of the law is none other than that of guaranteeing that under no circumstances may gametes and pre-embryos be legally considered marketable assets, whereby, in accordance with the abovementioned law, the precept challenged is in no way unconstitutional” (§ 11).

In the recent judgment of the European Court of Human Rights (ECHR), of 27 August 2015, ‘Parrillo v. Italy’, the ECHR did not dare go so far and state that a frozen embryo is not a person, but nor did it state the contrary, given that it does not tackle the sensitive and controversial

27. Judgment issued as a consequence of the constitutional challenge moved by deputies of the Popular Party Parliamentary Group. The law was challenged in its entirety and subsidiarily, against different sections of it (BOE n.º 162. Supplement of 8 July 1999).

problem of determining when life begins. In the case being studied, the plaintiff was an Italian citizen who, once her plan to form a family had been frustrated due to the sudden death of her partner, wished to be able to decide to donate her *in vitro* embryos to scientific research, despite the fact that Italian law did not allow it. The Court believes that embryos are not assets in the sense of article 1 of Protocol No. 1 of the Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)<sup>28</sup>, because it understands that the said precept has a purely financial and patrimonial scope (214-215). From this, it should be deduced that it does not rule out the existence of a property without this economic value, unless it should wish to create something as improbable as a *tertium genus* between property and person. In reality, the majority of the judges consider that embryos are a constituent part of the plaintiff's genetic material and biological identity, and, consequently, they constitute a part of her (§ 158). The argument serves to assert the right of self-determination over one's own body (§ 159) and, consequently, to acknowledge that the right to decide what the fate of the embryos should be comes within what ought to be considered the right to private life (article 8 of the ECHR)<sup>29</sup>.

### 3. THE FACT THAT FINANCIAL GAIN IS PROHIBITED DOES NOT IMPLY THAT THE DISPOSAL OF ORGANS, TISSUES OR FLUIDS IS PROHIBITED

It is as common to claim that organs and parts of the body are *res extra commercium* as it is that the person can dispose of them altruistically<sup>30</sup>.

28. Article 1 of the Additional Protocol to the Convention for the Protection of Human Rights and Fundamental Freedoms: “[1] Every natural or legal person is entitled to the peaceful enjoyment of his possessions. No one shall be deprived of his possessions except in the public interest and subject to the conditions provided for by law and by the general principles of international law”.

29. Another matter is that the ECHR finally granted the Italian State a wide margin of appreciation and understood that it had not violated the precept. On the very controversial judgment, a note in Winkler, Matteo (2006), “Il divieto italiano di ricerca sugli embrioni al vaglio della Corte europea dei diritti umani (nota a CEDU, 27.8.2015, Parrillo vs. Italia)”, *Il Familiarista*, 8 January, retrieved from [www.academia.edu](http://www.academia.edu), consulted on 26 July 2016. More critical, see Farnós Amorós, Esther (2016), “La reproducción asistida ante el Tribunal Europeo de Derechos Humanos: De Evans vs. Reino Unido a Parrillo vs. Italia”, *Revista de Bioética y Derecho & Perspectivas Bioéticas*, 36 [pp. 93-111], pp. 106-108. Especially in disagreement, see Torroja Mateu, Helena (2016), “¿Un Derecho de Propiedad sobre los embriones in vitro? ¿Un derecho a decidir su donación a la ciencia? Un controvertido debate (TEDH, Parrillo vs. Italia)”, *Revista General de Derecho Europeo*, 39, pp. 1-24.

30. Thus, Lacruz *et al.*, *Elementos...*, p. 72; Navas Navarro, “Le statut juridique...”, in *Travaux...*, p. 121; Farnós Amorós, Esther (2011), *Consentimiento a la reproducción*

Therefore, they cannot be sold –although it is obvious that some parts of the body *can* be sold– but they can be donated, because that does not hurt feelings nor is it contrary to social morality<sup>31</sup>. The consequence is, contrary to what is generally claimed, that they are assets that *are* traded<sup>32</sup>. The only thing that is prohibited is remuneration for the transplantation of organs or any financial gain arising from the donation of tissues or other materials.

The prohibition of financial gain is a general principle in international legislation and codes of ethics, for example, the European Convention on Human Rights and Biomedicine,<sup>33</sup> the Charter of Fundamental Rights of the European Union<sup>34</sup>, the World Health Organization’s Guiding Principles on Human Cells, Tissue and Organ Transplantation<sup>35</sup>, or the Council of Europe Convention against Trafficking in Human Organs<sup>36</sup>. As a result of research into biological materials of human origin, non-remuneration is also imposed by the Recommendation of the Council of Europe (2006) 4<sup>37</sup>, to mention just one of the many codes of ethics that exist internationally. National laws are no exception<sup>38</sup>. One only has to cite part of the abundant

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*humana asistida. Crisis de pareja y disposición de embriones*, Atelier, Barcelona, p. 142, note 432. Similarly, in France, Libchaber, Rémy (2004), “La recodification des biens” in *Le Code civil 104-2004. Livre du Bicentenaire*, Dalloz-Litec-LexisNexis, Paris [pp. 297-372], p. 343: “[À] fin de protection individuelle, l’extrapatrimonialité est limitée à celui qui pourrait faire de son corps une source de richesse...”

31. In Italy, article 5 of the Italian CC clearly does not prohibit any act of disposal and other laws regulate kidney donation [article 1pr. of L. of 26 June 1967, n.° 458, “Trapianto del rene tra persone viventi” in the *Gazzetta Ufficiale* of 27 June, n.° 160, special edition] or of part of the liver [article 1 of the Law of 16 December 1999, n.° 483, in the *Gazzetta Ufficiale* n.° 297 of 20 December 1999]. Mazzoni, Cossimo Marco (2001), “Diritti della personalità”, in Bessone, Mario (ed.), *Lineamenti di Diritto Privato*, Giappichelli, Turin, 2nd ed. [pp. 65-71], p. 66, calls attention to the reference “quasi esclusivamente di natura patrimoniale” contained in article 5 of the Italian CC, although only to warn that “si è andato quasi del tutto a perdere a favore dell’altro principio fondamentale della libertà del soggetto”.
32. Von Bar, *Gemeineuropäisches...*, p. 137.
33. Article 21 of the Convention of Oviedo (see reference in note 8): “[T]he human body and its parts, as such, must not be the object of financial gain”.
34. Article 3.2, third dash (DO C 364, 18 December 2000).
35. Principles approved by the 63rd World Health Assembly, May 2010, in its resolution WHA 63.22. See Guiding Principles 5, 6 and 8.
36. See article 4.1, letters *b* and *c*, of the Council of Europe Convention against Trafficking in Human Organs, of the Council of Europe, 9 July 2014.
37. Article 7 Recommendation (2006) 4 of the Committee of Ministers to Member States on Research on Biological Materials of Human Origin (Adopted by the Committee of Ministers on 15 March 2006 at the 958th meeting of the Ministers’ Deputies).
38. Von Bar, *Gemeineuropäisches...*, p. 137, note 90; Hernández, “Sistema...”, pp. 470-471.

legislation in Spain<sup>39</sup>, Italy<sup>40</sup>, Portugal<sup>41</sup>, France<sup>42</sup> and England<sup>43</sup>. Nor does the transposition of Directive 2004/23, in relation to cell and tissue donation<sup>44</sup>, and Directive 2010/45, concerning organs destined for transplantation<sup>45</sup>, leave any other margin.

According to the Bioethics Committee of Catalonia, on ethical considerations in living-donor transplants, donation in exchange for a material compensation may be a free act, but it is not a fair act because it violates the principle of equality. If donation in exchange for a material good is accepted, only the poorest people would consent the exchange. It is not acceptable even under the best possible conditions, when the insurance agencies act as intermediaries and avoid direct transactions, which may be regulated by the laws of the market that always favour the richest<sup>46</sup>.

### 3.1. COMPENSATION FOR THE DISCOMFORT CAUSED

The prohibition of financial gain is not incompatible with being able to pay compensation for the discomfort caused. One only has to look at the legislation on blood donation to see this<sup>47</sup>. However, it is sometimes

39. Article 2 of Law 30/1979, 27 October, on organ removal and transplantation; articles 4.2 and 7 Royal Decree 1723/2012, 28 December, regulating activities of obtainment, clinical use and territorial coordination of human organs used for transplantation, and establishing quality and safety standards (BOE n.º 313, 29 December 2012); articles 7.1, 58.3 of Law 14/2007, 3 July, of Biomedical Research (BOE n.º 159, 4 July 2007).

40. Article 6 of Law of 26 June 1967 n.º 458, “Trapianto del rene tra persone viventi”, in the *Gazzetta Ufficiale* of 27 June n.º 160, special edition).

41. Article 5 of Law n.º 12/93, 22 April, *colheita e transplante de órgãos*.

42. Article 1211-4 *Code de la Santé Publique*.

43. Sect. 32 Human Tissue Act, 2004.

44. Article 12 Directive 2004/23/EC of the European Parliament and of the Council, 31 March 2004, relative to the establishment of standards of quality and safety for donation, obtainment, assessment, processing, preservation, storage and distribution of human cells and tissues (DO L 102, 7 April 2004). Regulation (EC) N.º 1394/2007 of the European Parliament and of the Council, 13 November 2007, on Advanced Therapy Medicinal Products (DO L 324, 10 December 2007) omits any consideration of remuneration, although the law’s Exposition of Causes refers to the abovementioned for the case of an Advanced Therapy Medicinal Product containing organs and tissues; in this respect, it stresses the need to observe the principle that donation is non-remunerated (§§ 14-15).

45. Article 13, Directive 2010/45, of the European Parliament and of the Council, 7 July 2010, on standards of quality and safety of human organs used for transplantation (DO L 207, 6 August 2010).

46. [https://canalsalut.gencat.cat/web/.content/\\_Sistema\\_de\\_salut/CBC/recursos/documents\\_tematica/transplantament\\_donant\\_viu.pdf](https://canalsalut.gencat.cat/web/.content/_Sistema_de_salut/CBC/recursos/documents_tematica/transplantament_donant_viu.pdf), p. 13 (updated on 25 May 2020).

47. In Spain, article 4 of Royal Decree 1088/2005, 16 September, establishing the technical requirements and minimum conditions of blood donation and of transfusion centres

stressed that there can be no commercial trafficking of human tissue and, by contrast, a “price” is put on this material<sup>48</sup>. Isn’t this a sign of commercialization?<sup>49</sup>. The answer probably depends on how high that compensation is; this would vary according to what the discomfort is and, above all, what risk is involved in removal. Thus, while donating semen is innocuous, the same cannot be said about egg donation, which besides requiring hormone treatment needs surgery. Financial compensation for this donation is therefore far higher. In 1997, and protected by the previous laws of assisted reproduction, which were deliberately vague, the Commission on Human Assisted Reproduction Techniques (which advises the Generalitat de Catalunya’s Department of Health on these matters) calculated that the compensable expenses included travel, meals and hours of work lost, and that they could amount to as much as 600 euros<sup>50</sup>. Then, article 5.3 of Law 14/2006, 26 May, on human assisted reproduction techniques<sup>51</sup>, specifically established that any financial compensation that may be awarded can only strictly compensate the physical discomfort and the travel and work expenses that may arise from donation, and it must not be a financial incentive. The precept adds that the Ministry of Health and Consumer Affairs, after a report from the National Commission of Human Assisted Reproduction, will periodically establish the basic conditions to guarantee observance of the non-remunerated nature of donation. In practice, with the margin imposed by clinics, the price seems to be considerably higher than that figure and hovers around 900 euros, according to some indications<sup>52</sup>, and between 1,000 and 1,200, according to others<sup>53</sup>. The amounts

and services (BOE n.º 225, 20 September 2005). In France, see article 1221-1 and 3 *Code de la Santé Publique*.

48. In Belgium, see article 6 *Loi relative à l’obtention et à l’utilisation de matériel corporel humain destiné à des applications médicales humaines ou à des fi de recherche scientifique*, 19 December 2008 and *arrêté ministériel fixant le prix du matériel corporel humain* 14 October 2009, retrieved from [http://www.fagg-afmips.be/fr/items-HOME/Lois\\_et\\_Arretes](http://www.fagg-afmips.be/fr/items-HOME/Lois_et_Arretes), consulted on 26 July 2016. In France the sale of certain products of the human body is legal (to be determined by decree of the Council of State), when it is the norm (Law 1211-8 *Code de la Santé Publique*). Cfr. Berlioz, *La notion de bien...*, p. 116.
49. Attention is focused on the existence of commercial practices with human tissues in different countries by Lenk, Christian, and Beier, Katharina (2012), “Is the Commercialisation of Human Tissue and Body Material Forbidden in the Countries of the European Union?” *Journal of Medical Ethics* (38), pp. 342-326.
50. My thanks to Dr María Casado for providing me with the information.
51. BOE n.º 126, 27 May 2006.
52. According to Farnós Amorós, Esther (2010), “European Society of Human Reproduction and Embryology 26th Annual Meeting. Rome, 27-30 June, 2010”, *InDret*, 3, p. 12. See also Olaya Godoy, María (2014), *Régimen jurídico de la tecnología reproductiva y la investigación biomédica con material humano embrionario*, Dyckinson, Madrid, pp. 281-282.
53. On the webpage of the Institut Marquès it was said: “[I]n our centre, we estimate this compensation to be €1,000 in the first cycle, €1,100 in the second, and €1,200 from the third onwards”, retrieved from <http://institutomarques.com/ca/reproduccio-assistida-2/>

are considerably lower in other countries, and particularly in the United Kingdom<sup>54</sup>. Naturally, the provision of compensation influences the age and civil status of donors<sup>55</sup>.

The problem is that it is generally not easy to know where compensation ends and remuneration begins. Besides, if we look closely, the price of a transaction does not have to be fair, or make a profit. Precisely with this argument French jurisprudence admits that blood may be the object of a contract for pecuniary interest between the blood transfusion centre and the donor (in the case, someone who has AIDS), although the price may be disguised as a sum given in compensation for expenses<sup>56</sup>. Furthermore, very often the process lacks transparency because financial compensation is replaced by compensation in kind<sup>57</sup>. Moreover, in view of the massive and indiscriminate advertising in universities or via Internet, it could be said that there is a real market in some countries<sup>58</sup>. It is the responsibility of the medical team to ensure that the procedure is correct and the authorities must ensure that donations are altruistic<sup>59</sup>.

### 3.2. THE PROBLEM OF TRANSPARENCY

Apropos of the presentation of the second report on the voluntary, non-remunerated donation of tissues and cells, the European Parliament

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*tractaments/donacio-dovuls-semen-i-embrions/*, consulted on 26 July 2016. This information does not exist anymore in the new Institute's webpage.

54. According to García-Ruiz, Yolanda and Guerra-Díaz, Diana (2012), "Gamete and embryo donation: a legal view from Spain", in Richards, Martin, Pennings, Guido, and Appleby, John B. (eds.), *Reproductive Donation. Practice, Policy and Bioethics*, Cambridge University Press, Cambridge [pp. 112-129], pp. 115.
55. García-Ruiz and Guerra-Díaz, "Gamete and embryo donation...", in Richard, Penning and Appleby (eds.), *Reproductive...*, pp. 121-122.
56. Tribunal de Grande Instance, Toulouse, 16 July 1992. See Berlioz, *La notion de bien...*, p. 119. It is also cited in Von Bar, *Gemeineuropäisches...*, p. 139, note 97.
57. Denouncing this lack of transparency in Spain, prior to the passing of the Law of Human Assisted Reproduction of 2006, Díaz Martínez, Ana (2006), "Las figuras contractuales en la reproducción asistida humana: especial estudio de la prestación de servicios de medicina reproductiva en centros privados", in Díaz Martínez, Ana (coord.), *Régimen jurídico-privado de la reproducción asistida en España: el proceso legal de reformas*, Dyckinson, Madrid, p. 87. For the United Kingdom, García-Ruiz and Guerra-Díaz, "Gamete and embryo donation...", in Richards, Pennings and Appleby (eds.), *Reproductive...*, p. 115.
58. In Denmark, sperm prices are announced at <https://dk.cryosinternational.com/donor-sperm/prices-and-payment> (updated on 25 May 2020).
59. See the document "Consideracions ètiques en els trasplantaments de donant viu", by the Bioethics Committee of Catalonia, January 2012, esp. pp. 16-17, retrieved from [https://canalsalut.gencat.cat/web/.content/\\_Sistema\\_de\\_salut/CBC/recursos/documents\\_tematica/transplantament\\_donant\\_viu.pdf](https://canalsalut.gencat.cat/web/.content/_Sistema_de_salut/CBC/recursos/documents_tematica/transplantament_donant_viu.pdf) (updated 25.05.2020)..

warned, in its resolution of 11 September 2012<sup>60</sup>, that much remained to be done. The Parliament observed that the tissues and cells donated, such as skin, bones, tendons, corneas and haematopoietic stem cells, are used more and more frequently in medical therapies and as raw materials for the production of advanced therapy medicinal products (ATMPs), and it recalled that Directive 2004/23/EC orders member states to endeavour to guarantee voluntary non-remunerated donations of cells and tissues, and that they should not be obtained through financial gain<sup>61</sup>. In view of the figures presented by states to the European Commission on the practice of voluntary non-remunerated donation, the report shows the following figures: of the 29 countries that sent the required clarifications, 27 have some kind of provision (binding or not) that governs the principle of voluntary non-remunerated donation of tissues and cells; 13 countries have guiding principles relative to the possibility of offering some type of compensation or incentives to the donors of tissues and cells; 19 countries had communicated that they were offering some kind of compensation or incentives to living donors of tissues and cells (except for reproductive cells); 14 countries were offering some kind of compensation or incentives to the donors of reproductive cells, and 4 countries were offering some kind of compensation or incentives to the relatives of deceased donors. The Parliament insists on the need to prohibit offering or obtaining profits or comparable advantages and, where applicable, the prior publicizing of the need or availability of tissues, and it reminds states of the therapeutic purpose that all donations must have. It observes that the Charter of Fundamental Rights (binding in the European Union) prohibits the human body or parts of it as such becoming the object of financial gain<sup>62</sup>, but it states that, despite that, doubts still exist about the compatibility with this ethical principle of certain types of compensation awarded in relation to donations, and in particular when they are paid to relatives of deceased donors.

Aside from ethical principles, the Parliament considers that non-remunerated donation is necessary to protect the health of the donor and the recipient, since the involvement of large sums of money may induce the donor to take risks and it may hinder the disclosure of risks in their medical records. It therefore asks the Commission to closely monitor the events being recorded in member states, to carefully examine all the reports from civil society and in the media about the infringement of the

60. Resolution of the European Parliament of 11 September 2012, on the voluntary and non-remunerated donation of tissues and cells (2011/2193[INI]) [DO EC 353, 3 December 2013].

61. See reference in note 44.

62. See reference in note 34.

principle of voluntary donation, and to take suitable measures. If necessary, they should even initiate infringement proceedings, and inform the Commission about the current practices and national criteria for the compensation of living donors, particularly with regard to egg donation. Moreover, the Parliament regards it as fundamental that all member states should clearly define the conditions under which compensation should be agreed, which it reminds them should be fair and proportional, bearing in mind that it must be restricted to the expenses incurred with the donation of tissues and cells (for example, travel expenses, loss of income, medical expenses and possible side-effects). It considers that this compensation must be transparent and be periodically audited. It asks member states to ensure that the compensation paid to donors is compatible with ethical principles and recommends that special attention be paid to this aspect when compensation is not paid to the donor but to their relatives if they have died.

The issue of transparency is being analysed by the European Commission for all the countries of the European Union, as the Parliament exhorted it to. The recent report on the application of article 12 of Directive 2004/23<sup>63</sup> reveals the difficulty of carrying out an exhaustive assessment of the application of the principle of voluntary non-remunerated donation by member states and it once again insists on the need to maintain this principle, not just for ethical reasons, but also because, as the Parliament advised, it could contribute to greater levels of safety for cells and tissues and, consequently, to improving the protection of human health. In particular, it states that:

“If donor payment were allowed, some individuals could find the monetary remuneration so important that they might hide relevant medical and/or behavioural information. Additional screening and testing may reduce, but cannot completely eliminate, the possibility of a transmission from donor to recipient. Therefore information provided by the donor or his/her family contributes to an accurate assessment of all risks associated to the application of donated tissues or cells”<sup>64</sup>.

However, prohibition, which still does not exist in every country, apparently does not prevent the donation of gametes from being remunerated

63. Report of the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, relative to the application of Directives 2004/23/EC, 2006/17/EC and 2006/86/EC, establishing standards of quality and safety for human cells and tissues (Brussels, 21 April 2016, COM 223 final).

64. Report..., p. 11.

in some countries. In others, the possibility of compensating tissue and cell donors is merely the description of the practices authorized. In some cases, therefore, it is a question of simple compensation, and in others, of real incentives that constitute remuneration in money or another kind of practice. Even so it is explained that differences in purchasing power between member states could explain why a measure is considered “compensation” in one country and an “incentive” in another<sup>65</sup>. Living donors sometimes receive compensation that bears some relation to objective indices (monthly income, purchasing power), at others they are fixed sums and, then, it raises doubts that only the establishments receiving tissues can establish the sums, especially if it turns out that they are significantly high in relation to average monthly income; in short, at other times compensation is merely the reimbursement of expenses previously incurred (travel, medicines), which are paid on the presentation of invoices. However, it is admitted that member states provide little information about the compensation arising from the discomfort caused, and attempts are made to justify this by, on one hand, the variety of situations that may arise (the need for previous tests, for previous medical treatment, the duration of hospitalization, the effects on the state of health and the ability to work); and, on the other, by the different practices followed in each hospital<sup>66</sup>. The relatives of deceased donors are occasionally paid as well and remuneration consists of payment of funeral expenses and burial or cremation, which the Commission clearly perceives as an incentive, above all in the absence of the deceased person’s consent and due to the lack of funds to foot the bill for those expenses<sup>67</sup>.

The report concludes with the need to foster a common understanding of article 12 of Directive 2004/23, which tackles the subject of the transparency of the decisions referring to the compensation of donors, and the type and the value of this compensation. At the same time, it proposes to look at the best practices addressed to tackling the sufficiency or self-sufficiency of cells and tissues, for the purpose of reducing shortages, which seems that it ought necessarily to be taken into account when making the principle of voluntary non-remunerated donation effective:

“There is a need to find the most appropriate solutions to ensure both the respect of the Article 12 of Directive 2004/23/EC and an adequate supply of tissues and cells to the patients in need across the Union”<sup>68</sup>.

65. *Ibid*, p. 12.

66. *Ibid*, p. 12.

67. *Ibid*, pp. 13.

68. *Ibid*, p. 13.

#### 4. CONCLUSION

In doctrinal terms, the debate about whether or not it is possible to be the owner of parts of the body or its products serves to establish categories and to determine which rules apply to them. Dogmatic categories serve to know, for example, if a person acquires through occupation the part that could be considered abandoned when separated from a body; or whether the semen that a clinic offers to cryopreserve may be the subject matter of a deposit agreement; or to ascertain the correctness of the expression “donation” when what is transferred are embryos. Some will think that it is better to choose the model of ownership because consent can always be revoked; but the reply is that no one can acquire ownership against the wishes of someone who does not want to give it up. A distinction could still be made between the principles of the personality rights when the organs, cells and tissues are still part of the body, and the principles of property rights when they have already been separated from it. However, recourse to one or another branch of the legal system rather depends on the answer that one wishes to obtain and, above all, it depends on the limits offered by the law. What cannot be ignored is that such a large number of legal transactions take place every day with parts of the human body or its fluids that it is no longer sensible to regard them as assets *extra commercium*. The fact that these transactions are paid for, and how, or with what sums, is, right now, the most important issue. Perhaps it will be necessary to start thinking of the virtue of incentives for donation if, as it seems, demand is clearly greater than supply in certain areas.

# Notes on the Human Body and its Parts in the Market

SALVADOR DARÍO BERGEL

## 1. INTRODUCTION

In traditional legislation and jurisprudence the human body was only an object of consideration as a biological unit and as the material support for the human person. The great law codes of the nineteenth century such as the French, the Italian and the German, despite that fact that they all began with an initial part devoted to “persons”, completely ignored their physical structure, and merely contained a few essential references to birth and death<sup>1</sup>.

The separate parts of the body did not arouse any further debate, as they were almost useless. Blood was the reason for a certain degree of legal consideration, and later, with the spread of organ transplants, they were included in the laws enacted. In the course of just a few years the subject generated acute legal observations, but at the same time it brought to the debate ethical and bioethical profiles whose importance should not be ignored<sup>2</sup>.

The circulation of the separate parts of the body, both domestically and internationally; the growing economic interest that they acquired

1. Rodotà, S. (2010), *La vida y las reglas*, Trotta, Madrid, p. 95.
2. Edelman, demonstrating this new reality, says that “the right had beautifully proclaimed that the law ensures the primacy of the human person, prohibits all infringements of their dignity and guarantees respect for the human being from the beginning of life (article 16 of the Civil Code); it had claimed that everyone is entitled to respect for their body, that this is ‘inviolable’ and that ‘its elements and its products’ cannot be the object of a patrimonial right (article 16-1); the fact was there, between these problems that were falling from the past and the biological representation of the body, an unbridgeable gap had been made even wider” (Edelman, B. [2009], *Ni chose ni personne: le corps humain en question*, Hermann Philosophie, Paris, p. 29).

(commercialization, industrial property rights); the impact on rights (such as privacy and intimacy), and the existence of biobanks for different purposes (the depositing of human materials for their subsequent use by the depositor, etc.), all alert us to the importance of the separate parts of the body, which can no longer be considered “things”, either legally or ethically.

## 2. THE HUMAN BODY AND THE PERSON

The human body, as the material support for the person, did not arouse any great attention in religious, ethical and legal debates until recently. Numerous religious and philosophical traditions distinguished, in the human being, the body –on one hand– with a meaning opposed to “something else” that was presented with different names: spirit, soul, person, liberty, etc., in which dignity was generally judged to be infinitely superior to the body. Within these concepts the body’s greater or lesser dignity arose from the fact of protecting an immaterial “substance”<sup>3</sup>.

Sgreccia, in a thoughtful study, identifies two fundamental concepts regarding the human body. One comes from a reductionist-materialist standpoint, and the other points to a subjective meaning of corporeality that is situated in the metaphysical-personalistic perspective based on the Aristotelian-Thomistic model. The former considers the body to be an object that people have or possess. Corporeality is part of people’s assets, from which it follows that the body is empirically manipulable, scientifically “disposable” by people. The other concept holds that people “are a body” and “do not have a body”. Through corporeality the person is expressed not only externally but also in the ontological dimension. The body thus conceived is no mere object that people may dispose of, but it acquires a value that is part of their acknowledged dignity<sup>4</sup>.

For the purposes of our study a warning must be given about the consequences that arise from one and the other stance. If the body is “people’s property”, they have the possibility of disposing of it on the same terms as they might dispose of an object belonging to them, with no other limitation, which would possibly entail the power to put it on the market as they saw fit. In a different position is the idea of the body-subject that recognizes not a link, but a relationship of identity between the subject

3. Hottois, G. (2001), “Voix: corps humain”, in Hottois, G. and Missa, J. N., *Nouvelle Encyclopédie de Bioéthique*, De Boeck Université, Brussels, p. 243.
4. Sgreccia, E. (1993), “Corpo e persona”, in Rodotà, S. (ed.), *Questioni di bioetica*, Saggiario-Laterza, Rome, p. 113.

and the parts of the body, even after being separated. These views of the body “subject” or “object” have given rise to two normative currents that, starting from different assumptions, reach irreconcilable conclusions: the European (prominent within it the French, which rescues the dignity of the fragmented body) and the Anglo-American (which favours the subject’s autonomy and extensive power to dispose of the body, its parts and its products)<sup>5</sup>.

Hottois shows that the French standpoint, which best expresses the continental tradition, is inspired on Rousseau and Kant<sup>6</sup>. About Rousseau, he points out that no individual freedom may have precedence over the general will, or public asset, that the state expresses. Relative to each person’s body, he conceives of it as a component of the social framework, and individuals would be usufructuaries of it rather than proprietors. In this concept the principle of beneficence is given preference over the principle of autonomy. From Kant comes the prohibition to exploit the individual, safeguarding their dignity. For Kant the person is not the body but by way of different religious-philosophical traditions and arguments (Catholicism and incarnation; Aristotelianism and substance, etc.), the model stresses the inseparability of person and body and the value (dignity) associated with the person is transferred through the latter.

The basis of individualistic (economic and political) liberalism that inspires the Anglo-American concept leads to a contractual practice of medicine and of human relationships in general. Hottois makes the following criticisms of this concept:

- The fundamental confusion between individual freedom (autonomy in the broad sense of the term) and individual and rational wishes, or which are profoundly determined by an individual’s economic, cultural and psychological situation.
- The idea that might is right and the social Darwinism that imbues all the ideologies of economic neoliberalism.
- The breakdown of society due to the destruction of solidarity and of all the symbolic social structures, and the abandonment of society to techno-structures manipulated by private interests<sup>7</sup>.

In short, as a basic principle the European tradition puts the dignity of the person first, its logical derivation being to give to the fragmented parts of the body and its products the same consideration as the whole body,

5. Hottois, G. (1999), *Essais de philosophie, bioéthique et biopolitique*, Brin, Paris, p. 61.

6. Hottois, *Essais...*, p. 61.

7. Hottois, “Voix: corps humain” ..., p. 250.

which leads to ruling out the intervention of the market in these spheres. On the contrary, the Anglo-American concept maintains the prevalence of personal decisions over the body, its parts and its products.

### 3. THE NEW PANORAMA

It now becomes necessary to speak of the “separate parts of the body”, to such an extent that for Rodotà the body is increasingly understood as a set of separate parts that brings us back to the hypothesis of the *homme machine*<sup>8</sup>. It was traditionally maintained that the separate parts of the body were the object of a right of ownership and therefore of enjoyment and disposal with no particular limitations. This power of disposal, going beyond the granting of a *ius in se ipsum*, was justified on the basis of various reconstructive perspectives: the first and most widespread considers extraction, one of the facts based on which the right of ownership originally emerges that is immediately incorporated into the patrimony of the person from whose body the part is removed, by virtue of the enduring connection between the individual and the part removed<sup>9</sup>. A second construct proposes the thesis of original acquisition, operating an analogous extension of the discipline applied to works of genius, as if the parts of the body were created at the moment of their separation<sup>10</sup>. A third theory equates the part removed to the fruit, upholding the application of the schema of fruition to justify acquisition<sup>11</sup>.

Speaking of the separate parts of the body nowadays necessarily entails referring to the problems it poses as the basis of the unique individual’s genetic data and their relationship with the economic interests in play around them. Hermitte, studying the commercialization of the body and its products, reflects on the fact that the Western world is passing relatively rapidly from a situation in which the idea of commercializing the human body brought to mind slavery, to a situation where it is linked to fabulous medical and pharmacological progress: blood, organs, substances, proteins, enzymes, hormones, antibodies, tissues, genetic material, all can be used for therapeutic or scientific purposes; that is, purely commercial ones, making the human body a “source of raw materials” for industry. The points in common between these two different realities

8. Rodotà, *La vida y las reglas...*, p. 93.

9. De Cupis, A. (1982), *Il diritto delle personalità*, in Tratt. Cicube Messineo, Milan, IV, p. 775.

10. Santoro Passarelli, F. (1997), *Dottrina generali del diritto civile*, Jovene, Naples, p. 52.

11. Criscuoli, cit. by Rossi, S., *Corpo umano (atto di disposizioni sul)*, Digesto della disciplina privatistiche, sezione civile, UTET, p. 250.

make it necessary to proceed with great caution to avoid returning to forms of exploitation that, although less violent, are no less harmful to respect for human dignity<sup>12</sup>.

Similarly, Tallacchini points out that the human body is rapidly changing under pressure from the new advances in biotechnology, and it poses unprecedented dilemmas for the law. These are, in particular, the dichotomies between body-subject and body-object, the equality or diversity of the parts of the body, the natural and artificial nature of products derived from human biological substances. She adds that even when the proprietary configuration of the component parts of the body is generally rejected –because it infringes human dignity– the notions used in the configuration of the acts of disposal and acquisition of the parts of the body remain immune to the idea of ownership. Although the connotation of the body as *res extra commercium* indicates the clear wish to exclude any economic consideration, paradoxically the market ends up as the only characteristic that unifies and determines the discipline of acts of disposal. Consistent legal protection of the body and of its parts –and removal to the market– could come through legal notions that stress their nature as a common good and share them, while still respecting individuals’ freedom and dignity<sup>13</sup>.

In this new panorama –as we have called it– an essential component is incorporated: the use and protection of the genetic information, of which each sample, organ or part of the human body is a carrier, no matter how insignificant it may be, a theme about which not enough in-depth research has been done in the sphere of private law<sup>14</sup>. Upon tackling this subject it becomes necessary to differentiate the genetic information of the species from that which each individual of the species carries. The genetic information of the species tends to configure a standard that is applicable to all its components and it is what makes it possible to distinguish it from other zoological species. The information contained in each cell of an organism, in the coding part of its genome<sup>15</sup>, is what makes it possible to single

12. Hermitte, M. A. (2001), “Commercialisation du corps et ses produits”, in Hottois, G. and Missa, J. N., *Nouvelle Encyclopédie...*, p. 207.

13. Tallacchini, M. C. (1999), “El cuerpo y sus partes. La ubicación jurídica de los materiales biológicos humanos”, *Revista de Medicina y Ética*, year X, n.º 1, January-March, Mexico City, p. 35.

14. Bergel, S. D. (2014), “Información genética y derecho”, in Casado, M. and Guillén, M. (coords.), *ADN forense: problemas éticos y jurídicos*, University of Barcelona, Barcelona, p. 25.

15. The fragments of nucleic acid must be understood as coding or expressive DNA, which determine, in the order of their nucleotides, the different genes that will define people’s characteristics through protein synthesis (expressed in proteins through

out individuals. This information –as is well known– lasts for someone’s entire lifetime and even for a long period after their death, which shows how important it is for forensic medicine<sup>16</sup>. This particular information –transformed into genetic data– enables us to know the individual’s different characteristics, which shows the need to protect it in defence of indisputable human rights (privacy, confidentiality, etc.). Although the function of genes and the information they carry about unique characteristics, or about a subject’s present or future predisposition to contract diseases or suffer alterations in the phenotype, has been exaggerated, it must be pointed out that such individual information makes it possible to trace their basic characteristics, which determines multiple legal effects.

When diagnosing diseases with a strong genetic component, WGS analyses offer a wide range of genetic data about the current state of health or the future risk, not just of the patient, but of their relatives and future descendants as well<sup>17</sup>. WGS can show up “accidental discoveries” and “discoveries of unknown significance”, contributing new ethical aspects to clinical practice. Laberge has clearly signalled the difference between the two types of information: while the human species’ genetic information is public in nature because it constitutes the geography of the species, individual information is private, as its possessor remains individualized<sup>18</sup>. Unlike the situation prior to the sequencing of the human genome, biological samples or the waste material arising from a surgical operation, since they contain the individual’s genetic data in the cells, have an important role to play in legal matters. On the outside, genetic material has a tangible, corporal appearance; by virtue of this material nature that is the support, it seems to transcend the realm of things. If the problem is relatively simple with regard to the support for genetic material, it is not so in relation to the information that the latter transmits. This is the basis of the individual, one might say, of their code, their biological image, which moreover makes it possible to identify the person; except for homozygotic twins, two human beings cannot have the same genetic

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RNA), determining the sequence of amino acids and of the proteins they code and the degree of expression of the gene in each tissue and each time. It will therefore determine the general appearance of a specific organism; in the case of human beings this DNA will be responsible for establishing, among other phenotypic traits, hair colour, eye colour, height, etc. (Mora Sánchez, J. M. [2001], *Aspectos sustantivos y procesales de la tecnología del ADN*, Comares, Granada, p. 18).

16. Bergel, “Información genética y derecho”, in Casado, M. and Guillén, M. (coords.), *ADN forense...*, p. 25.
17. WGS: initials in English of Whole Genome Sequencing.
18. Laberge, C. M. (1992), “Qualification de l’information génétique”, in Knoppers, B.; Cadet, L. and Laberge, C. M., *La génétique: de l’information à l’informatisation*, Litec, Paris, p. 68.

information. Genetic information is closely linked to the person and represents at the same time the starting point of their life; some will say it is a living message<sup>19</sup>.

Another outstanding point in the new panorama is that of the location of the parts of the body in space, in different places, which forces the law to test privacy protection methods in accordance with the nature of each repository and the agreed destination for their use. In this new situation biobanks unquestionably play a uniquely important role. The growth and the diversification of biobanks constitute a core characteristic to be taken into consideration<sup>20</sup>. The danger entailed in the indiscriminate use of samples and the associated genetic information, which are deposited in human genetic data banks, or biobanks, is a subject that is becoming increasingly clear as new applications of their use in larger fields emerge, which increasingly imply more restrictions of individual freedoms and of fundamental rights and entail flagrant violations of people's privacy and dignity. Against the rapid advance and the increasingly greater possibilities of obtaining, classifying, storing and using genetic data mediated by a technology that is being developed tremendously quickly in industrialized countries, and which is rapidly being incorporated in peripheral countries, laws in the spheres of civil and criminal law, but also computer and copyright law, are being forced to move more rapidly towards the inclusion of genetic data and the use of biobanks<sup>21</sup>. There are biobanks for tissues, tumours, genetic material, and so on, that mostly collect biological samples for research purposes. Furthermore, those containing umbilical cord blood –which is reserved for supposed autologous and heterologous transplants– have mushroomed, as have those for the preservation of eggs for use at a later date when they are implanted in depositors or designated third parties.

This novel panorama means that the centre of the debate has shifted from the human body as a whole to its separate parts. Here it is important to establish the conditions and limits of their circulation: what are

19. Mazen, N. (1988), "Reflexion juridique sur le matériel génétique de l'homme", in Draï, Raphaël and Harichaux, Michele (orgs.), *Bioéthique et droit*, PUF, Paris, p. 194.
20. Biobanks: broadly speaking, a biobank is understood to be any repository of biological material, from a significant proportion of a population of individuals, in which, in organized fashion and with well-defined objectives, biological samples and information associated with them are stored for later use in accordance with the planned purposes. Orfao de Mattos, A. (2011), in Casabona, Romeo C. M. (ed.), *Enciclopedia de bioderecho y bioética*, Book I, Chair in Law and the Human Genome, Granada, p. 129.
21. Keyeux, G. (2012), "Bancos de datos genéticos humanos: el equilibrio vacilante entre ciencia y derechos humanos", in Penchaszadeh, V. (coord.), *Genética y derechos humanos*, Paidós, Buenos Aires, p. 260.

the rights derived from the “genetic self-determination” of the subject? What responsibility do the people in charge of safeguarding and preserving materials have if they infringe the conditions under which they were deposited? The point of departure for all this is the consideration of the kind of right that is assigned to the subject from whom the samples or tissues come. Be warned that biobanks generally contain not just the subject’s genetic information, but also a dataset of his or her medical records<sup>22</sup>.

Regarding this new development, Rodotà considers that it poses the problem of what each person’s ordinary relationship should be with the reality of a body that has been dispersed. In the social dimension –he considers– this new ordinary condition implies veritable co-management of the body between the subject to whom the information refers, who retains the right to control it wherever it may be, and the subjects that manage it<sup>23</sup>.

#### 4. HUMAN BODY PARTS, SUBSTANCES AND WASTE

In relation to the human body the different categories of parts, products or substances and waste must be established. The parts are segments that make up the permanent structure of the body, whether they are solid or liquid, and whatever their relative importance in its functioning and its size (organs, tissues, cells, genetic material, blood, cerebrospinal fluid, etc.). By the role they play one may speak of elements necessary for the conservation of the body, and elements that are useful or useless. Regenerable and non-regenerable elements are spoken of differently, pointing to the consequences that their cession may have. The principle of inviolability of the human body is normally opposed to all disposal (relinquishing) of a non-regenerable element, since dispensing with it would represent a definitive assault on the living person<sup>24</sup>. The principle according to which the human body is off-limits to commerce applies equally to regenerable organs. In this category we must distinguish between the organs that make up the anatomical structure of the human body and which fulfil

22. The increasingly widespread tendency is to have biobanks with various entry and exit pathways for the samples of genetic information (genetic data) and the medical information on lifestyle and genealogy, as well as the biometric information for the civil identification of individuals. The possibility of exchanging information between the different data repositories, accessing it from remote servers, or ceding this information to third parties, merely requires passwords, an authorization from the data custodian or some slightly more complex formality to be able to gain access to this entry and exit pathway of the information in biobanks (Keyeux, “Bancos de datos genéticos humanos...”, p. 239).

23. Rodotà, *La vida y las reglas...*, p. 101.

24. Harichaux, M. (1988), “Le corps objet”, in Draï, R. and Harichaux, M. (coords.), *Bioéthique et droit*, PUF, Paris, p. 130.

a specific function, and secretions, a function by which a cell or a tissue creates a substance that plays a part in the physiology of the organism. Non-permanent elements of the body include, among others, products or substances such as breast milk and sperm. Nails and hair have a common fate, elimination, along with their lack of usefulness. Hair was considered “a future movable thing”<sup>25</sup>. Hair roots hold genetic information, and would be part of the forecasts observed in relation to this information.

Waste materials are defined as what is left after any operation and cannot be used again for another operation. The notion of scraps has a more restrictive meaning.

The characteristic thing about waste materials is that they are strictly useless for the human body. For a long time they were incinerated or handed over for research without the issue of their appropriation attracting the attention of jurists.

## 5. THE DIFFERENT POSITIONS CONCERNING THE SITUATION OF THE SEPARATE PARTS OF THE BODY IN LEGAL SYSTEMS

There are several question marks hanging over the issue, such as what power does an individual retain over his or her separate parts, or what role is played by informed consent in this framework. Aside from this, patents are being granted, and “biological drugs”, made with human biological materials, are being sold more regularly. This problem may belong largely to industrial property law, but we cannot deny that civil law has its own responsibilities in this field<sup>26</sup>.

The body –Rodotà observes– is presented as a new legal object. The externalization of the “new object” body is expressed in the dichotomies among which the right of the body moves. In the first place we have the difficulty of making the subject of the body coincide with the body and the separate parts. Thus the problem is posed of the similar or different structure of the parts themselves, and finally the natural or artificial nature of the technologically separated bodily components is questioned, adding that the overall legal status of the separated parts is in any case one of harmony, not just because the general principles that govern it, but very often also the uniformity of technical laws that they define in their

25. Harichaux, “Le corps objet”, in Draï, R. and Harichaux, M. (coords.), *Bioéthique...*, p. 134.

26. Bergel, S. D. (2011), “Aportes para un estatuto de las partes separadas del cuerpo”, *Revista de Derecho y Genoma Humano*, n.º 35, July-December, p. 67.

types of use, are well defined<sup>27</sup>. These considerations may justify the need to sanction the status of the separated parts of the body.

Echoing an unquestionable reality, Edelman, a French philosopher and jurist who has been studying this subject for some time, wonders whom the human body belongs to. The human body understood as a “biological body” –he points out– is divided between science, industry, the human race and the person; everybody claims it, everybody invokes, over its products and components, the “right” to use it or even to exploit it, and the person, its original owner, is caught in a terrible dilemma: either they refuse to make their body available, and then medicine, economic development and, why not, the human race, would suffer for it, or they agree to sell it *in parte qua*, and it would be their dignity that would suffer; worse even, a new form of slavery could take root on the planet<sup>28</sup>.

This is the problem, posed in dramatic terms, facing the study and the situation of the body and its parts due to this new reality. From the contributions made by jurisprudence we can differentiate in this case various positions with respect to the situation of the rights over the body and its parts: *a*) the existence of a patrimonial right over the separate parts (ownership); *b*) extension to the orbit of the rights of personhood; and *c*) intermediate positions. Let us now refer to each position.

### 5.1. SITUATION IN THE ORBIT OF PATRIMONIAL RIGHTS

The subject –according to this idea– would have a patrimonial right over the separate parts, which in this case are considered to be “things”. Regarding this position, it has been maintained that the framework of patrimonial rights would be the most effective way to protect people’s rights, given that property law offers precise rights of control, and in this way people’s rights to control what happens with the pieces of their anatomy would be acknowledged. Even admitting the existence of a patrimonial right of the individual over the body and its parts, it would be very hazardous to consider the existence of a right of control or similar. This would not emerge from a search for the arguments put forward in favour of it.

On this subject Angoitia Gorostiaga points out that even admitting the individual’s legal possession of the most essential assets of their person, a careful analysis of the effective contents attributed by its own supporters to *ius in se ipsum* would lead to the conclusion that, in actual fact, the

27. Rodotà, *La vida y las reglas...*, p. 93.

28. Edelman, *Ni chose ni personne...*, p. 31.

latter would not result in the possession of a true subjective right, but in that of a series of faculties that under no circumstances would configure a legal power similar to that which derives from a (dominative) right<sup>29</sup>. In Spanish jurisprudence, Pilar Nicolás Jiménez considers that the parts of the living human body are not things when they are not separate from it, whereas they are when they are no longer a part of it, as would be case with the cadaver. She adds that the separate parts of the body are not in the public domain because they do not belong to the state, nor to provinces or towns and cities; thus they are *res nullius* or *res derelictae*, or they are private property, being inclined to this last opinion, as their possessor is the subject from which they come, which is consistent with the right of disposal that the individual enjoys to donate parts of their body<sup>30</sup>. The idea of the subject's right of ownership over the separate parts of the body creates some questions that are difficult to answer. Can the nature of something that initially made up the body, the physical support of the person, change and become an appropriable thing due to the fact of being separated? Considering a separate part of the body to be a thing implies allowing it to be traded. In my opinion this distorts the consideration and the respect that the human body deserves, which must be extended to its parts.

Kant had already perceived the consequences of conceiving of a person's right of ownership over their body when he pointed out that man is not the proprietor of himself, as this would be contradictory. Insofar as he is in fact a person, he is an individual to whom the ownership of other things may pertain. If on the contrary he were his own property, he would be a thing. It is impossible to be a person and a thing; based on this, he is not allowed to sell a tooth or any other part of himself<sup>31</sup>.

Even when lawmakers are allowed to place limits on this trade, by the introduction of principles relative to public order, considering that the greatest guarantee of human dignity is given by the fact of subjecting everything relative to the parts to the regime of the rights of ownership, far from finding a suitable channel for its treatment, it complicates the scene. Ownership is indissolubly linked to patrimony and this is precisely a question of dissociating the body and its parts from the market.

29. Angoitia Gorostiaga, V. (1996), *Extracción y trasplante de órganos y tejidos humanos*, Marcial Pons, Madrid, p. 142.

30. Nicolás Jiménez, P. (2006), *La protección jurídica de los datos genéticos de carácter personal*, Chair in Law and the Human Genome, Bilbao, p. 343.

31. Kant, I. (1996), *Lecciones de ética*, cited by Berlinguer, G. and Garrafa, V., *O mercado humano*, UNB, Brasilia, p. 135.

Bernardo Edelman, referring to the much-studied ‘Moore’ case<sup>32</sup>, says that there is a drastic difference between the fact of having a right of ownership over one’s body and being the owner of a person. This drastic difference is unquestionably essential: if by selling my cells I was selling myself I would be reduced to slavery; if on the contrary they are “disposable”, if they are no more than “any thing” of mine without being my person, then I could alienate them and still be free. Put another way, the mere fact of formulating this difference would imply maintaining that the individual was the proprietor of the body and that it would be necessary to distinguish between the person, who is situated in the order of freedom, and their bodily elements, which are in the order of things<sup>33</sup>.

It would be strange if the simple fact of separation should turn the part of the body removed into a saleable item. Criticizing the consequences that would be derived from it, Rodotà points out that it is precisely the financial compensation that reveals the irruption of the body and life in the sphere of ownership, abandoning its exclusive assignment to the dimension of personhood, backed up by qualitatively different and stronger principles and guarantees. If the criterion is the market, words like equality and dignity may be distorted, they become less important, and with them the autonomy of the person, falsely confined to freedom and marketability, is dissolved<sup>34</sup>.

## 5.2. “THE PERSONALITY RIGHTS APPROACH”

For this school of thought, the separate parts of the body continue to be a component of the human person. It is precisely the relationship that it maintains with the person from which it comes that ensures that the principle of protection of the person’s integrity continues to be applied to the human material removed from the body<sup>35</sup>. In this line of reasoning, the person’s right to self-determination encompasses the acknowledgement of their dignity extended to the body and the anatomical pieces removed

32. The ‘Moore’ case refers to the lawsuit brought by a patient whose spleen was removed in a surgical operation and who later claimed rights deriving from the commercial exploitation of the cell line obtained from that organ. A detailed account can be found in the study by A. Kemelmajer de Carlucci, in Bergel, S. D. and Minyersky, N. (2004) (orgs.), *Genoma humano*, Rubinzal-Culzone, Buenos Aires, p. 47.

33. Edelman, *Ni chose ni personne...*, p. 55.

34. Rodotà, *La vida y las reglas...*, p. 117.

35. Knoppers, B. and Hirtle, M. (1996), “Bancos de materiales humanos, derechos de propiedad industrial y cuestiones relativas a la titularidad: nuevas tendencias en la literatura científica y posiciones en la materia internacional”, *Revista de Derecho y Genoma Humano*, n.º 5, July-December, p. 98.

from it. This includes the right to control what happens with the tissues and cells removed, a faculty completely different and separate from patrimonial rights. The most effective way of ensuring the subject's right to self-determination over their body and especially over the elements that were once part of it and which are now separate, is through informed consent. The requirement and the control of the observance of informed consent about the use to be made of the separated parts is established in an instrument of the first order for the protection of the rights of personhood involved in the matter.

In the Italian legal system legal-positive reflection has sought to reconstruct the whole and the parts, extending the matter of the acts of disposal of the body to the rights of personhood, and observing that although the separated parts of the body are not the human being, they nevertheless must have personhood as a normative point of reference, and they come within its sphere of being deserving of protection. The way of attracting biological materials to the sphere of the subject –Tallacchini shows– has been to extend to them the correlation of personhood that is non-patrimoniality; but this intention, even though it may be wholly shared, has not always achieved its goal<sup>36</sup>.

In France, Law 94-653 of 27 July 1994, one of the block of so-called laws of bioethics, envisaged adding article 16-1 to article 16 of the Civil Code, which stipulates that the human body, its elements and its products, cannot be the object of any patrimonial right, reaffirmed by article 16-5, by establishing that contracts whose purpose is to confer a patrimonial value on the human body, its elements and parts, are null and void, and 16-6 which establishes that no remuneration can be given to the person who lends themselves to experimentation on their person, to the removal of an element from their body, or to the removal of a product of it. To reaffirm the non-patrimonial nature of the separate parts of the body, the change to the Criminal Code included in the same group of laws established as a crime the ablation of an organ from a living adult person without having obtained their consent, the extraction of tissues, cells or products from a person's body in exchange for payment, the removal of a tissue, cell, or the harvesting of a product from a living person without them having expressed their consent.

For its part, the Civil Code of Quebec, in the Book on Persons, Title II, adheres to the approach of the rights of personhood by considering

36. Tallacchini, M. C. (1999), "El cuerpo y sus partes. La ubicación jurídica de los materiales biológicos humanos", *Revista de Medicina y Ética*, year X, no. 1, January-March, Mexico City, p. 35.

human material to be part of the person and not a thing that can be the object of appropriation.

In short, by admitting that the separate parts of the body must have the same treatment as the whole body, the approach of personal rights is the one that best expresses the respect for the dignity of the human being that is undoubtedly involved in the issue.

### 5.3. ALTERNATIVE APPROACHES

In Canadian jurisprudence an alternative approach has been proposed, based on a three-tier classification<sup>37</sup>. Personal rights of the subject are derived from the consideration of the human body as a global entity. The second tier refers to pieces removed from the body that may be the object of “alienation” and are therefore no longer part of the person but have become things. On a third level, as the dissociation increases between the part removed and the person from which it comes, it considers that the restrictions imposed on its circulation should be reduced. The laws regulating patrimonial right and specifically ownership (control) would govern the corporal elements removed, once they gain access to this level.

Referring especially to genetic material –which could be applied, with the exceptions of the case, to all other biological materials– Litman and Robertson consider that the categories of rights of persons and of real rights do not fit the case, pointing to the construction of a right *sui generis*, which would be the most suitable with regard to the possibility it offers, by making it easy to move according to particular contexts and circumstances that may arise<sup>38</sup>.

In my opinion, legally speaking the whole body cannot be distinguished from the separate parts. Of course the legal description of them will be directly related to the philosophical position to which one adheres. If we start from the idea of the inviolability and non-commerciality of the body based on the dignity that should be conferred on it as the support of the person, there can be no doubt that the approach of personal rights must be extended to the detached parts. Here, there is a symbolic representation that makes everything human a part of the same regime.

Granting the subject from whom a part was removed the right of ownership over it implies at the same time leaving the market with the

37. Marusyrk, R. W. and Swain, M. S. (1990), cited in Knoppers, B. and Hirtle, M. “Bancos de materiales humanos...”, p. 103.

38. Litman, M. N. and Robertson, G. (1996), cited in Knoppers, B. and Hirtle, M., “Bancos de materiales humanos...”, p. 104.

possibility of appropriating it outside all ethical considerations. Tallacchini's position on this subject is interesting, since she introduces the notion of *res communes omnium* to this debate. The application of this notion as human patrimony to the discipline of acts of disposal and acquisition of the parts of the body, limiting the subjective powers of disposal and connecting the means and the ends of acquisition, makes it possible –in her opinion– to introduce greater rationality between subject and body, as well as an objective fate of the body for qualified uses. This configuration introduces a consistent perspective of respect for individual freedom and supportive behaviour. As far as acts of disposal of the body are concerned, she understands, the physical limits of integrity should be maintained, without distinguishing for this purpose between materials used for therapeutic ends, on the one hand, and research, on the other. With regard to acts of acquisition of biological materials, the non-proprietary but supportive and communal confirmation of these assets should result –in the author's opinion– in a review of the laws referring to patents, to human and biological matters, and it should establish connections of use with respect to such materials<sup>39</sup>.

## 6. IMPORTANCE OF THE GENETIC INFORMATION OF DETACHED BODY PARTS

While the body remains whole, people exercise control with respect to the knowledge that third parties may acquire of their genetic information, since the obtainment of the materials that generate it must have their consent. When parts are separated from the subject (for example, the removal of organs, tissues, biological samples<sup>40</sup>, surgical waste)<sup>41</sup> the problem arises of the exercise of the rights over one's own genetic information contained in the genome, which as we know is repeated in every cell in the organism. Due to this problem rights emerge that are derived from the importance of the data that such information carries and of the consequences that may arise from its knowledge by unauthorized third

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40. Biological samples: any sample of a biological substance (for example blood, skin, bone cells or blood plasma) that houses nucleic acids and contains the genetic material characteristic of a person (article 2.IV of UNESCO's International Declaration on Human Genetic Data).

41. Article 22 of the European Convention on Human Rights and Biomedicine, 1997, establishes that when, during the course of an operation, any part of the human body is removed, it may only be preserved or used for any purpose other than that which was the reason for its removal by compliance with the corresponding information and consent procedures.

parties<sup>42</sup>. These data –as stated in the UNESCO International Declaration on Genetic Data, 2003– are unique because:

- They can indicate the genetic predisposition of individuals.
- For the family, including descendants and sometimes the whole group to which the person in question belongs, they can have important consequences that may be perpetuated for generations.
- They can contain information whose importance is not necessarily known at the time the biological sample is taken.
- They can be important from the cultural point of view for individuals or groups<sup>43</sup>.

Hence the safeguarding and protection of genetic data entails not only the individual's control over the information extracted from their body, but also over that contained in the biological samples taken from it. All this puts us in the area of the protection of privacy<sup>44</sup>. Samples do not as such constitute personal information, but they do contain information of this kind –genetic– that may be discovered through the relevant analysis. The constant appearance of new lines of biomedical research increasingly raises the possibility of resorting to stored samples. It is precisely the possibility of using them for a purpose other than the one initially planned by the subject when they ceded them (informed consent) that may pose ethical and legal issues. Ever since it has been possible to carry out a genetic analysis of the nucleic acids contained in a sample, this becomes crucially important as an object of protection, since it would be pointless to protect

42. The genome contains two types of information: *a*) that which derives from its coding part (which covers a small insignificant part). This information contains data that affect the sphere of privacy and it is what interests us here; *b*) that which derives from the non-coding parts that serve to identify it and is very useful in forensic genetics.

43. Article 3, paragraph *a*) of the Declaration on Genetic Data, 2003.

44. If the information contained in our genome is so important and we already have sufficient technical knowledge to obtain it and some knowledge to be able to interpret part of that information, it is clear that, as a society, we have to know how and when genetic tests can be performed on us, to determine who should have access to these data and to regulate the use that may be made of them. The privacy of personal genetic information is one of the hottest topics in the field of genetics and bioethics. We ought to consider tackling a genomic policy and one of responsible personalized medicine, the obtainment of informed consent in national databanks, the impact of genetic tests on private health insurance, possible potential genetic discrimination, the lack of regulation of direct to consumer genetic tests, or the cancellation of data in forensic genetic banks. Thus, there are questions deserving of special attention by bioethicists, scientists, doctors, legislators and magistrates, because our future and that of our society depends on their response (Marfany, G. [2014], “Bancos de datos genéticos o ¿qué dice mi ADN de mí?; regulación y privacidad”, in Casado, M. and Guillén, M. [coords.], *ADN forense...*, p. 199).

the results of the analysis (secondary genetic information – genetic data) if the biological materials from which the information comes are not similarly protected<sup>45</sup>.

I have referred previously to the existence of the individual's right of self-determination as regards their genetic information, which results in their power to dispose of and control their own genetic data<sup>46</sup>. Derived from the right to genetic self-determination are the rights over the taking of samples, over the processing of the data obtained and over their use and conservation. A basic condition for collecting biological samples must be the subject's prior, freely given, specific informed consent, which in principle is revocable at any time. No one can be deprived of access to their own genetic data, and these must not be used for a purpose other than the one that emerges from the informed consent given at the time it is collected. It is obvious that the genetic data derived from the coding part of the genome places us in the sphere of the protection of privacy and intimacy<sup>47</sup>. As Romeo Casabona understands it, it falls to everyone

45. The precision of genetic identification techniques and the reliability of those that make it possible to anticipate diseases or defects make the use of these data essential in different fields. International declarations and legal texts that have dealt with specific aspects of these treatments are intended to respond to the contradictory requirements that arise here: those of the potential use of this personal information for legitimate purposes and that of wrapping it in all kinds of precautions, limiting, with strict criteria, access not just to it but, previously, to the biological material necessary to obtain the genetic data in question (Murillo de la Cueva, P. L. [2014], "La protección de la información genética", *Revista de Derecho y Genoma Humano*, special issue, p. 215).
46. Bergel, "Información genética y derecho", in Casado, M. and Guillén, M. (coords.), *ADN forense...*, p. 38. The West German Constitutional Court, in its judgment of 15 December 1983, concerning the constitutional nature of the population census law, laid down the following jurisprudence regarding the right to self-determination: "it covers the power to basically decide for oneself when and within what limits it is right to reveal situations about one's own life". The right to informative self-determination arises, in the opinion of Seoane Ramírez, from the analysis of a case of automated personal data processing. However, the right to informative self-determination should equally be applied to non-automated processing insofar as the emphasis is not placed on the nature of the actions liable to threaten the general right of personhood, but on the restrictions that such conducts originate in the exercise of the said right and its repercussions, both individual or subjective and institutional or objective.
47. The right to genetic privacy is defined as the right to determine the conditions of access to genetic information. It is primarily a subjective right of the individual who owns it which he or she activates reactively or repressively against attacks, and which has not only a "negative", or exclusionary, facet preventing others from learning about our genome, but a "positive" or performative facet, whereby it makes it possible to demand intervention by the public authorities to pursue and punish the attacks carried out (Ruiz Miguel, C. [2001], "La nueva frontera del derecho a la intimidad", *Revista de Derecho y Genoma Humano*, n.º 14, January-June, p. 147). The protection of the right to privacy, reservation or secret, applied to genetic privacy, seems to

to decide to whom it is disclosed, when and how widely, whereby the transmission to third parties of the information obtained through genetic analysis, without the prior informed consent of the interested party, or of their legal representative in the case of a minor or a person lacking legal capacity, must be prohibited<sup>48</sup>. It is pointed out that in light of the available scientific knowledge, the person from whom a part of the body has been removed must retain the right of self-determination regarding the genetic information contained in it (whether an organ, a tissue, or lesser parts such as genes, proteins and cells), a right that safeguards their intimacy and privacy. After the acknowledgement of this right of genetic self-determination, everything relative to the removal, manipulation and circulation of the materials carrying genetic information (biological samples) becomes crucially important with regard to the personal rights involved<sup>49</sup>.

## 7. ENDS PURSUED WITH THE DETACHMENT OF BODY PARTS AND THE APPLICABLE LEGAL REGIME

Parts of the body may be removed for different purposes, such as for instance:

### 7.1. THE SALE OF PARTS OF THE BODY

The sale may refer to organs, tissues or any other parts. The sale of organs perhaps constitutes the most indecent form of the market's influence over the body, as it implies the mutilation of the individual, evidently affecting their vital functions. Regrettably, it is a widespread practice in relation above all to kidneys and retinas, which has given rise to growing concern by the international community, since they circulate

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be a suitable instrument for preventing future discrimination based on structurally genetic considerations (Figueroa Yáñez, G. [1999], "El derecho a la intimidad, reserva o secreto. Cambio de perspectivas a partir de la investigación sobre el genoma humano", *Revista de Derecho y Genoma Humano*, n.º 11, July-December, p. 57).

48. Romeo Casabona, C. M. (2003), *Genética y derecho*, Astrea, Buenos Aires, p. 73.

49. The acknowledgement of the subject's self-determination over their genetic data is only possible when the data is associated with the subject. When the genetic data are irreversibly dissociated from a particular subject all possibility of exercising the said right disappears. The data simply dissociated from an identifiable person, but which can be identified using diligence that does not require an extraordinary effort are in an intermediate situation. They are the data that jurisprudence calls "pseudonymized", with respect to which the source subject conserves their rights of self-determination (Nicolás Jiménez, *La protección jurídica...*, p. 326).

from under-developed countries towards central countries, constituting a veritable market. The entry of body parts in the market stems from a basic assumption: the recognition of the freedom that the person selling their parts supposedly has –a freedom that, as we know, does not exist<sup>50</sup>. Those who turn to the market offering parts of their body –organs especially– find themselves in a situation of manifest inferiority in relation to the possible buyers, which is accentuated depending on what is on offer (offering blood or sperm is not the same as offering a kidney or a retina). In all cases the vulnerability of the person selling is evident, something that makes the transaction doubly despicable, as besides the affront to human dignity of the act itself there is also the exploitation of a state of need that subjects the seller to a mutilation.

Admitting or consenting to transactions such as those relative to human organs is a serious affront to people’s dignity<sup>51</sup>. Turning the human body into merchandise –say Nelkin and Andrews– violates the integrity of the body, exploits powerless people, interferes with values of the community, and distorts the projects of science<sup>52</sup>. The right to bodily autonomy –as shown by the eminent Italian bioethicist G. Berlinguer– must be valid not only in the face of the arbitrary nature of political power, but also against the all-embracing power of the market. It is not acceptable to confront basic freedoms with a distorted idea of the “common good”; in the event of it being admitted, freedom and common good would be sacrificed together<sup>53</sup>. We shall have to consider also that our generation is for the first time in history facing the possibility of using detached parts of ourselves, which could represent an extremely high expression of synergy between science and solidarity, or a biotechnological form of human exploitation<sup>54</sup>.

50. At the end of the twentieth century we witnessed the commercial fragmentation of the human being. The limits between the uses and abuses of the human body gradually became more subtle and vague. This new presentation of the problem leads to a reconsideration of the similarities and the differences in relation to the past and the many manifestations of that twofold characterization of human beings as subject and as object of change that now includes almost every one of the organs used for transplants (Berlinguer, G. and Garrafa, V. [1996], *O mercado humano. Estudo bioético da compra e venda de partes do corpo*, UNB, Brasília, p. 17).

51. The World Health Organization (WHO) estimates that there are 10,000 cases of clandestine transplants each year. In March 2015, in Santiago de Compostela 14 European countries, under the auspices of the Council of Europe, signed an International Treaty against Organ Trafficking that considers this practice to be a crime. It covers the use, transfer, preparation, storage and the simple offer of money (Vizoso, S., *El País*, Madrid, 26 March 2015).

52. Nelkin, D. and Andrews, L. (2002), cited by Berlinguer, G., *Bioética cotidiana*, Siglo XXI, Mexico City, p. 173.

53. Berlinguer, G., *Bioética cotidiana...*, p. 151.

54. *Ibid.*, p. 171.

## 7.2. DONATION

Donation is the commonest way of justifying the separation of parts of the body. It may be for different purposes:

### 7.2.1. Donation for transplants

The issue has been the object of a special law in Argentina, a criterion that is transferred to other legislations. In accordance with article 14, the removal of organs or anatomical materials *inter vivos* for transplant purposes between related people, in accordance with the provisions of article 15 and concordant with the law, is permitted when it is deemed reasonable that it will not seriously damage the donor's health and there are prospects of success for saving the life or improving the health of the recipient.

The altruistic ends motivating the ablation of the organ and the limit of preserving the life and health of the donor are clear. Obviously, transplantation to a specific subject means that it is impossible to sell the donated material, which in this case makes the issue of the lack of secrecy of the genetic information carried by the material to be transplanted less important.

### 7.2.2. Donation for scientific purposes

The issue is related directly to the assumptions under which donation takes place. Here the informed consent granted by the donor becomes crucially important. Donation, if it is particularly related to a piece of scientific research, means that the recipient body has to restrict the research to the terms indicated. If the research is extended to other areas informed consent must be reiterated. For the purpose of not hindering scientific investigation it has been proposed to extend consent to all kinds of research. The consent must express the details of the research, including duration, ends pursued, communication to the donor of the results of the research, and exclusion of all financial gain.

## 7.3. PRESERVATION OF THE MATERIAL GIVEN BY THE DONOR FOR LATER USE

The most common use is the case of depositing umbilical cord blood for use by the depositor or by a third party in accordance with the instructions given. Although the possibilities of successfully using the stem cells

extracted from umbilical cord blood for autologous transplants are very slim, it is a procedure whose practical use is growing. Here the possibility may arise of use by an institution for transplantation to third parties who may possess similar immunological characteristics, as in the case of the public banks (for example, the one in Hospital Garrahan), or that of deposits in private institutions for use by the depositor only. This item may also include the deposit of eggs for use at a later date by the depositor, with a view to delayed maternity. About the elements deposited for later use by the depositor one cannot strictly speak of ownership, but of a power of disposal alien to the nature and purposes of real rights, which is governed, in principle, by the instructions given when they are deposited.

With regard to the new functions of the separate parts of the body, Rodotà considers that the body is a social object. A more intense degree of socialization is reached when distributive capacity results in an explicitly social use of the body, by making its parts or products available to others. This is what happens, for example, when in a spirit of solidarity consent is encouraged for the donation of organs for transplants<sup>55</sup>.

## 8. THE CONTRADICTIONS ARISING FROM THE NEW REALITY

The increasingly marked entry of detached body parts on the market through different legal mechanisms (buying and selling, leasing, patents, etc.) brings with it a novel problem between the body, the support of the person, and the parts of the body that, turned into objects, wander around in different places and for different purposes, as Rodotà puts it<sup>56</sup>.

This issue has also been dealt with by Tallacchini. The first difficulty we can see in legally configured corporality refers to the gap existing between the body considered to be a “subject” and an “object”, a difficulty that is intertwined with the distinction between “the whole” and “parts” of the body. The two pairs rarely coincide<sup>1</sup> 2and they are generally discontinuous. The first paradox of the body consists in the fact that it is both the place and the means of subjectivity –the body subject– in which “the subject is the body”, as the object of acts with which the subject disposes of him or herself –the body object– in which the “the subject possesses the body”. And as an object in itself, in such acts the subject may dispose of their own body as the entirety of themselves –of their own life– or they can dispose of parts of it<sup>57</sup>. The fragmentation of the body and the resulting

55. Rodotà, *La vida y las reglas...*, p. 116.

56. *Ibid.*, p. 93.

57. Tallacchini, “El cuerpo y sus partes...”, p. 41.

conversion of the separate parts into “things” provide the ethical justification for acts of disposal.

Today the act of disposing of the body as such would be strange, outdated, and it would produce an adverse moral judgment: selling the body –living or dead (cadaver)– is inadmissible, in need of no laws to endorse it. The immorality of the act is so patent that its justification would imply placing ourselves outside the law. On the other hand, when we fragment the body and we confer on the resulting parts the nature of “things”, the moral rule is extenuated to the point of extinction. What determines its commerciality (entry on the market), or excludes it, is the part’s importance in the anatomy and the physiology of the body. Thus, we talk of renewable or non-renewable parts. In principle, non-renewables would not be given the status of things and renewables, depending on the case, might or might not enter commercial trade.

When we enter the realm of the relative, the exceptions depend on changing criteria, influenced at all times by the needs of the market. The body, we might say, is relatively off-limits to commerce. Its parts –according to changing criteria– can enter the economic sphere. With regard to its fragmentation the criteria are diverse: necessary and unnecessary parts; regenerable or non-regenerable parts; the level of human intervention on the biological material (important or less important intervention); size of the part, etc. These issues are the object of contrasting standpoints and these days one must acknowledge that economic pressures are very likely to end up definitively breaking the unified treatment of the separate parts of the body.

A French philosopher who was on the National Consultative Ethics Committee presents the outlines of the debate in these terms: by considering the limits of the person not so much in time as in space, that is, when one goes from the whole body to smaller and smaller parts, is using the same criterion valid? (He is referring to non-commerciality). In spirit, without doubt; in the letter, definitely not, as the nature of the problem changes. Here, the human being no longer exists, the divided body is no longer the individual. To what extent is it sensible to acknowledge the least amount of humanity and confer dignity on it?

In the organ, in the tissue, the analogy seems less obvious: here, the individual remains biologically identifiable (the human form); the person is present socially in the donation that may be made of them. For this reason the refusal to see them as things is strong, although threatening. But going down the scale we have cells, genes, proteins. Insofar as all specific trace of humanity is erased, what remains here

of humanity? Here we are faced with a great paradox: in his latest constitution man is not made of human material; the living being is not made of life; how to maintain here the cardinal distinction between the person and the thing?

In any case –Sève points out later on– the necessary dialectization of the traditional dichotomy between person and thing cannot avoid the pitfalls of laxism, apart from properly marking the transitional nature of the parts of the body, large or small, in the meaning that Winnicott has attached to the adjective: they are objects in which the subject is invested more than ever and it is there where the game stops. So much for Sève’s ideas<sup>58</sup>. Well, with regard to this idea, I consider that the shape or the size of the parts of the body must not be a crucial point in the debate. Taking one of the examples given, the human gene, I consider that apart from its minuscule size, invisible to the human eye, it is part of the genome that in the words of UNESCO is “the distinctive sign of our species”. Would the fact of it entering intellectual property law have any ethical support? On this point, Anne Fagot-Largeault says that “the genome is not sacred; what *are* sacred are the values associated with the idea that we create of humanity”<sup>59</sup>.

It is difficult to regard the debate as over, especially when progress in biology confronts us with the category of “biological drugs”<sup>60</sup> created on the basis of transferring or manipulating elements that belong to the human body (cells, proteins, etc.). In my opinion, the issue is not about the volumetric importance that a part of the body may have, but it rather points to the symbolic representation of all the elements that make up, or once did, the human body. It is obvious that if we take a hand or an arm we will easily be able to see that they are human, and that in a cell or a gene, in order to see if it was human we would only have to resort to investigations that would determine it. But the issue cannot be reduced to these terms. Without enshrining the body and its component parts, respect for the dignity of the human being entails the exclusion of any human material, no matter how tiny, from commerce.

58. Sève, L. (1994), *Pour une critique de la raison bioéthique*, Odile Jacob, Paris, p. 105.

59. Fagot-Largeault, A., cited by Sève, *Pour une critique de la raison bioéthique...*, p. 108.

60. Directive 2009/120/EC of 14 September 2009 defines genome therapy drugs as having the following characteristics: *a*) they include an active ingredient that contains a recombinant nucleic acid, or is made up of it, using human beings or administering to them with the aim of regulating, repairing, replacing, adding or eliminating a gene sequence; *b*) its therapeutic, prophylactic or diagnostic effect depends on the sequence of the recombinant nucleic acid that it contains or the product of the genetic expression of that sequence.

## 9. THE PRINCIPLE OF NON-COMMERCIALITY OF THE BODY: ITS SOURCES AND SCOPE

From the orbit of bioethics, Dora Porto –an eminent Brazilian anthropologist and bioethicist– notes that the right to one’s own body is an inalienable existential condition of all human beings. Inherent to life, that right emanates from two superimposed parameters: legitimacy, embodied in the person’s very existence in the world, manifested as a moral and social being in the materiality of their body; and legality, socially conferred by rules and laws outlined in the attempt to safeguard the lives of individuals and that of the social body, ensuring their dignity<sup>61</sup>. It has always been maintained that the human body remains outside patrimonial law. This principle –as Mazeaud upholds it– is a traditional law, a legal axiom, that no one felt the need to demonstrate<sup>62</sup>. For neither Roman law nor intermediate law was it seen as a problem. Some clues have appeared recently in the Napoleonic Code to guide the interpreter, without a clear rule being established. As it has been pointed out repeatedly, codified civil law appeared more as a law of patrimony than as a law of people, relegating the study of the rights of the human person to the spheres of natural law or philosophy. We must not forget, moreover, the close interdependence between that extra-commerciality and the impossibility of people disposing of their bodies. In fact, non-disposability and extra-commerciality are frequently put forward as the two sides of the coin struck simply by Christian philosophy to preserve the natural dignity of all human beings<sup>63</sup>.

For Mazeaud the French code did not establish a text aimed at placing the person outside commerce. Later, generations of jurists all repeated that the human person is above conventions. Nobody disputed the principle or expressed the need to justify it, nor even to analyse it. In Carbonnier’s opinion, identifying the person in the human body gives it a particular place in legal circles and to some extent it endows it with a sacred nature. The human body is doubly protected: 1) against the attacks of other people by virtue of its acknowledged inviolability; and 2) against the individual’s power of disposal, by virtue of the limitations imposed on the autonomy of the will. The human body is off-limits to commerce in

61. Porto, D. (2008), “Derecho sobre el cuerpo propio”, in Tealdi, J. C. (dir.), *Diccionario Latinoamericano de Bioética*, UNESCO, Bogotá, p. 233.

62. Mazeaud, L. (1953), “Los contratos sobre el cuerpo”, in *ADC*, January-March, p. 81.

63. Angoitia Gorostiaga, V. (2002), “Extracción de órganos y tejidos de donantes vivos con fines de trasplante y prohibición de lucro, y utilización de una parte del cuerpo humano”, in Romeo Casabona, C. M. (ed.), *El convenio de los derechos humanos y biomedicina*, Comares, Bilbao, p. 307.

the sense of article 1128 of the *Code*. Although it may seem that the human body is something external to the person, it is basically identified with it. However, as the person is indivisible it has been necessary to signal a limit to the freedom of juridical acts to safeguard freedom generally, without this implying that any and all legal acts or conventions, directly or indirectly related to the human body, entail an infringement of public order<sup>64</sup>.

The scientific progress recorded since the middle of the twentieth century has led to an emphatic reassertion of the principles of non-commerciality and of non-disposability of the separate parts of the body, arising fundamentally by the fact of the market being incorporated in the debate. We are now witnessing the commercial fragmentation of the human body. Its limits, between the uses and abuses of the body, gradually became subtler and more imprecise<sup>65</sup>.

Tallacchini makes an important observation about the non-commerciality of the parts of the body, by pointing out that what the parts of the body have in common is their configuration *extra commercium*, but it is not enough to entrust the legal guardianship of the body and its parts predominantly to a single criterion: just prohibiting its commercialization will not take the body off the market. Such a prohibition is necessary but insufficient if the legal instruments that prevent acts of disposal and acquisition are not drafted coherently<sup>66</sup>. Berlinguer and Garrafa claim, in this direction, that the knowledge and appreciation of the body are some of the greatest conquests of mankind, stressing the need to create a system of laws and cultures addressed to the confirmation of the dignity of the body<sup>67</sup>.

In the United Kingdom, the Nuffield Council on Bioethics considered a while ago that the commercialization of human tissues must be prohibited, with the exception of certain body products, such as hair and nails, that can be bought and sold as they are considered common waste products<sup>68</sup>. The growing use of biobanks and the resulting circulation of human materials fully justified the principle of non-commerciality being extended to the separate parts of the body.

In Europe, and in France above all, jurisprudence and various legal and bioethical instruments began configuring a trend, destined to incorporate

64. Carbonnier, J. (1960), *Derecho civil*, Book I, volume 1, Bosch, Barcelona, p. 218.

65. Berlinguer, G. (1993), "Il corpo come merce o come valore", in *Capitalismo, natura, socialismo*, Rome, p. 98.

66. Tallacchini, "El cuerpo y sus partes...", p. 39.

67. Berlinguer and Garrafa, *O mercado humano...*, p. 43.

68. Cited in Knoppers and Hirtle, "Bancos de materiales humanos...", p. 73.

this principle in positive law, expressed in the French laws of 1994. The National Consultative Ethics Committee had played a central role in this movement since 1984. After several rulings that pre-announced the criterion imposed, in Ruling No. 21 of 13 December 1990 the principle of non-commerciality was explicitly established, adding “to say that the human body is outside commerce, even outside the market, implies formulating two complementary propositions: on the one hand, a person’s body or one of its elements must not be the object of a contract; and on the other, it cannot be traded by anybody”<sup>69</sup>.

In 1988, in a lucid and enlightening essay, Hermitte pointed out that the traditional legal categories are insufficient to institute “the thing of human origin and with a human purpose” whose status would point to taming the market mechanisms that otherwise could lead the human body to the process of production, a process that is already underway in certain sectors. What must be blocked –he wonders– in the mechanisms of the market economy? Financial gain necessarily, which may be legitimate in some sectors, but above all the systematic rationalization that permits individual agreements. The organized offer –he concludes– is not the same as the spontaneous one. All rationalization entails a threat to human dignity, by going from the individual to the collective offer. An isolated offer is different to an organized offer, socially structured. It is this work of total rationalization of the use of the human body that the legal system must control; it is a gradual shift from the notion of “outside commerce” to the body “outside the market” that we must begin to make<sup>70</sup>.

In the report prior to the approval of the laws of 1994, Noëlle Lenoir pointed out in relation to the non-commerciality of the human body and its parts that the same prohibition includes all its component parts, including genetic material<sup>71</sup>. Upon discussing the changes to the laws of bioethics, the Council of State reasserted that the legal and ethical principles of non-disposability and non-commerciality that apply to the whole of the human body have been strongly reconfirmed with regard to the genetic elements and the genome. Bioethics, in France especially, indissolubly associates the principle of the non-commerciality of the body with the fundamental principle of people’s dignity. The “Euro-French model” of the body outside the market ideally establishes the individual body as

69. Siccard, D. (coord.) (2003), *Travaux du Comité Consultatif National d’Éthique*, PUF, Paris, p. 136.

70. Hermitte, M. A. (1988), “Le corps hors du commerce, hors du marché”, *Archives de Philosophie de Droit*, n.° 33, Sirey, Paris, p. 323.

71. Lenoir, N. (1991), *Aux frontières de la vie: une éthique a la française*, Book I, La Documentation Française, Paris, p. 120.

inviolable, non-disposable, non-transferrable; it is neither the individual's patrimony nor property, and, therefore, under no circumstances is it marketable or monetizable, not even its tiniest parts<sup>72</sup>. In this direction, the Convention on Human Rights and Biomedicine (Convention of Asturias) establishes in article 21 that the human body and its parts must not, as such, be sources of financial gain.

## 10. THE SEPARATE AND INDUSTRIALIZED PARTS: THEIR REGIME

This is a relevant issue in relation to the progress made in the life sciences, above all with regard to the production of so-called "biological drugs" or of "advanced therapy medicinal products".

To introduce the debate I consider it useful to refer to Ruling No. 93 of the French National Ethics Committee on the patentability of stem cells and, with respect to this, testing a reasoned critique. The document maintains that in accordance with European recommendations, patentability would be possible "if they are products derived from the human body; that is, isolated stem cells, thanks to an *in vitro* technical procedure"; in such a case they cannot be compared to stem cells and they are therefore patentable. Here we should pause, given that concepts are taken for granted that do not have a pacific meaning. In the first place, the text distinguishes, with respect to stem cells – a criterion that could well be transferred to other parts of the body – between "natural ones" and "those obtained through technical procedures", a difference in itself highly questionable. It is open to objection since the current state of scientific knowledge does not make it possible to generate a cell in a laboratory, due to its elementary structure and complex functioning. Taking this into account, it is not feasible to admit that manipulated cells could be "products derived from the human body" to make their commercialization possible<sup>73</sup>.

In another part of the document the opinion gets into ontological criteria: "according to the way in which we differentiate between the biological entities considered, the ethical and commercial approaches take

72. Hottois, *Essais de Philosophie...*, p. 62.

73. A. Kornblihtt, an internationally prestigious researcher, shows us that every cell comes from another cell, there being no evidence of the spontaneous generation of cells from living matter. In fact, although we know the majority of their molecular components in quite a lot of detail, no scientist has been able to create a cell in a test-tube from the mixture of chemical substances (Kornblihtt, A. [2013], *La humanidad del genoma*, Siglo XXI, Buenos Aires, p. 20).

a different direction". In this line of reasoning "raw biological material" is distinguished from a "chemical molecule". In the Committee's opinion, between both there is a hard-to-define area between the biological and the chemical. This area includes the "intermediate entities", biological products but treated to such a degree that they have lost part of their biological structure, cells for example, products of cellular therapy, cell and tissue bioengineering. For these entities –it adds– the question of knowing whether they can be considered biological realities, pharmaceutical specialities or industrially manufactured drugs remains open. It seems impossible –it adds– to establish any dividing lines, any criteria.

I understand that speaking of "biological entities" or "intermediate entities" compared with "pharmaceutical specialities" or "manufactured drugs" is not consistent with the acknowledgment of the principle of non-commercialization of the human body and its parts. I bring the opinion of Labrusse-Riou to the debate: the different perspectives of the law and of medicine are not a priori conflictive. Conflict arises from the interaction of bodies treated as things and their scientific or medical use, which causes the "de-subjectivization" of the person and generates a market of life. The body thus becomes a raw material, an object of commerce or production, and this leads him to formulate questions whose answers demand profound reflection: what does the body represent for the law? What is the nature of the rights over the body? Do scientific or medical ends justify an exorbitant right? What we say about the body at this stage of the game must be transferred to the separate parts and the products<sup>74</sup>.

The "grey areas" between the natural parts of the body and the "transformed parts that have lost their biological status" simply constitute a rhetorical device to justify the advance of the market over the human being. In Tallacchini's opinion, one of the dilemmas of corporality concerns the creation of products made from biological substances, but artificially transformed, to the extent that they are classed as "bioartificial constructs"; biological inventions, understanding that the main problem relative to the "body artefact" consists in assessing whether the biotechnologies alter the human materials to the extent that they can be considered artificial objects definable as "inventions"<sup>75</sup>. While there was no possibility of financially exploiting biological materials, there was generally little interest in the separate parts of the body. The new methods of operating on the body, the biotechnologies, the

74. Labrusse-Riou, C. (2007), *Écrits de bioéthique*, PUF, Paris, p. 136.

75. Tallacchini, "El cuerpo y sus partes...", p. 49.

patentability of the biological, have transformed the meaning of commerciality: rather than a priceless superior entity, the body has become a worthless entity and exclusion from the market is synonymous with free appropriation<sup>76</sup>. The declared non-patrimoniaity of the body constitutes, in Tallacchini's opinion, too weak an argument, if it represents the only defining limit and criterion (the negative one) of a concept of the individual whose space of autonomy is, in fact, delimited by the market.

What can be deduced from everything we have said and pointed out should not be interpreted as a position opposed to the progress of medical research. Obtaining biological drugs or advanced therapy medicinal products is an indisputable advance insofar as they can contribute to increasing the therapeutic or diagnostic arsenal for the benefit of humankind. What does require a dispassionate discussion is the way in which they will be made available to individuals. In this area I do not believe that it can be treated the same as a speciality composed of chemical molecules. The human origin must play an important part in which, above and beyond economic interests, the principle of solidarity is made a priority, to which the foundations of article 15 of the *Code* allude. Furthermore –and now in the sphere of industrial property– I must reiterate my opinion in the sense that simple human intervention is insufficient to generate a patentable invention; it is necessary for it to express a “human creation”, a more complex issue that places us on the dividing line between a patentable invention and that which is not (discoveries, contributions of basic science, natural laws, etc.)<sup>77</sup>.

## 11. THE ARTIFICIAL PARTS INCORPORATED IN THE BODY

The use of pieces to replace deteriorated or non-existent parts of the body is increasingly common in medical practice (for example, mechanical hip implants, dental implants) or to fulfil specific purposes (pacemakers, cochlear implants, orthopaedic limbs, pieces obtained with nanotechnology, to mention just a few). These parts that functionally make up the body must be subjected to the status of separate parts of the body. Orgaz suggested that even after they were placed in the body they remained things, although unattached, as they were for “the indispensable use of the debtor”. Commenting on it, Tobías points

76. *Ibid.*, p. 57.

77. Bergel, S. D. (2013), “La invención y los requisitos objetivos de patentabilidad”, in Correa, C.; Bergel, S. D. and Kors, J., *Régimen legal de las patentes de invención*, Book I, La Ley, Buenos Aires, p. 179.

out that it is an explanation that does not now satisfy the sensibility of justice; it is more pertinent to consider that things cease to be things and become part of the body, forming a unit with it. I agree with this author, who considers that the parts designed to last that are implanted in the human body lose this condition and acquire a new legal direction, becoming parts of the human body<sup>78</sup>.

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78. Tobías, J. W. (2013), "Los actos de disposición de partes separadas del cuerpo y el proyecto de Código Civil y Comercial", in *La Ley*, B (Jurisprudence Section).

# Part two



# Should Surrogacy be Permitted in Spain? The State of the Question and Some Considerations\*

ESTHER FARNÓS AMORÓS

## 1. SURROGACY TODAY

Through surrogacy<sup>1</sup> a woman subjects herself to assisted reproduction techniques, in exchange for a sum of money or for altruistic reasons, to be impregnated and carry a foetus on behalf of an individual or a commissioning couple to whom she undertakes to hand over the baby or babies that may be born. In countries where it is permitted, surrogacy has traditionally been used by heterosexual couples where the woman's uterus is

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Most of the case law cited in this chapter is taken from *Aranzadi*, a private database accessible from the main law libraries. The *Aranzadi* database references include AC (Court of First Instance and Appellate Court decisions), AS or JUR (regional High Courts of Justice and European Court of Human Rights decisions) and RJ (General Board of Registers and Notaries and Supreme Court decisions) followed by the year in which the decision was published and its identification number.

1. In the Spanish version of this chapter, the use of the expression *gestación por sustitución* (surrogacy) is justified, apart from its greater neutrality, because it is the expression used by Spanish law (see section 3): Lamm, E. (2013), *Gestación por sustitución. Ni maternidad subrogada ni alquiler de vientres*, Publicacions i Edicions de la Universitat de Barcelona, Barcelona, pp. 24-27.

missing for congenital reasons, or, as is more often the case, because she has had to have it removed completely or in part for medical reasons. People also resort to surrogacy when the woman's reproductive organs are not functional due to sterility or infertility, which prevents her from conceiving or successfully carrying through a pregnancy; or because pregnancy is ruled out for medical reasons. Nowadays, more and more single men and couples formed of two men are resorting to surrogacy. At the same time, some women are resorting to surrogacy for aesthetic purposes or because, given their age, having a baby is not advisable. These latter cases pose ethical dilemmas more important perhaps than those posed by surrogacy itself, in relation to the limits of assisted reproduction techniques.

In legal systems where surrogacy has been practised since the 1980s (typically, in some American states, such as California), it is usually formalized on the basis of commercial agreements, whereby the individual or the commissioning couple pay the surrogate a sum of money, in theory to cover the reasonable basic expenses arising from the pregnancy, and an additional sum to the agency acting as the intermediary, which has the task of finding the ideal candidate to carry the baby and formalize the agreement between the parties<sup>2</sup>.

There are two types of surrogacy, traditional and gestational<sup>3</sup>. In the former, the surrogate provides her own eggs, and she is inseminated with sperm from the intended father or a donor. The progress made in assisted reproduction techniques, especially since the 1990s, has led to this type being replaced by the second one, in which conception takes place from the egg or eggs of a woman other than the surrogate, who will normally be the intended mother. If the latter is unable to produce eggs or cannot do so in conditions of viability, they are supplied by another woman related to her through friendship or kinship or, as often happens in practice, by a donor. Given that gestational surrogacy dissociates genetic and gestational maternity, the fertilization of the egg or eggs with the intended father's sperm has to be performed in the laboratory, after recourse to a technique more sophisticated than insemination, in vitro fertilization (IVF). The resulting embryo or embryos are then transferred to the surrogate's uterus. Despite the greater physical, emotional and financial burdens entailed in IVF as opposed to artificial insemination, the greater practical incidence of gestational surrogacy can be explained

2. See my article "Inscripción en España de la filiación derivada del acceso a la maternidad subrogada en California. Cuestiones que plantea la Resolución de la DGRN del 18 de febrero de 2009", *InDret*, 1/2010, pp. 1-25.
3. Weisberg, D.K. and Appleton, S.F. (2006), *Modern Family Law. Cases and Materials*, Aspen Publishers, New York, pp. 1109-1110.

because it allows a genetic bond to be established between the baby and the intended mother and the absence of any genetic bond between the baby and the surrogate minimizes the risks, when the baby is born, of her refusing to hand it over to the intended parent(s), as happened in the case of Baby M, covered massively by the media<sup>4</sup>. Therefore, some of the legal systems that permit surrogacy only grant it legal validity if this requirement is met<sup>5</sup>.

An argument against the validity of surrogacy agreements has often been that the bonds created during pregnancy and childbirth prevent the surrogate from making a completely free decision at the time she signs the contract. According to this thesis, the woman who *ex ante* renounces the child she is carrying in favour of another woman, can never make a decision in a wholly voluntary and informed way. These arguments are closely linked to those that denounce the objectifying and biased nature, from a gender point of view, of surrogacy agreements, and the potential they have for the exploitation of women, especially those from more disadvantaged ethnic groups and social classes, by individuals or couples from powerful classes<sup>6</sup>. The Spanish Supreme Court has used the argument concerning the commercialization of the human body, together with the one that maintains that these contracts encourage child trafficking, in its pronouncements, which will be the subject of discussion in this chapter.

On the contrary, it is argued that considering these agreements to be ineffective not only trivializes the part played by free will in women's reproductive decisions, but it also helps to reinforce the stereotypes relative to the unpredictability of their decisions and to the inevitability of their biological destiny. Ultimately, for those who uphold this thesis, the

4. *In Re Baby M.* was decided by the New Jersey Supreme Court in 1988 (537 a.2d 1227 [N.J. 1988]). Mary Beth Whitehead gave birth to a baby girl, conceived with her eggs, and sperm from William Stern, who had to be handed over to the Sterns as soon as she was born. However, after giving birth Ms Whitehead changed her mind and refused to hand the baby over to the Sterns. The New Jersey Supreme Court considered the surrogacy agreement to be null and void, whereby it declared the baby to be the daughter of Ms Whitehead and Mr Stern. However, based on the best interests of the child, the court granted custody to the Sterns, guaranteeing Ms Whitehead a visiting regime that could be increased. A good summary of the case can be found at <http://www.nytimes.com/video/us/100000002781402/babym-and-the-question-of-surrogacy.html>, consulted on 21 April 2016.
5. This is the case, for example, of Greece (article 1458 Civil Code) or Israel (Act 5756 of 1996). This is also the line followed in Russia and Ukraine, see Lamm, E., *Gestación por sustitución...*, pp. 170 *et seq.*
6. See, especially, Radin (1991), who also suggests that in the current system surrogacy agreements are barely distinguishable from "baby selling": Radin, M., "Reflections on Objectification (Symposium on biomedical technology and health care: social and conceptual transformations)", *Southern California Law Review*, 341, pp. 352 *et seq.*

annulment of surrogacy agreements extols the experiences of gestation and childbirth above and beyond women's decision-making power, and their emotional, intellectual and interpersonal expectations<sup>7</sup>. Some of the people in favour of these theses consider that legal validity should be granted to these agreements, provided they are made free of charge, since they constitute an act of altruism that makes the realization of the right to procreate possible, and which, moreover, is consistent with organ donation. From this point of view, surrogacy could be likened to a "loaning of the uterus"<sup>8</sup>.

Now, almost 30 years after the high-profile Baby M. case, and after heated debates about the ethical dilemmas posed by "doing business" with certain legal assets, surrogacy is once again in the news, given the boom in so-called "reproductive tourism"<sup>9</sup>. In Spain, where, as we shall see, surrogacy agreements are considered null and void, more and more single people and heterosexual and homosexual couples are entering into them in other countries and coming back with a baby that they hope to formally register as their child. The tension between those who oppose regulation and those who support it shows up the social division that the subject still arouses today<sup>10</sup>.

7. The maximum representative of this position is Shultz, M. M. (1990), "Reproductive Technology and Intent-Based Parenthood: an Opportunity for Gender Neutrality", *Wisconsin Law Review*, 297, pp. 370-371 and 378-379; and (2005), "Taking Account of Arts in Determining Parenthood: a Troubling Dispute in California", *Washington University Journal of Law & Policy*, 77.
8. In this respect, see the statement by the Catalan gynaecologist S. Dexeus, published in *La Vanguardia* on 8 May 2015: "Si se puede donar un riñón también debería poderse prestar un útero" (If a kidney can be donated, then it ought to be possible to lend a uterus as well) (available online).
9. In favour of the more neutral expression "cross-border reproduction", which I shall use from hereon, see Shenfield, F. *et al.* (2010), "Cross-border Reproductive Care in Six European Countries", 25(6), *Human Reproduction*, 1361. On the phenomenon in the context of surrogacy in particular, see Engel, M. (2014), "Cross-Border Surrogacy: Time for a Convention?", in Boele-Woelki, K.; Dethloff, N.; Gephart, W. (eds.), *Family Law and Culture in Europe: Developments, Challenges and Opportunities*, Intersentia, Antwerp, pp. 199-216.
10. In June 2015 a group of female Spanish intellectuals signed the manifesto "No somos vasijas" (We are not vessels) against surrogacy (available online). A reaction, in my opinion sensible, to this manifesto can be found in Antonia Durán Ayago's blog, <http://diarium.usal.es/aduran/2015/06/25/ese-locuaz-feminismo/>, consulted on 21 March 2016. In favour of the regulation of surrogacy in Spain the activity of Son Nuestros Hijos stands out, an association of mostly same sex parents that has promoted a petition to allow the registration in Spain of children born abroad via surrogacy, see <http://sonnuestroshijos.blogspot.com.es/>, consulted on 21 April 2016. For its part, in Spain the Asociación por la Gestación Subrogada has backed a popular legislative initiative for its regulation, see <http://www>.

## 2. DIFFERENT APPROACHES TO THE SAME PHENOMENON, THE BOOM IN INTERNATIONAL SURROGACY AND A “LIBERALIZING” TREND

Reality has made the initial debate about the advisability of legalizing surrogacy especially complex. Commercial permission for it in Ukraine, Georgia, Russia, India, some states of the USA and Mexico, and its prohibition in other countries’ legal systems, allows citizens of these latter countries to resort to surrogacy. In this context, increasing numbers of Spanish citizens are gaining access to surrogacy in other legal systems<sup>11</sup>. The problems the issue poses in a globalized world such as ours are the object of growing academic interest<sup>12</sup>.

Between 2006 and 2010 alone, five of the major surrogacy agencies reported that the number of these agreements signed in the USA by foreign citizens had increased by 1,000%, and by 2008 almost 40% of these agencies’ new “clients” were foreign, a figure in stark contrast to the less than 5% reported in previous years<sup>13</sup>. It is currently estimated that more than half of the “clients” of surrogacy agencies based in the USA are foreigners<sup>14</sup>.

The phenomenon of cross-border reproduction, insofar as it allows access in another legal system to assisted reproduction techniques that are prohibited or not practised in one’s own, is often seen as a safety valve that avoids moral conflict in countries, in that it allows their citizens to

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*gestacionsubrogadaenSpain.es/index.php/2013-10-16-13-08-07/texto-ilp*, consulted on 21 April 2016.

11. Principally in the USA, where it is estimated that, in 2014, 2,000 babies carried by a surrogate for national and international commissioning couples were born, almost three times as many as a decade earlier. See “Coming to the U.S. for Baby, and Womb to Carry It”, in *NYTimes.com*, 5 July 2014. For economic reasons, among others, Russia and, until recently, Thailand and the Mexican state of Tabasco have already displaced this first destination and in turn, other traditional destinations such as India, whose administrative problems make foreign citizens’ access to surrogacy inadvisable. With respect to the case of Tabasco, see note 21, and for India, see note 34.
12. See Trimmings, K. and Beaumont, P. (eds.) (2013), *International Surrogacy Arrangements: Legal Regulation at the International Level*, Hart, Oxford-Portland (Oregon). This study originated in an investigation directed by both professors of the University of Aberdeen, funded by the Nuffield Foundation.
13. See preliminary report n.º 10 of the Hague Conference on Private International Law, about the problems deriving from international surrogacy agreements, drafted in March 2012, p. 8 (available online).
14. See the data supplied by the Growing Generations agency, based in Los Angeles (California), published in “Coming to U.S. for Baby, and Womb to Carry It”, *NYTimes.com*, 5 July 2014.

escape from restrictive laws<sup>15</sup>. This is the underlying idea in the case ‘S.H. and others v. Austria’, resolved by the European Court of Human Rights (ECtHR), which is interesting, despite not being specifically about a surrogacy agreement. The case analysed the Austrian law on assisted reproduction techniques (1992) and, in particular, its prohibition of gamete donation for the practice of artificial insemination and IVF, the only assisted reproduction techniques that allowed the two appellant couples to have children related genetically to at least one of their members. The final decision of the Grand Chamber, of 3 November 2011 (JUR 2011/369437), contrary to that of Sect. 1, of 1 April 2010 (JUR 2010/97861), exonerated Austria of responsibility, stressing countries’ margin of appreciation to regulate such a sensitive issue as this, claiming, moreover, that Austrian citizens could already access the techniques requested in other countries that allowed them (§ 114). This last point is disquieting, especially because it is nonsense to state that a right acknowledged by the European Convention for the Protection of Human Rights (ECHR) has not been infringed due to the fact that it can be exercised in another legal system<sup>16</sup>.

Despite the fact that the current trend is legalization, encouraged in part by cross-border reproduction and the many benefits it brings, the approach to surrogacy in different countries’ legal systems still varies greatly, and this continues to stimulate mobility<sup>17</sup>. Among the countries that follow a prohibitive model are France, Germany, Italy, Austria, the Mexican state of Querétaro<sup>18</sup> and the U.S. states of Arizona, Michigan and the District of Columbia. Spain, for reasons that are stated in section 3 of this chapter, instead follows a “model of ineffectiveness”, given that surrogacy agreements are not prohibited, they simply do not have legal implications. The Mexican state of Coahuila takes this same

15. The original expression is by Pennings, G. (2004), “Legal harmonization and reproductive tourism in Europe”, *Human Reproduction*, vol. 19(12), 2689-2694: “Reproductive tourism should be seen as a *safety valve that avoids moral conflict*, and as such, contributes to a peaceful coexistence of different ethical and religious views in Europe” (p. 2694, *in fine*).
16. Along these lines, see Scherpe, J. (2016), *European Family Law: The Present and Future of European Family Law*, vol. IV, Elgar, Cheltenham-Northampton, p. 92.
17. For more details, see the excellent analysis of the issue made by Trimmings and Beaumont, *International Surrogacy...*, and Lamm, *Gestación por sustitución...*, pp. 171-192.
18. It should be pointed out, however, that on a national level Mexico reformed the General Health law in April 2016, which only permits surrogacy by strict medical indication, between Mexicans and not for profit, and it envisages prison sentences of 6 to 17 years and fines for those persons who pay a woman to carry the baby, among other cases. Due to this regulation, states like Tabasco and Sinaloa, which up till then allowed commercial surrogacy, must restrict it to the altruistic kind.

approach<sup>19</sup>. In a different position we find the legal systems that follow a permissive model, either legally or through case law. Among them we can in turn distinguish between those that follow an altruistic model, which does not permit surrogacy agreements signed for commercial purposes, including the United Kingdom, Portugal<sup>20</sup>, Greece, the Australian states, New Zealand, Israel and the American state of New York; and the legal systems that permit these agreements even when they are signed for commercial purposes, among them Russia, Ukraine, the Mexican states of Sinaloa and Tabasco<sup>21</sup>, and the U.S. states of California, Illinois, Texas and Utah. Furthermore, among the legal systems that have chosen a permissive model, the system of transferring legal parentage from the surrogate to the intended mother or father, once the baby has

19. Lamm, *Gestación por sustitución...*, p. 126.

20. The admission of surrogacy in Portugal, limited to heterosexual couples in which the woman finds it impossible to become pregnant, was made in May 2016, based on a reform of article 8 of Act 32/2006 of medically assisted procreation, of 26 July, which prohibited it. However, in June 2016 the president of the republic exercised his right of veto and, after many difficulties, the Act 25/2016, of 22 August (*Diario de República*, n.º 160, 22 August), is not still in force at the time of this text being translated into English (May 2020). The Act only allows the surrogate to be compensated for expenses relative to her health, and establishes the legal parentage of the baby in favour of the “beneficiaries”, at least one of whom must have provided their gametes. The surrogate, for her part, cannot provide them. The act also regulates the contract, the duty of secrecy regarding the identities of those taking part in the process, and the sentences to be served by those taking part in an illegal surrogate pregnancy.
21. With the aim of avoiding cross-border reproduction, both states restrict the practice to Mexican citizens, although this is a new development in Tabasco. Given that this state had become a sort of “surrogacy paradise” encouraged, in part, by US agencies that were offering this practice along with idyllic stays in Cancún, there was great interest in reforming the regulation contained with respect to this in the civil code of 1997, see <http://www.diariopresente.com.mx/section/principal/135703/urge-regular-maternidad-subrogada-tabasco/>, consulted on 21 April 2016. On 13 January 2016 Decree 265 was published in the state’s official bulletin, which adds a new chapter to the civil code of 1997, entitled “De la gestación asistida y subrogada” (articles 380 Bis, 380 Bis 1, 380 Bis 2, 380 Bis 3, 380 Bis 4, 380 Bis 5, 380 Bis 6 and 380 Bis 7). The new regulation restricts the practice to heterosexual “spouses or partners” when “the intended mother suffers from a physical impossibility or a medical contraindication to carry the foetus in her uterus”. Furthermore, the contract is considered null and void when agencies, offices or third parties intervene, and the parties to it are required to be Mexican citizens. Although the new regulation still does not say anything about the commercial nature, or not, of the practice, it does not exclude commercial surrogacy, which would continue the line maintained up to now. Retrieved from [http://periodicos.tabasco.gob.mx/media/periodicos/7654\\_sup.pdf](http://periodicos.tabasco.gob.mx/media/periodicos/7654_sup.pdf). Nevertheless, the regulation mentioned in note 18 and approved at a national level must be borne in mind, which would limit surrogacy to that practised altruistically on a national level, whereby the states of Tabasco and Sinaloa will have to adapt the practice of surrogacy to this regulation.

been born, is different. Thus, while some legal systems have opted for a system of judicial pre-approval that involves the transfer of legal parentage prior to birth<sup>22</sup>, others have chosen a system of judicial transfer of legal parentage post-birth<sup>23</sup>. Both mechanisms have their advantages and disadvantages. A system of pre-approval allows the baby to be considered the child of the intended parent(s) from the moment it is born, and guarantees its factitious integration in the family, its rights being protected with respect to the intended parents from that very instant. The system of post-birth transfer of legal parentage is considered to be more respectful of the surrogate's consent and of her right to change her mind, within a period, if she so wishes, analogous to what happens in cases of adoption immediately after birth<sup>24</sup>. Among the legal systems that have a commercial model there are also important differences with regard to the total cost of access to surrogacy, something that is crucial for individuals when accessing treatment in one legal system or another<sup>25</sup>. The total cost oscillates between the €20,000 and €25,000 that a Spanish couple who gained access to the treatment in India paid, and the €100,000 to €150,000 for accessing the treatment in the USA<sup>26</sup>. Apart from the different approaches to surrogacy, as has been made clear in this section, one sees that even in the legal systems with a prohibitive model there is a "liberalizing" trend consisting of legitimating, normally through

22. This is the option followed by Greece (article 1458 Civil Code) and California (Sect. 7633 Cal. Fam. Code), through a system of the legal transfer of parentage, and also by the Mexican state of Tabasco. In this last case, the judge ratifies the notarial contract through a voluntary jurisdiction procedure prior to the birth (article 380 Bis 3 and 380 Bis 5 Civil Code).
23. The paradigmatic case is United Kingdom: parental orders, regulated in Sect. 54 of the Human Fertilisation and Embryology Act (HFEA), must be requested from the judicial authority after a period of six months since the birth.
24. Thus, in accordance with the Spanish Civil Code (article 177.2.2.IV) and the Catalan Civil Code (article 235-41.2), the mother's assent cannot be given until six weeks have passed since birth.
25. As well as the standard of living in the country where the technique is accessed, the final cost may be influenced by circumstances such as the specific treatment that must be carried out; the possible intermediation of an agency; other costs: legal, medical, travel and accommodation; and even those resulting from the loss of income (*lucro cesante*) that the surrogate may experience; as well as her possible legal or contractual obligation to take out an insurance policy.
26. On the case of India, whose legislation is under review, see note 34. Between these two extremes we find countries like Greece and Ukraine, where the cost oscillates between €30,000 and €50,000; Mexico, where, at least until the national regulation mentioned in note 18 came into effect, between €30,000 and €60,000 was paid; Russia, where the cost of the treatment stands at between €60,000 and €70,000; and Kazakhstan, where it is about €80,000. Information about this can be found at: <http://www.rtve.es/noticias/20140801/preguntas-respuestas-sobre-gestacion-subrogada-ventres-alquiler/976260.shtml>, consulted on 21 April 2016.

the courts, surrogacy agreements signed abroad, often by resorting to the “best interests of the child”<sup>27</sup>. As we shall see in the next section, on the situation developing in Spain, this trend is not only observed with regard to the establishment of the baby’s legal parentage in favour of the intended parent(s)<sup>28</sup>, but also when awarding these people social maternity and paternity benefits.

### 3. THE SITUATION IN SPAIN

#### 1. THE POINT OF DEPARTURE: NULLITY OF THE AGREEMENT AND “CROSS-BORDER REPRODUCTION”

For biological reasons, the only way in which gay single men or male couples can gain access to assisted reproduction techniques, to become parents, is through surrogacy agreements, which article 10.1 of Spanish Act 14/2006, of 26 May, on Human Assisted Reproduction Techniques (BOE no. 126, 27 May) declares null and void<sup>29</sup>.

27. Critical of the problems that this trend poses, Trimmings, K. and Beaumont, P. (2016), “Parentage and Surrogacy in a European Perspective”, in Scherpe, J. (ed.), *European Family Law: Family Law in a European Perspective*, vol. III, Elgar, Cheltenham-Northampton, pp. 281-282.
28. By way of example, the recent judgments can be cited of the German Supreme Court (Bundesgerichtshof) of 10 December 2014 (XII 713 463/13), which considers that it is no infringement of German public order to acknowledge a legal parentage link established via surrogacy in California by a male couple if at least one of the two provided the genetic material and the surrogate did not; the Colombian Supreme Court (SU696/15) of 12 November 2015, which in an identical case considers that a strictly formalist response to the question cannot be given when there are children involved and, out of consideration for the best interests of the child and the principle of non-discrimination, it orders the registration of the children’s dual parentage. In a case of internal surrogacy in which, due to the wife’s medical problems, the woman’s sister acted as the surrogate, the judgment of the Court of Lomas de Zamora (Buenos Aires), of 30 December 2015, reaches the same conclusions based on the wish to procreate and on the child’s human rights. The same solution was reached by judgment n.º 301 of collegiate family court 5 of Rosario (Argentina), on 27 May 2016 (*S. G. G. y otros*), in a case in which the surrogate was a friend of both intended parents, a heterosexual married couple. The surrogate was married and had children. Some of the judgments cited in this note have been provided by courtesy of Dr Eleonora Lamm.
29. This act, hereinafter Act 14/2006, establishes that “the contract by which gestation is agreed, with or without a price, performed by a woman who renounces maternity in favour of the contracting party or a third party, will be null and void”. The consequence of the said nullity is that maternity will be determined by childbirth (article 10.2 of Act 14/2006), without prejudice to the possible paternity claim with respect of the biological father (article 10.3 of Act 14/2006).

Spain, until recently only a passive subject of cross-border reproduction, given the greater ease of access to assisted reproduction techniques in general, and to egg donation in particular<sup>30</sup>, has become an active subject of surrogacy<sup>31</sup>. It is estimated that almost 1,000 children of Spaniards were born in the USA in 2003, predictably gestated in this way<sup>32</sup>.

Due to the nullity of surrogacy agreements, the Directorate General of Registries and Notaries (DGRN), an administrative body in charge of Civil Registers attached to the Spanish Ministry of Justice, issued the Order on 5 October 2010, on the registration in Spain of parentage of children gestated abroad through surrogacy (BOE no. 243, 7 October). The Order allows legal parentage in favour of the intended parent(s) to be registered and has legal implications in Spain, provided that there is no stated maternity in favour of the surrogate. A basic requirement for registration is the presentation of a *judicial* resolution from the child's country of origin that proves it. This requirement, which has come in for criticism<sup>33</sup>, is intended to guarantee the protection of the child's interest, ensuring that child trafficking has not been committed, and that the surrogate's capacity and freely given consent are respected<sup>34</sup>.

30. Thus, the possibility of using donated gametes and the "compensation" offered for them, the guarantee of the donor's anonymity, the non-exclusion of unmarried couples and of lesbians from access to assisted reproduction techniques, and its lower costs and the shorter waiting lists, have made Spain one of the main reproductive destinations of couples and recipients from other countries, but also of egg donors. See Shenfield *et al.*, "Cross Border Reproductive Care..."; Romeo Casabona, C. M.; Paslack, R. and Simon, J. W. (2013), "Reproductive Medicine and the Law: Egg Donation in Germany, Spain and other European Countries", *Rev Der Gen H*, 38/2013, pp. 15-42. Especially interesting is the interview with Guido Pennings, "Toda Europa viene a Spain a buscar óvulos" (All of Europe comes to Spain in search of eggs), published in *La Vanguardia* on 20 May 2014 (available online).
31. See my works "Surrogacy Arrangements in a Global World: the Case of Spain", *International Family Law*, 1/2013, pp. 68-72; and (2019), "Surrogacy in Spain", in Scherpe, J.M.; Fenton-Glynn, C. and Kaan, T. (eds.), *Eastern and Western Perspectives on Surrogacy*, Intersentia, Cambridge –Antwerp– Chicago, pp. 60-61.
32. Durán Ayago, A. and Blanco-Morales Limones, P. (2014), "Los vientres de alquiler (La cara y la cruz)", *Actualidad Jurídica Aranzadi*, n.º 881, 20.3.2014, p. 2. For updated information see my work "Surrogacy in Spain", pp. 60-61.
33. Thus, it is stated that the requirement could enter into contradiction with Spanish registry legislation, in that it also permits the recognition of foreign registry certificates: Carrascosa González, J. (2011), "La filiación en el derecho internacional privado", Yzquierdo Tolsada, M. and Cuenca Casas, M. (eds.), *Tratado de derecho de familia*, Book V, Aranzadi-Thomson Reuters, Navarre, pp. 501-502.
34. After this Order, between May and December 2011 at least 15 appeals were lodged with the DGRN. Of them, 11 were resolved in favour of the appellants, intended parents; three were rejected and one was resolved by accepting the withdrawal of the promoters. In 12 cases access to surrogacy had taken place in the United States, while in the three resolved negatively, access had taken place in India.

## 2. THE RESOLUTION OF THE DIRECTORATE GENERAL OF REGISTRIES AND NOTARIES OF 18 FEBRUARY 2009

### 2.1. Precedents and the progress of the case

The case that opened the discussion about surrogacy in Spain was the one that gave rise to the DGRN's Resolution of 18 February 2009 (RJ 2009, 1735), which agreed to the entry on the register of two birth certificates

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The non-recognition abroad of legal parentage derived from surrogacy in India, given the absence of a judicial resolution to prove the hoped-for parentage and the identity of the surrogate, may have led to that country halting the signing of these agreements with foreign intended parents, and reforming the legislation in force to restrict the practice of commercial surrogacy: on the administrative guidelines adopted on this matter in 2012 by the Indian Ministry of the Interior, widely criticized, see Malhotra, A. and Malhotra, R. (2014), "India: Surrogacy for Single and Unmarried Foreign Persons: a Challenge Under Indian Law", in Atkin, B. (ed.), *The International Survey of Family Law. 2014 Edition*, Jordan Publishing Ltd., Bristol, pp. 165-179. Exceptionally, the DGRN's Resolution of 15 April 2013 (JUR 2013\327711) does not recognize legal parentage derived from surrogacy carried out in the United States, given that only the hospital report and the invoice for the birth were provided. The Order has also been applied to the effects of permitting the registration of legal parentage in Spain in at least one case in which the *exequatur* of the foreign judgment was hoped for: see the decision of the Court of First Instance n.º 1 of Pozuelo de Alarcón of 25 June 2012 (AC 2013/281). And in the social order it has been applied by several courts for the purposes of recognizing paternity and maternity grants to the intended parents, in application of an "attenuated public order", the courts that have refused these grants being in the minority: see the judgments by the High Court of Justice, Social, Madrid, 1.<sup>st</sup> Chamber, of 12 February 2016 (JUR 2016, 79841); Catalonia, 1.<sup>st</sup>, 15 September 2015 5214/2015 (AS 2015\2019); Madrid, 1.<sup>st</sup>, 17 July 2015 (JUR 2015, 202928); Catalonia, 1.<sup>st</sup>, 1 July 2015 (AS 2015, 1826); Castilla-La Mancha, 1.<sup>st</sup>, 27 May 2015 (AS 2015, 1332); Canary Islands, 1.<sup>st</sup>, 27 March 2015 (JUR 2015, 214175); Madrid, 3.<sup>rd</sup>, 23 December 2014 (AS 2015, 406); Madrid, 3.<sup>rd</sup>, 13 March 2013 (JUR 2013, 291496); Catalonia, 1.<sup>st</sup>, 23 November 2012 (AS 2013, 845); Madrid, 4.<sup>th</sup>, 18 October 2012 (AS 2012, 2503); and Asturias, 1.<sup>st</sup>, 20 September 2012 (AS 2012, 2485). For the purpose of unifying the jurisprudence, in 2016 the Plenary Session of the Labour Chamber of the Supreme Court issued three judgments with by it acknowledges surrogacy as a situation protected by paternal leave in case of maternity, adoption or fostering: see the judgments of 19 October 2016 (JUR 2016, 247184), 25 October 2016 (JUR 2016, 273617) and 16 November 2016 (JUR 2016, 270902). In Europe, the Court of Justice of the European Union (CJEU) considers that member states cannot be forced to issue maternity leave to workers who have become mothers via surrogacy: in this respect, see CJEU judgments, Grand Chamber, 18 March 2014 (cases C-167/12 and C-363/12), in which the Court resolved two preliminary rulings formulated in relation to the requests of two intended mothers from the UK and Ireland. Despite the case law of the CJEU, the government of the UK approved these leaves, regulated in Sect. 122 and in appendix 7 of the Children and Families Act 2014. The fact that altruistic surrogacy has been permitted in the UK since 1985 was undoubtedly relevant to the passing of this regulation.

issued in California, establishing the paternity of two Spanish men, a married couple, with respect to twins gestated by a surrogate and born in October 2008 in that state<sup>35</sup>. As they were presumed to have been “born of a Spanish father or mother”, under the terms of article 17a) of the Spanish Civil Code, the children were considered Spanish, whereby their legal parentage had to be governed by Spanish law (article 9.4 CC)<sup>36</sup>.

However, given that, in cases of access to surrogacy abroad, legal parentage has already been established in accordance with a foreign law, it must be recognized in conformity with Spanish law, provided the conditions are met and the connections with the foreign country exist that are required for the recognition of foreign decisions or acts, without this posing a question of applicable law<sup>37</sup>. The DGRN, based on the argument of discrimination with respect to same-sex female couples, whose dual maternity deriving from recourse to assisted reproduction techniques could be determined from 2007 onwards (article 7.3 of Act 14/2006), and recourse to the best interests of the child, recognizes foreign birth certificates for the purposes of registration of paternity in Spain. As it does not create an effect of *res judicata*, the Resolution left open the option of

35. A detailed analysis of this Resolution, of the practice of surrogacy in California and of the judicial proceedings followed in that state to establish the legal parentage of children conceived via surrogacy can be seen in my article “Inscripción en España de la filiación...”, already cited. See also note 22 of this chapter.
36. In relation to the law applicable to legal parentage the problem arises of the “double mirror”, as the application of articles 9.4 and 17 CC entails that the determination of the child’s nationality depends on its legal parentage, which in turn depends on its nationality. However, when it is proven that genetic material from at least one of the applicants was used for generation, article 17 CC makes it possible to solve the question: see Blanco-Morales Limones, P. (2011), “¿Y tú de quién eres? Problemas actuales del derecho de familia”, in *Lección inaugural curso académico 2010/2011*, University of Extremadura, 27 September 2010, pp. 19-20 (unpublished paper provided by courtesy of Prof. Antonia Durán Ayago). Throughout the process that gave rise to this case, the children’s Spanish nationality was not doubted, something that is open to criticism, since the Supreme Court judgment questions whether the twins were born to a Spanish father or mother, the only title of legitimation of nationality they would have: see Álvarez González, S. (2014), “3.2. Filiación”, *Revista Española de Derecho Internacional*, vol. LXVI, 2/2014, pp. 273-277.
37. Despite its importance, this point is all too often overlooked. Warnings have been issued from the point of view of Private International Law by, among others, Quiñones Escámez, A. (2009), “Doble filiación paterna de gemelos nacidos en el extranjero mediante maternidad subrogada. En torno a la RDGRN del 18 de febrero de 2009”, *InDret*, 3/2009, pp. 1-42; Álvarez González, S. (2013), “Filiación natural y filiación adoptiva. Aspectos internacionales”, in Gete-Alonso and Calera, M. del C. (ed.), Solé Resina, J. (coord.), *Tratado de derecho de la persona física*, Book I, Thomson-Civitas, Cizur Menor, pp. 416 and 428-429; and Heredia Cervantes, I. (2014), “Inscripción de relación de filiación derivada del recurso a gestación por sustitución en el extranjero”, *CCJC*, 96/2014, pp. 177-214, on pp. 200-201.

challenging paternity, whereby the public prosecutor lodged an appeal before the Court of First Instance no. 15 in Valencia that, by the ruling of 15 September 2010 (AC 2010/1707), revoked registration on the understanding that article 10 of Act 14/2006 had been used fraudulently<sup>38</sup>. The court considered, moreover, that there was no discrimination, given that the impossibility of registering legal parentage resulting from a surrogacy agreement was not based on the sexual orientation of the intended parents, but on the nullity of these contracts, which applied equally to heterosexual couples. To protect the interest of the children, the Court addressed the commissioning couple to bring a paternity claim by the biological father (article 10.3 of of Act 14/2006) and the other member of the couple to apply for adoption (article 178.2.1st CC). The 10th section of the Appellate Court of Valencia, by its ruling of 23 November 2011 (AC 2011, 1561), and subsequently the 1st Chamber of the Supreme Court, by its ruling of 6 February 2014 (RJ 2014, 736), confirmed this pronouncement. The Plenary Session of the 1st Chamber of the Supreme Court, by decision of 2 February 2015 (JUR 2015, 45930), declared this judgment to be in conformity with the law, and rejected the appeal against annulment of proceedings. Although the Appellate Court and the Supreme Court carried out a review of the legality of the institution susceptible to recognition and concluded that it is contrary to Spanish international public order, the Supreme Court corrected the Appellate Court on this point, which, based on article 23 of the Law of 8 June 1957, of the Civil Registry (hereinafter LCR), had applied Spanish substantive law directly<sup>39</sup>. I shall now analyse the Supreme Court's judgment, passed by five votes to four and which clearly shows the division that exists with regard to surrogacy in Spain.

## 2.2. Surrogacy before the Supreme Court

### 2.2.1. *Sound judgment in the methodology and the more debatable nature of the substantive arguments*

The Supreme Court focuses on analysing whether the decision by the administrative authority of the Californian civil registry, to register the children's birth and establish their legal parentage in accordance

38. Against this, see Blanco-Morales Limones, P., "¿Y tú de quién eres?...?", p. 23. The author understands that there is no fraudulent forum shopping; along the same lines, see Carrascosa González, "La filiación en el derecho...", pp. 494 and 504.

39. A positive assessment of the Supreme Court judgment on this point, by Durán Ayago, "Los vientres de alquiler...", p. 2.

with Californian legislation, can be recognized, and have implications –specifically, the establishment of legal parentage in favour of the appellants– in the Spanish legal system. As it has before it a foreign birth certificate that establishes the legal parentage of two children, the Supreme Court initially resorts to articles 23 LRC and 81 and 85 of its Regulation, all of them about recognition of foreign documents, for the purpose of verifying whether it meets its requirements: reality of the fact entered, regularity and authenticity of the same (that is, that the registration that is the basis of the certificate, with regard to the facts that it certifies, has guarantees analogous to those required by Spanish Law for registration); and legality in accordance with Spanish law (control of content of the entry that is the object of the said certificate that may make it possible to refuse its entry in the Spanish civil registry when it is contrary to Spanish international public order)<sup>40</sup>. Upon reviewing the legality of the foreign registry certificate in accordance with Spanish legislation, the majority decision considers that surrogacy is contrary to Spanish international public order, whereby it cannot have legal implications in Spain. Opposed to the appellants' argument, according to which the recognition of legal parentage determined in the Californian registry certificate does not contradict Spanish international public order because this prevents a surrogacy contract from being considered valid and executed in Spain, but not the entry in the Spanish

40. This certificate does not even mention surrogacy, as this datum, like that of recourse to assisted reproduction techniques, has no access to the registries. These data only appear in the foreign judgment, which is the title constituting the legal bond of parentage between the children and the intended parents. It is not known why neither the surrogacy agreement nor the judgment of the Californian court conferring paternity of the twins on the appellants was brought to the proceedings, as the Supreme Court criticizes in § 1.7. For Bercovitz Rodríguez Cano, R., the defence of public order in this case required the submission of both documents: "Paradojas de la vida", *Aranzadi Civil-Mercantil*, 3/2014 (BIB 2014/1533). Private International Law distinguishes, moreover, between evidentiary recognition and substantial or material recognition: while the former, which is what took place in the case, demands fewer requirements and does not have effects of material *res judicata*, creating a *iuris tantum* presumption, the latter does have them. For Quiñones Escámez ("Doble filiación paterna...", pp. 13-15), in the case the prior recognition of the judgment should have been required to pass the legality review, given the existing cause-effect relationship between this and the birth certificates and this decision being the title on which registration was based. Similarly, see Álvarez Rodríguez, A. and Carrizo Aguado, D. (2014), "Tratamiento legal del contrato de gestación por sustitución en el derecho internacional privado español a la luz de la STS del 6 de febrero de 2014. Dime niño, ¿de quién eres...?", *La Notaría*, 2/2014, p. 63. In the words of Heredia Cervantes ("Inscripción de relación de filiación...", pp. 208-209), it would have been enough for the Supreme Court to allege the requirement that is derived from articles 23 LRC and 85 of its Regulation that the certificate must prove the reality of the fact registered, to have had a decisive (and correct) argument against registration.

civil registry of the legal parentage arising from such a contract, which is an ultimate and peripheral consequence of the same, the Supreme Court considers it decisive that the legal parentage whose entry in the civil registry is hoped for is in fact the direct and principal consequence of the surrogacy contract (§ 11). Below, this argument, the most important one invoked by the Supreme Court, is analysed, followed by the other two that support it.

### 2.2.2. *Surrogacy contrary to the Spanish international public order*

Although the Supreme Court is right to apply this methodology (recognition), the arguments it uses to support its decision are more debatable. Firstly, it is difficult to invoke being contrary to public order with respect to a regulation, article 10 of Act 14/2006, which is actually not prohibitive, but which is limited to not recognizing a particular contract's implications in Spain<sup>41</sup>. Secondly, the Supreme Court reviews public order with respect to a particular method (surrogacy) and not to the implications involved in the registration of a specific foreign document in Spain<sup>42</sup>. It is an abstract review that is incompatible with incidental recognition of a foreign registry certificate that was no more than a registry reflection of a previous judicial resolution and which only required, as the dissenting opinion of the judgment correctly notes, checks to be made on whether Spanish international public order was being infringed *in the specific case*<sup>43</sup>.

41. Cf. with the 2nd Additional Provision of the legislative proposal that gave rise to the previous Act 35/1988, of Assisted Reproduction Techniques, which *did* formally prohibit the figure and contemplated penalties for it. Furthermore, in the criminal case law falling on the crimes of supposition of birth and alteration of the child's legal parentage, state or condition (articles 220 to 222 of the Criminal Code) there is not one single judgment related to the conduct described by article 10 of Act 14/2006: on this subject, see my study "Surrogacy arrangements...", pp. 69-70. Although the majority of authors who have spoken about this matter presuppose that it is a prohibitive law, they do not justify it. Against the prohibitive nature of the law see, especially, Atienza, M. (2009), "De nuevo sobre las madres de alquiler", *El Notario del Siglo XXI*, n.º 27, 13.10.2009; Álvarez González, S., "Filiación natural...", and Heredia Cervantes, I. (2013), "La Dirección General de los Registros y del Notariado ante la gestación por sustitución", *ACD*, Book LXVI, 2013, fasc. II, p. 710. The latter refers, moreover, to how contradictory it is for a prohibitive law to *reward* the biological father with the possibility of taking action to claim parentage, under the terms of article 10.3 of Act 14/2006.
42. See, especially, Heredia Cervantes, I. (2014), "El Tribunal Supremo y la gestación por sustitución: crónica de un desencuentro", in *El Notario del Siglo XXI*, n.º 54, 9.4.2014; and "Inscripción de relación de filiación...", pp. 209-212.
43. Along the same lines, from Private International Law, see Durán Ayago, A. (2012), "El acceso al Registro Civil de certificaciones registrales extranjeras a la luz de la Ley 20/2011: relevancia para los casos de filiación habida a través de gestación por

On the contrary, the Supreme Court, without having to hand either the surrogacy agreement or the foreign judicial resolution<sup>44</sup>, concludes by presuming that any surrogacy agreement is exploitative:

In our legal system and in that of the majority of countries with legal systems based on similar principles and values, it is not accepted that the spread of adoption, even international, and progress in assisted human reproduction techniques may infringe the dignity of the surrogate and the child, commercializing pregnancy and parentage, “objectifying” the surrogate and the child, allowing certain intermediaries to do business with them, making possible the exploitation of the state of need in which poverty-stricken young women find themselves, and creating a sort of “wealth-based citizenship” in which only those who have large financial resources can establish parent-child relationships, off-limits to the majority of the population (§ 3.6).

### 2.2.3. *Absence of discrimination*

In line with the previous courts, the Supreme Court also rejects the appellants’ argument based on discrimination with respect to couples formed by two women who gain access to assisted reproduction techniques, who since 2007 have been allowed by lawmakers to register maternity (art. 7.3 of Act 14/2006). According to the Supreme Court, “the cause of the refusal to register legal parentage is not that both the applicants are men, but that the pretended filiation arises from surrogacy, contracted by them in California” (§ 4.2). With this, the Supreme Court makes it known, as previous courts had already done earlier, that the consequence (the nullity of the agreement) would be the same if the couples that had resorted to surrogacy in these circumstances were heterosexual. Although I feel that this line of argument is the right one<sup>45</sup>, it is still surprising that access

sustitución”, *AEDIPR*, Book XII, p. 302; Heredia Cervantes, “La Dirección General...”, p. 694; Álvarez González, “Maternidad subrogada...”, and Parrón Cambero, M. J. (2014), “Ventre de alquiler: *mater semper certa est, pater semper incertus est*”, in *La Ley*, n.º 8269, 12.3.2014, pp. 1-5. In relation to the previous judgment that the Supreme Court now confirms (also commented on in *REDI*, 2012-2013-Pr., pp. 213-216), Álvarez González, S. (2013): “Reconocimiento de la filiación derivada de gestación por sustitución”, in Forner Delaygua, J.; González Beilfuss, C. and Viñas Farré, R. (coords.), *Entre Bruselas y La Haya. Estudios sobre la unificación internacional y regional del Derecho internacional privado. Liber Amicorum Alegría Borrás*, Marcial Pons, Barcelona, pp. 83-84; and “Filiación natural...”, pp. 435 *et seq.*

44. See note 40.

45. See, in this respect, my criticism of the DGRN’s Resolution on which this judgment is based: “Inscripción en España...”, p. 15. I do not share the opinion of those who

to surrogacy in the United States by Spanish couples only came to light and was questioned in 2010, in relation to the couple formed of two men in the case I am commenting on<sup>46</sup>.

#### 2.2.4. *The best interests of the child*

Lastly, the Supreme Court resorts to the best interests of the child. Although the Supreme Court admits that “the non-recognition of the legal parentage established in the Californian registration may damage the legal position of the children (§ 5.8)” and that the decision adopted “may cause problems for the children whose legal parentage is being discussed” (§ 5.11), it also claims that “the general clause of the fundamental consideration of the best interests of the child contained in the legislation does not permit the judge to obtain any results in its application” (§ 5.6), whereby it considers it decisive that the establishment of a legal parentage that contradicts the criteria envisaged in the law for its establishment also supposes harm for the child, which infringes its dignity and makes it an object of commercial traffic (§ 5.8).

This argument once again comes into conflict with that of the dissenting opinion, according to which “there is no public order if in the case it would go against the interests of a child, a perfectly individualized flesh and blood person”<sup>47</sup>. As a consequence, the baby’s dignity is not, nor cannot be, affected by the fact of having been conceived to be loved and brought up by the person who did not give birth to it and, in ordinary circumstances, it causes the child no harm whatsoever<sup>48</sup>.

consider that the impossibility of access to surrogacy by couples formed by two men constitutes discrimination with respect to article 7.3 of Act 14/2006 making article 10 unconstitutional: Cerdeira Bravo de Mansilla, G. (2014), “Copaternidad y matrimonio entre hombres y derogación tácita y parcial de la proscrita gestación por sustitución, fundada por razones de igualdad”, *RDP*, July-August, pp. 3-27.

46. The previous situation was one of veritable “legal secrecy”: Álvarez González, S. (2015), “Gestación por sustitución o la crisis de la autonomía del legislador de DIPR (y quizá también del legislador de Derecho Civil)”, p. 1 (working paper available online). I refer to the data already supplied in this chapter (see section 3.1 of this chapter) according to which in 2003 there were almost 1,000 births of Spaniards in the USA presumably gestated in this way: see Durán Ayago and Blanco-Morales Limones, “Los vientres de alquiler”, p. 2. See also my work “Surrogacy in Spain”, pp. 60-61.

47. Along these same lines see, previously, Durán Ayago (“El acceso al Registro Civil...”, pp. 302-304), for whom, when analysing whether surrogacy infringes, in the specific case, Spanish international public order, the best interests of the child principle emerges in all its intensity and may even displace the rigour of article 10 of Act 14/2006. Blanco-Morales Limones said the same, “¿Y tú de quién eres?...”, pp. 22-24.

48. See Álvarez González, “Reconocimiento de la filiación...”, pp. 82 and 83.

With respect to this, the British courts have granted parental orders in favour of commissioning couples when a surrogacy agreement has been signed abroad that did not comply with Sect. 54(8) of the Human Fertilisation and Embryology Act (HFEA) of 2008, which only allows such agreements to be ratified if they are limited to compensating the “expenses reasonably been incurred [...] unless authorised by the court”<sup>49</sup>. In these circumstances, the courts have maintained that, “the welfare of the child is not just the first issue that the court should consider, but the main one” and that “it is hard to imagine a set of circumstances in which, bearing in mind the welfare of the child, the court could refuse to issue a parental order, without the sums that were paid to the surrogate or the clinic mattering”<sup>50</sup>. Nevertheless, it may be said that this case law has opened the door to commercial or lucrative surrogacy in the United Kingdom<sup>51</sup>.

The inclusion of the general clause of the best interests of the child in our legal system has extended to family law the technique of jurisprudentially developing the law through the application of general clauses<sup>52</sup>. As a general clause, its main advantage is that it makes it possible to adapt the solutions to the criteria of social awareness that must prevail in the application of such a changing issue as the values impressed on family law by specific characters. Its main disadvantage is, on the other hand, the problem posed by personal interpretation, which may give rise to notable deviations on what social awareness considers acceptable at any given moment<sup>53</sup> and which has led to the social and normative overstating of the child’s best interests, and to an abuse of the term and the

49. The discretion this precept grants the courts is described as “paradoxical”: Trimings and Beaumont, “Parentage and surrogacy...”, p. 256.

50. “The difficulty is that it is almost impossible to imagine a set of circumstances in which, by the time the case comes to court, the welfare of any child (particularly a foreign child) would not be gravely compromised (at the very least) by a refusal to make an order”: on this point, *Re X and Y (Foreign Surrogacy)* [2009] 1 FLR 733. See also the most recent cases *Re L (A Minor)* [2011] 1 FLR 1423, *Re X (Children)* [2011] EWHC 3147 (FAM) and *Re C (Parental Orders)* [2013] EWHC 2408 (FAM). In the last one, the Californian surrogate was paid \$51,200, the agency \$15,000, and the clinic \$28,195.

51. Lamm, *Gestación por sustitución...*, pp. 141-142.

52. See Torres Perea, J. M. de (2014), “Aplicación de cláusulas generales en el derecho de familia ¿una nueva vía para la creación jurisprudencial del Derecho?”, in Díez-Picazo, L. (coord.), *Estudios Jurídicos en Homenaje al Profesor José María Miquel*, vol. II, Aranzadi – Thomson Reuters, Cizur Menor, pp. 3555-3576.

53. See Roca i Trias, E. (1994), “El ‘interés del menor’ como factor de progreso y unificación del derecho internacional privado” (reply to the admission speech given by Dr Alegria Borràs at the *Acadèmia de Jurisprudència i Legislació de Catalunya*), RJC, 4/1994, p. 975.

concept<sup>54</sup>. The judgment I am commenting on makes the negative consequences especially clear of resorting to vague legal concepts such as “international public order”, the “principle of *favor filii*” or the child’s best interests in order to confer validity, or not, on situations arising in other countries where they are perfectly legal<sup>55</sup>. Thus, disagreement over the concept “best interests of the child” may be observed between this judgment and the DGRN’s Resolution from which it is derived, among the different authors that have analysed it<sup>56</sup>; or between this judgment and those issued by the ECtHR on the subject of surrogacy, which are analysed in section 4 of this chapter. At the same time, it is certainly surprising that the 1st Chamber of the Spanish Supreme Court –in two cases very close in time to the one analysed, the object of which was to determine maternity with respect to the mother’s former female partner who had taken part in the parenting project of conception via assisted reproduction techniques (judgments of 5 December 2013, RJ 2013, 7566; and of 15 January 2014, RJ 2014, 1265)– should have legitimized the distancing from the letter of article 7.3 of Act 14/2006 to declare dual maternity, invoking precisely the best interests of the children involved. It is surprising that when it is a question of establishing dual paternity as a result of access to a surrogacy agreement, the Supreme Court clings to the letter of article 10 of Act 14/2006 to prevent the establishment of dual paternal link, alluding to the same best interests of the children. The analysis of the three judgments together allows us to confirm that the child’s best interest principle is, in reality, an ambivalent recourse in the hands of the courts<sup>57</sup>. Given that in the case there was no confirmation of which of the two appellants was the biological father of the children, the Supreme Court urges the public prosecutor to take the relevant action to determine, insofar as it is possible,

54. See De la Válgoma, M. (2013), *Padres sin derechos, hijos sin deberes. El laberinto jurídico de la infancia*, Ariel, Barcelona, pp. 137-161.

55. Álvarez Rodríguez and Carrizo Aguado, “Tratamiento legal...”, p. 65.

56. In favour of the thesis of the Supreme Court majority because “it has expounded with well-founded reasons the value that the best interests of the child may have in a particularly delicate case of determination of filiation”, see Quicios Molina, “¿Cómo puede determinarse...”, pp. 28-29. Along the same lines, although based more on ideological reasons, see Muñoz de Dios Sáez, L. F. (2014), “La gestación por sustitución: un fraude a la adopción (tras la sentencia del Tribunal Supremo del 6 de febrero de 2014)”, in *Anuario de la Facultad de Derecho de la Universidad Autónoma de Madrid*, 18/2014 (*Las fronteras del Derecho biosanitario*), pp. 289-329. The positions opposing it are in the majority, however: see, among others, Heredia Cervantes, “El Tribunal Supremo...”, and “Inscripción de relación de filiación...”, pp. 212-213; Durán Ayago and Blanco-Morales Limones, “Los vientres de alquiler...”, p. 2, and Marín Pedreño, C. and Marfil, J. A. (2014), “Surrogacy in Spain: Reality vs. Legality”, *International Family Law*, June, pp. 100-102.

57. For an analysis of the three cases, see my study “La filiación derivada de reproducción asistida: voluntad y biología”, *Anuario de Derecho Civil* 1/2015, pp. 5-61.

their correct legal parentage, bearing in mind their effective integration in a de facto nuclear family and the breaking of all ties with the surrogate. With this, the Supreme Court refers to the paternity claim with respect to the biological father, in the terms of article 10.3 of Act 14/2006, and to adoption with respect to the other appellant. This criterion, as well as ignoring the social reality<sup>58</sup>, ends up leading, in a more onerous way, to the same solution that the appellants were asking for, whereby it is unsatisfactory for the Spanish citizens who are currently gaining access to surrogacy and, more importantly, for the children involved, whose status remains indefinite for longer. If the option offered to the appellants by the court majority is ultimately aimed at guaranteeing the best interests of the children, why does the majority not take into account these same interests when it is a question of recognizing the validity in Spain of the surrogacy agreement signed elsewhere? Given that the child's best interests principle is based on its projection into the future<sup>59</sup>, it is especially surprising that in this case the Supreme Court should articulate an alternative and more onerous pathway for achieving its protection and it does not defend its interests immediately in the specific case. This is precisely the solution that the ECtHR has reached in the French cases that are analysed in section 4 of this chapter, in which it has associated the recognition of the children's legal parentage, with respect to their intended fathers, with the girls' right to their identity. This solution expresses, with good judgment, that the child's best interests, perceived as the right to an identity in accordance with that experienced, must constitute the connecting thread of all reflection in matters of legal parentage<sup>60</sup>.

### 2.3. Where are we?

When the judgment analysed was issued only about the recognition of a foreign birth certificate, it may be thought that the legal parentage

58. As Blanco-Morales Limones warned in 2010 (“¿Y tú de quién eres?...”, p. 22), “Prohibition, accompanied or not by sanctions, does not prevent, nor will it prevent, the birth of children via surrogacy. The current legal solution in Spain, *madre es la que pare* (the mother is the one who gives birth), does not resolve the conflicts. What is more, it may give rise to extremely unusual situations, as in Spain the mother is considered to be the woman who carried and gave birth to the child in a country where surrogate motherhood is permitted, and under the protection of that country's law she has no connection to the child she gave birth to”.

59. Roca i Trias, “El interés del menor”..., p. 976.

60. Tamayo Haya, “Hacia un nuevo modelo de filiación...”, p. 315. Private International Law also considers that stressing the personal identity of those born as an essential component of the right to their private life is clean and barely contaminable by other evaluative considerations that might surround the surrogacy process: Álvarez González, “Gestación por sustitución...”, p. 19.

registrations derived from the recourse to surrogacy that are based on a judicial resolution, as demanded by the DGRN's Order of 2010 –to which the Supreme Court does not even allude– should have no reason to feel threatened<sup>61</sup>. However, the restrictive concept of public order that the Supreme Court uses is also incompatible with the Order, whereby, de facto, its effectiveness could also be affected by the judgment<sup>62</sup>.

Act 20/2011, of 21 July, on the Civil Registry (BOE no. 175, of 22 July), remains silent about the reality of surrogacy, whereby the recognition of foreign resolutions may continue to depend on the assessment of public order that is still required for the recognition of foreign judicial resolutions (article 96.2.2nd, letter *d*) or on foreign certificates of registration (article 98.1, letter *d*)<sup>63</sup>. In accordance with article 98.2 of the same act, when the certificate constitutes a mere reflection by a registry of a previous judicial resolution, this will be the title that has access to the Registry, so the judicial resolution must be recognized in accordance with one of the procedures envisaged in the said article 96<sup>64</sup>. In this context, there is nothing to prevent the legal operators from following the same restrictive line as the Supreme Court by alluding to public order<sup>65</sup>, although the wish expressed

61. Heredia Cervantes, “El Tribunal Supremo...”, and “Inscripción de relación de filiación...”, pp. 213-214.
62. De Torres Perea, J. M. (2014), “Comentario de la STS del 6 de febrero de 2014 sobre maternidad por sustitución desde la perspectiva del interés del menor”, *La Ley*, n.º 8281, 28.3.2014, p. 9.
63. After many reforms, according to the 10th Final Provision of Act 20/2011, most of its contents, including the mentioned articles, will come into effect on 30 April 2021.
64. In accordance with Additional Provision 1, letter *c*, of Act 29/2015, 30 July, on international legal cooperation in civil matters (BOE n.º 182, 31 July), articles 94 to 100 of Act 20/2011 have the status of special laws in matters of international legal cooperation in civil and commercial matters, whereby Act 29/2015 will be of subsidiary application in reference to the acknowledgement of foreign resolutions (articles 44-49). However, this law will be applicable in those cases in which the *exequatur* is required (articles 52-55), which the DGRN's Order of 2010 reserves for the cases in which the foreign judicial resolution has not originated from proceedings analogous to Spanish ones of voluntary jurisdiction.
65. Finally, the abovementioned Act 19/2015 has not modified Act 20/2011 in the sense of granting validity in Spain to surrogacy carried out abroad and it only includes a very broad and vague mention to the possibility of renouncing maternity at article 44.4.II. Although the planned wording did not refer specifically to the legal parentage derived from recourse to surrogacy, it suggested that recognition would be possible of those agreements signed abroad if a *judicial* resolution was supplied, along the lines required by the cited Order of the DGRN of 5 October 2010, and recognition in Spain was carried out via *exequatur*. Besides the requirement of *exequatur*, it was surprising that a judicial resolution should be required when, as we have seen, Act20/2011 not only generally envisages the possibility of acknowledging foreign judicial resolutions, but also certificates of foreign registrations.

by the DGRN after the Supreme Court judgment of 2014 is that of maintaining the validity of the criteria of its 2010 Order<sup>66</sup>.

Six years after the publication of this Order, it is still surprising that article 10 of Act 14/2006 remains intact, and that in the surrogacy cases signed by Spanish citizens abroad, in accordance with the criteria of the said Order, the precept is being displaced by the decision of a non-legislative body. Legal uncertainty for Spanish citizens who wish to gain access to surrogacy and the risks of elitist discrimination that this poses are evident.

#### 4. SURROGACY BEFORE THE EUROPEAN COURT OF HUMAN RIGHTS: POSSIBLE IMPLICATIONS FOR SPAIN

The establishment of maternity by the fact of childbirth, based on the rule of article 10.2 of Act 14/2006, is not consistent with it being no longer the only criterion for establishing maternity. It is not, when in Spain the state lawmaker and some legislators in autonomous communities are already envisaging criteria for establishing legal parentage derived from assisted reproduction techniques based on intention, as happens with respect to the access of two women to assisted reproduction techniques (article 7.3 of Act 14/2006 and 235-8 and 235-13 CCCat)<sup>67</sup>, especially when the surrogate has renounced legal parentage in favour of an individual or a commissioning couple.

More and more countries are allowing surrogacy agreements to be signed in their territories, within certain limits that differ according to each one's legal system<sup>68</sup>. Aware of this, and of the growing boom in cross-border reproduction, the Hague Conference on Private International Law<sup>69</sup>

66. Thus, according to the DGRN's Report of 11 July 2014, "in the current legislative and jurisprudential state, the Order of 5 October 2010, on the regime of registration of filiation of babies born via surrogacy is fully valid, whereby it must continue to be applied by Spanish Civil Registries for the purpose of determining the possibility of registering birth and filiation in the cases that come within their sphere of application, without the Civil Chamber of the Supreme Court's judgment of 6 February 2014 constituting a legal obstacle to it".

67. See also Verdera Server, "Comentario a los artículos 7 y 8 LTRHA", in Cobacho (ed.) and Iniesta (coord.), *Comentarios a la ley 14/2006...*, pp. 261-262. Similarly, C. L. García Pérez regrets that "social or intentional maternity or paternity" is not valued in this branch, although it is in other areas of the LTRHA: "Comentario al artículo 10 LTRHA", in Cobacho (dir.) and Iniesta (coord.), *Comentarios a la ley 14/2006...*, pp. 382-384.

68. On this point, I refer to section 2 of this chapter.

69. Since 2010 it has been working on the project *Problems of Private International Law concerning the status of children, including the issues arising from international*

is working to draft common guidelines to permit the children born in this way to have clearly defined legal parents and civil status, by way of the recognition of international decisions<sup>70</sup>. When it affects countries in the Union, non-recognition may be contrary to the right to free movement (in this case, the baby's) recognized in article 21 of the Treaty on the Functioning of the EU (formerly article 18 TEC)<sup>71</sup>. Aside from this argument, the ECtHR has pressed for the internal recognition of the legal parentage derived from recourse to surrogacy abroad based on another even more important thesis: the protection of the rights of the children involved. The cases 'Mennesson (case no. 65192/11) and Labassee v. France' (case no. 65941/11)<sup>72</sup>, both resolved on 26 June 2014, were respectively about the status of twin girls carried by a woman in California and of a third baby girl carried by another woman in the state of Minnesota. In both cases the intended parents were heterosexual couples of French nationals residing in France. In them, Sect. 5 of the ECtHR unanimously declared that the refusal of the French state to recognize the bond of legal parentage between the babies and the commissioning couples is contrary to the babies' right in this respect to their private life, protected by article 8 of the ECHR and linked to identity<sup>73</sup>.

The French state, first administratively and then judicially, prevented the surrogacy agreements from being executed in France and, therefore, the children's legal parentage being recognized, appealing to French international public order and to it being contrary to the principle of non-disposability of the human body in these agreements. The ECtHR

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*surrogacy arrangements*, which has given rise to several preliminary reports available on the Conference's page (HCCH). After meeting in 2014, the Conference decided to postpone setting up a group of experts until 2015. In February 2016 it approved Preliminary Document n.º 3, which warns of the division between legal systems, depending on whether they refer to domestic laws for the solution of these conflicts or to foreign law. The document also highlights the need to draft common guidelines in matters of recognition of foreign public documents, such as birth certificates or voluntary recognitions of legal parentage, while it notes that in practice there is greater coherence relative to the recognition of foreign judgments.

70. Sceptical about this possibility, Engel, "Cross-Border Surrogacy...", pp. 210-211.
71. In Spain, see Carrasosa González, "La filiación...", p. 495. Also pointing to it, based on the majority of the studies that in the last few years have analysed the method of recognition in the EU, Álvarez González, "Reconocimiento de la filiación...", p. 88.
72. The 'Mennesson' case is accessible, in English and French, from the ECtHR database (HUDOC), and the 'Labassee' case, in French, from the same database (consulted on 13 August 2015).
73. The rulings of the ECtHR have been commented upon and applauded by Herrera, M. and Lamm, E., "Un valiente fallo del TEDH sobre gestación por sustitución. Prohibir, silenciar, regular o fallar", *La Ley* (Buenos Aires-Argentina), n.º 122, 2.7.2014, pp. 1 and 6-8.

considered that the impact of the French state on the children's identity, resulting in such apparently remote extremes as the impossibility of inheriting if those acting as their parents do not include it in their wills, was contrary to the children's best interests, exceeding the wide margin of appreciation enjoyed by states in matters as sensitive and lacking consensus as this, whereby France was ordered to pay €5,000 as compensation for the moral damages caused to each of the three girls, who were 14 and 13 when the ECtHR issued the judgments. Given that they had resided in France with their intended parents since shortly after they were born in the USA, the appellants did not succeed in proving that the impact on their family life, caused by the lack of recognition in France of their legal parentage with respect to the children, was insuperable, nor that it had prevented them from enjoying the same in France. On the contrary, the two families had been able to return to France shortly after the births, they lived together in that country in circumstances comparable to those of other families and there was nothing to suggest that the children ran the risk of being separated from the appellant couples by the French authorities<sup>74</sup>.

74. Cf. with 'Paradiso and Campanelli v. Italy' (case n.° 25358/12), resolved by Sect. 2 of the ECtHR on 27 January 2015 and reversed by the Grand Chamber on 24 January 2017. It is also a case of commercial surrogacy, although with some very special connotations that distance it from the two French cases and explain its different fate. The case affects an Italian couple who signed a surrogacy agreement with a Russian agency, whereby a woman from that country gestated a baby conceived from donated gametes. On the birth certificate issued in Russia it stated that the child was the son of the Italian couple. However, back in Italy the authorities refused to transcribe the certificate. Given that the couple in question not only infringed the prohibition then in force of resorting to heterologous fertilization (article 4.3 *Legge* of 19 February 2004, n.° 40), later declared unconstitutional by a Constitutional Court ruling of 9 April 2014, but also the law on matters of adoption, a children's court declared the child to have been abandoned and that it was eligible for adoption, as its biological parents were unknown and the commissioning couple could not be considered as such according to Italian law. Successive Italian courts refused to allow the child to be fostered by the commissioning couple and, aged almost eight months, he was handed over to social services and declared eligible to be fostered, and all contact between the child and the commissioning couple was prevented. More than a year later, the child was taken in by a family, awaiting adoption. Sect. 2 of the ECtHR firstly considered that there was an infringement of private and family life (article 8 ECHR) and judged the solution adopted by the Italian authorities to be disproportionate. On this point the Court's statement is especially important, according to which: "the reference to public order cannot become a *carte blanche* to justify any measure, given that the obligation to take into consideration the best interests of the child is the responsibility of the state, regardless of the nature of the bond, parental, genetic, or any other kind" (§ 80). The ECtHR ended by ordering the Italian state to pay the appellant couple €20,000, for the moral damage caused. However, the Grand Chamber reversed the former judgment and the court finally held by 11 votes to six that there had been no violation of article 8 ECHR. Despite admitting "the impact which the immediate and irreversible

The main difference that can be observed between the findings of the ECtHR and the Spanish Supreme Court is the value they attach to the best interests of the child: while the ECtHR places it above public order, the Spanish Supreme Court gives precedence to public order and therefore prevents surrogacy agreements from having legal implications in Spain. The European court's message is clear: the child's best interests takes priority in the definition of public order. How might the Spanish case fare in Strasbourg? Although it could be argued that reference to the paternity claim and adoption by the Spanish authorities marks the difference with the cases resolved by the ECtHR and envisages a possible punishment of the Spanish state, it must not be forgotten, as I made clear in point 2.2.4. of this chapter, that this constitutes a "second-best" solution. The non-recognition of these agreements' immediate effectiveness, and recourse, instead, to a paternity action followed by adoption, means that for a while the children have no specific legal parentage, with all the risks that implies. In its two findings against France, the ECtHR seems to underline the genetic bond existing between the intended father and the girls, which enables it to associate biological paternity with identity, and, consequently, with private life<sup>75</sup>. This raises the question of whether the ECtHR will continue to demand this bond between children conceived in this way and at least one of the intended parents<sup>76</sup>.

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separation from the child must have had on the applicants 'private life', the court concluded that "Agreeing to let the child stay with the applicants, possibly with a view to becoming his adoptive parents, would have been tantamount to legalising the situation created by them in breach of important rules of Italian law" (§ 215). On the irony of the solution offered by the Sect. 2 of the ECtHR, given that in the end it is the child's interest that prevents him from being handed back to the commissioning couple, see Beaumont, P. and Trimmings, K. (2015), "Recent Jurisprudence of the European Court of Human Rights in the Area of Cross-Border Surrogacy: Is there still a Need for Global Regulation of Surrogacy?", p. 14 (working paper available online).

75. In both cases, given the intended mother's fertility problems, the embryos created with eggs from a donor and sperm from the male member of the couple were gestated by an American woman for commercial purposes.
76. However, after the first edition of this collective work and before its translated version, on 10 April 2019 the Grand Chamber of the ECtHR issued an Advisory Opinion concerning the recognition in domestic law of a legal parent-child relationship between a child born through a gestational surrogacy arrangement abroad and the intended mother, requested by the French Court of Cassation in relation to the *Mennesson* and *Labassee* cases regarding the position of intended mothers who, differently from intended fathers, did not contribute genetically to the child. The Advisory Opinion is relevant as the court reinforces the thesis according to which the child's right to respect for private life within the meaning of article 8 of the ECHR requires that domestic law provide a possibility of recognition of a legal parent-child relationship with the intended mother, designated in the birth certificate legally established abroad as the "legal mother" and concludes that this same right does not require such recognition to take the form of entry in the register of

Nor should the fact that in the Spanish case the appellants were a same-sex couple, not affected by infertility in the medical sense, but structurally, distance it from the cases resolved by the ECtHR<sup>77</sup>. For male couples the only possibility of having a child in the context of a common parental project that has a biological bond with one of its members is surrogacy. Now that heterosexual couples can gain access to this practice, although abroad, I see no reason to prevent those of the same sex from using it. To judge by the reactions in Spain after the ‘Mennesson’ and ‘Labassee’ judgments, it seems that reality will ultimately prevail. Despite that, the Supreme Court, in its cited decree of 2 February 2015, confirming the Supreme Court’s judgment of 6 February 2014, fearing a possible condemnation of Spain, distances itself from the French cases, arguing that the French state did not grant the parties the possibility of establishing the children’s legal parentage by way of adoption and a legal claim, a possibility that *was* granted to the appellants by the Spanish state. This thesis, as I have already pointed out, is not without its problems if we consider the child’s best interests, the only one truly prevalent in the case<sup>78</sup>.

## 5. FINAL CONSIDERATIONS

### 1. MORAL AND BIOETHICAL NEUTRALITY

In various pronouncements, the object of which is access to particular assisted reproduction techniques by citizens of a member state, the ECtHR provides incentives for these citizens to access, in another legal system, assisted reproduction techniques not permitted in their own<sup>79</sup>. This case law, which in turn ends up promoting more liberal attitudes internally in states, is particularly detrimental to less wealthier citizens. Whether or

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births, marriages and deaths of the details of the birth certificate legally established abroad; another means, *such as adoption of the child by the intended mother*, may be used provided that the procedure laid down by domestic law ensures that it can be implemented promptly and effectively, in accordance with the child’s best interests. The Advisory Opinion is accessible, in English and French, from the ECtHR database (HUDOC).

77. In this respect, see Cahn, N. R. (2009), *Test Tube Families (Why the Fertility Market Needs Legal Regulation)*, NYUP, New York-London, pp. 134-135.

78. However, see the update and considerations made *supra* at note 76.

79. See the cases ‘S.H. and others v. Austria’ (§ 114), ‘Mennesson and Labassee v. France’, mentioned in sections 2 and 3.2.4, or ‘Parrillo v. Italy’ (case 46470/11, Grand Chamber 27.8.2015), on the prohibition by Italian law of the donation of embryos for research purposes (§ 178).

not the system will stand for these double standards is a disturbing question, especially given the domestic passiveness of legislators<sup>80</sup>.

In a globalized context, in which cross-border reproduction already makes it possible to avoid more restrictive laws, it is necessary to consider the purely symbolic role that many countries' laws could end up playing in matters of assisted reproduction techniques. Tolerance towards situations created validly abroad is not an acceptable solution if we bear in mind the risks associated with cross-border reproduction, especially the exploitation of citizens of third countries by those of developed countries. Ultimately, the pragmatic approaches to the issue, which choose to maintain the restrictive internal policies of assisted reproduction techniques because cross-border reproduction already makes it possible to gain access to them elsewhere, are based on a moral neutrality that is intolerable from the bioethical point of view, given that it has clearly negative collateral effects, such as the commercialization of a sector that due to its peculiarities cannot be left to the free market, besides the fact that it avoids a public debate that is essential in matters with a clear political and ethical dimension<sup>81</sup>. In this context, presenting the avoidance of restrictive laws as a *fait accompli*, which is an inevitable consequence of cross-border reproduction, is a serious mistake. It is too, from a human rights perspective, to punish the citizens who travel to another country to gain access to techniques prohibited in their own. These prohibitions may reinforce the discrimination against certain groups of people who request certain treatments outside their own country or it may even oblige them to go underground<sup>82</sup>.

Against the possibility of placing limits on cross-border reproduction that come into conflict with human rights, the need is imposed to reflect on the advisability of permitting surrogacy in Spain, while general guidelines and international instruments are passed to ensure that access to assisted reproduction techniques has a place in every legal system in

80. See Beaumont and Trimmings, "Recent jurisprudence...", pp. 10-14. In Spain, see Álvarez González, "Gestación por sustitución...", pp. 2, 18-20.

81. See Van Beers, B. (2014), "Is Europe 'Giving in to Baby Markets'? Reproductive tourism in Europe and the Gradual Erosion of Existing Legal Limits to Reproductive Markets", *Medical Law Review*, vol. 23(1), pp. 103-134.

82. The extraterritorial nature of the laws constitutes, in any case, an isolated strategy followed to date by just two countries, Turkey and Australia (states of New South Wales and Queensland), see Alkorta Idiákez, I. (2015), "La regulación de la reproducción asistida: evolución y tendencias actuales en el mundo", in Benavente Moreda, P. and Farnós Amorós, E. (eds.), *Treinta años de reproducción asistida en España: una mirada interdisciplinaria a un fenómeno global y actual*, *Boletín del Ministerio de Justicia*, n.º 2179, pp. 79-81 (available online).

minimum conditions of health and equality<sup>83</sup>. Nevertheless, the ambivalent positions held on this matter, like the one defended by the European Parliament, do not guarantee, in the short term at least, a univocal response in this direction<sup>84</sup>. In this context the *fait accompli* policies or ex-post solutions that arise when a baby conceived after resorting to surrogacy is already in the legal system of the intended parent(s) home country, must be prevented from displacing the ex-ante debate, internally indispensable, about whether surrogacy should be regulated in domestic law. In the event of an affirmative response the debate must revolve around *how*. With this, we are back to the original discussion, which arose in the USA in the late 1980s as a result of the case of Baby M., about the validity of surrogacy agreements<sup>85</sup>. Few issues with such a clear gender bias, with the exception of prostitution perhaps, are capable of generating such conflicting opinions.

## 2. SHOULD SURROGACY BE PERMITTED IN SPAIN?

My answer to the question at the beginning of this paper is a 'yes', although prudent. Why should surrogacy be permitted? Because, from my point of view, the law is a dynamic instrument that must respond to the demands of society. And in Spain there is a real demand in this respect. In the current description of surrogacy agreements in the Spanish legal system the recourse to "attenuated public order" by labour courts, including the 3rd Chamber of the Supreme Court, is significant. They have opted to recognize paternal leave to individuals or couples who resorted to surrogacy abroad<sup>86</sup>. Also significant is the existence of an Order by the DGRN that since 2010 has made it possible to grant these agreements civil law implications in Spain in matters of legal parentage<sup>87</sup>. In this context, and as part of an altruistic model consistent with the 1997

83. See Trimmings; Beaumont, "Parentage and Surrogacy...", pp. 281-282; Penasa, S. (2013), "Converging by Procedures: Assisted Reproductive Technology Regulation Within the European Union", *Medical Law International*, vol. 12(3-4), pp. 300-327, on pp. 323 and 325.

84. The parliament's initial position was to guarantee clearly defined legal parents and civil status for the child conceived in these circumstances: see *A comparative study on the regime of surrogacy in EU Member States*, 2013 (available online). A report by the same parliament, published in 2015, advocates the prohibition of a practice that in its view infringes women's dignity: see paragraph 114 of the Annual Report on Human Rights and Democracy in the World 2014 and the European Union's policy on the matter.

85. On this point, I refer to section 1 of this chapter.

86. See note 34 of this chapter.

87. See section 1.1 of this chapter.

European Convention on Human Rights and Biomedicine<sup>88</sup>, I consider that it should be possible to subject surrogacy agreements to the models of contract law<sup>89</sup>. As I have already said in this chapter, at the moment surrogacy cannot be classed as an agreement contrary to Spanish public order and, consequently, to the general limits of contracting to which article 1255 of the Spanish Civil Code alludes. Nor is recourse to the category *res extra commercium* (article 1271 CC) any use, which has typically made it possible to remove goods and services like those described here from the contractual model. Today, this category poses more challenges than ever, especially in relation to organs, tissues, fluids and genetic material, the donation of which Spanish legislation already allows, under certain conditions<sup>90</sup>.

The permissive model is, moreover, consistent with the prevailing concept of parentage, based more on intention than on biology, and in which surrogacy is just another form of legal parentage by will<sup>91</sup>. At the same time, the renunciation of maternity entailed in these agreements is nothing new in Spain, given that –differences aside– the donation of gametes also includes an implicit renunciation of legal parentage (article 8.3 of Act 14/2006) and this same renunciation is the basis for adoptive parenthood (articles 180.4 CC and 235-49.2 CCCat).

One of the most important basic objections when the regulation of surrogacy is considered in Spain is the fear that this practice may allow single men and male couples to gain access to paternity<sup>92</sup>. It is also feared that it may be accessed for banal reasons, such as avoiding having to go through a process of gestation for aesthetic reasons, avoiding discomfort, or a greater focus on work. These ‘slippery slope’

88. “Article 21. Prohibition of financial gain. The human body and its parts, as such, must not be the object of financial gain”.

89. An economic analysis of the law states that “a certain kind of regulation of these ‘markets’ could possibly be admitted for the purpose of avoiding excesses”: see Bullard González, A. (2006), “¿Qué puede ser objeto de un contrato? Sobre alquileres de vientres, madres sustitutas, prostitución, pornografía, drogas y otros postres”, in Bullard González, A., *Derecho y Economía. El Análisis Económico de las Instituciones Legales*, 2nd ed., Palestra, Lima, pp. 287-313, on p. 303.

90. Arroyo Amayuelas, E. (2016), “Componentes del cuerpo humano y material genético: superar la condición de *extracomercium*”, paper presented at the Symposium *El derecho de propiedad en la construcción del derecho privado europeo: índices, sistemas adquisitivos y objetos*, Faculty of Law – University of Barcelona, 9 and 10 June.

91. On this point, see the paragraph that begins section 4 of this chapter and my article “La filiación derivada de reproducción asistida...”.

92. In 2013 it was estimated that 85% of the Spaniards who were travelling to the USA to gain access to surrogacy were doing so as a heterosexual couple, while male couples and single men made up the remaining 15%: see my paper “Surrogacy arrangements...”, p. 69.

arguments, always present when we analyse questions with a marked bioethical component such as reproduction derived from resorting to assisted reproduction techniques<sup>93</sup>, must no longer delay the debate about the regulation of surrogacy in Spain. It is a debate that must be public because it requires a pronouncement on who should be able to gain access to paternity and maternity, and in what circumstances, and ultimately about what the fate of the children thus conceived will be if finally the intended parent(s) do not want to or cannot take care of them.

While this permissive approach, although based on altruism, may be classed as utilitarian, pragmatic or relativist from the moral point of view, prohibiting or not granting validity to surrogacy, besides ignoring the social reality, implies admitting the fallacy that all surrogacy agreements are, per se, exploitative for the surrogate and harmful for the baby. This standpoint assumes that the consent given by the surrogate is not, nor can it be under any circumstances, informed consent. The principal mistake in this attitude lies in considering the consent of a Californian surrogate with an average socioeconomic level to be as uninformed as that of a surrogate from the Indian region of Madhya Pradesh, recruited in a “baby farm”<sup>94</sup>. This point of view prejudices, moreover, the interest of a child as yet unborn, with respect to which it cannot yet be stated what its interest will be, without falling into a paradox<sup>95</sup>.

Making a case for regulating surrogacy does not imply accepting commercial surrogacy, as there are goods and services that must be removed

93. Warnock, M. (2002), *Making Babies: Is There a Right to Have Children?*, Oxford University Press, Ontario, Canada, pp. 51-52.

94. The media has contributed to this stereotyped, unitary, unnuanced view of surrogates, not only insinuating that any surrogacy agreement is exploitative, by presenting as widespread the situation of poverty in which some of these women doubtlessly find themselves, but also by transmitting a biased view of the phenomenon, presenting only the case of those who resort to surrogacy in the USA and gain access to a fully informed surrogate, who has carried babies for others on previous occasions and who says she is “happy” carrying for others. This is the view offered, for example, by the report of the TV3 programme *30 minuts*, entitled “Nens que no vénen de París”, retrieved from <http://www.ccma.cat/tv3/alacarta/30-minuts/nens-que-no-venen-de-paris/video/5557406/>, consulted on 2 June 2016.

95. When a particular intervention may lead to the existence of a person, the arguments based on their welfare are problematic to say the least. Thus, the decision to bring a child into the world or not is always meaningless in the face of an objection based on its best interests, as it implies either not bringing it into the world, or bringing a different individual into the world: see Parfit, D. (1984), *Reasons and Persons*, Oxford Paperbacks, Oxford, pp. 358-359.

from the strict laws of the market if one wishes to avoid injustice, corruption and exploitation<sup>96</sup>. Obviously, the defence of a non-commercial model will mean, as happens in the United Kingdom, the number of surrogates failing to match demand, but this is a limit inherent to any regulated model of access to assisted reproduction techniques, and it involves respecting the symbolic value that laws have in matters as sensitive as the one being analysed.

These same considerations can be made with respect to the advisability of doing away with the traditional rule of the gamete donor's anonymity: although a legislative reform in this respect may negatively affect the number of donors, I consider that its potential reduction is not an argument, at least from the bioethical point of view, for still keeping anonymity<sup>97</sup>. Non-regulation, and also a limited regulation of non-remunerated surrogacy, generates shortages on the supply side, which provides incentives for a black market to flourish that is unacceptable in this field for reasons of health and equality. Therefore, with the aim of guaranteeing the surrogate's freely given consent and avoiding the commercialization of human beings, within the altruistic contractual model a compensatory model is proposed similar to the reasonable compensation that in Spain is already envisaged for the donation of gametes (article 5.3 of Act 14/2006), although for obvious reasons the amount of compensation must be greater in the case of surrogacy. Although in practice this compensation often exceeds the limits of what is *reasonable*, especially with reference to the *donation* of eggs<sup>98</sup>, this risk, in both the cases of egg donation and of surrogacy, is one more argument for ensuring that consent really is *informed* consent, through its regulation. Informed consent is not truly controlled if, as happens in Spain in relation to egg donation, or in some of the countries where surrogacy is practised, the state lets clinics and intermediaries do as they wish, in a virtually unregulated

96. Sandel, M. J. (2012), *What Money Can't Buy. The Moral Limits of Markets*, Farrar, Straus and Giroux,.

97. Alkorta Idiakez, I. and Farnós Amorós, E. (2017), "Anonimato del donante y derecho a conocer: un difícil equilibrio", *Oñati Socio-Legal Series*, vol. 7, n.º 1, retrieved from <http://ssrn.com/abstract=2782321>, consulted on 27 May 2020. In this same line, see the reports issued by the Catalan Committee on Bioethics (2016) and the Spanish Committee on Bioethics (2020): [https://canalsalut.gencat.cat/web/.content/\\_Sistema\\_de\\_salut/CBC/recursos/novetats/arxius/dret\\_a\\_coneixer\\_origens.pdf](https://canalsalut.gencat.cat/web/.content/_Sistema_de_salut/CBC/recursos/novetats/arxius/dret_a_coneixer_origens.pdf), <http://assets.comitedebioetica.es/files/documentacion/Informe%20del%20CBÉ%20sobre%20el%20derecho%20de%20los%20hijos%20nacidos%20de%20las%20TRHA.pdf> consulted on 29 May 2020.

98. Itziar Alkorta warned of this risk in 2006, "Donación de óvulos" (Egg donation), in *El País*, 28 March (available online).

situation<sup>99</sup>. As I see things, there is room in the altruistic model for compensatory proposals like those based on compensation for the loss of income suffered by the surrogate if she was working when she agreed to gestate for another, as well as her reasonable living expenses, and medical expenses and other pregnancy-related ones. On the other hand, other proposals, such as those based on maximum compensation corresponding to three times the inter-professional minimum wage in the country where the surrogate normally resides, for the nine months of pregnancy and the three post-partum<sup>100</sup>, are debatable as they present greater risks of exploitation, especially in women out of work and/or in a situation of poverty.

The comparison between surrogacy and “baby-selling” is unfortunate because it ignores that the two realities stem from different presuppositions: in surrogacy there is an agreement prior to conception between the surrogate and the intended parent, and the wishes of the latter are essential for conception to take place, while in “baby-selling” business is done with a human being that has already been born. At the same time, seeing as I consider that surrogacy must be distinguished from adoptive parenthood as an institution for the protection of children, the requirement that at least one of the intended parents, if they are a couple –or the individual, if it is a single person– should supply their genetic material if possible, and for the surrogate not to make any genetic contribution, once again distances surrogacy from “baby selling”. In turn, this requirement facilitates the resolution of possible cases of a change of mind by the surrogate, who for example refuses to hand over the baby, or by the intended parents, due for example to them getting divorced<sup>101</sup>. Beyond their repercussions in the media, these cases are anecdotal<sup>102</sup>. Despite this low probability, which is currently thought to be even lower, when almost 100% of surrogacy agreements involve gestational surrogacy the

99. Recently the Spanish press has echoed the lawsuits brought by two Spanish couples against the Barcelona-based company Subrogalia, which was creating embryos in a clinic in Barcelona without the Ministry of Health’s authorization and sending them abroad to be transferred to a surrogate. The company alleged that it was rescinding the contracts as a consequence of the legislative changes that had taken place in Mexico, without returning to the couples the sums of money that they had paid in advance: “He hipotecado mi vida por un hijo que no tengo” (I have mortgaged my life for a child I do not have), *La Vanguardia*, 18 May 2016 (available online).

100. Trimmings and Beaumont, *International Surrogacy...*, pp. 544-545.

101. In Thailand, a baby with Down syndrome conceived via surrogacy was abandoned by an Australian couple, who nevertheless kept his twin sister: “Calls for international surrogacy rules after Thai Down’s case”, *Family Law Week*, 4 August 2014 (available online).

102. See Lamm, *Gestación por sustitución...*, pp. 290-291.

law must envisage solutions, especially because if the surrogacy ends successfully there will be a baby whose possible lack of protection will have repercussions for society. Although the contractual model of remedies in the case of non-compliance does not quite match this context, allowing the revocation of these agreements at any time contributes to a stereotyped view of women, based on the exaltation of experiences like pregnancy and childbirth<sup>103</sup>, and it may also be contrary to legal certainty and, most important of all, the child's best interests, especially when one party intends to revoke the agreement after it is born. Therefore, a period of between six weeks, consistent with the period granted to the biological mother to agree to adoption<sup>104</sup>, and the six months post-partum, consistent with the period envisaged in British law to request the paternal order in favour of the intended parent<sup>105</sup>, could be useful for confirming the validity of the agreement<sup>106</sup>. This position assumes that surrogacy is not a normal contract whose object is ordinary goods and services. Precisely for this reason, the surrogate's right to choose to have an abortion must be protected especially, and it must not be restricted or penalized, since otherwise it would mean unwanted interference in her physical safety that would affect her freedom of choice.

As has been clearly seen in this chapter, the lack of internal regulation no longer stops citizens from one country moving to another to gain

103. See the references cited in note 7.

104. Article 5.5 of the European Convention on the Adoption of Children (revised), issued in Strasbourg on 27 November 2008 and in force in Spain from September 2011. This is also the option followed on surrogacy by Sect. 54(7) of the British HFEA, according to which "the agreement of the woman who carried the child is ineffective for the purpose of that subsection if given by her less than six weeks after the child's birth". See also note 24 of this chapter.

105. See note 23.

106. Another matter altogether is that of whether any compensation could be envisaged for the out of pocket expense and the loss of income suffered by the intended parents when the surrogate refuses to hand over the baby, bearing in mind especially that one of them at least, if not both, will have supplied their gametes. Although this is an issue that will have to be resolved by the judge depending on the specific case, given that it has to do with the establishment of legal parentage, the possibility should be studied of compensation in favour of the intended parents if the agreement does not eventually become effective. On this point, although compensations for the "loss" of pre-embryos or genetic material by assisted reproduction centres are exceptional (see note 511 of my monograph (2011), *Consentimiento a la reproducción asistida. Crisis de pareja y disposición de embriones*, Atelier, Barcelona, p. 168), ideas favourable to it are gaining acceptance: see Fox, D. (2016), "Reproductive Negligence", *Columbia Law Review*, vol. 117. However, any possible regulation on the issue should bear in mind the influence of a possible compensation on the surrogate's free consent, especially regarding her right to choose to have an abortion.

access to a practice that is not permitted or has no legal implications in their own country. For the purpose of avoiding contributing to the commercialization of the phenomenon, making certain countries “reproductive paradises”, more and more legal systems are permitting altruistic surrogacy but they subject it to the existence of some link or point of connection with the legal system<sup>107</sup>. These measures, along with those consisting of the criminalization of the agencies that act as intermediaries between the intended parents, the surrogate and the centre that practises the surrogacy, must be taken into account by any proposal for regulation.

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107. Thus, Sect. 54(4)(b) of the British HFEA requires that, at the time of application and issuance of the parental order, at least one of the members of the commissioning couple must have their residence in the United Kingdom. For its part, article 1458 of the Greek Civil Code requires that, in order to gain access to surrogacy in that country, the surrogate and both intended parents must be Greek citizens or permanent residents, along the same lines as the Portuguese regulation and the Mexican one, approved at national level and in some states in particular. On these more recent regulations, see notes 18, 20 and 21.

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# Organ and Tissue Donation and Transplantation: Altruism or Business?

CHLOË LLESTÉ

## 1. INTRODUCTION

These days, organ transplantation is internationally considered to be the therapy of choice in end-stage organic diseases causing permanent organ failure.

Unlike the other fields of medicine, transplantation, of organs, tissues and cells, has the peculiarity of not depending solely on technological and pharmacological progress, but principally on society. Organ, tissue and cell donors are citizens who altruistically donate part of their body so that it can be transplanted to other citizens<sup>1,2</sup>. This means that a great variety of factors influence the donation process, from the organization of the health system to the education of the professionals, the religious faith of society, and the legal framework of this activity. The experience accumulated and the results obtained in the last 30 years have led to an increase in indications for transplantation, which means a greater demand for organs. Bearing in mind that in most parts of the world organ donation has not increased to the same extent, the lists of sick people waiting to receive an organ are constantly growing<sup>3,4</sup>. This shortage of organs has

1. Manyalich, M. (1999), "Organization of Organ Donation and Role of Coordinators: Transplant Procurement Management", *Saudi J Kidney Dis Transplant*, 10 (2), pp. 175-182.
2. Manyalich, M., Valero, R. and Páez, G. (2007), *Transplant Coordination Manual*. tpm/Fundació IL3 – University of Barcelona, Barcelona.
3. Organización Nacional de Trasplantes, retrieved from <http://www.ont.es/infesp/Paginas/DatosdeDonacionyTrasplante.aspx>.
4. World Health Organization (WHO), Data and Statistics, retrieved from <http://www.who.int/research/en/>.

become a serious problem in the health systems of the most developed countries<sup>5,6</sup> and it is an undeniable reality in most countries.

The latest figures published by the World Health Organization (WHO) in the Global Observatory on Donation and Transplantation (GODT) calculate that around 120,000 organs are being transplanted each year in the world, less than 10% of the estimated needs. Moreover, the majority of these transplants are performed with organs from living donors<sup>7</sup>. The imbalance between the high demand for transplants and the lack of organ donors in the majority of countries in the world is conducive to the trafficking of organs, tissues and cells and the existence of illegal mechanisms that take advantage of this need.

According to the WHO's Organs Watch, of the 70,000 kidneys transplanted every year in the world, 20,000 come from living donors, 10,000 of which are obtained illegally<sup>8</sup>. Sick people waiting for an organ traveling to countries where organs can be purchased from living or deceased donors, or their illegitimate inclusion on local waiting lists, are some examples of these illegal actions.

The desperation of the sick people who cannot be treated in their own countries due to the lack of an efficient organ donation programme leads once again to the exploitation of the most disadvantaged and vulnerable people. International bodies, such as the WHO and The Transplantation Society (TTS), have voiced their concerns about this situation as it increases inequality and infringes basic human rights.

A large number of portals are currently accessible on the Internet that facilitate this kind of transaction and put individuals or intermediaries from different countries in contact with one another. Basing themselves on individual freedom, many countries continue to legitimize the existence of these markets.

In the international sphere, only in the 2010s did attention begin to be paid to this situation. In recent years articles, cases and field studies have been published identifying the networks, the trials of surgeons, nephrologists, organ brokers, "kidney hunters", recipients and sellers of organs.

5. IRODAT – International Registry of Organ Donation and Transplantation, retrieved from [www.tpm.org](http://www.tpm.org).
6. Mañalich, R.; Páez, G.; Valero, R. and Manyalich, M. (2007), "IRODAT: the International Online Registry for Organ Donation and Transplantation 2007", *Transplantation Proceedings* 2009, July-August, 41 (6), 2030-2034.
7. Global Observatory on Donation and Transplantation (GODT) (2014), *Organ Donation and Transplantation activities 2012: Organización Nacional de Trasplantes*, 7 January.
8. [www.who.int](http://www.who.int).

The complex nature of these illicit networks explains why it is so hard to tackle them. The obstacles for putting an end to them include differences in legal jurisdictions, incompatible laws and the immunity of the professionals involved<sup>9</sup>.

The solution to this worldwide problem has to be the local development of organ donation systems. This activity must be regulated at governmental level and introduced in hospitals by healthcare professionals to allow citizens to become, after their death, altruistic donors of organs and tissues. Spain has been a world leader in organ donation for 25 years, reaching a rate of 39 donors per million inhabitants in 2015. The Spanish Model in Organ Donation has become an international point of reference. With its educational programme, Transplant Procurement Management (TPM), supported by the University of Barcelona, the Donation and Transplantation Institute (DTI), a not-for-profit foundation that has been acknowledged by the National Transplant Organization (ONT) and the WHO, conducts international cooperation projects to adapt this model to other countries so that they can become self-sufficient in the obtainment of organs for transplantation and thus fight organ trafficking.

## 2. DEFINITIONS

It is important to point out the work that has been done since the Declaration of Istanbul in May 2008<sup>10</sup> to define and classify the different forms of exploitation of human beings for the purpose of removing organs, tissues or cells. In this first multilateral declaration it was agreed that organ trafficking included three key elements:

- Action to recruit, transport, transfer or receive living or deceased donors, or their organs.
- A means by which the action is carried out: the use of force or other forms of coercion, abduction, fraud, deception, the abuse of power or of a position of vulnerability, or the payment and/or receipt of money or profits to achieve a person's consent, or that of a third party, in order to gain control over the donor.
- Deliberate human exploitation in order to remove organs for transplantation.

9. Ambagtsheer, F. and Weimar, W. (eds.) (2016), *Pabst Science Publishers*, D-49525 Lengerich, retrieved from [www.hottproject.com](http://www.hottproject.com).

10. "The Declaration of Istanbul on Organ Trafficking and Transplant Tourism", *Transplantation*, 86(8), pp. 1013-1018.

These terms are based on the Palermo Protocol<sup>11</sup>, but the terms used are still ambiguous, given that they are vague and vast. For this reason, the commercialization of human organs and the broad spectrum of practices and ways in which it is carried out continue to arouse controversy and cause confusion in the literature.

As a summary, and with the aim of simplifying the most widely used terms, these are the internationally accepted definitions<sup>12,13</sup>.

- Commercialization of transplantation: a practice in which a human organ is treated as a product, bought or sold to obtain material gain.
- Travel for transplantation: the movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes.
- Transplant tourism: travel for transplantation becomes transplant tourism if:
  - It includes organ trafficking and/or commercialization of transplantation.
  - The resources (organs, professionals and transplant centres) are used to provide patients from another country or region with a transplant, and it is done to the detriment of the country's ability to provide its own population with transplants.
- Organ black market: an illegal organ transplant market that coexists with a legal system of organ donation.

### 3. ILLICIT ORGAN TRAFFICKING PRACTICES

Despite the denials for many years of the existence of practices of human exploitation for the purpose of removing organs for transplantation, in the last ten years work has been done to bring to light the mechanisms, networks and the *modus operandi* of these practices in different parts of the world.

11. United Nations Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, Supplementing the United Nations Conventions Against Transnational Organized Crime, United Nations Office on Drugs and Crime, Vienna, Treaty series, vol. 2237, 2000.
12. European Union (EU) (ed.) (2010), "European Parliament and the Council of the European Union. Standards of Quality and Safety of Human Organs Intended for Transplantation", in L 207/14 Brussels, *Official Journal of the European Union*.
13. Council of Europe (2002), *Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Transplantation of Organs and Tissues of Human Origin*, Strasbourg 24-1-2002.

As a result of these investigations cases and articles have been published that describe the complexity and, in many cases, the sophistication of these transnational conspiracies that involve healthcare professionals, intermediaries, sellers and, sometimes, government institutions.

To understand these conspiracies is it necessary to learn about the profile and the motivations of the different actors involved:

1. Recipients: in some cases they are also identified as “buyers”. There are different reasons why a patient with a chronic disease needing a transplant decides to have one illegally, using organ trafficking, but in all cases it is based on desperation and an attempt to survive. There are patients on a waiting list, or on a dialysis programme, in countries where they find the waiting time too long, patients that have not yet been placed on a waiting list, who are offered a faster “system”, patients who are not in a condition to have a transplant, or patients from countries where transplantation is not offered as a therapeutic option<sup>14,15,16,17</sup>. The majority of these recipients come from countries with a high Gross Domestic Product (GDP) and they obtain the information directly from the healthcare professionals treating them, Internet portals, or relatives and acquaintances who live in countries offering this type of “service”. In Israel, the health system covered expenses for transplants abroad until 2010<sup>18,19,20</sup>.

The results obtained from these transplants have been made public and they show a greater occurrence of post-transplant complications, due mainly to infections. The survival rates of the recipients and of the

14. Berglund, S.S.L. (2012), “‘I had to leave’: Making Sense of Buying a Kidney Abroad”, in Gunnarson, M. and Svenaeus, F. (eds.), *The Body as a Gift, Resource and Commodity: Exchanges of Organs, Tissues and Cells in the 21st Century*, Södertörn studies in practical knowledge, Huddinge, pp. 321-342.
15. Canales, M.T., Kasike, B.L. and Rosenberg, M.E. (2006), “Transplant Tourism: Outcomes of United States Residents who Undergo Kidney Transplantation Overseas”, *Transplantation*, 82(12), pp.1658-1661.
16. Geddes, C.C.; Henderson, A.; MacKenzie, P. and Rodger, S.C. (2008), “Outcome of Patients from the West of Scotland Traveling to Pakistan for Living Donor Kidney Transplants”, *Transplantation*, 86(8), pp. 1143-1145.
17. Higgins, R. (2003), “Kidney Transplantation in Patients Travelling to India or Pakistan”, *Nephrol Dial Transplant*, 18, p. 851.
18. Finkel, M. (2001), “This Little Kidney Went to Market”, *NY Times Magazine*, pp. 1-13.
19. Schepers-Hughes, N. (2006), “Kidney Kin: Inside the Transatlantic Transplant Trade”, *Harvard International Review*, 27(4), pp. 62-65.
20. Muraleedharan, V.R.; Jan, S. and Ram Prasad, S. (2006), “The Trade in Human Organs in Tamil Nadu: the Anatomy of Regulatory Failure”, *Health Econ Policy Law*, 1(Pt 1), pp. 41-57.

organs transplanted are significantly lower than survivals in transplants performed legally<sup>21,22,23,24</sup>.

2. Organ suppliers: also called “donors”, “sellers”, “suppliers”, “commercial living donors” or “victims”. Their main motivation is financial compensation, given their state of poverty, indebtedness or the impossibility of maintaining their families<sup>9</sup>.

The majority of these “donors” come from poor developing countries or those in which there is social and economic inequality. These organ-exporting countries are, according to accessible data, India, China, the Philippines, Pakistan, Bangladesh, Kazakhstan, Ukraine, Russia, Iraq, Jordan, Egypt, Romania, Moldova, Kosovo, Turkey, Israel, Brazil, Colombia, Peru and Bolivia. In most of them the profile is the same: poor young men with a low level of education. Many of these citizens are captured by a person or an agency (normally brokers), or they answer advertisements posted on the Internet by recipients or specialized organizations. These “donors” may be operated on in their own country, where the recipient goes to have the transplant, in the recipient’s own country, or in another country where both (recipient and donor) go to be operated on<sup>25,26,27</sup>.

It is mentioned that for the great majority of them the sale of organs has not improved their financial situation; on the contrary, it has shortened their life expectancy and made their quality of life worse<sup>28,29,30</sup>.

21. Fan, S.T. and Wang, H.B.K.L., “Follow up of Chinese liver transplant recipients in Hong Kong”, *Liver Transplantation*, 15(5), pp. 544-550.
22. Gil, J.; Madhira, B.R.; Gjertson, D.; Lipshutz, G.; Cecka, J.M.; Pharm, P.T. *et al.* (2008), “Transplant Tourism in the United States: a Single-Center Experience”, *Clin J Am Soc Nephrol*, 3(6), pp. 1820-1826.
23. Inston, N.G.; Gill, D.; Al-Hakim A. and Ready, A.R. (2005), “Living Paid Organ Transplantation Results in Unacceptably High Recipient Morbidity and Mortality”, *Transplant Proc*, 37(2), pp. 560-562.
24. Prasad, G.V.R.; Shukla, A.; Huang, M.; D’A Honey, R.J. and Zaltzman, J.S. (2006), “Outcome of Commercial Renal Transplantation: a Canadian Experience”, *Transplantation*, 82(9), pp. 1130-1135.
25. Mendoza, R.L. (2012), “Transplant Management from a Vendor’s Perspective”, *Journal of Health Management*, 14(1), pp. 67-74.
26. Shimazono, Y. (2007), “The State of the International Organ Trade: a Provisional Picture Based on Integration of Available Information”, *Bull who*, 85(12), pp. 955-962.
27. Scheper-Hughes, N. (2000), “The Global Traffic in Human Organs”, *Current Anthropology*, 41(2), pp. 191-224.
28. Budiani-Saberi, D. and Mostafa, A. (2011), “Care for Commercial Living Donors: The Experience of an NGO’s Outreach in Egypt”, *Transplant Int*, 24(4), pp. 317-323.
29. Paguirigan, M.S. (2012), “Sacrificing Something Important: The Lived Experience of Compensated Kidney Vendors in the Philippines”, *Nephrol Nurs J.*, 39(2), pp. 107-117; quiz 18.
30. Navqui, S.A.A.; Ali, B.; Mazhar, F.; Zafar, M.N. and Rizvi, S.A.H. (2007), “A Socioeconomic Survey of Kidney Vendors in Pakistan”, *Transplant Int.*, 20(11), pp. 934-939.

3. Brokers: individuals who facilitate the process and act as mediators between donors, healthcare professionals or centres, and recipients, for a fee.

They may be healthcare professionals, agencies, hospitals or even laboratories that process blood samples for the HLA type necessary to demonstrate compatibility between the donor and the recipient. Brokers can also provide transport, accommodation, documents and other formalities associated with the process<sup>31,32</sup>.

4. Healthcare professionals: surgeons, transplant doctors (nephrologists, hepatologists, cardiologists, immunologists, and others), anaesthesiologists and transplant coordinators are the main healthcare professionals directly involved in these illegal practices. Their main motivation is financial gain and they can work in their own country or travel to perform the operations in other countries.

There are other actors involved in the schemes, such as the hospitals or medical centres where the operations are performed. They are usually private centres, although in some cases they have been found in public hospitals. The medical laboratories where the compatibility tests are carried out have sometimes worked as mediators in the process. There is also the role played by medical insurance companies who have incentivized these illegal practices by partially covering their cost. In some cases even governments have been involved in the schemes.

There are different types and *modus operandi* in organ trafficking. These are the principal cases identified:

#### LIVING DONORS IN THEIR OWN COUNTRY

This is the most common practice and it is performed in both poor countries such as India, Pakistan or the Philippines, and in rich countries like the USA or Israel. In some cases the donor and the recipient are from the same country, and in others the recipient travels to the donor's country, where the operation is performed. The donor has, in all cases, lower economic status than the recipient, and is paid a sum of money.

31. Moniruzzman, M. (2012), "'Living Cadavers' in Bangladesh: Bioviolence in the Human Organ Bazaar", *Med Anthropol Q.*, 26(1), pp. 69-91.

32. Passas, N. (2012), *Cross-Border Crime in the Interface Between Legal and Illegal Actors*, Wolf Legal Publishers, Nijmegen.

## LIVING DONORS TRAVELLING TO THE RECIPIENT'S OWN COUNTRY

In these cases the transplant is performed in a hospital in the recipient's own country, and a living donor is found in another country and brought there by a broker. Healthcare professionals very often hide behind ignorance of this practice, given that donors unrelated to the recipient are accepted and there is no investigation of any financial transactions between them. Most cases of this kind have been recorded in the USA.

## TRANSPLANTS PERFORMED IN THIRD COUNTRIES WITH LIVING DONORS

These conspiracies, more complex, are more difficult to identify since in some cases none of the actors involved is from the country where the transplant is performed. They may be carried out in recognized centres to which the recipient goes with his or her presumably altruistic living donor. For example, citizens of Saudi Arabia have done this for many years, travelling to acknowledged centres in the USA or India to have a transplant together with a living donor from another country. On other occasions, the transplant centre is not known and it performs the transplant illegally, as was the case in Kosovo, where a Turkish surgeon was working for an Israeli broker who brought recipients mainly from Israel to a clinic in Kosovo, and the living donors came from Eastern European countries. In South Africa, another Israeli broker put recipients from Israel in contact with Brazilian and Romanian donors, and the transplants were performed by a team of South African surgeons.

## INCLUSION ON FOREIGN WAITING LISTS

Some organs can only be obtained from cadaveric donors (heart and lungs, chiefly) and in the case of the liver the transplant of the whole organ is sometimes indicated, whereby a liver from a deceased donor is also needed. Cadaveric donation is far more regulated than inter vivos donation, and recipients residing in, or citizens of, the country are usually included on waiting lists by healthcare professionals. The best-known case was that of Israeli citizens who with the help of their national health system were included with false identities on Colombian waiting lists. The surgeons and centres involved in this scheme were acting without the consent of the national authorities.

## MANIPULATION OF WAITING LISTS

Organ adjudication algorithms are very complex and they include analytical data to identify the seriousness of the condition of patients on waiting lists. These and the movements that are made on them are regulated by the State bodies responsible for organ donation and transplantation. However, the analytical data entered are hard to verify and the system is based on trust and the professionalism of the medical teams. In Germany, in the last three years several cases have been uncovered of fraudulent manipulation of analytical results by healthcare professionals for the purpose of giving patients an unfair advantage and prioritizing their transplant.

## CADAVERIC DONORS ON DEMAND

Up to January 2015, the legal source of organs for transplantation in China was people sentenced to death in that country. Due to the increase in cases of transplant tourism in China from 2000 onwards by recipients from other countries (USA, Saudi Arabia, UK, Germany, Israel, Japan) and the booming business that it represented for hospitals, in 2009 the Chinese government prohibited foreigners from having transplants in China. From that moment on work began in hospitals to introduce other systems of voluntary donation by people who had died in the hospitals, and now only this source, voluntary deceased donors and the associated living donors, are authorized in China.

## REGULATED COMPENSATION OF LIVING AND CADAVERIC DONATION

Without being part of what we understand as organ trafficking, there are other practices in which financial compensation for the donation of organs for transplantation is regulated nationally. This is the case in Iran, which during the first Gulf War established financial compensation from the government to unrelated donors who gave a kidney, as an emergency measure due to the destruction of dialysis centres. This practice has persisted, although because donors are paid very little, in many cases the recipient tops it up illegally. In the last ten years Iran has worked intensely on the construction of a national cadaveric donation system based on the public hospitals, and it is producing results.

Another case is Saudi Arabia, where relatives of brain-dead donors are compensated financially in the event of their relative's organs being

donated. In Qatar the relatives' compensation is not financial, but they are offered the chance to enjoy healthcare and other social support. In both cases the families are usually foreign (from Pakistan, Bangladesh, the Philippines, etc.) and they do not have Saudi or Qatari citizenship.

#### 4. PRICES AND FEES

There are huge differences in the payment received by donors for selling their kidney or a piece of their liver in different countries. Also notable are the differences in the fees paid by recipients for transplants. In the study published by the HOTT project, co-funded by the European Commission<sup>9</sup>, these data are reflected:

Payments to donors:

Country	Organ	Payment in dollars
Iran	Kidney	1,219
India	Kidney	1,070
Pakistan	Kidney	1,377–1,600
Philippines	Kidney	2,133–6,368
Bangladesh	Kidney	1,400
Colombia	Kidney	1,712
Colombia	Liver	1,881

Fees for transplants:

Country	Organ	Payment in dollars
India	Kidney	20,000
Pakistan	Kidney	7,271
Egypt	Kidney	35,000–40,000
China	Kidney	42,000
China	Liver	63,000–75,000

#### 5. ETHICAL CONCLUSIONS AND ASSESSMENTS

The organ-trafficking practices described (or people-trafficking for the purpose of removing their organs for transplantation) clearly show that this is a worldwide legal, medical and social problem with a complex solution, which must be approached internationally. However,

it will take too long for regulatory procedures to be applied internationally, and in many cases they will be virtually inoperative. We must unquestionably continue working at this level to reach agreement, and for these crimes to be judged and condemned, but tackling the problem as a medical and technical matter, or one of regional/national organization, seems more practical and effective. If it were possible for patients who need an organ transplant to be operated on as quickly as possible without taking into account their country of residence or financial status, this situation would not exist. Self-sufficiency in organs for transplantation is not achieved without institutional support involving governments. Resources must be allocated to train professionals in this activity and to apply the necessary means in hospitals to identify and assess potential organ donors in order to carry out the process satisfactorily.

Organ trafficking violates the bioethical principles of non-maleficence, autonomy and justice, as well as damaging the integrity of the medical profession and diminishing trust in organ transplantation. For all these reasons a convincing reaction to this situation involving international cooperation and the exchange of knowledge is necessary.

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# The Commercialization of Genetics

CARME BARROT

## 1. USING GENETICS TO DIAGNOSE DISEASES

The study of the human genome has made it possible to understand how genetic inheritance plays a part in people's health or the predisposition that some disorder may manifest in the long run.

A medical solution has not always been found for these illnesses; in some cases preventive control is established in order to act as soon as it manifests and to choose to use less aggressive drugs.

This knowledge has led new entrepreneurs to create new businesses, on the Internet especially, where for a modest price of approximately 300 euros<sup>1,2</sup> a kit can be bought for obtaining samples that will later be sent to an address where susceptibility to one or more diseases will be determined. The latest search results on the Internet enable us to find companies selling a system in which it is the patient-customer who does the tests and obtains the result.

These companies' webpages are usually designed in gentle sober colours, with a predominance of different shades of grey and white, similar to those that are associated with hospitals, medical centres or doctor's surgeries. They give an impression of rigour, seriousness and trustworthiness. But who is actually behind the company? Do they have the necessary knowledge and training to manage the information resulting from the tests? Are they modern-day charlatans?

A typical situation is the company contracted via the Internet that sends a kit for obtaining samples to the home of the customer-patient,

1. Pro forma, retrieved from <http://www.promofarma.com/tellmegen-kit-baby-1ud>, consulted on 27 May 2016.
2. TRKGenetics, retrieved from <http://www.trkgenetics.com/genotest/productos>, consulted on 27 May 2016.

without any kind of control or guarantees of how the sample is being taken. No request is made for informed consent, signed by the person interested in studying their DNA. In any case, what value could a signed piece of paper have without an authorized person confirming the signatory's identity? And in the case of a minor, supposing that they are being cared for by their parents, who has to give consent – the father, the mother, or both of them?

It may well be that not all companies are opportunists and that they really do intend to help possible patients-customers, but how can we tell them apart?

Let us imagine a person diagnosed with a serious disease like cancer, for example. In the age of computers, many people's first step will be to search for information on Internet. Among the results obtained they will find that one of the factors involved in the development of tumours is related to genetics. Company X offers the possibility of doing a genetic study to establish how susceptible the interested party and their family are to suffering this same type of cancer. The person, who is at this time, particularly vulnerable, considers that if their relatives do this study it will provide important information for the treatment and the management of the disease. When the results arrive by email or by post they will be accompanied by a medical report. At no time has company X made contact with the affected person, nor does it have their medical records, nor will it do any monitoring. The person affected will have to use their skill and knowledge in order to manage the information obtained in the best way possible.

## FAMILY TIES

A genetic disease does not only affect its carrier. There is the likelihood of it being transmitted to their children, or of other members of the family also being affected or being carriers.

The reactions of the different family members to a genetic disease may entail psychosocial problems between them, for example arguments and broken relationships.

Establishing the possibilities of transmitting a genetic risk to children and how to manage this information requires professional help, not just for the carrier but the whole family.

Should the prior consent be requested and obtained of the relatives who may be affected by the disease or the anomaly, either as people directly

affected or as carriers, before beginning the information process? We are not talking about presumed consent here, but can a refusal be accepted when there is a risk of transmission to children?

### DOCTOR-PATIENT RELATIONSHIP

The medical code of ethics comes into conflict with these business practices. A doctor has the obligation to personally explain to their patient the results of the tests, to make visual inspections, to explain to them what options they have –in the event of there being any– and to establish a treatment and monitoring schedule if the patient agrees to it. If necessary, the doctor could carry out an exhaustive study of the person, their lifestyle and their relatives, in order to improve the diagnosis and the possible treatment<sup>3</sup>.

There are also laws that limit medical action and the relationship with the patient, especially Law 41/2002, regulating patient autonomy and rights and responsibilities in matters of clinical information and documentation<sup>4</sup>, and Law 14/1986, 25 April, of general health<sup>5</sup>. According to these laws, the patient is entitled to be informed in a comprehensible, sufficient and continual way and to give their informed consent for medical action to be performed on their person.

### GENETIC COUNSELLING

Once the genetic risk has been determined in an individual, a methodology for genetic screening will be established among their closest relatives. Long-term medical records of the person and their family, and a family tree as extensive and truthful as possible, continue to be very helpful elements for deciding on and guiding the genetic study, as well as facilitating risk assessment in each patient.

Predictive testing will only be carried out in patients with a clinical or family history that demonstrates the presence of the genetic disorder. Asymptomatic patients must be given as much information as possible about the risks of suffering the disease, the possibilities of therapy and

3. Consell de Col·legis de Metges de Catalunya. Codi de Deontologia, Barcelona, Ambient Gràfic, 2005.
4. Law 41/2002, 14 November, basic regulator of patient autonomy and rights and responsibilities in matters of clinical information and documentation (BOE 15.11.2002).
5. Law 14/1986, 25 April, General Health (BOE 29.04.1986).

psychological support. In cases where it is advisable, and provided the patient agrees, the person must be monitored and their social environment studied.

The results of genetic counselling will be given in probabilistic terms and in such a way that the patient can fully understand them, especially with regard to the foreseeable consequences for them and their children, so that they can make properly informed decisions.

## CONCLUSIONS

Most of the companies contracted on the Internet will not associate the medical action with genetic counselling. It is not very good for business to have a medical record, psychological support and someone to answer the patient's questions by phone or email 24 hours a day, seven days a week. The easiest thing is to provide simple results with a minimum of interpretation that matches as closely as possible all the scenarios that may arise with the little information that they have.

## 2. FORENSIC GENETICS

Genetics also plays a part in the forensic sciences and legal medicine. Paternity tests and identifications are methodologies used in some criminal cases and form part of the evidence presented to the judge.

In the practice of judicial identification it is understood that genome analysis will be used solely for the purpose of identifying an individual or a piece of evidence. For this reason, the study made can only focus on the markers that aid identification, and those associated with diseases will be avoided. The judge will ensure that the genetic information is not used for any purpose other than the one necessary for the judicial process.

## FORENSIC GENETIC TESTING ON THE INTERNET

The companies offering forensic genetic services on the Internet generally concentrate on paternity, maternity or sibling testing. Those interested obtain the kinship information from two samples and remain anonymous thanks to the distance, the fact that they do not have to be physically present, and that the rest of the family is unaware of it. Prices can vary between 200 and 400 euros to process two samples; on most webpages it is necessary to call first to ask about prices.

Very few of them offer identifications based on two anonymous samples, the problem and a sample for reference. They would be the clearest cases of violation of personal privacy.

Webpages do not always mention that the resulting reports are not valid for presentation to a judge or in the registry office. A high percentage of cases seek information that will be useful to them for divorce proceedings or inheritances and they will need it to be possible for the report to be presented in court. For this an authorized person (police, judicial or medical) has to make an identification with a document (national identity card, passport, driving license, etc.) and a chain of custody is maintained of the samples until they reach the laboratory where they will be analysed. In these cases, companies charge higher rates, between 750 and 800 euros. Information about these can only be obtained by contacting the company. Some pages point out the need for additional identity documents and on only one webpage does it mention the need to certify the chain of custody of each sample to be analysed<sup>6</sup>. The subsequent report is sent by email or post, and in some cases this increases the price by about 10 euros.

## THE IDENTITY OF THE PROFESSIONALS

The first problem is once again the same as in the case of genetic testing for disease: who are the people behind this business?

Do they have sufficient knowledge to do the test and interpret the results? It is a fact that businesses have always existed offering medical or forensic solutions without those in charge having any medical knowledge, but the Internet makes it easy for the people behind webpages to remain anonymous.

## PATERNITY REPORT

The second problem is which persons are entitled to a copy of the report. Let us begin with the fact that DNA is the information that individualizes us and contains the codes of our molecules and their regulators. But that information is shared 50/50 between the biological mother and father (ignoring here mitochondrial DNA, which only comes from the mother), which means that information is not only obtained about one person, but also about their parents, and an undefined part of the rest of the family: grandparents, aunts and uncles, cousins, and so on. This

6. Progeny, retrieved from [http://www.progenie-molecular.com/Paternidad\\_1\\_ES.html?gclid=CNuZlrKN9cwCFa0W0wodJowN4w](http://www.progenie-molecular.com/Paternidad_1_ES.html?gclid=CNuZlrKN9cwCFa0W0wodJowN4w), consulted on 27 May 2016.

means that the study of someone's genome involves not just them, but all their biological relatives too. When a father requests a paternity test about a child without the mother being aware of it, two ethical problems arise:

1. According to the medical code of ethics and the Spanish Civil Code<sup>7,8</sup> the genetic study would always have to be accompanied by the relevant report signed by the person providing the sample. And in the case of minors or dependents, authorization must be given by the legal guardians. This means that fathers and mothers, who have not had care of the child withdrawn, would have to agree to the test being done, and they are moreover entitled to refuse.
2. Everyone involved in the test would be entitled to have a report of the study. In the case of minors or dependents, it would be their legal representatives. Therefore, in the case of a paternity test involving a minor, their legal guardians should also receive a report with the results of it.

## CONCLUSIONS

Performing these tests without the interested parties being present to sign; without consent given for the study to be carried out; and without the identification of the people requesting the test, those providing the samples for the study, and those performing it and reporting the results so that customers-patients can understand them properly – in all these cases the tests are legally null and void.

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  8. Spanish Civil Code.

4. Law 41/2002, 14 November, basic regulator of patient autonomy and rights and responsibilities in matters of clinical information and documentation (BOE 15.11.2002).
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# Emergent Research and Markets: Websites, Apps, Big Data, Biological Samples and Genetic Information

MÍRIAM MÉNDEZ GARCÍA

## INTRODUCTION

This chapter considers some of the practical difficulties that Research Ethics Committees (REC) have to deal with in their daily work as a consequence of the great variety of duties conferred on them by the law and, in large part, by situations unforeseen in it, but which arise in practice<sup>1</sup>. The main situations of conflict that Research Ethics Committees have to resolve in the fulfilment of their legally established duties will be listed.

- The activity of RECs is regulated by different laws:
- Law 14/2007, 13 July, on Biomedical Research (hereinafter, LBR)<sup>2</sup>.
- Royal Decree 1716/2011, 18 November<sup>3</sup>, establishing the basic requirements for the authorization and functioning of biobanks for the purposes of biomedical research and the processing of biological samples of human origin, and regulating the functioning and organization of the National Biobank Register for biomedical research (hereinafter, RDLBR).

1. Paper presented in February 2016 in the context of the 10th Seminar on UNESCO's Universal Declaration on Bioethics and Human Rights. Article 21. Transnational practices: the human body in the face of the global market.
2. Law 14/2007, 3 July, of Biomedical Research.
3. Royal Decree 1716/2011, 18 November.

- Royal Legislative Decree 1090/2015, 4 December<sup>4</sup>, regulating clinical trials with drugs, RECs with Drugs and the Spanish Registry of Clinical Studies.
- Regulation (EU) no. 536/2014 of the European Parliament and of the Council, 16 April 2014<sup>5</sup>.
- Royal Legislative Decree 1/2015, 24 July<sup>6</sup>, approving the recast text of the Law on guarantees and rational use of drugs and health products.

These laws confer on Research Ethics Committees (in all their versions, CREC, DREC, REC...) the duty of pondering the methodological, ethical and legal aspects of the proposed research protocol, as well as the balance between anticipated risks and benefits arising from the project. RECs perform the following functions that the said legislation confers on them:

- Assessing clinical trials with drugs and health products.
- Post-authorization studies with drugs.
- Assessing observational studies.
- Acting as a Biobank Ethics Committee.
- Authorizing the exceptional use of biological samples.
- Assessing biomedical research projects.

Furthermore, and aside from the legal requirements that have just been mentioned, they occasionally act at the request of the researchers themselves, for the purpose of validating clinical cases or scientific articles that they wish to publish, because academic journals almost always demand that manuscripts submitted for publication should have been previously assessed by an REC.

Together with the great variety of functions they must perform, there are other elements that make the RECs' job more difficult, such as:

- Committees must analyse extremely complex ethical and legal aspects, something that obliges them to have specialist technical and legal knowledge (apps, human genome).

4. Royal Legislative Decree 1090/2015, 4 December, regulating clinical trials with drugs, Drug Research Ethics Committees and the Spanish Registry of Clinical Studies.
5. Regulation (EU) n.º 536/2014 of the European Parliament and the Council, of 16 April 2014.
6. Royal Legislative Decree 1/2015, 24 July, approving the recast text of the Law on guarantees and rational use of drugs and health products.

## 11. EMERGENT RESEARCH AND MARKETS: WEBSITES, APPS, BIG DATA, BIOLOGICAL...

- The technical and material resources that RECs have available are clearly insufficient for tackling the volume and the complexity of the cases they have to assess.
- The negative external perception of the RECs' duties, which are sometimes considered to be a mere formality or an obstacle to be overcome by researchers.

Therefore, the large number of duties that they have to fulfil, together with the technical difficulties, often oblige RECs to analyse practical cases for which the law offers no solution whatsoever. The situations that arise most frequently are described below:

### 1. ANALYSIS OF RESEARCH PROJECTS WITH WEBSITES AND APPS

- The use of information technologies in research is causing an increasing number of projects to include apps or websites, either for their evaluation or for the use of apps and websites as elements or tools of the research project.
- When a project that consists of an app is assessed, the Committee has to deal with technical elements that make the analysis of the project more difficult and increasingly complex problems of confidentiality arise.
- It must be noted that approval of the research project is not the same as approval of the app, since its use, once it has been placed on the market, will contain other technical, financial and normative elements beyond the Committee's scope and powers.

### 2. TREATMENT OF INTERNATIONAL REQUESTS FOR SAMPLES

- The RDLBR envisages, in article 31, the assessment of the suitability of samples coming from abroad, but it does not make any provision in relation to these samples. This poses an obvious problem: how should an REC analyse the projects that request the use of samples coming from abroad?
- The RDLBR envisages three possible regimes: project, collection and biobank. In the case of the last two, and in accordance with the legally established requirements, the Carlos III Institute of Health must be notified of their establishment, which makes the existence

of collections or biobanks abroad very difficult, if not impossible. Samples may only leave Spain to go to a project, as biobanks or collections in the sense of the RDLBR do not exist. This, in practice, is not manageable, since there are requests for samples to be incorporated in repositories based outside Spain.

- The question is, then, what should be done in these cases? Not authorizing samples to leave the country would harm research, but at the same time it must be guaranteed that the samples leaving Spain are processed with the same guarantees as samples processed in Spain, and this will be one of the RECs' objectives. To achieve this goal the recipient must be made to undertake that it will process the samples in conditions similar to those that, for example, would be required in a collection.

### **3. REQUESTS FOR SAMPLES THROUGH INTERMEDIARY COMPANIES**

The LBR is based on the principle of non-remuneration for the donation of samples (article 7) and it expressly establishes the prohibition for source subjects or biobanks to profit from the use of the samples. However, what happens in the cases in which it is neither the source subject nor a biobank that makes a profit through the use of the samples, but a third party acting as an intermediary between the biobank and the laboratories/companies that wish to have those samples, and which charges a fee for putting both parties in contact with one another?

On this point, RECs must consider whether it is licit to establish an intermediation business dealing in human biological samples or whether, on the contrary, this intermediary work is against the law.

### **4. REQUESTS FOR SAMPLES FOR TECHNICAL VALIDATIONS AND OTHER EXTERNAL REQUESTS**

Another of the requests that RECs have to deal with, likewise not envisaged in the law, are requests for samples made directly to a researcher for the purpose of carrying out validation techniques. In this respect, the LBR's statement of reasons establishes that the use of samples for purposes of technical verification and quality control must comply with the principles of the law, but beyond this generic provision the law does not

make any further specification. Therefore, how should these situations be tackled? What must an REC demand?

In these cases a distinction must be made between the internal use of surplus samples for technical verification and quality control, something that is done routinely in the same centre where the patient is being attended to and poses no risk to them at all, and external requests for technical verification and quality control by laboratories.

What should be done in this last case: agree to free use or demand the consent of the donor of the sample as if it were an investigation? In this case, the objective is to avoid healthcare centres becoming sample markets, and consequently minimum precautions must be demanded, such as: the cession of unidentified samples, the return or destruction of samples once they have been used, and the signing of an agreement to transfer the material; or demanding in all cases that the researcher should request the patients' informed consent to hand over samples to biobanks or collections unconnected to the hospital where they are being attended to.

## 5. REQUESTS FOR EXTRAORDINARY USE OF BIOLOGICAL SAMPLES

RECs can authorize the exceptional use of samples for research, following the criteria established in the second transitory provision of the LBR, article 58, and articles 24 and 26 of the RDLBR. Committees therefore have the possibility of exceptionally authorizing the use of biological samples, but always on the condition of compliance with particular criteria.

The table below describes the complex regime of exceptional authorization by RECs, and also the laws that must be complied with. We distinguish the samples prior to the coming into effect of the law from those after it.

### Pre-LBR samples

Type of samples	Anonymized	Identified
Normative reference	2nd TD LBR	2nd TD LBR

Type of samples	Anonymized	Identified
Conditions of use according to LBR	Sample may be used after being submitted to CREC	<p>The CREC shall authorize the use of the sample if the following requirements are met:</p> <ul style="list-style-type: none"> <li>• It is an investigation in the general interest.</li> <li>• The investigation will be less effective or impossible without the data identifying the source subject.</li> <li>• There is no express objection by him or her.</li> <li>• The confidential nature of the personal data is guaranteed.</li> </ul>

#### Post-LBR samples

Origin of the sample	Living donor	Deceased donor
Normative reference	Article 58 LBR Article 24 RDLBR	Article 26 RDLBR
Conditions of use according to LBR	The REC shall authorize the use of the sample if the following requirements are met: There is no viable alternative available for the project.	Samples that come from deceased donors may be used provided there is no record of express objection by the source subject.

Origin of the sample	Living donor	Deceased donor
	<p>It is an investigation in the general interest.</p> <p>The investigation is carried out in the same institution that requested consent for the obtainment of samples.</p> <p>The investigation will be less effective or impossible without the source subject's data.</p> <p>There is no express opposition by the source subject. The donor's confidentiality is guaranteed.</p> <p>The effort, the time, and the human, material and financial means necessary for obtaining consent have been assessed.</p>	<p>If there is no record of express consent given in life by the deceased, and for the purpose of finding out if objection exists, their last wishes will have to be consulted.</p> <p>If there is no record of any Advanced Directives, the relatives and the healthcare professionals who treated them will have to be consulted for the purpose of finding out if there is any opposition to the use of samples.</p> <p>If the project is sensitive and has some direct clinical implication for the relatives, they will additionally be asked if they wish to be informed of the results that are clinically relevant for them.</p>

It is especially difficult to interpret a legally vague concept such as “reasonable effort”; what should be understood by it and how should it be interpreted? An idea for resolving this situation would be to add the consideration of “sensitive project”, being more demanding, with regard to efforts and resources, in projects that involve the obtainment of genetically relevant information for the source subject of the samples, and *a contrario sensu*, being less demanding in projects classed as not sensitive.

## 6. BIG DATA AND GENETIC INFORMATION PROJECTS

Finally, it is necessary to point out that it is increasingly usual for RECs to have to assess big data projects that moreover include genetic data, whose main characteristics are:

- Data obtained through the analysis of human biological samples, and as a result subject to a specific regime of obtainment and conservation.
- Singular data that provide unique information about the source subject of the sample, which affect not only the subject from whom the sample comes but also their relatives.

Genetic data analysis provides a great deal of sensitive information, whereby their use without the proper precautions may give rise to discriminatory behaviours based on this type of information.

In this context special caution must be exercised in the analysis of these kinds of projects, and other prior questions must also be borne in mind, especially if the participation is permitted in them of partners with commercial or financial interests in the use of the data.

In view of this great variety of situations, the importance must be noted of multidisciplinary teamwork for establishing criteria and protocols through which firm criteria may be established for the purpose of always taking the same action in similar situations. Furthermore, collaboration between RECs is urgently needed to homogenize criteria between centres and to standardize forms and documents.

Lastly, due to the recent coming into effect of the RLD on clinical trials, we must ask ourselves what consequences its practical application will have for DRECs. This law changes the system of assessing trials, it being the promoter who will choose the DREC responsible for the approval of the trial. This makes it necessary to consider what criteria the promoter will bear in mind to choose the DREC responsible for the assessment: criteria of speed, of effectiveness or, on the contrary, it will especially bear in mind the more or less restrictive interpretation of the current law by different Committees, which, as has been said, have a lot of room for manoeuvre.

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# The Trend Towards the Commercialization of Human Body Parts and of Privacy in Research with Biological Samples and Data (Big and Small)

ITZIAR DE LECUONA

## 1. INTRODUCTION

Human subject research has to be assessed by independent multidisciplinary ethics committees in order to guarantee its quality and respect for the rights and interests of the people involved and taking part<sup>1</sup>. As a member of two Research Ethics Committees (REC)<sup>2</sup> I have witnessed the growing trend towards the commercialization of biological samples of human origin and of personal data. Human body parts (biological samples included) and personal data (and therefore privacy) are monetized in a society that has opted for scientific and technological research in order to stimulate economic and social progress. Research and scientific and technological applications are news almost every day in the media, including economics supplements, which have lately been describing the impact of digitization on business, the advantages of big data analysis and

1. See, for example, article 12, "Research Ethics Committees", of Law 14/2007, 3 July, of Biomedical Research (LIB).
2. Bioethics Committee of the University of Barcelona (member since 2011) and Research Ethics Committee of the Hospital Clínico in Barcelona (member since 2012), which functions as the same Hospital's Biobank External Ethics Committee, a possibility that the law allows. See article 6.2 b) of Royal Decree 1716/2011, 18 November, *whereby the basic authorization and functioning requirements are established of biobanks for biomedical research purposes and of the processing of biological samples of human origin, and the functioning and organization of the National Biobank Register for biomedical research are regulated.*

the successes of Iberian biotech companies<sup>3</sup>. I consider that practices in research associated with biological samples of human origin stored in biobanks, and the personal data flows in research with public big data, might occasionally not fulfil the established objectives, supposedly addressed to the common good and the public interest.

Bioethical reflection must help to define the problems and the opportunities of the application of scientific and technological progress, and to stimulate an informed debate in society about its impact on human beings –including future generations– and on the environment in which they live. If it does so too late and without a proper analysis and understanding of what we are facing, its contribution will be futile and it will have given rise to unwelcome practices due to the “naivety” of its principles, considered in the abstract. Bioethics will thus have encouraged an institutional discourse of safety and control of research that is far removed from reality. Bioethics will have been unable to adapt to the new scenarios in research and innovation, a facilitator of markets, because it continues to use old patterns for dealing with new and very complex problems in research and medical care.

Identifying commercial interest where there should only be research, and preventing a price from being placed on human beings (broken down into parts and data), is the challenge facing bioethical reflection in research ethics committees. For this chapter, certain practices have been chosen in the context of biobanks, as well as the situation of research into the use of big data. It is my intention to look at new situations for which bioethical analysis is not ready, and for which there is no suitable legal response either. Both these issues urgently need to be resolved. In a context of growing scientific and technological progress, a prior analysis of the ethical feasibility of any and all research and innovation is necessary, so that it really is ethical. The main objective of this chapter is to contribute to the conceptualization of the problems and to make proposals to

3. Among other news items: “La biotecnología ibérica se mete en la gran liga. Los acuerdos entre varias empresas ponen a España en el mapa mundial de la industria”, *El País*, 24 April 2016, retrieved from [http://economia.elpais.com/economia/2016/04/22/actualidad/1461343830\\_526950.html](http://economia.elpais.com/economia/2016/04/22/actualidad/1461343830_526950.html); “‘Big data’, la nueva materia prima. La privacidad gana importancia en un mundo donde los datos tienen todas las actividades”, *El País*, 4 June 2016, retrieved from [http://economia.elpais.com/economia/2016/06/03/actualidad/1464954943\\_672966.html](http://economia.elpais.com/economia/2016/06/03/actualidad/1464954943_672966.html); “Seguros en la era del Gran Hermano. El big data analysis revoluciona el sector con productos a medida del cliente”, *El País*, 25 April 2016, retrieved from [http://economia.elpais.com/economia/2015/04/23/actualidad/1429805089\\_612660.html](http://economia.elpais.com/economia/2015/04/23/actualidad/1429805089_612660.html); “A tu banco le importa lo que haces en las redes sociales”, *La Vanguardia*, 1 August 2016, retrieved from <http://www.lavanguardia.com/economia/20160731/403556388480/banco-redes-sociales-credito-algoritmo-big-data-scoring.html>. Consulted on 26 August 2016.

improve the research system, changing the ways in which biological samples and personal data flow, and patterns are established and behaviours are controlled in the field of health care.

Citizens supposedly empowered by technology –as advocated by digital business models and European research programmes<sup>4</sup>– will be astonished when they see that their genome and their purchasing patterns are in the hands of third parties with all sorts of interests. And that, since they have their data, if these third parties wish to venture into a new area of business, their offers will hit the target. When these citizens realize how little control there is over their data and the unwanted uses of their information and their privacy, what will happen? They might not be bothered, they might think it's fine – or not so fine, when they discover that this information is also in the hands of a private insurance company with which they wish to take out an insurance policy. When one of these citizens has Alzheimer's disease, they will no longer be able to wonder why years earlier they received in their email inbox a huge amount of advertisements for mobile phone apps about how to exercise their memory, cameras that film their habits in order to forget as little as possible and offers of homes for people with dementia. The answer must be sought in big data analysis, technology that will already have predicted their future and which, under the guise of supposed effectiveness, will already have determined the cost of their illness for the healthcare system<sup>5</sup>. In human subject research prices are established and there are markets for biological samples of human origin and data hiding behind the free status and the civic altruism established by law:

Donation and use of human biological samples will be free of charge, whatever their specific origin, and under no circumstances shall the compensations that are envisaged in this law be lucrative or commercial. Donation implies, furthermore, the waiving by donors of any economic or other right over the results that may be derived directly or indirectly from the investigations that are carried out with the said biological samples<sup>6</sup>.

4. In order, for example, to grow old actively in the context of a single digital market, <https://ec.europa.eu/digital-single-market/en/research-and-innovation-ageing-well-ict>, consulted on 26 August 2016.
5. See the information available in open access on the European Union's website on Economics and Digital Society, under the slogan 'What can big data do for you?', retrieved from <https://ec.europa.eu/digital-single-market/en/what-can-big-data-do-for-you>, consulted el 26 August 2016.
6. Article 7 of Law 14/2007, of 3 July, of Biomedical Research. See also article 30 of Royal Decree 1716/2011, 18 November, *whereby the basic authorization and functioning requirements are established of biobanks for biomedical research purposes and of the processing of biological samples of human origin, and the functioning and organization of the National*

We must remember that research is the basis of our healthcare system and that the interests of science and of society must not prevail over those of the individual<sup>7</sup>. This chapter is not opposed to research with human biological samples or to the biobanks where they are stored and managed. Nor is it against big data analysis in research. Quite the contrary, it is a text in favour of such research, but without hidden markets, and in favour of bioethical reflection that understands the reality, that comprehends the problems from a multidisciplinary perspective, and which contributes solutions and alternatives, actually taking part in the different and very diverse processes of the creation and application of knowledge.

## 2. PUBLIC ASSETS AT THE SERVICE OF PRIVATE INTERESTS?

The experience I have accumulated in the assessment of projects has enabled me to see that proposals appearing to be a research project, but which in fact are not, are occasionally submitted to committees; practices designed for financial gain are disguised and presented, cloaked in the altruism that the system preaches. They are practices that may even be illicit and which cannot always be detected from the start but which, once they are identified, should not be authorized.

Some new business models are based on the financial gain obtained from human body parts<sup>8</sup> and from privacy by way of gathering and commercializing personal data. This may happen, for example, with certain health and wellness mobile apps (health apps), for which, in my opinion, neither the legal framework is sufficiently prepared, nor bioethical reflection has been brought up to date, in order to confront the new challenges that it now has to deal with in human subject research. Situations have

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*Biobank Register for biomedical research are regulated. "Cost-free status of the donation and use of biological samples of human origin. 1. The donation and use of biological samples of human origin will be free of charge, in accordance with the provisions of articles 7 and concordant ones of Law 14/2007, of 3 July. 2. The compensatory payment that may be established for the obtainment of biological samples of human origin for biomedical research purposes will only strictly be able to compensate the physical discomfort, the travel and work expenses and other problems that may arise from the taking of the sample, and it shall not represent a financial incentive. 3. Any publicity or promotional activity by the authorized centres that may encourage the donation of human cells and tissues must respect its altruistic nature, and it may under no circumstances incentivize donation through the offer of financial compensation other than the strict compensation envisaged in the previous section".*

7. Article 2. Instrument of Ratification of the Agreement for the protection of human rights and the dignity of the human being with respect to the applications of Biology and Medicine (Convention on Human Rights and Biomedicine), Oviedo, 4 April 1997.
8. Article 21 of the abovementioned Convention on Human Rights and Biomedicine.

also been detected in which it has been impossible to obtain proof of information and informed consent of the patients or source subjects of the biological sample –from other countries, for example– in order to cede it to research projects. Quality, traceability and security –principles on which the law is based– are called into question<sup>9</sup>. Although there may be a black market for samples and data, generally speaking this is not something that is obvious.

In my opinion, colonialism in the twentieth and twenty-first centuries can also be explained through bodies<sup>10</sup>, their parts and the associated personal data, generators of financial gain in different contexts, with an exponential ability to make money due to their potential exploitation and commercialization in different sectors and even by the company that gathers them. The digital society also feeds on these new trends in human subject research. The data-driven economy that Europe is wholeheartedly pursuing<sup>11</sup> stimulates health and wellness business models that are fed by personal data and behaviours, and information associated with sensitive data, such as health data, and other sociodemographic data, without their owners being aware of it and without them having any ability to control them. These situations are unwanted by the owners of the information and the biological samples; nor do they have any place in a system based on altruism and the public interest, in which the benefits of research should be for the good of the citizens.

Europe has opted for biobanks to share biological samples of human origin, so that research can be done with them and thus contribute to the increase of generalizable knowledge and to the development of therapies, treatments and operations to improve people's living conditions. Although the governance of biobanks has concerned the European Commission<sup>12</sup>, and the requirements demanded by law to set up a biobank

9. In the context of a Biobank External Ethics Committee's activity and in accordance with the regulations covered by Law 14/2007, 3 July, of Biomedical Research, and Royal decree 1716/2011, 18 November, *whereby the basic authorization and functioning requirements are established of biobanks for biomedical research purposes and of the processing of biological samples of human origin, and the functioning and organization of the National Biobank Register for biomedical research are regulated*.
10. Along these lines, see Lysaught, M.T. (2009), "Docile Bodies: Transnational Research Ethics as Biopolitics", *Journal of Medicine and Philosophy*, 34, pp. 384-408.
11. See the Commission's communication to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions "Towards a thriving data-driven economy" (com/2014/0442 final), available on EUR-Lex database, retrieved from <http://eur-lex.europa.eu/legal-content/ES/TXT/HTML/?uri=CELEX:52014DC0442&from=EN>, consulted on 26 August 2016.
12. See the report on biobanks by the European Commission's Expert Group (2012), *Biobanks for Europe: A challenge for governance*, retrieved from <http://www.coe.int/t/dg3/>

are diverse and rigorous<sup>13</sup>, for the moment the same cannot be said for big data research. The impact that in the context of research these practices have on people's rights calls for a change in the dynamics of who is researching, who is directing, who is assessing and controlling and who is authorizing the research. This also leads to a demand for changes in the market and to consider as a point of departure that bodies and body parts (samples included), as well as personal health data, should be kept out of commerce, and they should of course not be quoted on the stock exchange. Compliance with this condition seems impossible in the market society<sup>14</sup> in which we live, where even university professors are obliged to place their knowledge and innovation on the market<sup>15</sup>.

### 3. PART I: BIOLOGICAL SAMPLES OF HUMAN ORIGIN AND BIOBANKS

In 2007 the Spanish Law of Biomedical Research (LIB) was passed. Among other issues related to human subject research, it establishes the legal framework for the use of biological samples in research. Samples that were previously kept in refrigerators, some of them similar to the ones we have at home, but full of human biological material: blood, DNA, tumours, brains, and so on. But what is a biological sample? "Any biological material of human origin liable to be conserved and which may contain information about the genetic make-up that characterizes a person"<sup>16</sup>. To become organized in order to share this material, so valuable for research purposes, from basic to clinical, that is the commitment. On this point, we have to distinguish between an anonymized or irreversibly dissociated biological sample, an unidentifiable or anonymous biological sample, and a coded or reversibly dissociated biological sample<sup>17</sup>.

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*healthbioethic/Activities/10\_Biobanks/biobanks\_for\_Europe.pdf*. See also *Recommendation cm/Rec (2016)6 of the Committee of Ministers to member states on research on biological materials of human origin*, by the Council of Europe, revising the Recommendation of 2006. Retrieved from <http://www.coe.int/en/web/bioethics/biobanks>, consulted on 26 August 2016.

13. Chapter IV of Law 14/2007, 3 July, on Biomedical Research.
14. Sandel, M. (2013), *Lo que el dinero no puede comprar. Los límites morales del mercado*, Debate, Barcelona.
15. European Knowledge and Innovation Communities (KICs) are one example. See EIT Health, European Institute of Innovation and Technology, which is part of the European Union. I am a member of its Advisory Board on ethical, social and legal aspects.
16. Article 3 o) of Law 14/2007, 3 July, on Biomedical Research.
17. Law 14/2007, 3 July, on Biomedical Research, article 3 p) "Anonymized or irreversibly dissociated biological sample": a sample that cannot be associated with an identified or identifiable person, since the connection with any information that may identify

And what is a biobank? A “public or private establishment, not for profit, which houses a collection of biological samples created for the purpose of diagnosis or biomedical research, and organized as a technical unit with criteria of quality, order and destination”<sup>18</sup>. What is the problem in this case? That research resources and infrastructures such as public biobanks should not be associated, for example, with what are known as intermediaries of biological samples of human origin; that is, companies whose job it is, among other services, to position the samples in return for money. These companies demand, moreover, the commercial exclusive for “placing” samples for financial gain that have been donated by citizens altruistically, free of charge.

It is that simple and that serious<sup>19</sup>. From a mercantilist point of view, biobanks are gold mines to be exploited. If those who manage them and take part in their functioning biobank external ethics committees included – are not coordinated and prepared scientifically, technically and ethically (including human resources and materials), profit gains ground. What seems to be a research project may conceal a sale of biological samples of human origin that makes money for the biobank. Nobody said that this situation was not interesting from the strategic and financial point of view. Moreover, these practices have –formally– the backing of the relevant ethics committees, whereby the contradiction occasionally arises of bioethical reflection contributing to undesirable consequences in research activity due in part to the lack of time for proper analysis and expertise.

What appearances conceal must be detected by ethics committees, which have the obligation to be organized and to adapt to these unwelcome trends, in order to give the response needed by research – as we conceive of it, not as we put it into practice. And that objective *is* clearly regulated. Another thing entirely is that we have a model of ineffective research ethics committees that have to shoulder the entire burden. In the “bio-techno-datatified” market society, initiatives appear that are

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the subject has been destroyed, or because this association requires an unreasonable effort; q) “Non-identifiable or anonymous biological sample”: a sample taken without a connection to an identified or identifiable person, whose provenance is therefore unknown and it is impossible to trace the origin; and r) “Coded or irreversibly dissociated biological sample”: a sample not associated with an identified or identifiable person, due to the information that identifies that person having been replaced or dissociated using a code that enables the reverse operation.

18. Article 3 d) of Law 14/2007, 3 July, on Biomedical Research.

19. “Mi tumor se vende en el extranjero”, *El País*, 26 July 2016, retrieved from [http://politica.elpais.com/politica/2016/07/24/actualidad/1469369527\\_015224.html](http://politica.elpais.com/politica/2016/07/24/actualidad/1469369527_015224.html), consulted on 26 August 2016.

sophisticated and tempting from the business point of view. They are complex structures that need a very keen eye to figure them out and which require a dedication that exceeds the powers permitted by the current model of research ethics committees in Spain.

I am sounding the alert here about a negative trend for the credibility of the science and technology system, a system that, in research, needs and will need the participation of the owners of the biological samples of human origin and the data, and the backing of assessors involved in ensuring that the altruism is not quantified. The source subject –“An individual, living– whatever their state of health may be –or deceased, from whom the biological sample comes” (article 3 v, LIB)– does not really know what this supposed free status conceals: exploitation and commercialization. And what is wrong with that? Some will say that, if a profit is made, part of it should be allocated to the owner of the sample and the data. But the fact is that the decision is already made, since we are obliged to waive any financial gain when we donate a biological sample for research purposes. Others will opt for a model based on compensation, and for others it will be a civic obligation, like someone paying taxes. Our altruism-based model must make solidarity prevail above any social, mercantile and even scientific interest.

We must prevent this altruism from being quantified in euros and converted into prices. Translational research gives rise to this kind of practice; the law and cultural contexts influence this type of model. Different regions have different ideas about what public and private assets are. Elsewhere the same companies acting as intermediaries for biobanks, whose operations we prohibit, are not only permitted, but they are welcomed and form part of the profitable alliances between research and markets. It is the Biobank External Ethics Committees that have the problem<sup>20</sup>; it is their job to

20. See Article 15. Royal decree 1716/2011, 18 November, *whereby the basic authorization and functioning requirements are established of biobanks for biomedical research purposes and of the processing of biological samples of human origin, and the functioning and organization of the National Biobank Register for biomedical research are regulated*. “Biobank External Committees. 1. External scientific and ethics committees shall be comprised of a minimum of four members with sufficient knowledge of the subjects related to the functions indicated in sections 2 and 3 of this article, who shall not take an active part in the biobank’s activity. Both committees shall have their own internal operational regulations, which will establish the appropriate mechanisms to ensure independence and the absence of conflicts of interest in these committees’ decision-making processes. In the event that, in relation to a specific issue, any member of the external committees shall have a direct personal or professional interest, they shall refrain from intervening. The biobank will make public the identities of the members of the external committees. The functions of the external ethics committee may be assumed by an already existing Research Ethics Committee, which will apply its own rules. [...] 3. The functions of the ethics committee shall be: a) To

promote this altruism and, to some extent, guarantee it. The LIB gives them the power to trace the biological sample<sup>21</sup> and grants them some room to manoeuvre, whereby it is these committees that have to decide, in specific cases, on the cession (or not) of samples for research purposes, depending on the circumstances<sup>22</sup>, a not inconsiderable decision-making capability.

Avoidance of the commercialization of biological samples of human origin donated to a biobank is something that depends largely on research ethics committees and Biobank External Ethics Committees, committees overloaded with work and which generally allege the lack of means and human resources to properly carry out the functions that they are assigned by law. Thus, in addition to the task of assessing projects and monitoring the ones authorized, there is that of tracing the biological samples of human origin, monitoring that has been regulated by law for many years<sup>23</sup>, but which does not constitute a habitual practice. I believe

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ethically assess the applications for donating samples and the data associated with them. In the event that the committee issues an unfavourable ruling, this will be binding; b) To advise the scientific director about the adaptation of the established procedures to ensure the quality, the security and the traceability of the data and samples stored and of the procedures associated with the workings of the biobank, from the ethical point of view; c) To advise the scientific director about the ethical and legal aspects envisaged in the biobank's good practices document; d) To decide the cases in which the individualized sending of information to the source subject will be essential, in relation to the provisions for the donation of their samples and to the results of the analyses performed when they may be important for their health, and e) To assist the scientific director on any other issues that he/she may submit for consideration; and article 29". "Ruling of the Research Ethics Committee. In order to carry out an investigation with biological samples of human origin, the favourable ruling will be necessary, in all cases, of the Research Ethics Committees of the establishment on whose premises the samples are going to be used, or, failing that, of the committee to which the centre is assigned for which the person in charge of the investigation works".

21. Traceability, according to the Law of Biomedical Research, is the "ability to associate a specific biological material with registered information referring to each step in the process of obtaining it, and throughout the entire research process" (article 3 x).
22. See second transitory provision of the Law of Biomedical Research for samples obtained prior to its coming into effect, and article 58 for those obtained afterwards. Also De Lecuona, I. (2011), *Los comités de ética como mecanismos de protección en investigación biomédica: Análisis del régimen jurídico español*, Civitas, Cizur Menor. See also the Communication "El archivo de parafina y la interpretación del 'esfuerzo no razonable'. El caso del banco de tumores del biobanco del Hospital Clínico de Barcelona IDIBAPS" presented at the 5th National Biobanks Congress held in Lleida in November 2015 and which was awarded the prize for the best oral presentation. Authors: Ángela Martín, Itziar de Lecuona, Míriam Méndez, Marta Aymerich, María Jesús Bertrán, Neus Riba, Míriam Cuatrecasas, Anna Bosch, Raquel Bermudo.
23. The law on clinical trials has testified to this since 1978. See Royal Decree regulating clinical trials of pharmaceutical products and medicinal preparations (BOE, N.º 108, 6 May 1978, pp. 10683-10684).

that most committees would readily acknowledge that this monitoring is not done simply because “it is not possible”. “It is not possible” is precisely what should not be accepted. Research is knowledge, it is power, it generates profit. Money is available, and it should be, in order to equip the system with the means for proper monitoring, not just approving projects and then switching off. In my opinion, the repeated idea that “there’s no time, there’s no money and there are no resources” for RECs is a fallacy that allows certain research practices to continue that ought not to have a place any more, with which a false sense of security is generated that endorses other interests, not the ones it ought to protect and promote. These other interests, sometimes far removed from the public interest or the essence of scientific research, stimulate a market where each body part and datum obtains an economic value and acquires unwelcome uses.

In my opinion, and from the legal point of view, in our context we have muddled through with an imperfect law to regulate research other than clinical trials that laid the foundations in 2007 and was developed in 2011, and which has established a system to coordinate biobanks that has given rise to double standards. Public and private biobanks advance along different paths when they should not, because the fact is that private biobanks are subject to the same regime. But, although all biobanks should be registered in the National Biobank Register<sup>24</sup>, it is impossible to ensure that all private biobanks comply with the law currently in force. One often reads in research projects that the biological samples of human origin that are collected will belong to this or that pharmaceutical or biotech company; and/or that if results are found that determine the source subject from the genetic point of view and turn out to be in the company’s interest, he or she will not be informed of this. From the assessment point of view and taking into account the current law, in our context this situation is unacceptable. The promoter is therefore told that it must comply with the requirements that are demanded or it will not be able to carry out its research<sup>25</sup>.

The double standards are in connection with the situation of the biological samples of human origin that are sent abroad. The samples that come from other countries are regulated and must comply, as is to be expected, with the laws in force in Spain<sup>26</sup>. But what happens when a company

24. ePlatform for the register of biobanks and collections of samples reporting to the Instituto de Salud Carlos III, which structures the research in our context. See also the provisions applicable in Law 14/2007, 3 July, of Biomedical Research.

25. Article 59 of Law 14/2007, 3 July, of Biomedical Research.

26. Article 31 del Royal Decree 1716/2011, 18 November, *whereby the basic authorization and functioning requirements are established of biobanks for biomedical research purposes*

authorized to operate in our research, development and innovation (R+D+i) system is based abroad, and the biological samples of human origin will be taken there? There are no answers to this, apart from research ethics committees' powers to establish requirements and to demand proof of compliance with what was agreed. Is a trade in samples "made in Spain" thus fomented in other places? Are ethics committees aware of their responsibility in this respect? Research assessment infrastructure has become obsolete, overtaken by innovation in the commercial use of human samples and data. It may seem an exaggeration, but it is not. Research does not have to be a wholly not-for-profit activity, but incentives should not be given to private or spurious interests in what ought to be the public interest. Putting a price on samples is serious, although unsurprising in a society in which everything has one. So there is no longer any discussion about whether or not people should participate in research altruistically, but there *is* about the price the promoter is prepared to pay. For example, whether it is right or wrong to receive 150 euros for a lumbar puncture when others are prepared to offer up to 300 euros for this same procedure. Put simply, do they buy people's wishes? What would you do if you had to decide about these matters in research? A lumbar puncture makes it possible to extract fluid of human origin in order to investigate with it. Blood is also a biological sample. Neither the discomfort nor the risks in the extraction of these samples are the same. Nor are the prices of the same tests, depending on who requests them in order to do research and how much money they have.

I remember a project in which the reason put forward for not compensating the participants in it was summed up as follows: when there is money involved wishes are corrupted and not only can one not decide freely, but there is no motivation to take part in projects and collaborate with scientific and technological research. Do you find it appropriate or inappropriate that a patient should be "compensated" for their participation in an investigation with a credit card –which will generate for them an obligation with a bank– so that they can make purchases of up to X euros? Don't you think it's great? The person involved, if they had the

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*and of the processing of biological samples of human origin, and the functioning and organization of the National Biobank Register for biomedical research are regulated. "Use of biological samples of human origin coming from other countries. Biological samples of human origin from other countries may only be used for biomedical research purposes when, in their obtainment, storage or conservation and cession, besides the guarantees envisaged by the law relative to the entry and exit of samples to and from Spanish territory, the guarantees envisaged in the present Royal Decree and any other applicable laws have at least been observed, which will be assessed by the Research Ethics Committee assessing the research project and, where appropriate, by the biobank's external committees".*

slightest idea of how much behaviours and data are worth now, would understand that with their participation they lose a lot and gain little. Not just in euros, but in the protection of their privacy in different facets of their life. These situations occur in research. How about 12 euros?<sup>27</sup> How about 50 euros? Do you think it's a little or a lot? Meals and travel apart? It's up to you, it depends on what these people might have to go through: risks, discomfort, etc. Okay, it depends. Case by case and step by step. There are no protocols or consensus on this subject, information is not shared between committees, there are no national or local forums devoted exclusively to dealing with these matters, bearing in mind that their regulation cannot be considered recent: the LIB dates from 2007 and its regulatory development from the end of 2011.

The object of this chapter is not the "rates" of the participants in research that refer to the person as a whole; the interesting thing here is what human beings' body parts and data are worth, including from the deceased. In any case, I shall just mention that it is traditionally considered right for healthy volunteers to receive compensation for taking the trouble to participate in research. Patients taking part receive no compensation whatsoever, because it is the research itself that will compensate them, producing potential benefits for them or for the sick people they represent.

The danger to physical or mental integrity should not be associated with a mere question of financial "compensation" –in short, a price– whose amount is, moreover, hard to establish. But knowing that its quantification will depend largely on the committee's corrective judgment, it would be desirable, for the purpose of grounding the decision, for there to be pre-established procedures and registers to turn to. Regrettably, to date no work has been done in the direction of the establishment of scales of "value" of the body, parts of it, or of people's data in research.

So far I have been pointing out problems that clearly show research ethics committees' inability to react, but what about the integrity of science and of the responsible research and innovation talked about so much these days?<sup>28</sup> It seems obvious that not everything should come

27. See Dal-Ré, R.; Carné, X. (2006), "¿Los pacientes deben recibir una remuneración económica por su participación en ensayos clínicos terapéuticos?" *Medicina Clínica*, vol. 127, N.º 2, June, pp. 59-65.

28. References may be multiple. See, for example, the European Code of Conduct for Research Integrity published by ALLEA (All European Academies), now being revised and which the European Union is thinking of establishing as the code of reference for its compliance by researchers in the context of research projects funded by framework programmes (i.e. Horizon 2020), retrieved from <http://www.allea.eu>.

down to research ethics committees' ability to evaluate and control via the monitoring of projects and donations of samples for research purposes.

The outsourcing of activities –in business language– is another risk of the commercialization of data in research related to the donation of biological samples in the context of clinical trials and other kinds of biomedical research in which people take part<sup>29</sup>. What do you, dear reader, think about a travel agency organizing your journeys to the hospital or centre where the research in which you have voluntarily agreed to take part will take place? You will probably say OK, no problem. You will think, in the good faith people have in research, that the different agents involved in the project will keep it confidential and that the professional secret is a guarantee, or at least that is what you read on the project's participant information sheet, and that the research is subject to compliance with Organic Law 15/1999, 13 December, of Personal Data Protection (LOPD). However, what will your opinion be about the company chosen for this task asking you if you like flying or what your favourite means of

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*esf.org/fileadmin/Public\_documents/Publications/Code\_Conduct\_ResearchIntegrity.pdf*. With regard to responsible research and innovation, see for example the RRI European project to understand the areas that comprise it, and in which ethics is fundamental, and to access examples of Tools *http://www.rri-tools.eu/*, consulted on 26 August 2016. I am particularly interested in pointing out article 18 of Unesco's Universal Declaration on Bioethics and Human Rights (2005). In the context of the application of the principles it establishes: Article 18 "Decision-making and addressing bioethical issues. 1. Professionalism, honesty, integrity and transparency in decision-making should be promoted, in particular declarations of all conflicts of interest and appropriate sharing of knowledge. Every effort should be made to use the best available scientific knowledge and methodology in addressing and periodically reviewing bioethical issues. 2. Persons and professionals concerned and society as a whole should be engaged in dialogue on a regular basis. 3. Opportunities for informed pluralistic public debate, seeking the expression of all relevant opinions, should be promoted".

29. In research in human beings, orders for data processing are made and compliance is required with the current law of personal data protection that, by the way, is almost 20 years old, Organic Law 15/1999, 13 December, of Personal Data Protection. In Europe revision has been underway of the 1995 Data Protection Directive, on which the Spanish law is based. The revision process began in 2012 and the final text came into effect in April 2016, and it leaves a great deal to be desired on the issues being dealt with here. Regulation (EU) 2016/679 of the European Parliament and of the Council, of 27 April 2016, relative to the protection of physical persons with respect to personal data processing and the free circulation of these data and due to which Directive 95/46/EC (General Data Protection Regulation) is repealed. Available at the EUR-Lex database, retrieved from *http://eur-lex.europa.eu/legalcontent/EN/TXT/?uri=uriserv:OJ.L\_.2016.119.01.0001.01.ENG&toc=OJ:L:2016:119:TOC*, consulted on 26 August 2016.

transport is and what your favourite foods are, when it is not necessary to take a plane to travel to the research centre?

Were these questions really necessary? By the way, the company is a multinational based in, for example, the USA, and it so happens that you as a participant live close enough to the research centre or hospital to walk there. Should you fill in an online survey giving your travel and food preferences, your habits, in the context of research into, for example, Parkinson's disease? No, but if you do, which you almost certainly will, because you will not be thinking about what it says here but you will be more worried about your health (or your illness), or about other people's, you will be providing personal data in one context to be exploited in others, disproportionately and almost certainly against your will but determined by the situation. Nevertheless, in research the patient's absolute transparency ought not to be the norm; their habits should not be noted in order to make a possible prediction about what they could (or should) do next summer, or about what their favourite restaurant near where they live should be. The commercial exploitation and the monetization of data through user profiles are obvious. It is information obtained in the context of research that will be used for other purposes. Who today can guarantee that it is not?

Research initiatives have been detected that invited people to supply data about their personal health and that of relatives suffering from genetically based diseases who could be potential donors of biological samples. The aim was for sensitive personal information to be shared via Internet pages, without being able to guarantee security in processing or in access by third parties to the data obtained. They were Internet pages in which the potential participant was exposed to sharing information completely unnecessarily and not without risks. In the first place, because the accuracy and the need for the data is not guaranteed, and, secondly, because the possible discrimination that the owner of the data and their relatives might suffer if that information falls into the wrong hands could not be ruled out either. It is considered normal –and in my opinion it should not be– for candidates to take part in research projects to enter their data on Internet or the social networks. Our research and healthcare system is supposed to be designed to avoid inequality and discrimination, including the genetically based kinds<sup>30</sup>. They are recurring initiatives and it is true that in other contexts they are the accepted standard. But transnational collaborative research cannot just impose rules unconnected to our objectives and means. In our context, at least, it should not be like that. And not just because RECs declare that there

30. Read, among others, Law 14/2007, 3 July, of Biomedical Research.

are other alternatives less harmful and invasive for the rights of the people involved, which is true; also because neither researchers nor doctors should collaborate with databases that do not ensure confidential processing of personal data<sup>31</sup>. These professionals should avoid data trafficking and its unwelcome uses. It is a deontological obligation of the first order, to do with scientific integrity, and without reducing the issue to the requirement for informed consent that, in my opinion, is not always the solution to problems in research.

So far we have identified some scenarios and problems, from biological samples and biobanks to research with big data and the development of health and wellness mobile apps. We must be prepared to detect what seems to be research but is merely market niches. It is also necessary to carry out an examination that gauges the impact on the rights and interests of the people taking part or involved, and of their relatives or close friends, in research projects that are presently booming. We should be thinking about individualized genetic information or predictions of habits and behaviours to improve decision-making in research and business.

#### 4. PART II: BIG DATA ANALYSIS APPLIED TO RESEARCH (BIG DATA) AND HEALTH APPS (*MHEALTH*)

We are witnessing a paradigm shift in the context of research, health care, and in the sphere of business. Initiatives and companies are now organized around data and not so much around processes, as we were previously used to. Data and the combination of datasets become valuable due to the information they express and their financial quantification, something that arouses great interest in public and private enterprise, on the basis of their exploitation and commercialization<sup>32</sup>. It can thus be understood why Facebook has acquired the WhatsApp instant messaging

31. Take as an example the Code of Ethics of the Doctors' Association of Barcelona, articles 40 and 41. Retrieved from [http://www.comb.cat/cat/colegi/docs/codi\\_deontologic.pdf](http://www.comb.cat/cat/colegi/docs/codi_deontologic.pdf), consulted on 26 August 2016.

32. See the Opinion Document of the University of Barcelona's Bioethics and Law Observatory, the research centre of which I am a member, on *Bioethics and Big Data: Exploitation and Commercialisation of User Data in Public Health Care*, January 2015, available in PDF format and open access and in three languages (Catalan, Spanish and English, retrieved from <http://www.publicacions.ub.edu/refs/observatoriBioEticaDret/documents/08209.pdf>, consulted on 26 August 2016. It is an interdisciplinary study that has been included in the reference documentation to propose the reform of the Catalan big data analysis project of July 2015, and which replaces the VISC+ project (More value to health information), on big data that began life in 2013, not without criticism. For more information on this project see <http://www.bioeticayderecho.ub.edu/es/tags-noticias/big-data> and the information available at the Agency for Health Quality and

service, because of its true scope, but above all what it could potentially produce: exponential profits based on personal data, once the terms and conditions have been accepted<sup>33</sup>. Although there are multiple definitions of big data, focused on different aspects depending on the field of research (health, smart cities, natural catastrophes, etc.), there is agreement that volume, variety and speed define big data. Volume, due to the huge amount of data; variety, due to the mixed nature of the kinds of data available in a dataset, and speed, due to the rapidity with which data can be accessed and analysed<sup>34</sup>.

Big data is a technology that is developing new tools to combine, analyse and exploit new datasets, establish correlations and obtain important information, making it possible to precisely predict individuals' behaviours and trends, but those of groups as well. It could be said, without wishing to be exhaustive, that big data is the result of the development of communication and information technologies, artificial intelligence, Biocomputing, and the widespread massive use of smartphones, as well as information storage services in clouds. Information and data everywhere, available in different devices at the same time, all connected or with the possibility of being connected. Computers –fixed and portable– and tablets online, the Internet of Things, biometrics<sup>35</sup> and wearables<sup>36</sup> are all examples that create a favourable atmosphere for the impending development of big data. The social networks are one of the areas in which they are present<sup>37</sup>. It can thus be understood why projects researching into big data have as their goal to develop apps, for example health apps<sup>38</sup>, and healthy

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Assessment of Catalonia, [http://aquas.gencat.cat/es/projectes/analitica\\_dades/index.html](http://aquas.gencat.cat/es/projectes/analitica_dades/index.html), consulted on 26 August 2016.

33. See news item "La nueva letra pequeña de WhatsApp: cómo hará dinero con tus datos", *El Confidencial*, 26 August 2016.
34. McAfee, A. *et al.* (2012), "Big Data: The Management Revolution", *Harvard Business Review*, vol. 90, N.º 10, pp. 61-67. See also Mayer-Schönberger, V. and Cukier, K. (2013), *Big Data: A Revolution That Will Transform How We Live, Work, and Think*, Houghton Mifflin Harcourt.
35. Using fingerprints to identify someone is an example of biometrics.
36. They are electronic devices that can be worn by people as an accessory or as part of their clothing or accessories. These devices can be connected to Internet and they make data exchange possible. One example is a jacket that measures heart rate.
37. On the problems and biases in the application of big data analysis in the field of epidemiology see Pérez, G. (2016), "Peligros del uso de los *big data* en la investigación en salud pública y en epidemiología", *Gaceta Sanitaria*, vol. 30, N.º1, Jan-Feb.
38. On health apps see (2015), *The App Intelligence: Informe 50 mejores apps de salud en español*, Observatorio Zeltia, Madrid. Retrieved from <http://www.theappdate.es/static/media/uploads/2014/03/Informe-TAD-50-Mejores-Apps-de-Salud.pdf>, consulted on 26 August 2016. See also the World Bank report, Qiang C.Z., Yamamichi, M., Hausman V. and Altman, D.G. (2012), *Mobile*

lifestyles as the first step, before advancing in specific applications. The thin line between research and markets that health big data creates can also be seen; in fact, where there is big data research there is a market. The combination and exploitation of data enables us to obtain the information that we wish to find, but it also makes it possible to obtain data that, although they might not seem important, become highly sought after, for the information they express and predict, and because they enable decisions to be made that favour certain interests.

A figure becoming increasingly important in big data analysis is the data scientist, who has to solve complex problems in different areas of different disciplines, for example marketing or life sciences, who handles data from multiple sources and who seeks to extract invisible patterns in order to examine them, including all the possible variables. Along with data scientists there are other professionals such as the data miner, a computer scientist who resorts to, among others, the methods of artificial intelligence and statistics, and to database systems, also with the aim of discovering patterns. These are people with scientific backgrounds, highly specialized, who are absolutely necessary, as are hackers to certify the security or the weakness of computer systems. They are professionals who, of course, research ethics committees need as members in order to analyse what is going on in big data research, to make decisions about whether or not to authorize certain research projects and also to distinguish between what is market and what is big data research, what are commercial uses<sup>39</sup> and what are research practices.

The reader should think about big data analysis and also apparently harmless free mobile apps, about the link between big data and health apps: they need and reinforce one another. Data is now hard currency (in the twentieth century it was genes, now in the twenty-first it is data) and yet everything seems to be free. The person supplying data discloses an infinite amount in return for access to technology that, as I have already said, empowers users (or at least that's what they say), in a voluntary and involuntary disclosure of privacy in different formats to which different business models with a variety of interests have access. But they always have one common interest: access to datasets –including personal

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*Applications for the Health Sector*, retrieved from [http://siteresources.worldbank.org/INFORMATIONANDCOMMUNICATIONANDTECHNOLOGIES/Resources/mHealth\\_report.pdf](http://siteresources.worldbank.org/INFORMATIONANDCOMMUNICATIONANDTECHNOLOGIES/Resources/mHealth_report.pdf), consulted on 26 August 2016.

39. Healthcare institutions are drafting protocols on the commercial uses of the brand with regard to developing mobile apps, to differentiate them from uses in research. Committees are being set up for this purpose to assess these situations. In my opinion, these committees should inform the institution's REC.

ones— that say absolutely everything about us and the people we are in contact with.

In my opinion, the supposedly empowered citizens to whom I referred become docile and exposed, naked and defenceless. Healthy and sick people are invited to get in touch on social media and also to “gamify” themselves (to play in order to improve their situation and their relationship with their illness, in a peer group where they are unique...). This perverse invitation presented as empowerment, and which is acceptable from a purely mercantilist point of view, is inundating the field of research, where these are not the objectives, as they are disproportionate and mercantilist. Data are needed to create ontologies through the programming of algorithms that serve to improve the decision-making of initiatives, companies, in research, etc., in the public and private spheres, or in a combination of both. Especially interesting is the use of big data analysis in research for medical purposes and the development of health apps whose goals are personalized medicine, the improvement of healthcare systems (to make them more efficient), learning about the adverse effects of medicines more quickly, predicting natural catastrophes, and their consequences in terms of the population’s health. The goals are worthwhile; the means are, for now, disproportionate. As we have not spent as much time analysing the legal, social and ethical implications<sup>40</sup> of big data as we have developing algorithms and putting them into practice, we have failed.

The lack of privacy<sup>41</sup> is the price being paid for allowing unwanted access to data, the totally disproportionate gathering and possession of different kinds of data, without their owner’s knowledge, by third parties unconcerned with the basic rules of human subject research: businesspeople, data miners, data scientists, people who have not been trained to respect confidentiality and process personal data. On this point, I recommend reading the reports on big data by the European Agency for Network and Information Security (Cybersecurity) (ENISA) and the European Data Protection Supervisor, especially Opinion 7/2015, on the challenges of big data (November 2015)<sup>42</sup>. In them the

40. Richards, N.M. and King, J.H. (2013), “Big Data Ethics”, *Wake Forest Law Review*, vol. 49, pp. 393-432.

41. Cohen, J.E. (2014), “What Privacy is For”, *Harvard Law Review*, N.º 126, pp. 1904-1933.

42. See ENISA’s compilation of publications on big data, available at <https://www.enisa.europa.eu> (apply filter “big data menu” law), in particular, *Privacy by design in big data*, December 2015, and the European Data Protection Supervisor’s webpage on big data, retrieved from [https://secure.edps.europa.eu/EDPSWEB/edps/Consultation/big\\_data](https://secure.edps.europa.eu/EDPSWEB/edps/Consultation/big_data), consulted on 26 August 2016.

challenges, problems and the impact –positive and negative– of the use of big data analysis on people’s rights in the digital society are made perfectly clear.

In this context projects are submitted to RECs for assessment, whose objective is to use mobile geolocation to identify people –suffering from certain diseases– who have pulled out of projects for reasons unknown. And what happens if someone does not wish to be located? What about the clause, so typically bioethical, about withdrawing voluntarily without any justification, thus exercising the famous withdrawal of the consent given?<sup>43</sup> Not to mention the possibility of the mobile telephone being mislaid, stolen or inherited by someone other than the person who took part in the research. Big data almost certainly takes all this into account. But what about the ethics? In one of its campaigns Amnesty International pointed out that by having one’s mobile switched on, “they know who we are sleeping with”<sup>44</sup>. Data (big and small) are valuable, in research too, of course. Remember that computerized medical records are digital platforms that allow access to personal data, and that, as we clearly see here, there is an investigative and commercial interest in cross-referencing medical records databases with other databases containing different kinds of information.

The trend in developing health apps associated with wearables and mobile devices is growing. Biometrics, biosensors, chips, smart glasses, smart watches, the Internet of Things, Internet downloads on laptops, tablets and devices connected to the smartphone that knows everything and decides for you, are all markets queuing up to gain access. From the scientific point of view, there may be some interesting research to be carried out; what needs to be ascertained is whether or not it is appropriate and necessary. And there are also some tempting market niches from the business point of view. Tempting and very profitable. Ageing well, wellbeing (autonomy and empowerment included) and healthy living are among the policies of the European Union, which funds research in information and communication technologies in these areas. Development has recently begun of a European code of conduct on privacy in the development and

43. See, for example, articles 5 and 16 of the Council of Europe’s Convention on Human Rights and Biomedicine, mentioned above, on the general rule of consent in health-care and research.

44. “The US National Security Agency gathers billions of cell phone location registrations every day, so they know where you got on the bus, where you went to work, where you slept and what other cell phones slept with you”. Snowden, E., “Privacy is for the Powerless”, retrieved from <https://www.amnesty.org/es/latest/campaigns/2016/03/edward-snowden-privacy-is-for-the-powerless/>, consulted on 26 August 2016.

use of health apps<sup>45</sup>. The bioethical problem lies in the obvious disproportion between means and ends. Gathering data for the sake of it and then exploiting them and seeing how and in what circumstances they can be made profitable – this is what must not be allowed. In practice, however, this trend is confirmed, in which data transfers (monetization included), neither wanted nor permitted, can be identified; they are moreover unacceptable, bearing in mind who will carry them out, how, for whom and when (including for how long). In my opinion these are the key questions for identifying what health research “is” and what it “appears to be, but is not”, because it pursues other ends and hopes to exploit and commercialize personal data obtained in the field of health care.

In Europe, the political and economic commitment to achieving a digital society and a data-driven economy is based on the reuse of information from the public sector, where the market can also find its place<sup>46</sup>. It is based on the need to be competitive on a global level and at the same time to apply the principle of transparency. Data protection as a system of guarantees is one of the bases of this decision, but in the sphere of the exploitation of big data and their possible commercialization, and in the field of health apps, this protection is not completely assured. Data and personal datasets make privacy valuable. The principles of personal data protection established by European laws, such as those of necessity, proportionality or data minimization, are difficult to comply with. In this respect, the results of the Eurobarometer –a survey of 28,000 Europeans carried out in March 2015– concerning data protection in the digital society are interesting. Eighty-one per cent of Europeans considered that they did not have complete control over their online personal data. Sixty-nine per cent would like to give their explicit approval before their personal data are gathered and processed, and just 24% of Europeans said that they trust online businesses such as search engines, social network pages and Internet services<sup>47</sup>.

45. The information is available in English only, for the moment, and the information is from 7 June 2016. It is a code to which people who develop apps and who observe the European data protection rules can voluntarily follow. “Code of Conduct on Privacy for *mHealth Apps* has been Finalised”, retrieved from [https://secure.edps.europa.eu/EDPSWEB/webdav/site/mySite/shared/Documents/Consultation/Opinions/2015/15-11-19\\_Big\\_Data\\_EN.pdf](https://secure.edps.europa.eu/EDPSWEB/webdav/site/mySite/shared/Documents/Consultation/Opinions/2015/15-11-19_Big_Data_EN.pdf), consulted on 26 August 2016.

46. Directive 2003/98/EC of the European Parliament and of the Council, 17 November 2003, relative to the reuse of public sector information. Available on the EUR-Lex database, retrieved from <http://eur-lex.europa.eu/legal-content/ES/ALL/?uri=CELEX:02003L0098-20130717>, consulted on 26 August 2016.

47. See the cited European data protection law of 2016. On the results of the Eurobarometer: information available at <http://ec.europa.eu/justice/data-protection/files/>

In my opinion, the ethical or bioethical dimension of big data technologies and health apps is not being sufficiently analysed. I predict, and I would like to be proved wrong, that in the coming years keeping data confidential will be extremely difficult and what others know about us will be totally beyond our control. The rights of access, control, rectification and opposition that we currently have as a guarantee are already in doubt, nor will it be possible to speak of anonymization (only in a few cases), and the concept of the re-identification of people and data should become widespread.

The fact is that while big data and the projects and initiatives that promote it were in their infancy, we did not spend enough time producing a glossary of concepts useful for understanding what we are talking about. We use new technology and we assess it with old, useless and ineffective points of reference. As a result a false sense of security is generated about something that has not been properly assessed and which could have perverse uses. Hence my criticism that ethics committees are not adapting properly to the new times. It is necessary to include in the conceptualization of big data the fact that this technology breaks the established rules for ensuring confidential data processing. Up to now, personal data anonymization –that is, ensuring that the link between the owner and the data is irreversibly broken– was the basis for justifying data processing without infringing rights. Thus, as no one could be identified, there was no problem. Those of us who move in healthcare and research are accustomed to using concepts such as reversibly coded or irreversibly dissociated data<sup>48</sup>, confidential processing and the obligation of confidentiality. But we are not at all used to talking about re-identifiable people or datasets. Big data makes this re-identification possible, whereby in the definition of big data it should be added that anonymization is dead and that we are entering a new scenario where the risk of re-identification exists. Moreover, it must be considered a working premise that those taking part in big data research must be given, and must understand properly,

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*factsheets/factsheet\_data\_protection\_eurobarometer\_240615\_en.pdf*, consulted on 26 August 2016.

48. Article 3 of Law 14/2007, 3 July, of Biomedical Research. Sections: *h*) “Anonymous data”: data registered without a connection to an identified or identifiable person; *i*) “Anonymized or irreversibly dissociated data”: data that cannot be associated with an identified or identifiable person, as the connection with any information that identifies the subject has been destroyed, or because the said association requires an unreasonable effort, understood as the use of a disproportionate amount of time, expense and work; *k*) “Coded or reversibly dissociated data”: data not associated with an identified or identifiable person, as the information that identifies that person has been replaced or dissociated using a code that permits the reverse operation.

information about its scope and significance. With their postcode, date of birth and gender it is possible to re-identify the majority of individuals “present” in a dataset<sup>49</sup>. This is possible if the motivation to do it is there, along with technicians who know how to do it and the necessary investment. The profits, broadly speaking, can be exponential. It would not be right to explain big data technologies without going into technical issues such as this, which pose a serious problem for researchers’ ethics, for the current data protection law and for society, which at the very least ought to know what really is going on.

Now imagine, dear reader, research projects that process big data about re-identifiable profiles in the medical sphere, such as IVH positives, or those suffering from Alzheimer’s, Parkinson’s or schizophrenia. Start with the data stored in computerized medical records of thousands of people affected by these diseases. Think of minors, persons unable to give consent themselves because of de facto situations, imagine the sensitive data that are going to be handled and feel concerned about the vulnerability of the citizens’ integrity and privacy. There are several possible combinations: accessing the downloads of their mobile devices, obtaining blood and other biological samples of human origin, geolocating them, obtaining and processing sensitive personal data through Internet surveys, combining them with their clinical data ... What is the purpose of these investigations? They are legitimate objectives, but in many cases out of all proportion. The goal of amassing data and then exploiting them generally spoils the research. The means should be proportional to the ends pursued, a rule that is not usually observed in big data research. Banks, mobile telephone operators and insurance companies are obviously interested in participating in the research, development and innovation system. They may become entitled to compete in research by joining forces with well-known researchers who are prestigious in different areas of knowledge and have, among others, the best computer engineers, specialists in artificial intelligence and data scientists. RECs should ask promoters and researchers who has access, how, what for, how long for, and demand from the start an assessment of the project’s impact on the human rights of the people involved and a risk minimization plan<sup>50</sup>. It would be a good

49. See Sweeney, L. (2000), *Simple Demographics Often Identify People Uniquely*, Carnegie Mellon University, Data Privacy Working Paper 3, Pittsburgh. Retrieved from <http://dataprivacylab.org/projects/identifiability/>.

50. In this respect, the European Union guidelines for research funding are clear (among others ethics self-assessment, available on Internet. Retrieved from [http://ec.europa.eu/research/participants/portal/doc/call/h2020/h2020-msca-itn-2015/1620147-h2020\\_-\\_guidance\\_ethics\\_self\\_assess\\_en.pdf](http://ec.europa.eu/research/participants/portal/doc/call/h2020/h2020-msca-itn-2015/1620147-h2020_-_guidance_ethics_self_assess_en.pdf), consulted on 26 August 2016 (2014 version).

idea, moreover, to analyse whether public-private science and technology systems have suitable computing back-up in our context; and whether investment by the state in the development of special secure clouds ought to be a priority, thus eliminating the need to resort to outsourced commercial services who cannot guarantee that the information they store will be processed with the same confidentiality and requirements as in the medical sphere<sup>51</sup>.

## 5. CONCLUSIONS AND PROPOSALS

The objective of this chapter has been to identify practices and problems in research with biological samples of human origin in the context of biobanks and in big data research, including personal data. There are market niches that go unnoticed in research projects, as well as mercantilist practices that are presented under their aegis. Research must not be stopped, though. It must be properly analysed for the purpose of clearly detecting what seems to be research but is actually the market; identifying the unwelcome illicit uses of samples and data; preventing privacy from being commercialized and supposed fairness being infringed, and avoiding discriminatory situations for the owners of the samples and the data. This is the duty of RECs. The scientific integrity of researchers is at stake in a field where people unconnected to research possess the funding and the right professional profiles to pursue commercial interests as well as purely research interests. It is necessary, in short and above all, to specify what should be off-limits to commerce in research.

Bioethics, which contributed so much to the creation of RECs in the 1960s, cannot be the only one to respond to the complexity and specialization that we are now witnessing. The paradigm on which bioethics was comfortably based in research is being torn apart by the potentiality of biobanks, big data and mobile apps, designed as business models in research and not solely and exclusively as research. It was a paradigm that eagerly pursued confidential data processing and whose safe-conduct was anonymization. Society, subject to mercantilist practices in research pointing towards digitization, heavily committed to biotech and data tech, needs to reflect first on the place occupied in its list of priorities by the human biological samples and datasets that identify us with names and surnames and turn us into potential sufferers of Alzheimer's and

51. These services are resorted to due to research and hospital institutions' lack of their own clouds. This is not at all advisable as we are talking about sensitive health data, but for the moment it is a fact that no in-house systems have been developed capable of offering the same services.

potential purchasers of certain products. Datasets construct and deconstruct identities and change our future according to the use now being made of them and who is doing it. Big data and, in particular, big data research are contributing to a new concept of human nature without the providers and owners of the data even being aware of it. This exciting big data, which does not cease to propose effectiveness and efficiency, more precise knowledge more quickly, has neither gathered nor cross-referenced sufficient data about what the ethical guidelines that ought to frame its work should be like.

It is the duty of RECs to avoid commerce in research and to monitor the approved projects, but for that they must be equipped with human and material resources with the support of the management teams of the research centres where they operate. They cannot apply obsolete patterns and rules to new problems in order to generate a false sense of security in which unwelcome practices prosper, including unwanted uses of biological samples of human origin and personal data. What we have is a model of ineffectiveness of RECs that must be reviewed and changed. Along these lines new organizational and working formulas are needed that include the greater involvement and professionalization of their members and a possible remuneration in keeping with the duties assigned to them. There is an urgent need for the activation of registers, established by law for many years, and this ought to be a priority for development and innovation plans in science and technology. In these registers the identities of who is accessing biological samples and data, how, when, with what funding and for what reason, could be consulted – samples and data that can be neither destroyed nor transferred outside the secure perimeters of public healthcare infrastructures, and a basic cornerstone of which are computerized medical records stored in databases.

As the law currently states, public biobanks must not pursue private interests, nor can they commercially exploit biological samples donated altruistically, in the face of the mercantilist trends described in this chapter that hope to exploit and commercialize samples donated by people. RECs –in their capacity as Biobank External Ethics Committees– must therefore not regard the traceability of biological samples of human origin as a merely residual task.

It is necessary to create operational networks between the different RECs concerning the practices that refer to biological samples in biobanks. At the same time, collaboration and permanent communication between the director of the biobank, the institution's legal services and the committees must be strengthened, in order to be on the lookout for possible business dealings in connection with samples.

## 12. THE TREND TOWARDS THE COMMERCIALIZATION OF HUMAN BODY PARTS...

Education, training and skills building, in both ethics and in technical issues related to translational practices in research with biological samples of human origin and personal data in the context of big data and health apps, are necessities of the first order.

Interdisciplinary analysis in the areas analysed is crucial. To be effective and to make the research assessment and monitoring system credible it is necessary for specialists in big data analysis to join RECs, as well as those in cloud computing and computer and network security systems, who will identify the strengths and weaknesses of the techniques for exploiting and combining data with the available computer systems. Only this way will it be possible to develop and apply creative solutions for proper personal data processing and the protection of privacy.

Public awareness must be raised about the concept of re-identification, which destroys the foundations of personal data protection, something that RECs have not internalized.

And, of course, research projects in big data and in health apps must incorporate an analysis of the impact of these initiatives on human rights, and outline plans to mitigate and minimize the risks along the lines established by the European Union.



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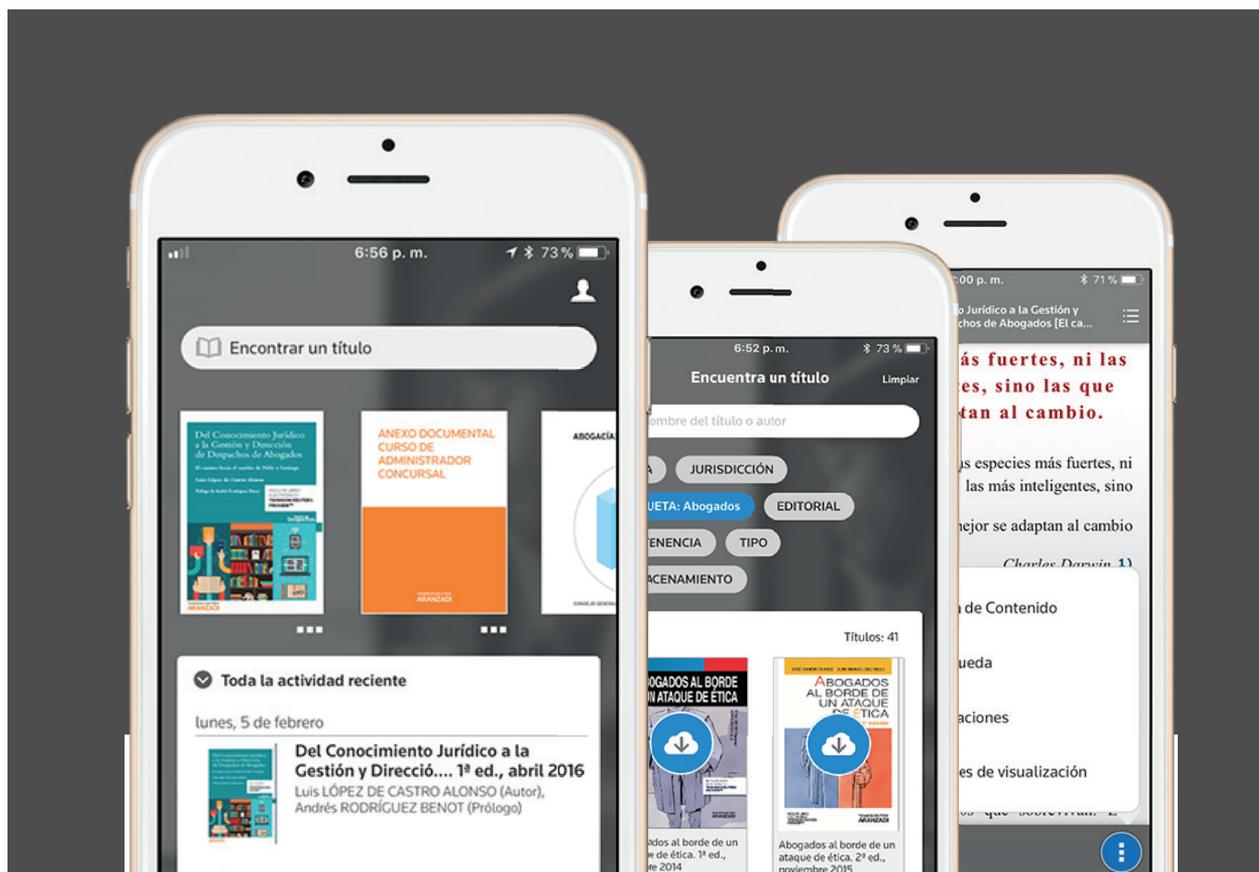
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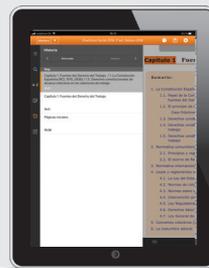
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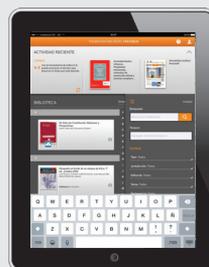
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