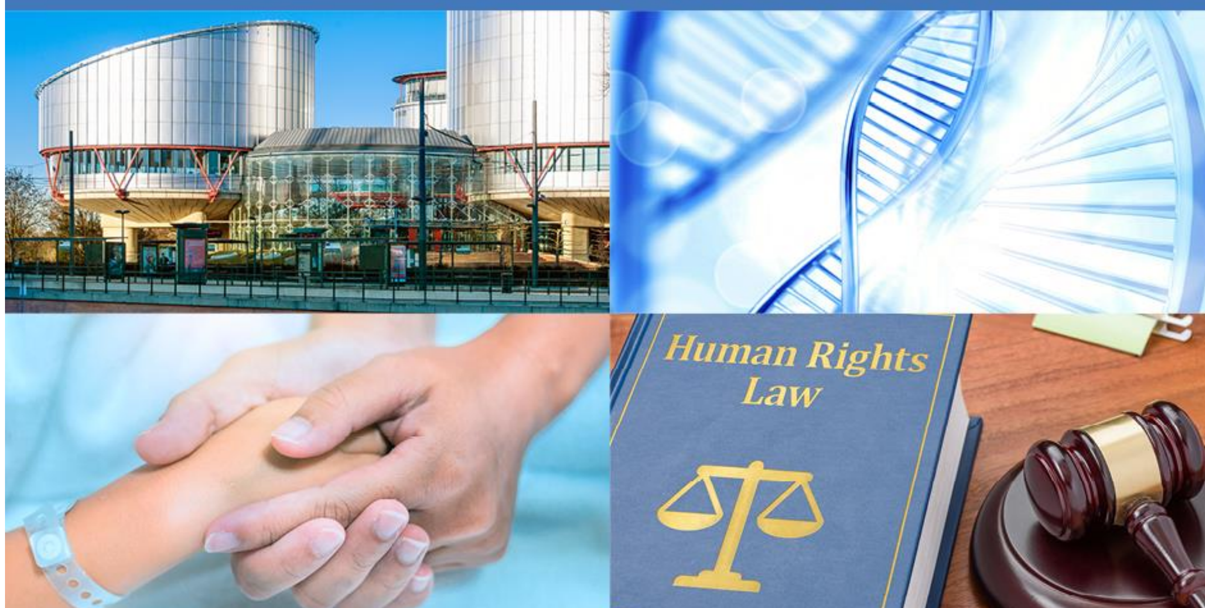
International case-law in bioethics: insight and foresight



High-level seminar
organised by the Committee on Bioethics (DH-BIO) of the Council of Europe under the auspices of the Cypriot Chairmanship of the Committee of Ministers

5 December 2016
Press Room,
European Court of Human Rights
Council of Europe, Strasbourg

Chairmanship of Cyprus
Council of Europe
November 2016 – May 2017
Présidence de Chypre
Conseil de l'Europe
Novembre 2016 – Mai 2017

9.30 OPENING SESSION

- **Mr Guido Raimondi,** President of the European Court of Human Rights
- **Ambassador Theodora Constantinidou,** Permanent Representative of Cyprus to the Council of Europe, on behalf of the Cypriot Chairmanship of the Committee of Ministers of the Council of Europe
- **Mr Philippe Boillat,** Director General, Directorate General of Human Rights and the Rule of Law

9.50 SESSION 1: HUMAN RIGHTS IN BIOMEDICINE: TRENDS AND CHALLENGES

Chair: *Dr Mark Bale, Deputy Director, Science Research & Evidence, Department of Health (United Kingdom), Chair of the DH-BIO*

Cases on Human Rights and biomedicine brought before the European Court of Human Rights (ECtHR): Common trends and challenges

- **The beginning and the end of life in the case-law of the ECtHR**
  Prof. Dr Helen Keller, LL.M., Judge of the European Court of Human Rights
- **The right for privacy in the case-law of the ECtHR**
  Dr Pere Pastor Vilanova, Judge of the European Court of Human Rights

10.50 Coffee break

11.20 SESSION 1 (CONTINUED): HUMAN RIGHTS IN BIOMEDICINE: TRENDS AND CHALLENGES

Chair*: Ms Brigitte Konz, Head Justice of the Peace (Luxembourg), Chair of the Steering Committee for Human Rights of the Council of Europe (CDDH)*

- **Impact of the ECtHR judgments at the national level**
  Mr Justice Peter Jackson, Judge of the Family Division of the High Court (United Kingdom)

  Ms Claire Bazy Malaurie, member of the Constitutional Council (France), member of the Venice Commission of the Council of Europe

12.00

- **Latest developments in Russian jurisprudence in the field of Human Rights and biomedicine**
  Mrs Tatyana Vavilycheva, Judge at the Supreme Court of the Russian Federation

12.20

- **The beginning of life and the prohibition of in vitro fertilization in the case-law of the Inter-American Court of Human Rights**
  Mr Roberto de Figueiredo Caldas, President of the Inter-American Court of Human Rights

12.40 Discussion

13.00-15.00 LUNCH BREAK

15.00 SESSION 2: FORWARD LOOK

Chair: *Prof. Michael O'Flaherty, Director of the European Union Agency for Fundamental Rights* (FRA)

- **Current trends in the development of the case-law at the national level**
  Prof. Grainne McMorrow, Senior Counsel (Ireland), substitute member of the Venice Commission of the Council of Europe

15.30

- **Round table: Forward look based on the existing case-law and national experience**
  Ms Claire Bazy Malaurie, member of the Constitutional Council (France), member of the Venice Commission of the Council of Europe
  Prof. Dr Aart Hendriks, Leiden Law School (Netherlands)
  Mr Justice Peter Jackson, Judge of the Family Division of the High Court (United Kingdom)
  Mrs Tatyana Vavilycheva, Judge at the Supreme Court (Russian Federation)

16.30 Discussion

17.00 Coffee break

17.30 CLOSING SESSION

- **Prof. Angelika Nußberger,** Judge and Section President of the European Court of Human Rights

- **Mr Christos Giakoumopoulos**, Director of Human Rights, Directorate General of Human Rights and Rule of Law

BIOGRAPHICAL NOTES, ABSTRACTS & FULL TEXTS

Mr Guido Raimondi

President of the European Court of Human Rights

Madam Chair of the Ministers' Deputies,
President of the Inter-American Court of Human Rights,
Supreme and Constitutional Court members,
Director of the Fundamental Rights Agency,
Director General,
Ladies and Gentlemen,

It is a great pleasure for me to welcome you this morning to the European Court of Human Rights for this seminar being held under the auspices of the Cypriot Chairmanship of the Committee of Ministers.

As we know, bioethics is not mentioned in the European Convention on Human Rights. The Convention's authors could not have imagined the progress which medicine and science would make in the second half of the 20th century and the issues which that would raise in legal and ethical terms. Fundamental rights are now permeating bioethics.

I am therefore delighted that a seminar on such a vital topic is being held at the seat of our Court. That is very significant.

We are having to rule on cases involving issues of bioethics increasingly frequently. The number of cases involving such issues has grown substantially since the beginning of the 2000's. You will be given a very comprehensive presentation of our case-law by my colleagues, Judges Nußberger, Keller and Pastor Villanova, who have agreed to take part in the seminar. I thank them sincerely for doing so.

Domestic and international judges are required to respond to the new issues arising in our societies. That places great responsibility on them, especially when there is no consensus in society at national or European level.

And the most sensitive issues submitted to us often involve bioethics. The presence here today of leading figures from so many different backgrounds as members of human rights courts, constitutional courts and judges and lawyers from a whole range of countries bears witness to the universal nature of the issues raised. That is not surprising if you consider the extraordinarily broad scope of bioethics.

My colleague, Helen Keller, will talk in a moment about the Court's case-law concerning the beginning and end of life.

In this connection, I was struck deeply by a recent case heard in France which concerned both points in life.

That case seems particularly interesting from the point of view of the issues which you are going to discuss today. An application had been made to the French *Conseil d'État* by a young woman who wanted her dead husband's sperm to be exported to Spain for the purposes of post-mortem insemination. This, however, is prohibited in France.

The *Conseil d'État* overrode the French law concerned and held that the relevant authority's refusal to grant the applicant's request was not consistent with the European Convention on Human Rights. This completely new issue had never been brought before our Court, and there is no consensus at European level either. The court concerned therefore engaged in an exercise in anticipating our case-law in holding that the French law on post-mortem insemination was compatible with the Convention, but that its application in the case in question involved excessive interference with the right to respect for private and family life as enshrined in Article 8.

That is therefore a case which will not be submitted to our Court. I am pleased that the solution to such a sensitive and complex issue has been found by a domestic court. We will never know what our Court would have ruled. Perhaps – but the question will remain unanswered – it would have applied the theory of the margin of appreciation, which is all the broader when what is at stake are social issues, general policy issues or issues of morality and bioethics, which is our subject today.

One concept which is not explicitly mentioned in the Convention is that of dignity. Yet the Court has confirmed it as an implicit principle in ruling that “the very essence of the Convention is respect for human dignity and human freedom.” The concept of dignity is a key instrument used by the Court when it has to rule on social issues. This has been seen, in particular, in the very high-profile cases concerning the end of life, for instance, the *Vincent Lambert* case, which you have all heard about.

This concept, which the Court uses cautiously, is particularly relevant in the field of bioethics, as it enables the Court to adapt its scrutiny to each particular case. It leads us to adjust our case-law so that the law of the Convention is able to respond to the infinite range of human circumstances.

I am sure that it will be present in your discussions today.

I deeply regret that my obligations prevent me from spending the day with you, and I hope that you have most interesting discussions. Thank you for your attention.

Ambassador Theodora Constantinidou

Chair of the Ministers' Deputies
Permanent Representative of Cyprus to the Council of Europe

Presidents of the European Court of Human Rights and of the Inter-American Court of Human Rights,
Judges, Ambassadors,
Ladies and Gentlemen,

It is an honour for me to open this seminar – the first event of the Cypriot Chairmanship of the Committee of Ministers, in the run up to the 20th anniversary of the Oviedo Convention in 2017 - the only internationally legally binding instrument on the protection of human rights in the biomedical field.

This comes at a time when Europe is facing many challenges to the values that form the very basis of our societies, in particular when it comes to human rights.

The biomedical field is not spared by these challenges. From health care practices to scientific and technical evolution – some even talk about "revolution" - the possibilities for improving the health and welfare of human beings are developing. But the capacities to intervene on human life for less commendable purposes are also increasing.

At a time when economic driving forces and priorities in the biomedical field are becoming stronger, it is particularly important that we do not lose sight of common values - of respect for human rights - and that we ensure appropriate and effective protection of all human beings.

This seminar on "International case-law and bioethics" is an opportunity to discuss ways of addressing the many, and often complex and sensitive, bioethical issues which are confronting us.

To that end, we need dialogue: firstly, a dialogue between medicine and law which are two fields that do not necessarily often interact. And secondly, we need a dialogue at the level of the judicial institutions at national and international level, in order that they may share their respective approaches.

We need also to foster co-operation within Europe and beyond its boundaries, drawing upon the expertise of the Council of Europe and its unique set of human rights legal instruments, such as the Convention on Human Rights and Biomedicine. Transnational challenges and threats, including in the biomedical field, require a global response.

I am particularly pleased to see the interest this event raises and the very high level of the participants.

Ladies and gentlemen, I trust that you will have fruitful discussions and I look forward to their outcome.

Mr Philippe Boillat

Director General of Human Rights and the Rule of Law

Mr President of the European Court of Human Rights,
Madam Chair of the Ministers' Deputies,
Mr President of the Inter-American Court of Human Rights,
Judges of the European Court of Human Rights,
Presidents and judges of the national high courts,
Your Excellences,
Ladies and Gentlemen,
Dear colleagues,

It is a real honour and pleasure to open this seminar today before such a distinguished assembly. Your presence testifies to the considerable interest in the theme at the heart of this seminar that prevails among the highest national and international judicial bodies.
I would like to thank Ambassador Constantinidou sincerely for supporting this event, organised under the auspices of the Cypriot Chairmanship of the Committee of Ministers.

It is also an honour, Mister President, to open this seminar in the prestigious setting of the European Court of Human Rights, recently awarded the Treaties of Nijmegen Medal for 2016. This prize rewarded the Court for its contribution to advancing the European project. The organisers highlighted in particular the "exceptional, innovative and important" work accomplished by the Court.

"Innovative and important" are two adjectives that could also be used to describe the work carried out by national and international judges with regard to the issues we are going to address today.

Ladies and Gentlemen,

It has been pointed out that the major developments in the biomedical field which we have been able to observe over the last 20 years have constituted, and continue to constitute, a source of considerable progress, especially for human health.

However, these developments, particularly technological developments, albeit encouraging in themselves, have also increased the possibilities of intervening in and controlling the human body and human life. As from the 1990s, given the important human rights issues that stem from them, the Council of Europe laid down protecting principles in the Convention on Human Rights and Biomedicine, so that these advances would not be misappropriated and used without due regard for fundamental rights or human dignity.

Today, in the face of accelerating scientific and technological progress, these concerns are more topical than ever.

The evolution, in both quantitative and qualitative terms, of the cases in this field brought before the European Court of Human Rights shows the complex and sensitive nature of the individual situations dealt with by the national courts, as can also be seen from the recently updated case law report.

In this connection, the importance of dialogue between judges should be highlighted. European judges, and first and foremost the judges of the national courts, have an essential role in implementing

the European Convention on Human Rights. The same applies to the Convention on Human Rights and Biomedicine, which covers a new judicial field. It is therefore a cause for satisfaction that this seminar, the first to be held on such a scale, constitutes an opportunity for dialogue between judges in the area of the Oviedo Convention.

The main objective of this seminar is to assess this evolution on both a national and an international level. The analysis of relevant national case law will also make it possible to identify emerging trends, in order to take a forward-looking view of possible new challenges for the protection of human rights in the biomedical field, new challenges which the international courts may have to address.

The presentations and discussions will also contribute to the reflection on intergovernmental work in this field; this intergovernmental co-operation helps to strengthen the effectiveness of the European Convention on Human Rights and the Oviedo Convention, as well as to reinforce the protection of human rights in the biomedical field in general.

Ladies and Gentlemen,

Next year, we will celebrate the 20th anniversary of the Oviedo Convention, the reference instrument on the protection of human rights in the field of biomedicine. This anniversary will be an opportunity for a major debate on the principles laid down in this convention in light of the new challenges posed for the protection of human rights in this field.

I am convinced that today's seminar will make a significant contribution to this reflection, and to the formulation of an intergovernmental action plan for responding to these issues.

I thank you sincerely for agreeing to participate and I hope your exchanges will be constructive and fruitful.

Session 1 - Human Rights in biomedicine: trends and challenges
Chairs

Dr Mark Bale

Chair of the Committee on Bioethics (DH-BIO)
Deputy Director, Science Research & Evidence, Department of Health (United Kingdom)

Mark Bale leads on a number of key emerging healthcare science areas and their ethical, legal and policy implications, with a particular emphasis on genomics and regenerative medicine. He is also Deputy Chief Scientific Adviser.
His current priorities are supporting the delivery of the Prime Minister's 100,000 genomes initiative, the Regenerative Medicine Expert Group and the UK Rare Diseases Strategy.
He also represents the UK on bioethics and biotechnology at the Council of Europe and OECD. He is the Chair of the Committee on Bioethics (DH-BIO), working under the authority of the Council of Europe's Steering Committee on Human Rights (CDDH).
Mark has a research background in microbial genetics and joined the Department of Health in 1999 after working on the occupational safety of GMOs and pathogens.

Session 1 - Human Rights in biomedicine: trends and challenges
Cases on Human Rights and biomedicine brought before the European Court of Human Rights (ECtHR): Common trends and challenges

The beginning and the end of life in the case-law of the ECtHR

Prof. Dr Helen Keller, LL.M.

Judge of the European Court of Human Rights

- Doctorate in environmental law, University of Zurich, 1993
- Master of European Law (LL.M.), College of Europe in Bruges, Belgium, 1994
- Research Fellow at Harvard University Law School, United States of America, 1995
- Research Fellow at the European University Institute of Florence, Italy, 1996
- Member of the American Society of International Law since 1996
- Legal Counsel in a law firm in Switzerland, 1996-2011
- Visiting researcher at the Max-Planck Institute for International Law of Heidelberg, Germany, 2000
- Professor of International Law, Constitutional Law and European Law at the University of Lucerne, 2001-2004
- Professor of International Law, Constitutional Law and European Law at the University of Zurich, 2004-2011
- Board Member of the International Law Commission, Swiss Section, 2008-2011
- Member of the United Nations Human Rights Committee (HRC), 2008-2011
- Visiting Scholar at the Centre for Advanced Studies in Oslo, Norway, 2010
- Judge of the European Court of Human Rights since 4 October 2011

Abstract

The topic of the beginning and end of life has been increasingly brought before the European Court of Human Rights. This sensitive topic deals with some of the most intimate of human rights, the right to respect for private and family life, together with the right to life and the prohibition on discrimination.
As the Court's case-law on this subject mainly revolves around them, two core principles will be addressed – consensus and margin of appreciation. In this framework, an analytical overview about how the Court defines these principles will be set out, followed by the crucial point of whether and how the Court takes into account the various materials of the Council of Europe.
Finally, an attempt will be made to point out the specific criteria needed for a consensus, together with their accompanying methodological challenges. These involve, in particular, the decrease in predictability when the Court does not apply a unified method in defining the margin of appreciation granted to the member states.

Full text

I. Introduction

1. First and foremost, I should like to thank the Council of Europe for convening the discussion on the beginning and end of life, and for inviting me to address you on the subject.
2. This sensitive issue, which has been increasingly brought before the European Court of Human Rights, deals with one of the most intimate of human rights, the right to respect for private and family life. The different approaches and jurisprudences differ from one State to another, and this leads to the understanding that the Court's case-law on the beginning and end of life mainly revolves around two core principles – consensus and margin of appreciation.
3. I will start by giving you an overview of the Court's case-law on the beginning and end of life. Then I will analyse how the Court defines the European consensus on the one hand, and the margin of appreciation on the other. A crucial point will be whether, and how, the Court takes into account Council of Europe materials, such as Conventions, Recommendations, et cetera.
4. Before I go into the details of the case-law, please allow me to mention the three main rights on the subject under the European Convention for the Protection of Human Rights and Fundamental Freedoms[1]: Articles 2, 8 and 14.

II. The Convention's Rights

5. According to Article 2 everyone's right to life shall be protected by law.
6. Article 2 is silent as to the temporal limitations of the right to life and, in particular, does not define "everyone" (*toute personne*) whose "life" is protected by the Convention. The Court has not determined the issue of the "beginning" of "everyone's right to life" within the meaning of this provision and whether an unborn child has such a right.[2]
7. Article 2 also states that in several instances, the right to life shall not be regarded as violated, as long as the use of force is used following an absolute necessity, for example in self-defence.
8. In 2004 the Court stipulated in *Vo v. France*[3], that abortion does not constitute one of the exceptions expressly listed in paragraph 2 of Article 2.[4] However, one could argue that it is compatible with the first sentence of Article 2 § 1 in the interests of protecting the mother's life and health.[5]
9. Secondly, Article 8 of the Convention[6] states that everyone has the right to respect for private and family life, home and correspondence.
10. The expression of private life within the meaning of Article 8 is a broad concept which includes, among other things, the right to establish and to develop relationships with other human beings.[7]
11. Article 8[8] also stipulates the lawful derogations from this right, only if they are in accordance with the law and are necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.[9]
12. Finally, Article 14, which is not an autonomous right, but has effect only in relation to other Convention rights, prohibits discrimination, and is violated when States treat persons differently in analogous situations without providing objective and reasonable justification. In 2002 the Court also considered that this right is violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.[10]

[1] Convention for the Protection of Human Rights and Fundamental Freedoms (as amended) (hereinafter: "ECHR"), Article 2.
[2] *Vo v. France* [GC], no. 53924/00, § 75, ECHR 2004-VIII.
[3] *Ibid.*
[4] (a) in defence of any person from unlawful violence; (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; (c) in action lawfully taken for the purpose of quelling a riot or insurrection.
[5] *Supra* note 2.
[6] ECHR (*supra* note 1**Error! Bookmark not defined.**), Article 8.
[7] *Costa and Pavan v. Italy*, no. 54270/10, § 55, ECHR 2012.
[8] ECHR (*supra* note 1), Article 8.
[9] *S.H. and Others v. Austria* [GC], no. 57813/00, § 110, ECHR 2011: "The Court reiterates that it is not contrary to the requirements of Article 8 of the Convention for a State to enact legislation governing important aspects of private life which does not provide for the weighing of competing interests in the circumstances of each individual case. Where such important aspects are at stake it is not inconsistent with Article 8 that the legislator adopts rules of an absolute nature which serve to promote legal certainty (see *Evans*, cited above, § 89)."
[10] *Pretty v. the United Kingdom*, no. 2346/02, § 32, ECHR 2002-III.

13. The beginning of life warrants, in general, not only the passive obligation of States to respect private and family life, but also the active obligation to protect it, by, among other things, providing the appropriate medical and legal measures.[11]
14. The main issues on the beginning of life dealt with by the Court are antenatal examinations, medically assisted procreation, surrogacy and qualification of the embryo.

III. The Beginning of Life

A. Medically Assisted Procreation

15. As to medically assisted procreation, in *S.H. and Others v. Austria,*[12] the Court ruled, in 2011, that a ban under domestic law on gamete donation for in vitro fertilization, is not a violation of Article 8,[13] and found that legislation showed a clear trend towards allowing it. Although this reflected an emerging European consensus, this agreement was not based on settled and long-standing principles established in the law of the Contracting States, but rather reflected a stage of development within a particularly dynamic field of law. In addition, it did not decisively narrow the States' margin of appreciation,[14] for example, by tracing the legislative purpose according to its language and to the competent national courts' interpretations.[15]
16. Nevertheless, in the above case,[16] the Court observed that it had to carefully examine the arguments taken into consideration during the *legislative process*, and "to determine whether a fair balance has been struck between the competing interests of the State and those directly affected by those legislative choices."[17]
17. The Court concluded that concerns based on moral considerations or on social acceptability must be taken seriously in such a sensitive domain, but that they were not in themselves sufficient reason for a complete ban on specific artificial procreation techniques such as ovum donation.[18]

B. Surrogacy

18. Turning to surrogacy, in *Mennesson v. France*[19] the Court stated in 2014, that the refusal to grant legal recognition to a parent-child relationship that had been legally established in another country as a result of surrogacy is a violation of Article 8 of the Convention.[20]
19. The Court observed that there was no consensus in Europe, either on the lawfulness of surrogacy arrangements or on the legal recognition just mentioned.[21]
20. This observation was based on a comparative-law survey conducted by the Court in 2014. The survey showed surrogacy to be expressly prohibited in 14 out of 35 member States – other than France – that had been studied.
    Surrogacy was expressly authorized in 7 member States and appeared to be tolerated in 4 others. In addition, in 13 of the 35 States, legal recognition of a parent-child relationship as a result of a surrogacy was possible.[22]
21. The lack of consensus showed that recourse to surrogacy raised sensitive ethical questions. The Court specified that the States ought, in principle, to be allowed a wide margin of appreciation, regarding not only the decision as to whether or not to authorize this method of assisted reproduction, but also whether or not to recognize the legal parent-child relationship to be issued from it.[23] Qualification of the Embryo
22. One of the most controversial ethical dilemmas is the factual and/or legal qualification of the embryo. In 1998 there were only a few member States who did so, and even those had widely different classifications.[24]

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[11] *Dubská and Krejzová v. the Czech Republic* [GC], no. 28859/11 and 28473/12), § 182.
[12] *S.H. and Others v. Austria* (*supra* note 9).
[13] *Ibid*, § 115; ECHR (*supra* note 1), Article 8.
[14] *S.H. and Others v. Austria* (*supra* note 9), § 96.
[15] *Ibid*, §§ 104–105.
[16] *S.H. and Others v. Austria* (*supra* note 9).
[17] *Ibid*, § 97.
[18] *Ibid*, § 100.
[19] *Mennesson v. France*, no. 65192/11, ECHR 2014.
[20] *Ibid*, §§ 100–102; ECHR (*supra* note 1), Article 8.
[21] *Mennesson v. France* (*supra* note 19), § 78. See also *Paradiso and Campanelli v. Italy*, GC, 25358/12 25358/12, forthcoming.
[22] *Mennesson v. France* (*supra* note 19), § 78.
[23] *Ibid*, § 79; *A, B and C v. Ireland* [GC], no. 25579/05, § 237, ECHR 2010.
[24] *Vo v. France* (*supra* note 2), § 40 – The European Group on Ethics in Science and New Technologies at the European Commission.

23. The two main, contrasting, visions were that "[h]uman embryos are either not considered as human beings and thus enjoy only a relative right of protection, or else they should be considered as enjoying the same moral status as human beings, and thus the same measure of protection."[25]
24. However, both in *Vo v. France* and *Parrillo v. Italy,*[26] the Court considers that this delicate issue need not be examined in the light of Article 2, even declaring it "neither desirable, nor even possible … to answer in the abstract the question whether the unborn child is a person" for the purposes of that Article. It also found that, although Article 1 of Protocol No. 1 does not apply to the latter case, an embryo cannot be regarded as a mere possession "human embryos cannot be reduced to 'possessions'".[27]
25. The need for protection of the embryo *in vitro*, was less divisive, though, as shown in a report drawn up in 2003. Nevertheless, while all countries have agreed on this, it is obvious, in the light of all the ongoing medical progress, that not only there should be a consensus on the definition of the embryo, taking account of the various European cultures and ethics, but also that re-examination of procedures and conditions ("involving the creation and use of embryos in vitro") is necessary. And, according to European Group on Ethics in Science and New Technologies at the European Commission, protection of the human embryo should be increased in line with its development.[28]

IV. The End of Life

26. Coming now to the end of life, the main issues dealt with by the Court are abortion and euthanasia.

A. Abortion

27. With regard to abortion, at the European level, the Court observed in 2004 that there was no consensus on the nature and the status of the embryo. This in spite of embryos beginning to receive some protection in the light of scientific progress, and the potential consequences of research into genetic engineering, medically assisted procreation or embryo experimentation.[29]
28. At best, it may be held that States commonly agree that an embryo belongs to the human race. Moreover, the Court found, in 2004, that many States, such as France and the United Kingdom, required protection for the embryo in the name of human dignity, without making it a "person" with the "right to life" for the purposes of Article 2.[30]
29. Neither in European domestic legislation, nor by the national courts interpreting it, was a foetus recognised as a person. The Dutch Court of Appeal in The Hague[31] [*recte: Juristenvereniging Pro Vita v. De Staat der Nederlanden (Ministerie van Welzijn, Volksgezondheid en Cultuur)* [1990] NJ 2986 (Hof, The Hague, 8 February 1990)], and the Austrian Constitutional Court had held that Article 2 should not be interpreted as protecting the unborn child, while the French Constitutional Council[32] had found no conflict between legislation on the voluntary termination of pregnancy and the constitutional protection of the child's right to health. That reading was consistent with the relevant legislation throughout Europe: 39 member States would allow a woman to terminate her pregnancy during the first trimester or on very broad therapeutic grounds.[33]
30. As there was no European scientific or legal definition of the beginning of life, the Court decided in 2010, in *A., B. and C. v. Ireland*[34]*,* that a broad margin of appreciation on legal protection was in principle to be accorded to the member States, to determine whether or not a fair balance was struck between the protection of the public interest in the right to life of the unborn, on the one hand, and the conflicting rights of the parents to respect for private life under Article 8 of the Convention on the other.[35]

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[25] *Ibid.*
[26] *Parrillo v. Italy*, [GC] no. 46470/11, ECHR 2015.
[27] *Vo v. France* (*supra* note 2), §§ 84–85, and *Parrillo v. Italy*, (*supra* note 26) § 215.
[28] *Vo v. France* (*supra* note 2), §§ 39–40 (The Working Party on the Protection of the Human Embryo and Foetus set up by the Steering Committee on Bioethics), and § 85; and *Parrillo v. Italy* (*supra* note 26), § 214.
[29] *Vo v. France* (*supra* note 2) § 84.
[30] *Ibid.*
[31] Erroneously referred to as "Netherlands Constitutional Court" by the Centre for Reproductive Rights in, amongst others, *Vo v. France, supra* note 2, § 62.
[32] Conseil constitutionnel français (Décision n° 74-54 DC du 15 janvier 1975)
[33] *Vo v. France, supra* note 2, § 62.
[34] *A, B and C v. Ireland* (*supra* note 2), § 185.
[35] *Ibid*, § 233.

31. In A., B. and C., the Court found that there had been a consensus amongst a substantial majority of the member States towards allowing abortion on broader grounds than accorded under Irish law.[36] However, even if it appeared from national laws that most member States had resolved those conflicting rights and interests in favour of greater legal access to abortion, the Court stated that this consensus could *not* be a decisive factor in the examination of whether or not the impugned prohibition on abortion for health and well-being reasons struck a fair balance between the conflicting rights and interests, notwithstanding an evolutive interpretation of the Convention.[37]
32. The said consensus was found in 2010 on the basis of comparative research done by the Court. It showed that it was possible to obtain an abortion by request in some 30 States. Having an abortion justified on health grounds and well-being was available in approximately 40 States, while an abortion based solely on well-being grounds could be had in some 35 States. Only three States (Andorra, Malta and San Marino) were more restrictive than Ireland, in having a prohibition on abortion regardless of the risk to the woman's life.[38]
33. In the light of this, the Court, in 2010, accepted the applicants' argument that there is a broader international trend towards access to abortion.[39] However, as said before, the Court did not find that this consensus ultimately narrowed the broad margin of appreciation of the States.[40]
34. This example is important for our purposes. It shows that the existence of a European consensus does not necessarily mean that there is a right under the Convention to have access to an abortion.[41]

B. Euthanasia

35. Going on to euthanasia, finally, in *Lambert and Others v. France*[42] of 2015, the Court considered that States must be afforded a margin of appreciation, not just as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the detailed arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of patients' right to life and the protection of their right to respect for their private life and for their personal autonomy.[43]
36. This margin of appreciation was not unlimited, however, and the Court reserved the power to review whether or not the State had complied with its obligations under Article 2 of the Convention.[44]
37. Research conducted by the Court in 2011 enabled it to conclude that the member States were far from reaching a consensus with regard to an individual's right to decide how and when their life should end.[45] Scrutinizing domestic legislation, the Court found that in Switzerland, pursuant to the Criminal Code, inciting and assisting suicide were punishable only where the perpetrator of such acts was driven to commit them by "selfish motives". By way of comparison, the Benelux countries, in particular, had decriminalized the act of assisting suicide, but only in very specific circumstances. Lastly, certain other countries accepted only acts of "passive" assistance. It should be noted that the vast majority of member States seemed to attach more weight to the protection of the individual's life than to his or her right to terminate it.[46] It follows that in 2011 the States enjoyed a considerable margin of appreciation in this area.[47]
38. Another comparative study, from 2012, showed that in a large majority of States (36 out of 42) any form of assisted suicide was strictly prohibited and criminalized by law. Yet, although in Sweden and Estonia, this act was not a criminal offence, Estonian medical practitioners were not entitled to prescribe drugs in order to facilitate suicide, while only 4 States allowed medical

[36] *Ibid*, § 235.
[37] *Ibid*, § 237: "It follows that, even if it appears from the national laws referred to that most Contracting Parties may in their legislation have resolved those conflicting rights and interests in favour of greater legal access to abortion, this consensus cannot be a decisive factor in the Court's examination of whether the impugned prohibition on abortion in Ireland for health and well-being reasons struck a fair balance between the conflicting rights and interests, notwithstanding an evolutive interpretation of the Convention (see *Tyrer*, § 31, and *Vo*, § 82, both cited above)."
[38] *Ibid*, § 112.
[39] *Ibid*, § 235.
[40] *Ibid*, § 236.
[41] But not necessarily: a broad consensus does not always lead to a violation (see *A.B.C. v. Ireland, supra* note 23), nor does no consensus automatically lead to 'no violation' (*Christine Goodwin v. United Kingdom,* No. 28957/95, GC, judgment of 11 July 2002, §§ 84–93). See also §66 below.
[42] *Lambert and Others v. France* [GC], no. 46043/14, ECHR 2015.
[43] *Ibid*, § 148.
[44] *Ibid*.
[45] *Haas v. Switzerland*, no. 31322/07, § 55, ECHR 2011; *Lambert and Others v. France* (*supra* note 42), § 145.
[46] *Haas v. Switzerland* (*supra* note 42), § 55.
[47] *Ibid*, § 55; *Lambert and Others v. France* (*supra* note 42), § 145.

practitioners to do so, subject to specific safeguards.[48] It follows here, too, that in 2012, and probably still today, member States were far from reaching a consensus, which would point towards a considerable margin of appreciation enjoyed by the States.[49]

39. Similarly, in 2015, the Court, relying on a comparative research report concerning 39 out of the 47 member States, indicated that there was still no consensus in practice in favour of authorising the withdrawal of treatment designed only to prolong life artificially, and in the majority of countries, was subject to certain conditions. In other countries legislation prohibited termination of treatment, or was silent on the subject.[50] In countries permitting such withdrawal, it was provided for either in legislation or in non-binding instruments, most often in a code of medical ethics.[51] Although detailed arrangements varied from one country to another, there was consensus as to the paramount importance of the patient's wishes in the decision-making process.[52] As the principle of consent to medical care was one of the aspects of the right to respect for private life, States had put in place different procedures to ensure that consent was expressed, or to verify its existence.[53] All the legislation allowing treatment to be withdrawn had enacted a legislative framework for patients to issue advance directives. In the absence of such directives, the decision lay with a third party, whether it was the doctor treating the patient, persons close to the patient or their legal representative, or even the courts. Some countries operated a hierarchy among persons close to the patient and gave priority to the spouse's wishes.[54] In addition to the requirement to seek the patient's consent, there were other conditions. The Court summarised it as follows: “Depending on the country, the patient must be dying or be suffering from a condition with serious and irreversible medical consequences, the treatment must no longer be in the patient’s best interests, it must be futile, or withdrawal must be preceded by an observation phase of sufficient duration and by a review of the patient’s condition.”[55]

40. So much as to the Court’s case-law. I would now like to turn to the consensus inquiry in more detail.

V. Margin of Appreciation and Consensus

41. As mentioned at the outset, the methodology of the Court with regard to cases concerning the beginning and end of life includes two important ideas – the consensus inquiry and the margin of appreciation.

42. The preamble to the Convention[56] stipulates that the aim of the Council of Europe is the achievement of greater unity between its members, and that one of the methods by which that aim is to be pursued is the maintenance and further realization of human rights and fundamental freedoms.[57]

43. The notion of "respect" of rights is not clear cut especially as far as positive obligations are concerned. Having regard to the diversity of the practices followed in the member States, the requirements of this notion vary considerably from case to case.[58]

44. In determining the scope of the obligations that the Convention imposes on the member States, the Court shows *deference to national decision-makers* against its conviction that the Convention must be interpreted in the light of progressive European conditions and attitudes. Striking the balance between these two competing goals is difficult, for although the Court has indicated that the Convention must be interpreted as a *living instrument* and in the light of present-day conditions, it has also acknowledged that the member States are entitled to a substantial degree of deference – a margin of appreciation for their actions. The justifications for respect and deference are considerable. The Court is keenly aware that the Convention continues to exist solely by consent of the member States. The Court has progressively narrowed the margin of appreciation doctrine by analyzing the degree to which common human rights practices can be discerned among the member States.[59]

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[48] *Koch v. Germany*, no. 497/09, § 26, ECHR 2012.
[49] *Ibid*, § 70.
[50] *Lambert and Others v. France* (*supra* note 50), § 72.
[51] *Ibid*, § 73.
[52] *Ibid*, § 76, 147.
[53] *Ibid*, § 74.
[54] *Ibid*, § 75.
[55] *Ibid*, § 76.
[56] ECHR (*supra* note 1).
[57] *Ibid*, preamble paragraph no. 4.
[58] *A, B and C v. Ireland* (*supra* note 23**Error! Bookmark not defined.**), § 248.
[59] L.R. Helfer, 'Consensus, Coherence and the European Convention on Human Rights', *Cornell International Law Journal*, vol. 26, 1993, pp. 136–140.

45. In the context of the State's positive obligations, when addressing complex scientific, legal and ethical issues concerning in particular the beginning or the end of life, and in the absence of consensus among the member States, the Court has recognised that the member States have a certain margin of appreciation.[60]

A. Breadth of the Margin of Appreciation

46. The Court pointed out that a number of factors must be taken into account when determining the breadth of the margin of appreciation to be enjoyed by the State when determining any case under Articles 2 and 8 of the Convention. Where a particularly important facet of an individual's existence or identity is at stake – a hard core aspect/*noyau dur*[61] – the margin will normally be restricted. Where there is no consensus, however, either as to the relative importance of the interest at stake or as to the best means of protecting it, particularly where the case raises sensitive moral or ethical issues, the margin will be wider.[62]
47. As the number of member States increases, this side of the Court's mandate gains in weight, for in such a larger, diversified community, the development of common standards may well prove the best, if not the only way of achieving the Court's professed aim of ensuring that the Convention remains a living instrument to be interpreted so as to reflect societal changes and to remain in line with present-day conditions.[63]
48. Consensus has therefore been invoked to justify a dynamic interpretation of the Convention.[64]

B. Elements of the Consensus Inquiry

49. The consensus inquiry is demonstrated, in European domestic laws and international and regional treaties.[65]

1. European Domestic Laws

50. With regard to European domestic laws, as part of the usual analysis, the Court pays careful attention to the specific steps the member States have taken to give effect to emerging European human rights norms. In some cases, a simple head count of legislative developments may satisfy the consensus inquiry, while in other cases States may have used different approaches to address the same issue. In the latter instance, the Court's task is more complicated, for it shall consider the various judicial, administrative and legislative responses that States have made and the extent to which such measures represent merely an accommodation of individual claims or a genuine recognition of the binding legal character of a new human rights principle.[66]
51. The Court's approach is that a matter in which the law appears to be continuously evolving and which is subject to particularly dynamic scientific and legal developments, needs *to be kept under constant review by the member States,*[67] and should not be determined by the Court.
52. With respect to which States should be examined by seeking a consensus, foremost, one can argue that it would seem that the Court should include all the member States of the Convention. By virtue of their membership to the Convention and of the Council of Europe, each State also accepts "the principles of the rule of law and of the enjoyment by all persons within its jurisdiction

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[60] *Lambert and Others v. France* (*supra* note 42**Error! Bookmark not defined.**), § 144.
[61] *Parrillo v. Italy* (*supra* note 26), § 169: "Furthermore, a number of factors must be taken into account when determining the breadth of the margin of appreciation to be enjoyed by the State in any case under Article 8. Where a *particularly important facet* of an individual's existence or identity is at stake, the margin allowed to the State will usually be restricted (…). Where, however, there is no consensus within the member States of the Council of Europe, either as to the relative importance of the interest at stake or as to the best means of protecting it, particularly where the case raises sensitive moral or ethical issues, the margin will be wider (…)." And § 174: "The Court observes at the outset that, unlike the above-cited cases, the instant case does *not* concern prospective parenthood. Accordingly, whilst it is of course important, the right invoked by the applicant to donate embryos to scientific research is *not one of the core rights* attracting the protection of Article 8 of the Convention as it does not concern a particularly important aspect of the applicant's existence and identity." (all emphasis added and references omitted by the authors).
[62] *A, B and C v. Ireland* (*supra* note 23), § 232.
[63] *Cossey v. The United Kingdom*, no. 10843/84, Dissenting opinion of Judge Martens § 3.6.3, ECHR 1990-A.
[64] *A, B and C v. Ireland* (*supra* note 23), § 234; *Haas v. Switzerland* (*supra* note 45), § 55.
[65] L.R. Helfer, (*supra* note 59), p. 139.
[66] *Ibid*, p. 139.
[67] *S.H. and Others v. Austria* (*supra* note 9), § 118.

of human rights and fundamental freedoms". We should therefore presume that each of these States has the proper quality to take their place among free and democratic societies.[68]

53. However, there is no reason for requiring the threshold to be at the other end of the spectrum, i.e., to require unanimity among the member States. Such a rule might give each member State too much power, and *de facto* veto power against the Court, to influence the decisions of the Court, since the position of a single State could scuttle an applicant's private-life claim. Unanimity also would be unworkable because there will always be a State that rejects the applicant's purported expectation – at least the State concerned in a specific case.[69]

54. There are democratic societies (as stipulated in Article 8(2) of the Convention), other than those of the Council of Europe, and the question thus arises whether the Court should include an analysis of those other countries as well. Nothing in the Convention's jurisprudence suggests that this would be inappropriate.[70] Consistent with this practice, the Court could in certain circumstances consult the views of non-member countries, with two important limitations. First, the Court should only consult States that share a common European heritage of political traditions, ideals, freedom and the rule of law.[71] Second, because of the risk of "picking and choosing" views from non-member States to influence a case, the Court should consult non-member countries only when truly necessary (i.e., when the practices of the member States are teetering on a balance of opposing views) and, in such a case, be as complete and inclusive as possible in selecting and including those non-member countries.[72]

2. International Law and Materials

55. In cases where it is not sufficiently clear how far a norm has evolved, even after careful analysis of the Convention's text and the national law reform trends, the Court can look to developments in international law to confirm the existence of a movement towards a common regional perspective in the member States' domestic legislation and to limit an individual State's discretion to adhere to a non-conformist position. International indicia of consensus provide strong evidence that the achievement of European unity with respect to a particular human right is a major goal in the member States of the Council of Europe, even if the current domestic practice of States does not yet conform to that aspiration.[73]

56. Yet, in resorting to international law beyond the Convention's ambit, not all developments need to be given the same weight. Global multilateral treaties relating to human rights which have been widely adopted by European States, and international norms which are recognized as customary law or *jus cogens*, should be given greatest force.[74]

3. Conventions and other materials of the Council of Europe

57. Treaties that have been opened for signature only to the member States of the Council of Europe should also be viewed as convincing evidence of a developing regional perspective on individual rights, particularly where they have been signed or ratified by a large number of States, given that international instruments that overlap to some degree with the Convention's substantive norms should have the strongest influence.[75]

58. With regard to hard law materials of the Council of Europe, the Court stated in *Parrillo v. Italy*, that the limits, imposed at the European level, with regard to the application of biology and medicine, such as stipulated in the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (hereinafter: "the Oviedo Convention"),[76] with the possibility for a State to grant a wider measure of protection, had aimed to temper excesses in the subject in question. This is the case, for example, of the ban on

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[68] H.T. Gómez-Arostegui, 'Defining Private Life Under the European Convention on Human Rights by Referring to Reasonable Expectations', *California Western International Law Journal*, vol. 35, 2005, p. 182.
[69] *Ibid*, p. 188.
[70] *Ibid*, p. 182.
[71] *Ibid*, pp. 182–183; ECHR, preamble paragraph no. 6 (*supra* note 1).
[72] H.T. Gómez-Arostegui (*supra* note 60), p. 183.
[73] L.R. Helfer (*supra* note 59), pp. 161–162.
[74] *Ibid.*, p. 162.
[75] *Ibid.*, p. 162.
[76] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine.

creating human embryos for scientific research in Article 18 of the Oviedo Convention, or the ban on patenting scientific inventions where the process involves the destruction of human embryos.[77]

59. In this context, in *Vo v. France*, the Court emphasized that the Oviedo Convention is careful not to give a definition of the term "everyone", and its explanatory report indicates that in the absence of a unanimous agreement on the definition, the member States decided to allow domestic law to provide clarification for the purposes of the application of the Oviedo Convention. The same is true of the Additional Protocol on the Prohibition of Cloning Human Beings and the Additional Protocol on Biomedical Research, which does not define the concept of "human being".[78]
60. Fortunately, the Court has never been faced with a real clash between the Oviedo Convention and domestic regulation.
61. Alongside the hard law materials, the Court also examines the Council of Europe's soft law materials. For instance, in *Lambert and Others v. France*[79] of 2015, the Court relied on the Guide on the Decision-Making Process Regarding Medical Treatment in End-of-Life Situations, which was drawn up by the Committee on Bioethics of the Council of Europe with the intention of facilitating the implementation of the principles enshrined in the Oviedo Convention. This Guide's aims are, *inter alia*, to bring together both normative and ethical reference works and elements relating to good medical practice of use to health care professionals dealing with the implementation of the decision making process, and to contribute, through the clarification it provides, to the overall discussion on the subject.[80]
62. An additional important source which may indicate regional development are the recommendations and resolutions of the Committee of Ministers, which are designed to encourage the member States of the Council of Europe to develop harmonious policies on matters of common interest, including human rights. In addition, slightly reduced weight can be accorded to recommendations and resolutions of the Parliamentary Assembly of the Council of Europe.[81]

VI. Conclusion

63. In conclusion, today, due to the diversity of the practices and the situations prevailing in the member States, the consensus and the States' margin of appreciation vary considerably from case to case[82] and in accordance with research conducted by the Court on European domestic laws, international treaties and regional arrangements, and also on Council of Europe materials.
64. Some authors argue that the doctrine of margin of appreciation is a black hole, allowing the Court to decide on a case-by-case basis without any predictability and without applying a unified methodological approach in defining consensus. For example, in the view of some scholars, the margin of appreciation doctrine's relative aspect is inconsistent with the universal character of human rights, because it subjects these rights to a cultural relativism.[83]
65. At least for our topic, we can discern certain elements of the doctrine of margin of appreciation – the margin depends on several aspects:
    Whether a core issue is involved, whether the legislator did take into account all aspects of the issue, whether the legislation is rather recent or not and whether there is an evolving European consensus. For defining the latter, the Court does not apply a unified method in all cases (e.g. the number of States taken into account etc.). This lack of a unified methodology is derived from budgetary constraints on comparative research, together with time restrictions, on the one hand. On the other hand, however, it might also be due to a lack of awareness of the methodological challenges in making comparative analytic research. Here we are exposed to an aspect which might need improvement. Ultimately one has to accept that judges are not specialised in making comparative and empiric research, but that they are human rights lawyers.

[77] *Parrillo v. Italy* (*supra* note 26), § 181–182.
[78] *Vo v. France* (*supra* note 2), § 84 : "The same is true of the Additional Protocol on the Prohibition of Cloning Human Beings and the Additional Protocol on Biomedical Research, which do not define the concept of "human being" (see paragraphs 37–38 above)."
[79] *Lambert and Others v. France* (*supra* note 42).
[80] *Ibid*, § 60.
[81] L.R. Helfer (*supra* note 59), p. 163.
[82] *A, B and C v. Ireland* (*supra* note 23), § 248.
[83] J.A. Sweeney, 'Margins of Appreciation: Cultural Relativity and the European Court of Human Rights in the Post-Cold War Era' (2005) 54 International and Comparative Law Quarterly p. 459, 460.

66. In case of a dispute on the beginning and end of life, the Court first seeks to have a European consensus on the dilemma in question. If there is a broad consensus among the Council of Europe member States, their margin of appreciation is *in general* quite limited, and *vice versa*.[84]
67. There is no clear guidance for the concrete methodology that the Court uses by seeking a consensus. Nevertheless, the quest for a consensus is mostly based on examining the national law of Council of Europe member States, but not necessarily all of them. The legal sources that are examined may be the States' domestic laws and their memberships in international treaties on the issue in question. Council of Europe materials may also assist in indicating a European consensus emerging in these matters.
68. A consensus can evolve over time. In areas where twenty years ago there was no consensus and therefore States enjoyed a large margin of appreciation, eventually the situation can be changed over time. This societal change might lead to a greater development in the Court's case-law.
69. The requirements for the consensus research vary in different areas of human rights law. For traditional areas (like pre-trial detention or *habeas corpus*) the Court requires a long standing practice in the member States.[85] There is an important element of genuinely evolved / experienced human rights standards in the member States of the Council of Europe. However, in areas such as the artificial procreation of life, which depend on new scientific research and on societal development, the Court does not require a long standing practice which becomes obsolete in areas of rapid evolution. The flipside of this is that the member States are under an obligation to review their legislation regularly.

[84] But not necessarily, see §34 above in the case of abortion.
[85] See for example *Buzadji v. the Republic of Moldova* [GC], no. 23755/07, § 45, ECHR 2016.

Session 1 - Human Rights in biomedicine: trends and challenges
Cases on Human Rights and biomedicine brought before the European Court of Human Rights (ECtHR): Common trends and challenges

The right for privacy in the case-law of the ECtHR

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Abstract

Medicine is constantly evolving and the progress made in this field triggers both the hope and the concern of the society. The presentation focuses on the right to privacy and putting together *the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine* with the case-law of the European Court of Human Rights (ECtHR), it analyses the evolution undergone by the ECtHR regarding the interpretation of Article 8 (right to respect for private and family life) of the European Convention of Human Rights and its application to new situations that have arisen as a result of medical progress. The analysis of Article 8 will be carried out through an overview of the ECtHR case-law in two areas: i) the duties of the medical professional and, particularly, the need for a previous consent as well as the protection of sensitive data and ii) the right to personal development and, specifically, to know the biological identity and to guarantee the recognition of transsexuals' rights. This lecture illustrates the existing conflict between law and science and the position adopted by the ECtHR which has managed to adopt a novel approach in its case-law and cope with the challenges emerged on account of medical progress.

Full Text

The right to privacy in the case law of the Court

A.- The obligations of the medical profession

- The need to obtain informed consent before carrying out intrusive medical examinations or treatment
- The protection of sensitive medical data

B.- The right to personal development

- The right to know one's biological identity
- The recognition of transsexualism

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The concerns raised by technological progress are not new. François Rabelais understood this. In his acclaimed novel "The Life of Gargantua and Pantagruel", Gargantua explains to his son Pantagruel that "science without conscience is but the ruin of the soul". Less well-known, however, is that he also recommends that his son should "suspect the abuses of the world". The spirit of Rabelais, who was a doctor – moreover, he carried out his profession not far from here, in Metz to be precise – inspires the work of Committee on Bioethics and that of the European Court of Human Rights ("the Court").

The advances in the field of medicine give rise to considerable hope, but also, at times, to a number of concerns that we must first identify and then analyse.

This approach also applies to the European Court of Human Rights. The Court focuses on these problems as they arise, addressing disputes mostly involving private individuals in conflict with states that have ratified the European Convention on Human Rights.

I would now like to talk about the relationship between the European Convention of Human Rights and the Oviedo Convention.

The European Convention on Human Rights, signed on 4 November 1950, is the progeny of the Universal Declaration of Human Rights of 1948. Several of its provisions can be directly or indirectly affected by the application of biology and medicine. In addition to respect for private life, protected by Article 8, we cannot forget the right to life (Article 2), the prohibition of inhumane treatment (Article 3), the prohibition of new forms of human exploitation (Article 4) and the right to freedom (Article 5).

The Convention on Human Rights and Biomedicine – the Oviedo Convention – was signed on 4 April 1997. It has been ratified by 29 member states of the Council of Europe. It was the first instrument specifically designed to preserve human dignity, rights and freedoms against the misuse of biological and medical advances. Next year we will celebrate its 20th anniversary. Its Preamble also makes reference to the Universal Declaration and to the European Convention on Human Rights.

Admittedly, the Oviedo Convention did not provide for a judicial body that could impose sanctions for violations of its provisions. However, this is not a failing that seriously undermines the protection of the rights it establishes. The national courts are the ones first and foremost responsible for ensuring compliance with this convention once it has been incorporated into their domestic legal systems. In addition, the European Convention on Human Rights should not be read independently but in harmony with the general principles of international law. It follows that nothing technically opposes Article 8 being interpreted by the European Court in light of the principles established in the Oviedo Convention.

I have counted at least 17 Court judgments in which the Oviedo Convention plays an important role. Among them, five concern Grand Chamber cases; the Grand Chamber being the most prestigious chamber of the Court. Comprising 17 judges from different countries and different legal traditions, it

ensures the consistency of and oversees the major developments in the case law. The five cases are the following: *Lambert v. France*, 2015, *Parrillo v. Italy*, 2015, *S.H and others v. Austria*, 2011, *Evans v. UK*, 2007 and *V.O v. France*, 2004. The twelve other cases were dealt with by the smaller chambers of seven judges. These were: *Elberte v. Latvia*, 2015, *Dvoracek v. Czech Republic*, 2015, *Petrova v. Latvia*, 2014, *Dubská v. Czech Republic*, 2014, *Costa and Pavan v. Italy*, 2013, *the Raëlien Movement v. Switzerland*, 2012, *V.C v. Slovakia*, 2012, *Girard v. France*, 2011, *Yazgül v. Turkey*, 2011, *Bogumil v. Portugal*, 2009, *Juhnke v. Turkey*, 2008 and *Glass v. UK*, 2004.

Reading these judgments is the best proof of the irrefutable value of the work of the Committee on Bioethics. I encourage you to continue with this work, with the human-oriented approach and the highest technical standards, which are your hallmark.

Today I have chosen to focus on European case law relating to the right to privacy. This concept is at the heart of Article 8 of the European Convention. Its first paragraph protects the four aspects of a person's autonomy: "Everyone has the right to respect for his private and family life, his home and his correspondence". The second paragraph of Article 8 sets out the limits that the states can place on those rights. The grounds are precisely stated. They constitute a *numerus clausus* and should be interpreted narrowly. They include measures concerning preventing public disorder, protecting health, protecting the rights and freedoms of others, etc. In the majority of disputes, the Court does not carry out an in-depth review into the legitimacy of the grounds given by the state to justify its interference. However, it obliges the respondent state to prove that the interference was legal and necessary in a democratic society, in the sense that the interference must correspond to an urgent social need and should not deviate from the values we share throughout Europe

A major development in this area concerns the scope of Article 8. Over time, this scope has expanded considerably and now covers a wide range of areas. As a result, the Court has extended its jurisdiction to a whole range of very sensitive issues, such as the physical and moral integrity of a person, the confidentiality of personal information, sexual freedom, and the right to personal development and a healthy environment.

We can see how the Court has given a new meaning to traditional principles. This is fully in line with the dynamic nature of the European Convention, which is not a rigid text, but a living legal instrument "which has to be interpreted in the light of present-day conditions" according to the well-established wording of the Court.

For example, as a result of advances in genetics, the concept of the protection of private life takes on a new significance. Is it not the case that genetic tissue analysis makes it possible to go even further into the biological privacy of the human body, even being able to provide information on future health? The 2008 Protocol relating to genetic testing for medical purposes requires a reasoned response to this major challenge coming from the unprecedented development of medical sciences. Your draft recommendation on the process of genetic testing for insurance purposes is consistent with this.

The European Convention on Human Rights and the Oviedo Convention are therefore texts that are closely interconnected. I would now like to focus on two topical issues: the obligations of the medical profession (A) and the right to personal development (B).

A.- The obligations of the medical profession

I shall refer to two aspects of this obligation: first, the informed consent of patients, and second, the protection of sensitive medical data.

The need to obtain informed consent before carrying out intrusive medical examinations or treatment

The need to obtain the patient's informed consent before carrying out intrusive medical examinations or treatment is a prime example of convergence between the two Conventions. Some medical examinations require clear interference into the private lives of individuals (Article 8 of the European Convention on Human Rights). Article 5 of the Oviedo Convention expressly requires a patient's prior informed consent that is made freely and is revocable at will.

The Court fully subscribes to the latter test.[86] In the case of *Glass v. UK*, for example, the Court held that the decision to administer diamorphine to a physically disabled minor, despite the repeated objections of his mother (and without referring the matter to the High Court), had to be analysed as violation of the respect for the private life of the child, particularly his right to physical integrity.

Another illustration of the Oviedo Convention being taken into account is to be found in a case concerning the sterilisation of a young Roma woman in a public hospital (*V.C. v. Slovakia*). The applicant had given her consent when in pain and frightened while in labour, which had been going on for several hours. The Court concluded that she had not understood the importance, nature, the consequences and especially the irreversibility of this surgical procedure.

Similarly, a gynaecological examination carried out while in police custody, without the informed and voluntary consent of the woman concerned, is also an invasion of her privacy (*Juhnke v. Turkey, Yazgül v. Turkey*). The same conclusion was drawn with regard to carrying out "virginity tests" for which no consent had been given during this part of the procedure (*Salmanoğlu and Polattaş v. Turkey*).

The case of *M.A.K. and R.K. v. the United Kingdom* (2010) constitutes a particularly serious violation of Article 8. It concerns the ten-day hospitalisation of a nine-year-old girl following an examination by a paediatrician who wrongly believed that bruising on the girl's legs was consistent with sexual abuse perpetrated by her father. Later on it was discovered that the bruises were due to a rare skin disease. The father's visits to his daughter had been restricted during her hospitalisation. In addition, a blood sample was taken from the young girl and intimate photos were taken without parental consent soon after her admission to hospital. The Court concluded that these latter acts had not been justified, particularly as the minor had been alone in hospital and the situation had not been urgent.

Lastly, in a recent case relating to taking tissue from a deceased person (*Elberte v. Latvia* and *Petrova v. Latvia*), the Court stated that the human body should always be treated with respect, even after death.

The protection of sensitive medical data

The right to medical information is set out in Article 10 of the Oviedo Convention. Everyone is entitled to know, if they so wish, any information collected about his or her health. We will not be looking at this first aspect today. This article of the Oviedo Convention also highlights the importance of the confidentiality of medical data. It focuses on the right to respect for private life. Your Convention converges once again with the right to the protection of private life enshrined in Article 8 of the ECHR. The protection of personal data, particularly medical, is deemed essential to ensure that everyone can exercise his or her right to a private life. We are all familiar with the social stigma and displays of intolerance experienced by those with certain medical conditions. It is a fundamental right that aims not only to respect the patient's privacy, but also to preserve his or her trust in the medical profession and healthcare services in general. Without effective protection of data, people requiring medical assistance could be tempted to hide their state of health and, eventually, put their own integrity in danger and that of third parties in the case of infectious illnesses. Accordingly, the Court considers that national law should contain sufficient and dissuasive measures in order to avoid non-authorised disclosure of personal medical data.

The case of *Armonas and Biriuk v. Lithuania* (2008) is one example showing that this guarantee is not always upheld, since the largest daily Lithuanian newspaper published a sensationalist article revealing that members of the medical staff at a centre helping those with AIDS had disclosed that two people were HIV positive. It was found that there had been a violation, in particular, on account of the derisory damages sum that had been allocated to the victims at the end of the civil proceedings brought against the newspaper.

In the case of *L.L. v. France* (2006), the applicant complained of the production and use of medical documents concerning him in court proceedings without his consent. In particular, he claimed a violation of Article 8. The Court condemned the respondent state because the Court of Appeal had revealed and made public the complainant's sensitive data, in particular by reproducing the passages

[86] See *Altuğ and others v. Turkey*, 30 June 2015 (paragraph 65).

of the report of a surgical operation in its judgment, when the person concerned had never given consent for the document to be made public, nor had he released his doctor from doctor-patient confidentiality.
The Court also judged that there had been a violation when medical data were not sufficiently protected from unauthorised access. This was the case in *I. v. Finland* (2008). The applicant stated that work colleagues had illegally consulted his confidential medical folder which contained information on his HIV infection.
In *P. and S. v. Poland* (2012), the administrators of a Polish hospital published a press release in which they announced their refusal to carry out an abortion. The journalists who contacted the hospital were informed of the circumstances of the case. The information disclosed to the public was sufficiently accurate to make it possible for third parties to discover the contact details of the abortion seekers and to get in touch with them. Indeed, following the publication of the press release, one of the abortion seekers was contacted by various people who pressured her to abandon her plan to have an abortion. The Court voted in favour of a violation of Article 8.

B.- The right to personal development

The right to personal development is another aspect of the right to a private life. It is the reason for which I am now going to look at the right to know one's biological identity. Then, I will focus on the legal recognition of transsexualism.

The right to know one's biological identity

Article 8 of the ECHR protects the right to personal development, which includes establishing one's own genetic identity and, in particular, the right to obtain the necessary information for this purpose. It is a question of discovering our origins. Birth, and especially the circumstances of it, are part and parcel of the private life of the child, then the adult. Article 1 of the Oviedo Convention also protects the identity of the person.

However, this right to know the identity of one's biological parents is not absolute, because it can collide with another competing right – that of a mother in distress who at the time of giving birth may have wished to express her desire for anonymity. Taking both rights into consideration, the Court held French legislation to be in conformity with the Convention, in particular as the applicant had the option of knowing the identity of her mother, subject to the latter's final agreement (*Odièvre v. France*, 2003).

However, there is no conflict between the rights of ascendants in the event of death. The Court pointed out in *Jäggi v. Switzerland* (2003) that it was not an invasion of the deceased's private life to take their DNA sample because the tests were carried out after death. Consequently, refusing to carry out a DNA analysis on a deceased person, in order to determine the biological origins of a third party, is not in conformity with the Convention.

Recognition of transsexualism

The Court has found against states that do not allow transsexuals to update their information on the civil registry to make it consistent with their new physical appearance. It considers that this is excessive interference with the right to respect for private life. *Goodwin v. UK* (2002) is a leading judgment. The Grand Chamber highlights that dignity – Article 1 of the Oviedo Convention – and freedom make up the essence of the European Convention, and that the personal sphere of each person is protected by Article 8 of the European Convention, including the personal right to establish the details of his or her identity. The Court considers that, from now on, a modern society must demonstrate tolerance in order to make it possible for transsexual persons to live in dignity and with respect, in conformity with the sexual identity they choose at the cost of great suffering. Accordingly, it acknowledges the need to legally recognise changes in gender.

The case of *Y.Y v. Turkey* (2015) is an extension of Goodwin, insofar as the Court concluded that a gender reassignment operation could not reasonably be subject to prior permanent sterilisation.

By way of conclusion, it can be maintained, without the risk of being overly mistaken, that bioethics has a very large potential scope. A part of the legal opinion maintains that the rights of bioethics are a third generation of human rights, after civil and political rights and liberties, and economic and social

rights. Bioethics law, stemming from provisions of a general scope and case law, is indicative of how law is evolving in an ever more complex society.

The disputes occurring at the crossroads between law and science, do not leave European judges empty-handed. Indeed, the techniques traditionally implemented by the Court, including balancing the different interests in play, will quite naturally be transposed in the disputes stemming from the rights defined in the Oviedo Convention. In addition, every decision relating to case law presents a degree of flexibility, in that it can adapt, without a doubt more easily than the legal texts, to changes in today's world.

We must therefore all rise to the challenges that we are faced with, but always with the higher objective of developing human rights. Thank you.

Ms Brigitte Konz

Head Justice of the Peace (Luxembourg)
Chair of the Steering Committee for Human Rights of the Council of Europe (CDDH)

A graduate of the law faculties of the Universities of Strasbourg and Paris I, Brigitte Konz has a Master's degree in Tax Law and a Postgraduate Diploma in Commercial Law and Economic Law. In Luxembourg she completed her training by obtaining a Certificate of Further Training in Luxembourg Law and passing the final exam following a legal internship.
She began her professional career as a lawyer and then became an Administrative Officer at the Luxembourg Registry.
From 1985 she held various judicial positions within the Luxembourg prosecution service and at the Luxembourg District Court, in particular as vice-president and president of a criminal division specialising in economic crime. She also worked at the Court of Appeal as a "counsellor" and appeals judge for child protection cases. She currently holds the position of Head Justice of the Peace at the Justice of the Peace Court in Luxembourg.
She has participated as an expert, on behalf of the Luxembourg Ministry of Justice, in the work of various Council of Europe committees and, since 2016, she has been chairing the Steering Committee for Human Rights.
She is also a member of the National Ethics Advisory Committee for Natural Sciences and Health and of the Luxembourg Sports Arbitration Board.

Mr Justice Peter Jackson

Judge of the Family Division of the High Court (United Kingdom)

Mr Justice Peter Jackson is a High Court judge in England and Wales, assigned to the Family Division. He became a barrister in 1978, practicing in a wide range of non-financial family law areas. He was appointed as a part-time judge in 1998, a Queen's Counsel in 2000 and a Deputy High Court Judge in 2003. He became a High Court Judge in October 2010 and has been the Family Division Liaison Judge for the Northern Circuit since October 2011.

Abstract

This presentation will focus upon the impact of ECHR bioethics caselaw on a trial judge in family law matters. As a working example, specific reference will be made to the speaker's own recent decision in *Spencer v Anderson (Paternity Testing: Jurisdiction)* [2016] EWHC 851 (Fam), which is to be found at http://www.bailii.org/ew/cases/EWHC/Fam/2016/851.html and the influence of decisions such as *Jäggi v Switzerland* [2008] 47 EHRR 30.

Full Text

It gives me great pleasure to participate today in such distinguished company. I am not an expert and I am not an academic, as you will easily discover. I am instead a trial judge looking for help when dealing with cases that need decisions. We are therefore descending from high level to the humble artisan at his workbench. I will speak from personal experience, giving as examples three cases in which I have recently been involved.

I am one of 20 judges assigned to the Family Division of the High Court of England and Wales. Our decisions are binding on inferior courts, persuasive to each other, and subordinate to rulings of the Court of Appeal and the Supreme Court. We are the trial judges for the most serious cases and for cases that involve points of law.

The first case I will discuss is one that I was called upon to decide last April. This was Spencer v Anderson (Paternity Testing: Jurisdiction)[87].

[87] [2016] EWHC 851 (Fam) http://www.bailii.org/ew/cases/EWHC/Fam/2016/851.html

The issue was whether the court can direct that a DNA sample given for medical purposes during a person's lifetime should be tested after his death to establish the paternity of another individual. The issue had not previously been decided in an English court.

The judgment, which is necessarily quite long at around 30 pages, considers four pieces of domestic legislation. These concern firstly declarations of paternity[88], secondly the ordering of genetic testing[89], thirdly the handling of human tissue[90], and lastly human rights[91].

The facts of the case were that Mr Spencer, aged 29, claimed that he was the son of the late Mr Anderson, who had died in his 40s. Mr Spencer's mother and Mr Anderson had had a brief relationship in the 1980s and had then gone their separate ways.

The case concerned a DNA sample that came into existence in this way. In 2006, Mr Anderson received treatment for bowel cancer. He agreed to the extraction of his DNA for medical reasons and also, because there was a family history of this form of cancer, to find out whether his condition was or a hereditary kind. The DNA was extracted and stored, but in fact testing was never carried out and Mr Anderson died of other causes in 2012.
Mr Spencer applied for an order that the hospital should release the stored DNA sample for testing to provide evidence of his paternity. He wanted to know who his true father was and whether he himself was at risk of cancer. Because of the possibility that Mr Anderson's cancer was hereditary, he had been advised by his own doctor to have regular intrusive examinations, which would otherwise be unnecessary.

Mr Spencer's claim was disputed by Mr Anderson's mother, who was his next of kin. It may perhaps be that there was an issue about financial inheritance, but that did not feature in the evidence before me.

Our domestic legislation on paternity testing allows the court to direct the taking of DNA samples. However, this legislation cannot be stretched to apply to samples that had already been taken for another purpose.

The legislation controlling the use of human tissue was passed in response to concerns about children's organs being removed after death and used for scientific purposes without the knowledge of their parents. The cornerstone of this legislation is the need for informed consent. However, it does not apply to DNA, which is not human tissue but chemicals extracted from tissue.

I was therefore faced with the question of whether the court has its own powers to order testing of an existing DNA sample in order to uphold the rights of the individuals concerned. The parties disagreed about whether such a power exists and, if it did, whether it should be used in this case.

Mr Anderson's mother relied on the fact that the paternity testing legislation does not provide for testing in such circumstances, and on the requirement for patient consent in the human tissue legislation. She argued that the high confidentiality of DNA should be respected and that allowing testing might deter people from providing medical samples if they could be used for other purposes without consent.

In response, Mr Spencer argued that he had a right to know his identity and that the interests of justice are best served by establishing the truth when it is readily to hand. Otherwise the question of paternity would have to be decided in ignorance of available scientific evidence.
It seemed to me that the arguments were quite evenly balanced, and it was fortunate that there were two European authorities on the point. The main one was *Jäggi v Switzerland*[92], a decision on Article 8. Mr Jäggi wanted to discover the identity of his natural father. The alleged father had refused to undergo testing during his lifetime and successive proceedings over the years had been dismissed by the Swiss courts. Finally, after the death of the alleged father, Mr Jäggi sought DNA testing, using

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88 Family Law Act 1986
89 Family Law Reform Act 1969
90 Human Tissue Act 2004
91 Human Rights Act 1998
92 [2008] 47 EHRR 30 https://wcd.coe.int/ViewDoc.jsp?p=&id=1019533&Site=COE&direct=true

the remains of the deceased man. The Swiss court again refused, saying that the applicant had been able to develop his personality despite his uncertainty as to his parentage. Before the ECHR, the Government justified the outcome by citing the need to preserve legal certainty and to protect the interests of others.

The ECHR disagreed. It held by a majority that there had been a violation of Article 8. Persons seeking to establish their identity have a vital interest, protected by the Convention, in receiving the information necessary to uncover the truth about an important aspect of their personal identity. In weighing up the different interests, consideration should be given, on the one hand, to the applicant's right to establish his parentage and, on the other hand, to the rights of third parties, to the inviolability of the deceased's body, to respect for the dead, and to the public interest in preserving legal certainty. However, the preservation of legal certainty cannot in itself be a ground for depriving the applicant of the right to ascertain his parentage.

In *Jäggi*, the Court referred to the 2006 admissibility decision in *The Estate of Mortensen v Denmark*[93]. There, the Danish Supreme Court had narrowly approved the exhumation of an individual to provide a DNA sample for paternity testing. The ECHR refused to consider the application. It held that the private life of a deceased person could not be adversely affected by such a request and that accordingly the person's estate had no right to bring an application. Here, nevertheless, was another example relevant to the case before me.

Returning to Mr Spencer and Mr Anderson, these European decisions helped me by emphasising:

- the importance Article 8 attaches to knowledge of one's identity
- the fact-specific nature of the inquiry
- the limits on the rights of a deceased person
- the existence of precedents for testing, even involving exhumation

My decision was that the court does have the power to direct testing outside the terms of the legislation. I said this:
"If the court was unable to obtain evidence of this kind, severe and avoidable injustice might result. Awareness of the implications of ordering testing without consent and of the wider public interest does not lead to the conclusion that the jurisdiction does not exist, but rather to the realisation that it should be exercised sparingly in cases where the absence of a remedy would lead to injustice."

I therefore directed that testing of the DNA sample should take place. In reaching this conclusion in an undoubtedly sensitive field, I acknowledged the *Jäggi* decision as a significant contributor to my thinking. I cannot say that I would not have reached the same result without its assistance, but it certainly provided useful legal scaffolding.

I should add that there is to be an appeal in this case, but even if I am found to have been wrong, the Court of Appeal will surely consider the European decisions I have mentioned.
For contrast, I would like to touch on our law on the withdrawal of life-sustaining treatment. This has developed over the last 25 years, starting with *Airedale NHS Trust v Bland* [94]. This was the case of Tony Bland, a young Liverpool supporter in a coma after the Hillsborough stadium disaster. More recently, we have the decision of our Supreme Court in *Aintree University Hospital NHS Foundation Trust v James*[95], an appeal in another case of my own concerning the criteria for the withdrawal of life-sustaining treatment. However, our domestic analysis has not so far made reference to decisions of the ECHR, for the good reason that none then existed.

Now we have the 2015 case of *Lambert v France*[96]. As you know, this was a disagreement between family members about the withdrawal of nutrition and hydration from a relative in a vegetative state. The French legislation of 2005 on patients' rights and end-of-life issues provides that treatment must not be continued with *'une obstination déraisonnable'* – unreasonable obstinacy. Where treatment appears to be futile or disproportionate or to have no other effect than to sustain life artificially, it may

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[93] Application no. 1338/03 file:///C:/Users/User/Downloads/001-75655.pdf
[94] [1993] AC 789 http://www.bailii.org/uk/cases/UKHL/1993/17.html
[95] [2013] UKSC 67 http://www.bailii.org/uk/cases/UKSC/2013/67.pdf
[96] 46043/14, judgment of 5 June 2015 http://hudoc.echr.coe.int/eng#{"itemid":["001-155352"]}

be discontinued or withheld. In its decision, the ECHR (by a majority of 12 to 5) upheld the decision of the Conseil d'Etat that treatment should be discontinued. The Court referred to the Oviedo Convention on Human Rights and Biomedicine and to the Guide drawn up by the Committee on Bioethics.

It is reassuring to find that the approach to a case of this kind in France and at the European level is familiar to those of us working in the English courts. These are heavy decisions and we do well to learn from others who face them. This is, after all, a subject on which views can strongly differ, as the minority opinion in *Lambert* shows: *"We regret that the Court has, with this judgment, forfeited the title of being 'The Conscience of Europe'".* I think we can expect to see reference to *Lambert* in a future English decision in this field.

Lastly, I would mention the very recent case of the 14-year-old girl who wanted to be cryogenically frozen after her death.[97] Her story was widely reported because of its sad and unusual facts. Legally, it was not about the rights and wrongs of cryonics, but about the rights of the child and her parents, and of third parties such as the hospital. However, the case may raise some interesting questions for the future: Is our long-established law that our bodies are not property (meaning that we have no right to dictate what happens to us after death) consistent with our human rights? Should a competent child have the right to make a will (they do in Scotland, they don't in England)? In what circumstances can the court make an order during a person's lifetime to govern what should happen to them after death? As to cryonics, the question arises as to whether this form of activity should be regulated following the experience on this case.

In my judgment, I described the case as an example of the new questions that science poses to the law, perhaps most of all to family law. These questions will not be scientific ones, they will be ethical ones.

But most of all, I believe that a case of this kind reminds us of how much things change and will continue to change. After all, it was not until the 1880s that cremation was recognised as lawful in the United Kingdom, and that came about in this way. William Price, an eccentric Welshman (and a druid) had a beloved son who died very young. He cremated the child's body on a funeral pyre at the top of a hill and was arrested on the assumption that he was doing something illegal. Only at his trial was it accepted that what he had done was not illegal at all. Cremation swiftly became widespread and was in due course regulated by the Cremation Act 1902. Before these events, everyone was buried. A century later, in the UK cremation is chosen in 3 out of 4 cases.

I notice that the useful research report on bioethics decisions of the ECHR lists 125 cases. 90 of these have arisen since 2010 and with only one exception, all of the decisions have been given since the year 2000. So who is to say what subjects will feature in a research report written even ten years in the future? The legal response to these bioethical questions is still in its infancy, and we will certainly have much to learn from each other as time passes.

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[97] *JS (Disposal of Body)* [2016] EWHC 2859 (Fam) http://www.bailii.org/ew/cases/EWHC/Fam/2016/2859.html

Ms Claire Bazy Malaurie

Member of the Constitutional Council (France)
Member of the Venice Commission of the Council of Europe

A graduate of the Paris Institute of Political Studies, Claire Bazy Malaurie holds a master's degree in law and a bachelor's degree in Russian. She also attended ENA (the French National School of Administration).

She began her career in the Ministry of Finance's Directorate of Foreign Economic Relations (DREE), before joining the Court of Audit. She has held several senior administrative positions: director at DATAR (state regional planning and development body), finance director in the Ministry of Development, director of hospitals in the Ministry of Social Affairs. She has also performed a number of government assignments in the areas of public administration, health and higher education. Ms Bazy Malaurie was appointed division president in the Court of Audit in 2006.

She was appointed to the Constitutional Council in July 2010 and was reappointed in March 2013 for a nine-year term.

Abstract

Judging by the reactions to the European Court of Human Rights' particularly high-profile ruling on surrogacy and the comments it triggered in many quarters, it could be said that there is real disagreement between France and the Court. Beyond the rhetoric, some recent decisions by the European Court of Human Rights and national courts illustrate the difficulties in terms of coexistence of case-law of different origin in this area.
This is not surprising because although it is not easy to define the notion clearly today, bioethics always involves friction between science, the law and values. While science may be universal, legal standards are not and it is not certain that values which in principle are universal can be set out uniformly in detail.
Supreme courts and constitutional courts have clear margins of discretion when it comes to interpreting the key principles of freedom and assertion of personal autonomy which apply in this area, as they are also accountable for the social acceptance of their decisions and the conformity of the latter with the legislation which they are required to apply.
This presentation will be illustrated with some examples of decisions, primarily from the Constitutional Council, but also from the *Conseil d'Etat* and the Court of Cassation.

Full Text

Impact of the ECtHR judgments at the national level - in France

I understand that what is required of me this morning is a presentation on French solutions, as compared with those proposed by the European Court of Human Rights, to issues described as "bioethical". Without going into unnecessary details about the division of competences among national courts or into the controversies surrounding the hierarchy of legal instruments, a debate which is too specific to France to be of any relevance here, it is indeed of interest to note that the solutions proposed by the different courts can complement or complete each other or sometimes conflict.
In choosing the subjects I will address, I have, however, excluded what I regard as questions of access to healthcare techniques and practices which have long been recognised in our legislation.

There is an area where no contradiction can be found between the decisions of the European Court of Human Rights and French legislation: the **use of genetic fingerprints in order to prosecute criminals**. Today, DNA tests are used as evidence. The conditions under which they are collected and stored in databases follow specific rules in France and I have not noted any difference between the Court's case-law and the French provisions, which the Constitutional Council has, incidentally, declared to be in conformity with the Constitution, insofar as they were subject to its review. The Constitutional Council moreover reiterated on that occasion that examining a person's genetic characteristics is prohibited and the genetic fingerprint is to be used only for identification purposes. It therefore confirmed a restriction on the use of new technologies in view of the aim pursued, which is a quintessential legislative technique in matters of bioethics: the law serves above all to afford guarantees regarding use of a technique which can evolve to such an extent that its applications go well beyond the initially determined purpose.

The limits set by French law are nonetheless sometimes "lower" than those established by the European Court of Human Rights. This applies to actions to **determine paternity**.
Many applications have been made to the European Court of Human Rights under Article 8 which protects "the right to an identity and to personal fulfilment, and the right to establish and develop relationships with other human beings…", you know the wording. The interest safeguarded has been described as "vital". In France, what we call "access to one's origins" is strictly regulated by the law, which protects anonymity whether in the case of giving birth anonymously or donating gametes. The Court has accepted this fairly recent French system (2002) "in view of the complex and sensitive nature of the issue" and in the name of States' margin of appreciation, but while referring to the need to reconcile the interests at stake (see the Odièvre judgment of 2003).

The debate is, however, of a different nature when it comes to determining paternity using DNA analysis. Proceedings to establish paternity can only be brought by a child (or the mother when the child is a minor); they are prohibited for children conceived through medically assisted procreation with a third party donor or following full adoption. Courts regularly weigh the interests at stake before allowing or refusing DNA testing in cases where this is possible. The methodological approach is therefore not very different from that of the European Court of Human Rights. As a commentator it is difficult for me to say much more about such searches for the biological truth in view of the complexity of the situations that arise, as shown by the circumstances of the Mandet v. France judgment of January 2016.

There is a case where there has been disagreement with the European Court of Human Rights, due to a different assessment of the issues at stake: this concerns the identification of a presumed father who is deceased. In 1996 a court allowed a genetic analysis of Yves Montand after his death, deeming that "as consent was then impossible, the consent requirement could not be applied". The Act of 2001, passed in reaction to the turmoil caused by this case, filled a loophole in the 1994 Act on bioethics and included in the Civil Code an obligation to obtain the individual's consent for any identification by means of his genetic fingerprint. This solution was advocated by Jean-François Mattei , who raised the following argument before the National Assembly : "*The dead who 'leave with their secrets' should be respected. Birth and death which are points of reference should not be tampered with, for fear of causing social upheaval".*
In the *Jäggi v. Switzerland* judgment delivered in 2006 the Court considered that refusal to take a DNA sample from a deceased person, which it described as "*a relatively unintrusive measure*", violates Article 8 of the European Convention on Human Rights in breach of the interests of the applicant child.

It considered that the right to rest in peace enjoys only temporary protection linked to the duration of the lease of the cemetery plot. France has not changed its position and was, in turn, found responsible for a violation in 2011 for having refused to establish a biological filiation when the person concerned had died during the procedure.

A decision of the Constitutional Council rendered in September 2011 enables a comparison of the solutions adopted. The Council held that this rule is in conformity with the Constitution because the legislature took into consideration the respect due to the human body when determining the rules of evidence applicable for establishing and contesting parental ties. Whereas, in weighing the interests at stake, the European Court of Human Rights gave precedence to the right to know one's parentage, the Constitutional Council preferred the third party right to inviolability of a deceased person's remains, the right to respect for the dead and the public interest in protecting legal certainty. Two courts dealing with fundamental rights, and two different solutions.

This is an area where the Civil Code, in conformity with the Constitution, runs counter to the solution retained by the European Court of Human Rights in response to an individual application.

In order to illustrate the difficulty that this difference can pose for the national courts, I will start with the case which is the most controversial in France, but perhaps also the most emblematic, that of surrogacy. In terms of medical technique, we are here on the familiar ground of medically assisted procreation. But it is clear that surrogacy and medically assisted procreation are not the same thing.

Surrogacy in all its forms is entirely prohibited in France: all surrogacy agreements are void as a matter of public policy. This prohibition is not the problem. The European Court has itself admitted that surrogacy can be prohibited by certain States. It is the consequences for children, in civil law, which are the subject of a heated debate.
Adhering to the principle that fraud taints everything, French courts long refused to allow the transcription in the civil status records of legal documents establishing parental ties when there was a suspicion that surrogacy might have been used. Neither an acknowledgement of paternity, backed by biological evidence, which is nevertheless the civil law rule, nor recognition by the intended mother after an adoption (the term maternal filiation is not even used here) were accepted until very recently. The Court of Cassation repeated this stance with each new case brought before it.

We know that the European Court of Human Rights found against France in June 2014, considering that refusal to register children's filiation with regard to their biological father and refusal to establish filiation in any way constituted a disproportionate invasion of the children's privacy.
The Court of Cassation changed its case law on 3 July 2015. In fact, a softening of the French stance had already occurred the previous year when the Minister of Justice instructed public prosecutors who are competent in such matters to allow the granting of a citizenship certificate to children when a parent (within the meaning of civil law) was French. But this did not solve the problem of the child's French civil status as a whole. In 2015 the Court of Cassation merely recognised the consequences of the father's nationality, relying on the authenticity of birth certificates issued abroad, which simultaneously implies that the mother is the one mentioned on the birth certificate.
However, this judgment of the Court of Cassation was heavily criticised, as had previously been the case with the Minister of Justice's circular. This criticism was mainly based on two kinds of arguments. Firstly, how can it be acceptable to override a rule adopted in the name of recognised ethical principles by giving legal effect to a situation regarded as ethically reprehensible, such as the non-availability of civil status and non-ownership of the human body? Secondly, is it not the case that birth by surrogacy is itself contrary to the child's best interests?

A recent decision by the *Conseil d'Etat* is another example of the tension that can exist between a rule based on a public order principle, in this case a prohibition, and a specific request to exercise a subjective right. This involved disregarding the ban under French law on using gametes collected in order to carry out medically assisted procreation when one of the partners in a couple had died and neither of them was French. It was by reference to the right to respect for private and family life, within the meaning of the European Convention on Human Rights, that the *Conseil d'Etat* accepted the request. I don't know what the European Court of Human Rights' solution would have been…

Let's recall that, in French law, the right to respect for private life and the right to have a normal family life do not have the same content as in the law of the European Convention on Human Rights. Let us

also remember that " the best interest of the child" is not a concept which is used by the Constitutional Council.

Of course, everyone may reply to these questions as they wish.
However, it is clear that one question will increasingly come to the fore in matters of bioethics: how does one enforce ethical rules established by law when ways to circumvent their effects have been found?

This analysis, which I have restricted to the decisions of the European Convention on Human Rights with which I am familiar and which deal with subjects also addressed by the highest national courts, shows the challenges that bioethics can raise for those who write the law and must ensure respect for fundamental rights.

The legal rules with regard to bioethics, whether couched in the Civil Code or in the Health Code, indicate the limits which must not be transgressed. The question we all face is that of possibly moving these boundaries: but when, how and where to? We will no doubt come back to this during the second half of our proceedings.

Mrs Tatyana Vavilycheva

Judge at the Supreme Court of the Russian Federation

Doctor of Law, judge in the family affairs and children's rights section of the Civil Affairs Panel of the Supreme Court of the Russian Federation (since August 2014). In 1995, graduated from N.I. Lobachevskiy State University of Nizhny Novgorod (faculty of law). Has been practising law since 1995. From July 2000 to May 2005, worked as a judge in Nizhny Novgorod District Court and from May 2005 to August 2014 as a judge in Nizhny Novgorod Regional Court. Defended her doctoral thesis on "Contemporary issues relating to the protection of human dignity (criminal law and criminological aspects)".

Abstract

Biomedical research on humans using human organs, tissue and genetic material has been going on since the birth of medicine, which, in effect, could not have advanced without human testing. Biomedical research, however, clearly involves interference in human life and as such requires mandatory legal regulation. Promoting the development of medicine and treatments for the purpose of creating and preserving human life and health is essential but protecting the basic human and civil rights involved here is a legal requirement and is not only a means of balancing the interests of science, society and individuals, but also a way of combating unlawful interference in human life.

All this poses a challenge for lawmakers and judges alike. Cases involving the use of new reproductive technologies, human organ and tissue transplantation, biomedical experiments on humans or the use of genetic engineering technologies are not only delicate but, often too, extremely complex. For example, issues related to the use of reproductive technologies to treat infertility, including treatments involving the use of donor and/or frozen reproductive cells, reproductive organ tissue or embryos, or surrogacy.

In the Russian Federation, surrogate motherhood is governed by the Family Code (Articles 51 and 52), Federal Law No. 323-FZ "On the fundamental principles of public health care in the Russian Federation" of 21 November 2011, RF Law No. 143-FZ "On Civil Status Records" (Article 16) of 15 November 1997 and RF Ministry of Health Order No. 107N "On the use of assisted reproductive technologies (ART) in the treatment of female and male infertility" of 30 August 2012. For example, Article 51, item 4, of the RF Family Code states that married persons who have given their written consent to the implantation of an embryo in another woman for bearing it, may be registered as the child's parents only with the consent of the woman who gave birth to the child (of the surrogate

mother). In essence, the law provides that primary consideration is to be given to the interests of the surrogate mother when deciding whether to grant the genetic (biological) parents maternal and paternal rights. Then there is the question of the rights and interests of persons whose reproductive cells were used to fertilise a woman who has become pregnant, and the rights of any children born using assisted reproductive technology.

Also topical is the question of obtaining informed consent for the use of various research methods involving human subjects, including issues related to organ and tissue transplantation in the case of "vulnerable" groups such as children, elderly persons, pregnant women, convicted prisoners and the mentally ill.

Bioethical issues arise in numerous spheres, and can continue to affect individuals, and their family members, throughout their lives. Bioethics and biomedicine, then, are an area where ethics, the law and science are closely intertwined, and legislation and case law can go some way towards resolving points of contention and conflicts related to the observance of human rights in this area.

Full Text

Biomedical research on humans involving the use of human organs, tissues and genetic material has been conducted ever since the birth of medicine, which, in effect, could not have advanced without the use of the human body. However, this research inevitably entails interference in human life, and as such requires mandatory legal regulation. Promoting the advancement of medicine and the creation of new methods and means of treatment in order to preserve people's lives and health is essential, but protecting the rights of persons who become involved in this research is a valid and legal requirement and is not only a means of balancing the interests of science, society and individuals, but also a way of combating unlawful interference in human life.

All this poses a challenge for lawmakers and law enforcers alike. Cases involving the use of new reproductive technologies, human organ and tissue transplantation, biomedical experiments on humans or the use of genetic engineering technologies are not only delicate, but often also extremely complex. Nowadays, courts have to deal with cases which call not only for the practical application of rules, but also the resolution of such vitally important questions as the reconciliation of legal provisions with moral/ethical rules – such as matters relating to the use of reproductive technologies to treat infertility, including treatments involving the use of donor and/or frozen reproductive cells, reproductive organ tissues and embryos, and surrogacy.

According to Article 55(1) of Federal Law no. 323-FZ of 21 November 2011 "On the fundamental principles of public healthcare in the Russian Federation", assisted reproductive technologies are methods of treating infertility whereby some or all stages of the conception and early development of embryos occur outside the mother's body (including with the use of donor and/or frozen reproductive cells, reproductive organ tissues and embryos, and surrogacy).

In the Russian Federation, legal relations in the field of surrogate motherhood are governed by the Family Code (Articles 51-52), Federal Law no. 323-FZ of 21 November 2011 "On the fundamental principles of healthcare for citizens in the Russian Federation" (Article 55), Federal Law no. 143-FZ of 15 November 1997 "On civil status records" (Article 16), and Russian Federation Ministry of Health Decree no. 107 of 30 August 2012 "On the procedure for the use of assisted reproductive technologies, contraindications and restrictions on their use".

To be a surrogate mother, a woman must be aged between twenty and thirty years, have at least one healthy child of her own, have received a medical report confirming that her state of health is satisfactory and have given her informed voluntary written consent to medical intervention. A woman who is in a registered marriage may be a surrogate mother only with the written consent of her spouse. A surrogate mother cannot simultaneously be an egg donor.

According to the provisions of Russian law, surrogacy entails bearing and giving birth to a child (including premature delivery) by agreement between the surrogate mother (a woman who carries an unborn baby after a donor embryo is transferred) and the potential parents whose reproductive cells were used for fertilisation, or a single woman who is unable to bear and give birth to a baby for medical reasons.

Citizens who are aged between eighteen and thirty-five years, are physically and mentally healthy and have undergone medical and genetic tests may be reproductive cell donors. When donor reproductive cells and embryos are used, citizens have the right to receive information about the

results of the medical and genetic tests on the donor, his/her race and ethnicity, and his/her external appearance.

Article 51(4) of the Family Code of the Russian Federation provides that a married couple who have given their written consent to the use of a method of artificial fertilisation or implantation of an embryo shall be registered as the parents in the register of births of a child born to them as a result of the use of these methods.

A married couple who have given their written consent to the implantation of an embryo into another woman so that she can carry it may be registered as the child's parents only with the consent of the woman who gave birth to the child (the surrogate mother).

The birth of a child who has been carried by a surrogate mother is registered with the State under the general procedure, taking account of the specific conditions laid down in the aforementioned legal provisions, and also the provisions of Article 16 of Federal Law no. 143-FZ of 15 November 1997 "On civil status records", ie a document issued by a medical organisation confirming that the surrogate mother consented to the registration of the aforementioned couple as the child's parents must be submitted at the same time as the document confirming the child's birth.

In essence, the law gives a preferential right to the surrogate mother in the granting of maternal and paternal rights to the genetic/biological parents. At the same time, there also arises the question of the rights and interests of the persons whose reproductive cells were used to fertilise the woman who carried the unborn baby (the surrogate mother), and the rights of the child who was born as a result of the use of the relevant assisted reproductive technology.

It is certainly true that the carrying of an unborn child by a surrogate mother creates a blood connection between that child and the surrogate mother, but it must also be remembered that the source from which the life of a child born in this manner derives is the embryo that was obtained through in-vitro fertilisation of reproductive cells from the genetic parents, so the unconditional priority that is given to surrogate mothers in terms of parental rights is not beyond dispute. This "priority" can be detrimental to the interests of a child who was born to a surrogate mother, who not only may be deprived of the opportunity to be brought up by the family of his/her genetic parents, but is also effectively exposed to the risk of being brought up in a single-parent family.

According to Article 3 of the Convention on the Rights of the Child of 20 November 1989, States Parties undertake to afford the child such protection and care as are necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her. These provisions are also laid down in the Family Code of the Russian Federation, which proceeds from the basis that family relationships are governed by, among other things, the principle of priority protection of the rights and interests of family members who are minors (Article 1(3) of the Family Code of the Russian Federation).

Equally important and topical is the question of the rights of the biological/genetic parents of a child born to a surrogate mother and how to take into account their mental suffering if they are deprived by the "will" of the surrogate mother of the opportunity to exercise their legal parental rights in respect of their child, whom they could not conceive and give birth to by natural means.

Attention must also be paid to the rights and interests of genetic fathers, because depriving a genetic father of his parental rights exclusively at the behest of a surrogate mother leaves open the question of the equality of the parental rights and duties of men and women and equal opportunities to exercise them.

In judicial practice in the Russian Federation, disputes do arise over the use of assisted reproductive technologies, including surrogacy.

In 2011, for example, a court heard a case brought by Mr and Mrs Ch. against a surrogate mother, R., and her former husband regarding the origin of a child born to the surrogate mother, cancellation of the entry of birth and a requirement not to obstruct the registration of the claimants as the child's parents. The claim was refused on the grounds that the surrogate mother did not give consent for the claimants – the genetic parents – to be registered in the register of births as the parents of the child to whom she gave birth.

Mr and Mrs Ch. applied to the Constitutional Court of the Russian Federation to challenge the constitutionality of the part of Article 51(4) of the Family Code of the Russian Federation that lays down the procedure for registering in the register of births a child born as a result of the use of an assisted reproductive technology such as surrogacy, and Article 16(5) of Federal Law no. 143-FZ of 15 November 1997 "On civil status records", and contended that these legal provisions are contrary to Articles 19 and 38 (paragraphs 1 and 2) of the Constitution of the Russian Federation as they allow genetic parents to be registered in a register of births as the parents of a child born to a surrogate mother only if she consents to this registration.

In its Ruling no. 880-O of 15 May 2012, the Constitutional Court of the Russian Federation refused to examine the application lodged by Mr and Mrs Ch. as it did not meet the admissibility requirements for applications to the Constitutional Court of the Russian Federation set out in the Federal Constitutional Law "On the Constitutional Court of the Russian Federation". In deeming the application lodged by Mr and Mrs Ch. inadmissible, the Constitutional Court of the Russian Federation held that the legally enshrined right of a surrogate mother to consent to the genetic parents of a child being registered as the parents when the child's birth is registered with the State implies that she has the opportunity to register herself as the child's mother when the record of birth is made, as shall also be recorded on his/her birth certificate, thereby determining that the woman who gave birth to the child has the rights and obligations of a mother (Article 47 of the Family Code of the Russian Federation). This model of legal regulation, which is not the only one possible, does not exceed the law-making powers of Federal lawmakers. Two separate opinions on this case were issued by judges of the Constitutional Court of the Russian Federation.

A different approach to the reconciliation of the rights of a surrogate mother and the rights of a genetic mother was taken by the court when it considered the claim made by M. against the surrogate mother B. and her husband B. disputing the motherhood of the surrogate mother and requesting that the genetic mother be recognised as the mother and that the child's birth certificate be changed.

In granting the claim made by claimant M., the court found that the surrogate mother had not expressed any intention to register herself as the child's mother, because her actions after the child was born did not indicate that she had begun to have any maternal feelings or a desire to exercise maternal rights or duties in respect of the child. The court established that, a few days before the child was born, surrogate mother B. had stopped communicating with claimant M., concealed her whereabouts and also her state of health and that of her future child from her, did not tell M. the place and time of the child's birth, and left the Russian Federation with the baby eight days after it was born (for the Republic of Cyprus).

The court also found that the circumstances of legal significance in establishing parenthood in relation to a baby who has been born are the birth of the child to specific biological parents and the fulfilment of parental duty, which did not occur in this case. The court also made reference to Articles 3, 7, 8 and 9 of the Convention on the Rights of the Child of 20 November 1989 and Articles 8 and 14 of the Convention for the Protection of Human Rights and Fundamental Freedoms, and stated that in this case, owing to the circumstances of the conception and as a result of the respondent's actions, the child had been deprived of the right to have contact with people to whom he was related by blood, and this could be regarded as discrimination. The court took account of the fact that, according to the genetic test adduced in evidence, the surrogate mother and her husband had no genetic relationship with the child, but the genetic link between M. and the child was confirmed. Furthermore, there was an agreement that services would be provided by the surrogate mother, who hid with the baby in another country, did not look after the child or take care of it and did not want to have any parental rights in relation to the new-born baby.

However, owing to the breaches of the provisions of procedural law that were committed when this dispute was heard, which the Civil Bench of the Supreme Court of the Russian Federation acknowledged to be material when it heard the case on cassational appeal, the judgment was set aside and the case was remitted for a fresh hearing. No final decision on this case has been taken to date.

It is stipulated by law (Article 55 of Federal Law no. 323-FZ of 21 November 2011 "On the fundamental principles of healthcare for citizens in the Russian Federation") that the right to use assisted reproductive technologies is open to men and women whether married or unmarried. The law provides that a surrogacy agreement can be entered into only by potential parents or a single woman who are/is unable to bear an unborn child and give birth to one for medical reasons. Single men are not mentioned in this legal provision.

Meanwhile, judgments recognising this right for single men have begun to surface since 2010. As arguments for granting these claims, courts cite the lack of a direct ban in law and the unacceptability of breaching the principle of equality of rights between women and men and also persons who are married or unmarried.

Legal disputes occur with regard to the recognition as unlawful of the refusal of civil status records offices, when officially registering a birth, to name a single unmarried man who has entered into a surrogacy agreement as the father, and also with regard to disputes over refusals to provide surrogacy services to unmarried single men.

In particular, over the past three years, 20 decisions have been pronounced, granting claims from single men to be registered as the fathers of children born to surrogate mothers, and ordering the

provision of surrogacy services on the grounds of a breach of the principle of gender equality. This case-law is erroneous and is not supported by the Supreme Court of the Russian Federation.

Courts deal with cases brought by the grandmothers of children who have been born through surrogacy with the use of biological material from their deceased sons, demanding that civil status records offices indicate the details of the deceased father and name the applicants as the parents on the birth certificate. Courts have rightly refused to recognise refusals by civil status records offices to perform state registration of children as unlawful on the grounds that the birth of children by this means was not a method of treating infertility, and demands made by a claimant who is the biological grandmother of a child to register her as the mother of this child and wishes to name her dead son as the father pose delicate ethical problems, do not further the aim of treating infertility and are contrary to the essence of a parental legal relationship.

In 2011, as part of a review of a legal provision, the Supreme Court of the Russian Federation heard a case brought by Mrs N. seeking to have section 6 of the Instructions for the use of methods of assisted reproductive technology, confirmed by Russian Federation Ministry of Health Decree no. 67 of 26 February 2003, invalidated. This section stated that donors of gametes provide their gametes (sperm or eggs) to other persons in order to overcome infertility and shall not assume parental duties in respect of the future child.

Mrs N. argued that the disputed part of the Instructions contradict Article 19(2) of the Russian Federation and Articles 49 and 80 of the Family Code of the Russian Federation and violated her right and the right of her daughter, born as a result of an assisted reproductive technological procedure, to establish paternity in relation to a person who had acted as a donor in exchange for a fee, understood the consequences of his actions and acted out of a desire to make money from this. The claimant also asserted that section 6 of the Instructions put her child in a position which was not equal to that of children who had been born as a result of natural conception.

In judgment no. GKPI10-1601 of 13 January 2011, the Supreme Court of the Russian Federation dismissed N.'s claim because, in accordance with the law, artificial insemination of a single woman at a facility which has obtained a licence to pursue medical activity is only possible where she has given her written consent for assisted reproduction technological methods to be used on her. At the same time, information concerning the identity of a donor is regarded by lawmakers as being subject to doctor-patient confidentiality and can be provided without the individual's consent only in the situations specified in Article 61 of the Fundamental Legislative Principles. The list of information about a donor which can be obtained by a woman who has sought specialised medical assistance involving the use of assisted reproductive technologies is limited to details of his medical and genetic tests, external appearance and ethnicity. In turn, a donor likewise does not have the right to receive information about the outcomes of the use of his biological material, and his written consent to the use of a method of artificial fertilisation is not required. A woman who approaches a medical facility for the purposes of artificial fertilisation enters into a legal relationship with that facility, which shall warn her in advance that the donor will not assume any parental duties in relation to the future child. The donor also enters into a legal relationship with the medical facility, which acquires all rights to the biological material when it is provided and is responsible for its use for medical purposes.

Therefore, a woman who has given birth to a child as a result of artificial fertilisation and the donor do not enter into any legal relationship with each other, so the provisions of Article 49 of the Family Code of the Russian Federation regarding the establishment of paternity through judicial proceedings are inapplicable to these cases and such a donor cannot be recognised as the father of a child conceived through the use of assisted reproductive technologies.

Russian Federation Ministry of Health Decree no. 67 of 26 February 2003 has now been annulled in connection with the publication by the Ministry of Health of the Russian Federation of Decree no. 107 of 30 August 2012.

Bioethical issues arise in numerous areas and can continue to affect a person and persons close to them throughout their lives, so bioethics, or biomedicine, is a field in which ethics, law and science are closely intertwined, and legal regulations and law enforcement practice go some way towards resolving points of contention and conflict concerning respect for human rights in this field.

At the Supreme Court of the Russian Federation, family disputes and the protection of the rights of children are a matter for the Judicial Panel for family affairs and children's rights, and matters concerning compensation for harm caused to health, including through the use of various medical technologies, are a matter for the Judicial Panel for labour and social affairs. The Supreme Court of the Russian Federation is currently working to generalise its case-law on cases concerning the origin of children with a view to a Plenary session ruling on this category of cases being developed and adopted.

Session 1 - Human Rights in biomedicine: trends and challenges
The beginning of life and the prohibition of in vitro fertilization in the case-law of the Inter-American Court of Human Rights

Mr Roberto de Figueiredo Caldas

President of the Inter-American Court of Human Rights

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Full text

Justice Brigitte Konz, Head Justice of the Peace (Luxembourg), Chair of the Steering Committee for Human Rights of the Council of Europe (CDDH)
Justice Peter Jackson, Judge of the Family Division of the High Court (United Kingdom)
Ms Claire Bazy Malaurie, member of the Constitutional Council (France), member of the Venice Commission of the Council of Europe
Justice Tatyana Vavilycheva, Judge at the Supreme Court of the Russian Federation
Distinguished judges; lawyers and advocates; representatives of human rights institutions; senior and junior members of academia; civil society representatives, ladies and gentlemen;

I consider it the highest honor to be among you today. Please accept the warmest regards on behalf of my fellow judges at the Inter-American Court and myself.

With progress comes change, and with change comes adjustment. As lawyers and judges of the twenty-first century, we face the permanent challenge of keeping up with technological and medical advances and exceeding our normative comfort zone. However, we do not walk this steep learning curve unguided. The Convention on Human Rights and Biomedicine, also known as the Oviedo Convention, is the first and only legally binding instrument on the protection of human rights in the biomedical field, and as such is the foremost legal instrument in our endeavor to reconcile traditional

human rights with innovation. Its purpose and object is set out to be the protection of dignity and identity of all human beings and the guaranteed, non-discriminatory respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

For the past 37 years, the Inter-American Court, besides providing effective protection and guarantee of human rights, has developed a comprehensive body of jurisprudence. It has addressed issues endemic to the region, such as amnesty laws, torture, and forced disappearances. However, in as much as these particular instances of human rights violations stem from a historical legacy of authoritarianism and violent political repression, there also exist challenges to human rights which are not the result of a conflicted past but instead relate to progress both in practical and normative terms. Indeed, it is well known that scientific progress brings with it the evolution of moral and social norms in a mutually reinforcing dynamic. A reverse phenomenon can be observed in the case law of the Inter-American Court: it is human rights violations associated to gender and sexuality that paved the way to reproductive health and reproductive rights. The case –law of the Inter-American Court on the matter of gender is vast, and the Court has analyzed the situation of vulnerability of persons in light of a gender perspective but also following an intersectionality approach in different cases. In this sense, reproductive rights are the incorporation of gender in the legal order that regulates sex and reproduction.

The *raison d'etre* of reproductive rights is to protect the possibility and choice of reproduction, and as suchsuch, the protection alternatives to infertility should be a priority. In *vitro fertilization* (IVF), a procedure in which a woman's eggs are removed from her ovaries and fertilized with spermatozoids in a laboratory in order to be implanted in that woman's uterus, is one of such alternatives. The lawfulness of this procedure was considered by the Inter-American Court in its first ever decision on this topic, *Artavia Murillo v Costa Rica.*

The facts, simple yet controversial, were as follows. The Costa Rican Constitutional Court issued a judgment whereby it declared unconstitutional and overturned an executive decree which regulated the practice of IVF, thus making Costa Rica the only Latin American country to prohibit in-vitro fertilization (or IVF).

The driving premise of the Costa Rican Court's reasoning was that conception took place from the moment of fertilization: a human embryo was then a person, and as such was fully entitled to the rights enshrined by the Costa Rican Constitution and the American Convention from that moment on. Since it was unlawful for a 'person' to be subjected to a disproportionate risk of death, the high likelihood – if not certainty – of voluntary or involuntary embryo destruction was held to be a violation of their right to life. The immediate effect of the judgment was that several individuals and couples seeking to benefit from this procedure – the ten applicants in this case among them – were given no option but to interrupt the treatment they were already undergoing or travel abroad in order to pursue it.

The Inter-American Court's starting point was to define reproductive autonomy as the choice to become a father or mother (or the choice to become genetic parents), a right encompassed by the broader right to a private life. Since the absolute prohibition of IVF amounted to an interference with the enjoyment of such a right, the Court proceeded to undertake a balancing exercise to determine whether the interference was legitimate and proportionate.

The Oviedo Convention does not prohibit or restrict in any way the use of embryos for reproductive purposes. Its only statement in relation to embryo rights refers to the need for their adequate protection when they are used for research purposes, and the prohibition of their creation for research purposes only. Put differently, the starting premise offered by the Oviedo Convention is as follows: it is possible to reconcile the dignity of all human beings with the handling of embryos insofar as their creation has an objective other than research and, if research is allowed by the relevant legal framework, the embryos are adequately protected during such process. The Inter-American Court has taken this reasoning one step further: respect for a person's human dignity necessarily demands the lawful possibility of the use of embryos.

Embryos do not have personhood. Neither the American Convention, nor the European Convention of Human Rights or even the Oviedo Convention define 'person'. Considering other international treaties besides the American Conventino the Inter-American Court determined that embryos could

not be understood to be 'persons' falling within the meaning of the American Convention, and as such were not entitled to the right to life.

The possibility of survival is the key element to defining conception. The American Convention states that the right to life is protected by law from the moment of conception onwards. However, the Court found that the meaning of the word 'conception' was ambiguous and randomly used as a synonym to either 'fertilization' or 'implantation', two very distinct moments in the IVF process. Rather than focusing on the uncertain and controversial beginning of human existence, the Court resolved this dichotomy by referring to the possibility of human survival, which was only made conceivable from the moment of implantation onwards.

The rule that the right to life must be protected from the moment of conception onwards is not absolute. Article 4.1 of the American Convention states that the right to life shall be protected 'in general, from the moment of conception'. The Court interpreted this to mean that the protection of the right to life was not absolute, but rather gradual and incremental per the development of the embryo.
After *In vitro Fertilization V. Costa Rica case*, the Court was confronted to a balancing exercise of an entirely different nature related to the performance of a pregnancy termination procedure in a request for provisional measures, in the case *Matter of B with regard to El Salvador*. The health of Mrs. B, an expecting mother suffering from lupus, was severely threatened by her pregnancy with an anencephalic fetus. This led her medical team to conclude that, in light of the impossibility of the fetus' survival, termination of the pregnancy was the best way forward; however, the procedure had been delayed due to administrative matters. The Court granted provisional measures to the effect that, among others, the State must guarantee that the necessary and effective measures were taken so that Mrs. B's doctor could adopt, without interference, all the medical measures he considered appropriate and convenient to protect her right to life and humane treatment. The measures are particularly significant considering the total prohibition of abortion in force at El Salvador.

The two cases I have just presented constitute the entirety of the Inter-American Court's jurisprudence on reproductive rights. Those assisting on behalf of the European Court of Human Rights will be rightfully startled given the extent amount of caseload of the institution they represent. As you would see in our case-law, we follow the developments of the European Court with great attention, as we quoted and have constant references to it. For instance, and just to quote and example, the doctrine of the margin of appreciation is one of the matters that we follow with interest at the European jurisdiction, since the Inter-American Court has never applied this doctrine. This and other substantive or procedural matters could show different approaches for the protection of similar rights. However, there are no better or worse ways to protect rights, but just diverse grasps applied to the concrete cases in order to fulfill the mandate that has been entrusted to our court, which is to protect and promote the human rights of the people. Thus it is always important to explore more and betters ways of dialogue between courts as occasions to to update our knowledge and permit the ''crossfertization'' of our case-law at national and international levels. A great example of what we call 'jurisprudencial dialogue' or 'judicial dialogue'' is this forum.

Bioethics is an evolving discipline, which in itself is representative of the character of life, law and, indeed, the Court's jurisprudence. To us jurists, adjusting and fine-tuning the law so that it is reflective of the demands of our times and keeps up with the pace of individuals and communities under our jurisdiction is a primary concern. The added difficulty to this task is that there is no contradiction between biomedical science and human rights, but between competing human rights considerations. As such, drawing the line between the ethical and the unethical becomes an ever-sophisticated and challenging task. Our duty as lawyers, judges and practitioners in the field is to remember that our primary contender is not science, but the law itself. Thank you.

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Professor Michael O'Flaherty is Director of the EU Agency for Fundamental Rights since 16 December 2015.

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Member (Alternate) of the Council of Europe, Venice Commission.
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Member of the National Crime Council Ireland 2007-2009 co-authored Problem Solving Justice - Alternatives to Custody - the Case for Community Courts.
Member of the Professor Genevra Richardson Expert Scoping Group reviewing the operation of the 1983 UK Mental Health Act 1994-98
Chair of the Mental Health Commission Review Tribunal reviewing the legality of detained patients (Ireland) 2006-2010
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Abstract

Abortion has always been a controversial area of Irish law and the Catholic church continues to play a central role in the debate. Abortion is legal in Ireland only when a pregnant woman's life is at risk, which includes a risk from suicide. Access to abortion in such cases is now governed by the Protection of Life During Pregnancy Act 2013,[98] and it came into force in January 2014.[99] Article 40.3.3 of the Irish Constitution gives an unprecedented level of protection to the foetus which gives rise to complex legal and ethical questions that have serious implications for women and healthcare professionals, reproductive autonomy, and women's human rights and bodily integrity.[100]
This paper will consider some of the ethical dilemmas that arise in this area, in particular, it will discuss the autonomy of the individual, discrimination against persons with disabilities, prenatal genetic testing, foetal abnormality and conscientious objection.
Both Euthanasia and assisted suicide are illegal in Ireland. Under the Criminal Law (Suicide) Act 1993, suicide was decriminalised but it provides for the criminalisation of assisted suicide.[101] It is an offence to aid, abet, counsel or procure the suicide of attempted suicide of another.[102] The maximum penalty for this offence is fourteen years in prison.[103] Again, similarly to abortion, social order and control are ranked as superseding the right of the individual to self-determination and these norms were heavily influenced by the moral domination of the Catholic church in Ireland, through medical ethics and legislation.[104]
Ethical issues such as the individual autonomy, the 'principle of double effect', the sanctity of life, the slippery slope argument and the duty to die will be discussed.
It will focus on the jurisprudence and case law in Ireland and its highly restrictive approach to abortion and euthanasia/assisted suicide and draw a comparison between the UK and other EU member States. The approach taken by the European Court of Human Rights (ECtHR) in these areas will also be examined.

Full text

> *Reflecting on the issues arising, prevalence of themes and key factors at the national level - in the Republic of Ireland, a comparison with other jurisdictions in the development of jurisprudence on Bioethics and a forward look to some of the challenges facing the European Court of Human Rights in the future.*

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[98] Protection of Life During Pregnancy Act 2013.
[99] Department of Health, Implementation of the Protection of Life During Pregnancy Act 2013: Guidance Document for Health Professionals (2014).
[100] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 93.
[101] Criminal Law (Suicide) Act 1993, s2(3).
[102] Ibid, s2(2).
[103] Ibid, s2(2).
[104] Tracie Keenan, 'Whose Life? Who's Right?' https://www.ucc.ie/archive/hdsp/ProTracie.htm accessed 26 October 2016.

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Identifying future topics and challenges on Bioethics for national courts and the EctHR

Abstract

Any consideration of trends in the development of the case law both at national level and at the European Court of Human Rights in the area of Bioethics can reasonably be expected to highlight its parallel course with biomedical advances. Many new challenges lie ahead for the European Court of Human Rights as new and heretofore unenumerated rights and remedies are sought. Ethics and biomedical advances make for uneasy bedfellows at the best of times unravelling old legal and moral certainties. Bioethical discourse at national level has focused primarily on abortion and euthanasia but a panoply of new biomedical techologies and scientific breakthroughs are identifying new legal complexities for which new tools may be necessary. The willingness to embrace scientific and medical advancements correlates to the openness of a society to discern where the advantage lies, and at what cost. And this is by no means devoid of political or religious input. This paper reflects on some of the bioethical preoccupations which pertain particularly in the Republic of Ireland.

The issue of Abortion dominates the bioethical debate in Ireland where both historically and even currently the Catholic Church carries great influence and still seeks to enshrine and enforce its tenets in the legal arena. Abortion is legal in Ireland only when a pregnant woman's life is at risk, which includes a risk from suicide. Access to abortion in such cases is now governed by the Protection of Life During Pregnancy Act 2013.[105] Article 40.3.3 of the Irish Constitution gives an unprecedented level of protection to the foetus which gives rise to complex legal and ethical questions that have serious implications for women and healthcare professionals, reproductive autonomy, and women's human rights and bodily integrity.[106]

Both Euthanasia and assisted suicide are illegal in Ireland. Under the Criminal Law (Suicide) Act 1993, suicide was decriminalised but it provides for the criminalisation of assisted suicide.[107] It is an offence to aid, abet, counsel or procure the suicide or attempted suicide of another.[108] Similarly to abortion, social order and control are ranked as superseding the right of the individual to self-determination and these norms were heavily influenced by the moral domination of the Catholic church in Ireland, through medical ethics and legislation.[109]

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[105] Protection of Life During Pregnancy Act 2013.
[106] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 93.
[107] Criminal Law (Suicide) Act 1993, s2(3).
[108] Ibid, s2(2).
[109] Tracie Keenan, 'Whose Life? Who's Right?' https://www.ucc.ie/archive/hdsp/ProTracie.htm accessed 26 October 2016.

This paper will also review the issues that arise in relation to medically assisted human reproductive technologies (ART) and the law.
It will focus on the jurisprudence and case law in Ireland and its highly restrictive approach to abortion and euthanasia/assisted suicide and draw a comparison between the UK and other EU member States. The approach taken by the European Court of Human Rights (ECtHR) in these areas will also be examined. With regards to ART, this paper will endeavour to analyse the approach taken by the ECtHR. It will also attempt a glance into the proverbial crystal ball to try to identify where the future challenges lie for the National and European Courts in the Bioethical field. It is important to reflect on the emerging evidence in the current shifting sands of political and social ideologies reflected in many newer governments all over the world – where rights and freedoms won decades ago are routinely being revisited restrictively by conservative governments and all too often these focus on limiting or reversing Women's rights to bodily integrity and autonomy. The old adage that she who rocks the cradle rules the world is I believe largely without foundation currently.

Introduction
The term "*bioethics*" often refers to the protection of the human being in relation to human rights and human dignity.[110] This paper is going to highlight firstly some of the issues that arise in relation to abortion and euthanasia, particularly in Ireland,where these two issues dominate the debate in bioethics, and it will also consider the position in other countries which have perhaps been a little more progressive in these areas. It will briefly discuss the historical background that has influenced the current issues, as well as the ethical dilemmas that arise and how these have been addressed in Ireland and elsewhere. Finally, this paper will give a brief review of the case law and the developing jurisprudence in Ireland in relation to abortion and euthanasia.

Abortion
Abortion is legal in Ireland only when a pregnant woman's life is at risk, which includes a risk from suicide. Access to abortion in such cases is now governed by the Protection of Life During Pregnancy Act 2013,[111] and it came into force in January 2014.[112] Abortion is not legal in Ireland in cases of rape, incest or foetal anomaly.[113] Every year an under estimated number of circa 5,000 Irish women travel abroad (mostly to the UK) to access safe and legal abortion services.[114]

Background

Today, Ireland remains a country with one of the most restrictive abortion laws in the world, dating back to 1861, with The Offences Against the Person Act.[115] Abortion is a key social policy issue and Ireland's national identity has been heavily influenced by the Roman Catholic religion.[116] This has not substantially changed since the 19th century, and as a result Irish abortion policy remains extremely restrictive.[117]

Article 40.3.3 (The Eighth Amendment)

As mentioned, the difficulties that arise in dealing with abortion in Ireland has been ongoing for many years. In 1983, the Eight Amendment, following an anti-abortion campaign, was added to the Constitution and this gave an unprecedented level of protection to the foetus in Irish law.[118] It acknowledges the right to life of the "unborn" and guarantees by its law to "defend and vindicate that

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[110] Research Report, *Bioethics and the case-law of the Court* (Council of Europe, 2012) 4.
[111] Protection of Life During Pregnancy Act 2013.
[112] Department of Health, Implementation of the Protection of Life During Pregnancy Act 2013: Guidance Document for Health Professionals (2014).
[113] Protection of Life During Pregnancy Act 2013.
[114] Irish Family Planning Association, *Sexuality, Information, Reproductive Health & Rights* https://www.ifpa.ie/Pregnancy-Counselling/Abortion-Irish-Law accessed 20 October 2016; This has created a dire inequality between those women who can afford to travel abroad to access safe health and reproductive services and those who cannot.
[115] Iga Kozlowska, Daniel Béland and André Lecours, 'Nationalism, Religion and Abortion Policy in Four Catholic Societies (2016) 22(4) Journal of the Association for the Study of Ethnicity and Nationalism 824, 827.
[116] Iga Kozlowska, Daniel Béland and André Lecours, 'Nationalism, Religion and Abortion Policy in Four Catholic Societies (2016) 22(4) Journal of the Association for the Study of Ethnicity and Nationalism 824, 827; The Irish Constitution of 1937 (Article 41.2) placed women in the heart of the home in their primary role as a mother.
[117] Iga Kozlowska, Daniel Béland and André Lecours, 'Nationalism, Religion and Abortion Policy in Four Catholic Societies (2016) 22(4) Journal of the Association for the Study of Ethnicity and Nationalism 824, 827.
[118] Stephen Donoghue and Claire-Michelle Smyth, ' Abortion for Foetal Abnormalities in Ireland; The Limited Scope of the Irish Government's Response to the *A, B and C Judgment'* (2013) 20 European Journal of Health Law 117.

right".[119] ***Article 40.3.3° now reads;***

"The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right.

This subsection shall not limit freedom to travel between the State and another state.
This subsection shall not limit freedom to obtain or make available, in the State, subject to such conditions as may be laid down by law, information relating to services lawfully available in another state."

In 1988, in *Attorney General (SPUC (Ireland) Ltd) v Open Door Counselling Ltd*,[120] it was even declared that the distribution of information regarding abortion was illegal.[121] A constitution that gives the biological existence of a foetus pre-eminence over other aspects of life gives rise to complex legal and ethical questions that have serious implications for women and healthcare professionals, reproductive autonomy, and women's human rights and bodily integrity.[122]

UK and Other EU Countries

EU member states have taken diverse approaches to the regulation of abortion.[123] Most countries in the EU generally make abortion available on demand during the first trimester, these include countries such as Austria, Norway, Sweden and Switzerland.[124] After this period, certain conditions apply. France, the Netherlands, Belgium, Finland and the UK would also be considered to be more progressive in their approach to abortion.[125] The above states allow the practice of abortion on average of up to 10 to 12 weeks of pregnancy, up to 24 weeks in the Netherlands and the UK, and up to 18 weeks in Sweden.[126]
The UK has a more liberal approach to abortion in comparison to Ireland. The Abortion Act 1967 (as amended via section 37 of the Humans Fertilisation and Embryology Act 1990), permits abortion when 'the pregnancy has not exceeded its twenty-fourth week and the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family'. However, if there is a substantial risk to the mother's life or foetal abnormalities, there is no time limit.[127] Doctors use their clinical judgment on whether to offer a termination on an individual case by case basis.[128] The number of abortions taking place after 24 weeks have always been small, representing approximately 0.1% of all abortions.[129]
In *Tsyiac v Poland*,[130] the ECtHR found that while the State regulations on abortion relate to the traditional balancing of privacy and the public interest, in cases of therapeutic abortion, they must also be assessed against the positive obligations of the State to secure the physical integrity of the pregnant woman. The ECtHR also held in relation to Article 2 of the ECHR that, in the absence of common standards in this area, the decision where to set the legal point from which the right to life

[119] Article 40.3.3 states that:
'The State acknowledges the right to life of the unborn and with due regard to the equal right to life of the mother, guarantees in its law to respect, and as far as practicable, by its laws, to defend and vindicate that right'.
[120] *Attorney General (Society for the Protection of Unborn Children (Ireland) Ltd) v Open Door Counselling Ltd* [1988] IR 593. It was held that the defendants were assisting pregnant women within the jurisdiction to travel abroad in order to have an abortion and therefore were ultimately assisting in the destruction of the life of the unborn. There no constitutional right to obtain such information; see also *Society for the Protection of Unborn Children (Ireland) Ltd v Grogan* [1989] IR 753.
[121] Ruth Fletcher, 'National Crisis, Supranational Opportunity: the Irish Construction of Abortion as a European Service' (2000) 8(16) Reproductive Health Matters 35-44.
[122] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 93.
[123] Luis Acosta, 'Abortion Legislation in Europe', *The Law Library of Congress* (Global Legal Research Centre January 2015).
[124] Ibid.
[125] Europe's Abortion Rules – No Single Policy (Euro News, 14 April 2016) http://www.euronews.com/2016/04/14/europes-abortion-rules---no-single-policy accessed 21 October 2016.
[126] Luis Acosta, 'Abortion Legislation in Europe', The Law Library of Congress (Global Legal Research Centre January 2015); Conditions do apply, for example, in Finland and the UK, the mother may require consent from her doctor and justification of a risk to her physical and mental health in order to proceed with the abortion.
[127] Abortion Act of 1976 (as amended in 1990) s1(1)(d).
[128] Jane Fisher, Director of Antenatal Results and Choices, 'Abortion for Fetal Anomaly: The Legacy of the Jepson Case', *Britain's Abortion Law, What it Says, and Why* (British Pregnancy Advisory Service 2012) 28.
[129] Ibid.
[130] *Tsyiac v Poland* App no 5410/03 (ECtHR, 20 March 2007) para 107.

shall begin is within the margin of appreciation of the states, in the light of specific circumstances and the needs of their own population.[131]
However, it is important to note that there is no absolute right to life of the foetus.[132] If Article 2 of the ECHR were held to cover the foetus, and its protection under this article were, in the absence of any express limitation, seen as absolute, an abortion would have to be considered as prohibited even where the continuance of the pregnancy would involve a serious risk to the life of the pregnant woman.[133] This would mean that the unborn life of the foetus would be regarded as being of a higher value than the life of the pregnant woman.[134] When giving an opinion on the new Constitution of Hungary in 2011, the Venice Commission made it clear that Article 2 of its Constitution could not be interpreted in this manner and that weighing up the various, and sometimes conflicting, rights or freedoms of the mother and the unborn child is mandatory.[135] Provided that such a balance of interests is met, the extension of the safeguards provided for the unborn child is in line with the requirements of the ECHR.[136]

Ethical Considerations
Autonomy

It is not within the scope of this paper to address all the ethical dilemmas that arise with regard to abortion, but I will endeavour to discuss some of the key issues. Central to the ethical debate concerning abortion are considerations of autonomy (of the woman) and rights (of the woman and the unborn child). The ethical principle of autonomy states that people should be free to make their own informed decisions about their healthcare.[137] Some are of the view that even if the foetus is a person, the overriding principle is the woman's right to choose what happens to her body.[138] On the other hand, some consider that abortion is wrong in any circumstance because it fails to recognise the rights of the foetus or it challenges the notion of the sanctity of all human life.[139]
Prenatal Genetic Testing

There are ethical and legal issues associated with prenatal genetic testing. There is concern that a foetus may be diagnosed with a relatively minor condition and yet the mother may decide to abort.[140] There is no prenatal national screening programme in Ireland, whereas, in some developed countries, such as the UK, ultrasound is an essential procedure in the management of all pregnancies and is part of a national screening programme.[141] In 2011, the ECtHR made it clear in *R.R v Poland,*[142] where a violation of Article 3 and 8 was found, that although there is no right to prenatal testing for a pregnant woman, any jurisdiction that permits an abortion where a serious foetal abnormality exists has to put the appropriate systems and guidelines in place to effect that law.[143] Shabbily treated by the doctors dealing with her case due to lack of proper counselling, procrastination and confusion, the applicant had been humiliated and a violation of Article 3 was found. The ruling also links the health of the mother to information regarding the health of the foetus.[144] This decision may indicate the conflicting views of the Irish Government and the European Court given that the ECtHR has linked the health of the mother under Article 8 to information regarding the health of the foetus which may create

[131] *Vo v France* App no 5394/00 (GC, 8 July 2004) para 82.
[132] Opinion on the new Constitution of Hungary adopted by the Venice Commission at its 87th Plenary Session (CDL-AD(2011)016-e, Venice, 17-18 June 2011) para 65.
[133] *X v The United Kingdom* App no 8461/78 (Decision of the Commission, 13 May 1980) para 19.
[134] *X v The United Kingdom* App no 8461/78 (Decision of the Commission, 13 May 1980) para 19.
[135] Opinion on the new Constitution of Hungary adopted by the Venice Commission at its 87th Plenary Session (CDL-AD(2011)016-e, Venice, 17-18 June 2011) para 66.
[136] Opinion on the new Constitution of Hungary adopted by the Venice Commission at its 87th Plenary Session (CDL-AD(2011)016-e, Venice, 17-18 June 2011) para
[137] Dónal Ó Mathúna, *Abortion Debate: Freedom of Choice is not Enough to Make Abortion Ethical* (Bioethics Ireland 25 September 2013) https://bioethicsireland.ie/abortiondebate/ accessed 16 October 2016.
[138] Ibid.
[139] Ibid.
[140] Stephen Donoghue and Claire-Michelle Smyth, 'Abortion for Foetal Abnormalities in Ireland; The Limited Scope of the Irish Government's Response to the *A, B and C Judgment'* (2013) 20 European Journal of Health Law 117, 134.
[141] Ibid.
[142] *RR v Poland* App no 27617/04 (ECtHR, 26 May 2011); see also *P and S v Poland* App no 57375/08 (ECtHR, 30 October, 2012) - this case further clarifies the ECtHR's stance that reproductive health services that are legal must also be accessible. It also develops important reasoning on the vulnerability of young rape victims as well as their right to personal autonomy in matters of reproductive choice, violations of Article 3, 5 and 8 were found.
[143] Ibid.
[144] *RR v Poland* App no 27617/04 (ECtHR, 26 May 2011); It is interesting to note that the prenatal tort of wrongful birth in the UK and USA also appear to frame a duty of care in terms of a deprived or lost opportunity of the parent to make an informed decision about the health of the foetus.

difficulties in the future. It is argued that once prenatal screening becomes more prevalent in Ireland there will be an obligation to provide these screening checks for foetal abnormality whether or not foetal abnormality is listed as a ground for legal abortion.[145]

Foetal Abnormality

Unlike the vast majority of other EU member states which allow for abortion on the basis of foetal abnormality, Ireland only allows for abortion where the life of the mother is at risk.[146] In the recent case of *Mellet v Ireland*, in 2011, the applicant discovered that her pregnancy carried a fatal foetal impairment and would not survive outside the womb.[147] The United Nations Human Rights Committee (UNHRC) found that Ireland's abortion law subjected the applicant to cruel, inhuman and degrading treatment and encroached on her dignity and physical and mental integrity by: 1) Denying her the reproductive health care and bereavement support she needed; 2) forcing her to continue carrying a dying foetus; 3) compelling her to terminate her pregnancy abroad; and 4) subjecting her to intense stigma.[148] This is a welcomed decision, with implications not only for Ireland, but internationally as well.[149] It is the first time that Ireland's prohibition on abortion, in itself, has been found to be a human rights violation.[150] The HRC will be supervising Ireland's compliance with this decision, to examine whether progress is being made.

Conscientious Objection

The unregulated use of conscientious objection of reproductive health care providers, mandatory waiting periods or biased counselling are increasingly imposing barriers to abortion services.[151] Conscientious objection's practice has denied many women access to reproductive health services, such as information about, access to, and purchase of contraception, prenatal testing, and lawful interruption of pregnancy. There are cases reported from Slovakia, Hungary, Romania, Poland, Ireland and Italy where nearly 70% of all gynaecologists and 40% of all anaesthesiologists conscientiously object to providing abortion services.[152] These barriers clearly contradict human rights standards and international medical standards.[153]

Review of the Case Law and Jurisprudence in Ireland

X Case and A,B and C v Ireland

Nine years after the eighth amendment was passed, the *X Case,*[154] in 1992, brought the abortion debate back into the public domain. It gained international attention when the High Court granted an injunction preventing a girl of 14 years who was suicidal after becoming pregnant as a result of rape to travel to the UK for an abortion. This decision was overruled by the Supreme Court which held that a pregnant woman has a right to a termination of her pregnancy if there is a 'real and substantial' risk to her life, as distinct from her health, that can only be averted by a termination of the pregnancy.[155] It was also held that an individual has the right to travel abroad and this cannot be curtailed because of a particular intent.[156] This case is significant as it was the first time in Irish history that the dominance

[145] Stephen Donoghue and Claire-Michelle Smyth, 'Abortion for Foetal Abnormalities in Ireland; The Limited Scope of the Irish Government's Response to the *A, B and C Judgment'* (2013) 20 European Journal of Health Law 117, 142.
[146] Ibid.
[147] See also *D v Ireland* App no 26499/02 and *D v District Judge Brennan and Others,* (Unreported, HC 9 May 2007).
[148] Human Rights Committee, *Views adopted by the Committee under Article 5(4) of the Optional Protocol, Concerning Communication no 2324/2013,* United Nations Doc CCPR/C/116/D/2324/2013 (9 June 2016).
[149] Abortion Rights Campaign, Press Release, *UN Human Rights Committee says Ireland's Prohibition on Abortion Violates Human Rights* (10 June 2016) http://www.abortionrightscampaign.ie/2016/06/10/press-release-un-human-rights-committee-says-irelands-prohibition-on-abortion-violates-human-rights/ accessed 10 October 2016.
[150] Ibid.
[151] Christine McCafferty, Report of the Council of Europe, *Women's access to lawful medical care: the Problem of Unregulated Use of Conscientious Objection* (20 July 2010); and Resolution 1763 (2010) of the Parliamentary Assembly of the Council of Europe.
[152] Edite Estrela, Committee on Women's Rights and Gender Equality Rapporteur, *Report on Sexual and Reproductive Health and Rights* (2013/2040(INI), European Parliament).
[153] World Health Organisation (WHO), *Safe Abortion: Technical and Policy Guidance for Health Systems* (2nd edn, 2012).
[154] *Attorney General v X (and Others)* [1992] IESC 1, [1992] 1 IR 1.
[155] *Attorney General v X (and Others)* [1992] IESC 1, [1992] 1 IR 1.
[156] *Attorney General v X (and Others)* [1992] IESC 1, [1992] 1 IR 1; Following this case two amendments were passed, and established the 'right to travel' and the 'right to information', see Constitution of Ireland, Thirteenth and Fourteenth Amendments of the Constitution Act, 1992.

of the anti-abortion lobby was challenged.[157] Despite parliamentary reports in 1996, 1999 and 2000 on the implications of the *X* case and of Article 40.3.3,[158] this remained the situation in Ireland for nearly two decades.[159]
Abortion has been a controversial topic in Irish law and one which the Government was finally forced to address following the landmark decision of the European Court of Human Rights (ECtHR) in 2010, in the case of *A, B and C v Ireland*.[160] The ECtHR found that, in the case of the first two applicants, A and B, (where their lives were not at risk) that Irish law struck a fair balance between the right to respect for their private lives and the rights invoked on behalf of the unborn. However, in C's case, the ECtHR found a violation of Article 8 (right to privacy and family life) of the European Convention on Human Rights (ECHR) for the state's failure to give legislative effect to the *X Case*.[161] The Court found that there was no accessible procedure to enable a woman in Ireland to establish whether or not she was qualified for a lawful termination of pregnancy in Ireland when her pregnancy was life-threatening.

Protection of Life During Pregnancy Act 2013

This case led to the enactment of the Protection of Life During Pregnancy Act 2013, to give effect to the limited right to abortion when the woman's life is at risk.[162] The Act deals with situations, inter alia, where termination of the life of the foetus is permitted in cases of a threat to the life of the woman due to physical illness and in emergencies, as well as situations where there is a real and substantial risk of loss of the woman's life by way of suicide.[163] Consideration of lawful abortion in cases of rape, risk to a woman's health, or fatal foetal anomalies was ruled out.[164] It reaffirms an individual's right to travel to another state and the right to obtain and make available information relating to services lawfully available in another state.[165] It makes it an offence to intentionally destroy unborn human life, which can attract a fine or imprisonment for a term not exceeding 14 years.
The Irish Government has been criticised over the 2013 Act[166] as it has been drafted to fully secure the most restrictive interpretation of Article 40.3.3. of the Constitution (the eight amendment).[167] Unfortunately, both the Act and guidance document oblige medical professionals to prioritise the preservation of the foetal life with little room for consideration of the appropriate care for the woman, regardless of whether it may lead to poor physical and mental health outcomes.[168]
The 2013 Act was passed within weeks of the publication of the Arulkumaran report on the tragic death of Savita Halappanavar.[169] This woman died after being refused a termination during complications related to her miscarriage because a foetal heartbeat could be detected.[170] This report highlighted the impossibility in clinical practice of distinguishing ethically or clinically between risk to life and risk to health.[171] The report also found that in another setting, clinical practice would have led

[157] Iga Kozlowska, Daniel Béland and André Lecours, 'Nationalism, Religion and Abortion Policy in Four Catholic Societies (2016) 22(4) Journal of the Association for the Study of Ethnicity and Nationalism 828.
[158] Irish Family Planning Association, *Abortion in Ireland: Legal Timeline* https://www.ifpa.ie/Hot-Topics/Abortion/Abortion-in-Ireland-Timeline accessed 22 October 2016.
[159] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 94.
[160160] *A, B and C v Ireland* App no 25579/05 (ECtHR, Grand Chamber, 16 December 2010); see also *Tsyiac v Poland* App no 5410/03 (ECtHR, 20 March 2007) – a violation of Article 8 was found for the State's failure to make a legal abortion possible in circumstances which threatened the applicant's health, and to put in place the procedural mechanism necessary to allow her to have this right realised (para 65).
[161] *A, B and C v Ireland* App no 25579/05 (ECtHR, Grand Chamber, 16 December 2010).
[162] Protection of Life During Pregnancy Act 2013 http://www.oireachtas.ie/documents/bills28/acts/2013/a3513.pdf accessed 3 October 2016; Guidelines for healthcare professionals was published in 2014, Department of Health, *Implementation of the Protection of Life During Pregnancy Act 2013: Guidance for Health Professionals* http://health.gov.ie/wpcontent/uploads/2014/09/Guidance-Document-Final-September-2014.pdf accessed 3 October 2016.
[163] Protection of Life During Pregnancy Act 2013.
[164] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 94.
[165] Protection of Life During Pregnancy Act 2013.
[166] Protection of Life During Pregnancy Act 2013 http://www.oireachtas.ie/documents/bills28/acts/2013/a3513.pdf accessed 3 October 2016.
[167] Irish Human Rights Commission, *Observations on the Protection of Life During Pregnancy Bill 2013* http://www.ihrec.ie/download/pdf/ihrc_observations_protection_of_life_in_pregnancy_bill_2013.pdf accessed 4 October 2016.
[168] Ibid.
[169] Health Service Executive, *Final Report: Investigation of Incident 50278 from time of patient's self-referral to hospital on the 21st of October 2012 to the patient's death on the 28th of October 2012* (June 2013) http://www.hse.ie/eng/services/news/nimtreport50278.pdf accessed 11 October 2016.
[170] Ibid.
[171] Irish Human Rights Commission, *Observations on the Protection of Life During Pregnancy Bill 2013* (July 2013) http://www.ihrec.ie/download/pdf/ihrc_observations_protection_of_life_in_pregnancy_bill_2013.pdf accessed 12 October 2016; see also, Doctors for Choice, *Submission to the United Nations Human Rights Committee for Ireland's Review under the International Covenant on Civil and Political Rights* (June 2014)

to an early termination of pregnancy.[172] The report recommends that guidelines should be developed for such cases as "a matter of urgency" to ensure a medical professional knows when to offer a termination" based on increasing health risk to the pregnant woman which could even threaten her life.[173] The report recognises that Irish law as it stands does not allow for best practice in the management of cases where a woman's health or life is at risk.[174]

Recent cases involving Article 40.3.3

The first known case of a decision under the Act - *Ms Y* case – came to public attention in August 2014, and provoked national debate on the new abortion laws. Ms Y was a teenage asylum seeker when she arrived in Ireland to discover that she was pregnant as a result of rape that had happened in her home country.[175] She was unable to gather necessary travel documents and financial means to travel to a state where abortion is legal.[176] At approximately 25/26 weeks of pregnancy, she was denied an abortion, even though it was apparent that she was suicidal, and she ultimately agreed to a caesarean section.[177] She was left with no other choice, as the alternative was for her to remain in hospital and continue with the pregnancy.
The *Savita Halappanavar*[178] and the *Ms Y* cases highlight the focus in Ireland on the preservation of foetal life and the marginalisation of the pregnant woman's experiences. The case of *Ms Y* illustrates that the 2013 Act could create new legal barriers to access to lawful abortion in the case of vulnerable women and when the risk of life arises from suicide risk.[179] However, there is a possibility that it could be argued that the course of action taken in this case was reasonable and appropriate under Article 40.3.3 as both the mother and baby survived and the rights of both of them were vindicated.[180]
In December 2014, the case of *PP v HSE,*[181] once again, illuminates that Article 40.3.3 can lead to terrible outcomes. PP was at 15 weeks of pregnancy when she experienced brain stem death. Since a foetal heartbeat was present the doctors were concerned about the legal implications of her pregnancy, arising from the State's obligation to vindicate the right of the unborn in Article 40.3.3. As a result, PP was placed on somatic life-support treatment even though there was no real prospect that the pregnancy could be maintained until viability, and in addition, this was done against the families wishes.[182] This continued for three weeks until the doctors were authorised by the High Court to end such treatment, as the 'state's interest in preserving foetal life does not require that it be prolonged at all costs'.[183]

Current Position

These recent judgments are unsettling as the notions of the woman's dignity, autonomy, and bodily integrity were entirely trumped by what was in 'the best interest' of the foetus under the eighth

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http://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/IRL/INT_CCPR_CSS_IRL_17440_E.pdf accessed 11 October 2016.

[172] Health Service Executive, *Final Report: Investigation of Incident 50278 from time of patient's self-referral to hospital on the 21st of October 2012 to the patient's death on the 28th of October 2012* (June 2013) http://www.hse.ie/eng/services/news/nimtreport50278.pdf accessed 11 October 2016.

[173] Ibid.

[174] Ibid.

[175] Ruth Fletcher, 'Contesting the Cruel Treatment of Abortion-Seeking Women' (2014) 22(44) Reproductive Health Matters 10-21; there is no official record of this case and no report has yet been published.

[176] Niall Behan, 'Opinion: Ireland's Law on Abortion is a Shambles Entirely of the State's Creation' (*The Journal.ie,* 16 August 2014) http://www.thejournal.ie/readme/abortion-laws-ireland-ms-y-1689733-Sep2014/ accessed 22 October 2016.

[177] Amnesty International, 'MS Y Case: Denied a Lawful Abortion' (21 March 2016) https://www.amnesty.ie/latest/stories/2016/03/21/ms-ys-case/ accessed 22 October 2016.

[178] See also *Z v Poland* App no 46132/08 (ECtHR, 13 November 2012) – this recent case again highlights how a legal framework surrounding abortion that is so repressive can function as a shield to doctors who do not want to perform abortions based on their conscience, and stifles the willingness of others to provide any care that might possibly have an effect on the foetus for fear of repercussions. However, based on the facts of the case the ECtHR found that there was no violation of Article 2 in its procedural limb.

[179] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 95.

[180] Máiréad Enright, 'Suicide and the Protection of Life During Pregnancy Act 2013' (*Human Right in Ireland,* 16 August 2014) http://humanrights.ie/constitution-of-ireland/suicide-and-the-protection-of-lifein-pregnancy-act-2013/. Accessed 22 October 2016.

[181] *PP v Health Service Executive* [2014] IEHC 622 (26 December 2014).

[182] Mary Carolan, 'Court Clears Way for Clinically Dead Pregnant Woman to be Taken Off Life Support' *The Irish Times* (Dublin, 26 December 2016).

[183] Máiréad Enright, 'PP v HSE: Practicability, Dignity and the Best Interests of the Unborn Child' (*Human Rights in Ireland,* 26 December 2014) http://humanrights.ie/gender-sexuality-and-the-law/pp-v-hse-futility-dignity-and-the-best-interests-of-the-unborn-child/ accessed 22 October 2016.

amendment.[184] According to the Court in *PP v HSE,* the foetus was capable of 'suffering distress' and was 'unfortunate' and is suffering a 'dreadful fate'.[185] As Enright rightly argues, 'that [the woman's] dignity and the unborn's best interest point in the same direction is coincidence'.[186]
In October 2016, a Citizens' Assembly was mandated by the legislature to report on five topics over the coming year and it is to submit a report to legislators over the legal restrictions on abortion in Ireland.[187] The objective of a Citizen's Assembly is to allow for a discussion of certain topics so that as a nation and society there could be a move from a position of contention, even contempt, to find a valuable consensus.[188] The Oireachtas committee will discuss the assembly's findings next year.[189]

Conclusion
In the past decade in Ireland, religiosity has declined and the churches' moral high ground has been shaken by various reports of clerical child abuse in the Catholic Church.[190] Despite such scandals, religious institutions continue to play a central role in the abortion debate.[191]
Ireland should make provision for the availability of pre natal testing and for the giving of information regarding the health of the foetus, as a matter of routine, in order to allow women to make an informed decision. The promotion of freedom and the prevention of suffering are fundamental goals which society ought to support, thus, the prospect of women being forced to suffer, which in some cases causes death, should be cause for concern.[192]
Ethical and legal issues go hand in hand and legal action taken is often due to practice considered to be unethical or in violation of ethical principles.[193] It is evident from cases such as the *Savita Halappanavar* case and *Ms Y*, that the Court's invocation of the best interest of the foetus is a particularly troubling development, in which the pregnant woman's interests were marginal to the preservation of foetal life.[194] In the *Savita* case, there was an apparent emphasis on the need not to intervene until the foetal heartbeat stopped, together with an under emphasis on managing the risk of infection and sepsis.[195] The case begs the question of whether it is ethical to postpone intervention until the trajectory of a woman's ill health crosses the clinical boundary that satisfies a risk to her life. In addition, how feasible is it for a clinician to clinically delineate the progression from a risk to health to a real and substantial risk to life?[196] As a medical professional, who is in a position of public trust, failure to provide assistance to someone in serious danger is an ethical violation of that trust.[197] Essentially, Article 40.3.3 required healthcare professionals to allow a pregnant woman's health to deteriorate to the point at which the risk to health became unambiguously a risk to life before considering therapeutic abortion.[198]

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[184] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 96.
[185] *PP v Health Service Executive* [2014] IEHC 622 (26 December 2014).
[186] Máiréad Enright, 'PP v HSE: Practicability, Dignity and the Best Interests of the Unborn Child' (*Human Rights in Ireland,* 26 December 2014) http://humanrights.ie/gender-sexuality-and-the-law/pp-v-hse-futility-dignity-and-the-best-interests-of-the-unborn-child/ accessed 22 October 2016; The concept of the unborn child's best interest in a very unusual one. For example, in England and Wales, a court cannot exercise its inherent jurisdiction in resepect of an unborn child *in utero*, though it may sometimes make orders to take effect in the event of its birth.
[187] 'Citizens' Assembly to Submit Report Over Legal Restrictions on Abortion' *RTÉ News* (Dublin, 15 October 2016) http://www.rte.ie/news/2016/1015/824276-citizens-assembly/ accessed 31 October 2016.
[188] Ibid.
[189] This should be interesting as a poll carried out before the first meeting found that a significant majority of Irish people want abortion legalised in cases of rape and fatal abnormality but do not want to see UK-style based abortion laws in Ireland.
[190] John Hooper, Riazat Butt, Rory Carrroll and Xan Rice, 'Keeping the Faith: How Bleak is the Future for Catholicism?' *The Guardian* (5 September 2010).
[191] Henry McDonald, 'Unionists Defeat Northern Irish Gay Marriage Bill' *The Guardian* (29 April 2013) http://www.theguardian.com/society/2013/apr/29/northern-ireland-gay-marriage-billfails accessed 16 October 2016.
[192] Barbara Hewson, 'Reproductive Autonomy and the Ethics of Abortion' (2001) 27 Journal of Medical Ethics 10, 11.
[193] Janice Rider Ellis and Celia Love Hartley, *Nursing in Today's World* (10th edn, Lippincott Williams and Wilkins 2012).
[194] Maeve Taylor, 'Women's Right to Health and Ireland's Abortion Laws' (2015) 130(1) International Journal of Gynecology & Obstetrics 96; see also *Z v Poland* App no 46132/08 (ECtHR, 13 November 2012).
[195] Health Service Executive, *Final Report: Investigation of Incident 50278 from time of Patient's Self-Referral to Hospital on the 21st of October 2012 to the Patient's Death on the 28th of October 2012* (June 2013) http://www.hse.ie/eng/services/news/nimtreport50278.pdf accessed 11 October 2016.
[196] General Nursing, *Abortion: Exploring the Ethical, Legal and Political Challenges* 6 www.undergraduatelibrary.org/system/files/3633p.pdf accessed 20 October 2016
[197] Janice Rider Ellis and Celia Love Hartley, Nursing in Today's World (10th edn, Lippincott Williams and Wilkins 2012).
[198] Irish Family Planning Association, *Supplementary information on Ireland in respect of restrictive laws on abortion* (9 August 2013) http://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/IRL/INT_CCPR_NGO_IRL_14878_E.pdf accessed 12 October 2016.

Euthanasia
Assisted suicide is when an individual takes his or her own life with the guidance, information and/or medication provided by a third party.[199] Euthanasia is the action of a third party to deliberately end an individual's life.[200] Both of these are illegal in Ireland. Under the Criminal Law (Suicide) Act 1993, suicide was decriminalised but it provides for the criminalisation of assisted suicide.[201] It is an offence to aid, abet, counsel or procure the suicide or attempted suicide of another.[202] The maximum penalty for this offence is fourteen years in prison.[203] In *Re a Ward of Court,* it was found that when death is imminent there is no legal obligation to engage in futile treatment as in the case of fruitless resuscitation of a patient who has suffered cardiac arrest when a doctor has formed a reasonable clinical judgment that treatment would be against the 'best interest' of the patient.[204]

Background

The Catholic church rejects euthanasia as a response to chronic or serious illness. The traditional catholic position is stated in the Declaration on Euthanasia,[205] which states that all human life regardless of its quality has sanctity and can never be deliberately destroyed.[206] While the Catholic church is against euthanasia and assisted suicide, their beliefs do not place an absolute value on life and it makes a moral distinction between directly killing a person and allowing a person to die – it allows for futile treatment that only postpones the inevitable to be discontinued.[207] Social order and control are ranked as superseding the right of the individual to self-determination and these norms were heavily influenced by the moral domination of the Catholic church in Ireland, through medical ethics and legislation.[208]

Ethical Considerations

When one thinks of euthanasia and the ethical issues surrounding this topic, the principle of autonomy and different moral values of the human person come to mind which leads to a wide diversion as to what is morally acceptable.[209] Ireland does not have a good record of dealing promptly with emerging ethical issues, and it is lagging behind other EU countries.[210] Ireland allows indirect action that can result in death where the intention is not to kill.[211] While it is not within the scope of this article to address all the ethical issues related to euthanasia and assisted suicide, it will briefly discuss some of the key issues.

Sanctity of Life

One of the key criticisms of assisted suicide and euthanasia is the sanctity of life, and critics believe that such practices are wrong in all circumstances – if life is ended in any form other than naturally, 'life is [denied] its inherent, cosmic value.'[212] Traditional sanctity of life advocates believe that life's 'deliberate ending is the deepest, most important part of the conservative revulsion against [such practices]'.[213]
The judiciary have circumvented the traditional conservative sanctity of life school of reason through engaging in 'act versus omission' dialogue.[214] Sanctity of life is a paramount issue when considering

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[199] David Quinn, 'Assisted Suicide – Ireland's Stance in a World's Context' *The Irish Medical Times* (Dublin, 1 July 2011).
[200] Ibid.
[201] Criminal Law (Suicide) Act 1993, s2(3).
[202] Ibid, s2(2).
[203] Ibid, s2(2).
[204] *Re a Ward of Court (No 2)* [1996] 2 IR 79.
[205] Declaration on Euthanasia, *The Sacred Congregation for the Doctrine of the Faith* (Rome, 5 May 1980).
[206] Roddy Tyrrell, 'Euthanasia from a Secular, Christian and Legal Perspective' (Lawyer.ie, 12 April 2012) http://www.lawyer.ie/euthanasia-law/ accessed 24 October 2016.
[207] Ibid.
[208] Tracie Keenan, 'Whose Life? Who's Right?' https://www.ucc.ie/archive/hdsp/ProTracie.htm accessed 26 October 2016.
[209] Roddy Tyrrell, 'Euthanasia from a Secular, Christian and Legal Perspective' (Lawyer.ie, 12 April 2012) http://www.lawyer.ie/euthanasia-law/ accessed 24 October 2016.
[210] Paul Cullen, 'Assisted Suicide Case Reveals Complexity of Subject' *The Irish Times* (Dublin, 29 April 2015).
[211] Paul Cullen, 'Assisted Suicide Case Reveals Complexity of Subject' *The Irish Times* (Dublin, 29 April 2015).
[212] Ronald Dworkin, *Life's Dominion: An Argument about Abortion. Euthanasia and Individual Freedom* (Harper Collins 1993) 195.
[213] Ibid, 214.
[214] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 94. See for example: *Airedale NHS Trust v Bland* [1993] AC 789 (HL) and *Re a Ward of Court (No 2)* [1996] 2 IR 79.

the morality of euthanasia and assisted suicide.[215] However, in limited circumstances, euthanasia or assisted suicide may serve sanctity of life better than a blanket prohibition which abandons individuals for principles; favouring concepts over humanity.[216]

The Slippery Slope Argument

The right of a person to make their own 'choice' about living or dying is often used by euthanasia advocates to generate support for legalisation.[217] The 'slippery slope' argument is by far the most common consideration advanced against proposals to legalise euthanasia,[218] and this sentiment was echoed in the judgment of Kearns P in *Fleming.* The slippery slope argument contends that if we begin making concessions to the current prohibition in order to facilitate assisted suicide, then the principle of autonomy will be abused in such a way as to permit suicide for malicious reasons, facilitate preying on the vulnerable or providing a cloak for murder.[219] The need to protect the vulnerable was partially the reasoning of the ECtHR in *Pretty*.[220]

Case Law

The body of case-law in the UK and Ireland on issues regarding end of life decisions focus on various legal principles, social policies and individual rights.[221] A number of exemptions to the current theoretical 'blanket' ban on euthanasia and assisted suicide have emerged.[222] The jurisprudence is unsatisfactory as it has provided for limited, case-specific exemptions, while purporting to maintain the prohibition of these actions, creating more confusion and uncertainty in this area of law.[223]

The United Kingdom

In *Airedale NHS Trust v Bland*,[224] the patient was in a persistent vegetative state and the House of Lords permitted the withdrawal of life support, on the grounds that it was not in his best interests to be kept alive where the application of such medical treatment was futile. The Court stressed the distinction between a positive act which would constitute euthanasia, and an omission which was merely allowing nature to take its course.[225]
In the case of *Pretty v United Kingdom*,[226] the applicant was diagnosed with motor neurone disease and her condition had deteriorated rapidly, she was paralysed from the neck down although she retained full capacity. She sought the assistance of her husband to commit suicide but a request to guarantee her husband's freedom from prosecution if he helped her was refused by the DPP (Director of Public Prosecution) as it was viewed to be improper to give any such undertaking in advance of any breach of the criminal law. The ECtHR found that there was no right to die contained in Article 2 (the right to life), and when read in conjunction with Article 3 (right to be free from inhumane and degrading treatment), no positive obligation arose and the State could in no way be obliged to provide the treatment sought by Pretty.[227] This case has been criticised on the basis that the UK legislation in relation to assisted suicide was drafted in such broad language as to leave prosecution of an individual to the discretion of the DPP. This was, however, clarified by the later decision of *R (Purdy) v DPP* in 2009.[228] Purdy's partner did not seek immunity from prosecution, but rather he sought clarification of his legal position and the House of Lords directed the DPP to clarify the position as to when he would pursue a prosecution pursuant to section 2(1) of the Suicide Act 1961.[229] Compassion

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[215] [215] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 94
[216] Ibid.
[217] John Griffiths, Heleen Weyers and Maurice Adams, *Euthanasia and Law in Europe* (1st edn, Hart Publishing 2008) 513.
[218] Ibid.
[219] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 94.
[220] *Pretty v The United Kingdom* App no 2346/02 (GC, 29 July, 2002).
[221] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 81.
[222] Ibid.
[223] Ibid.
[224] *Airendale NHS Trust v Bland* [1993] AC 789.
[225] *Ibid.*
[226] *Pretty v United Kingdom* App no 2346/02 (ECtHR, 29 April 2002).
[227] Ibid.
[228] *R (Purdy) v DPP* [2009] UKHL 45.
[229] *The Policy for Prosecutors in Respect of Cases Encouraging or Assisting Suicide* http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html accessed 29 October 2016 – compassion emerges

is now the 'key determining factor that places an act which remains criminal beyond the reach of the criminal courts'.[230]

In a landmark ruling in 2014, in *Nicklinson and Lamb v Ministry of Justice*,[231] the Supreme Court concluded that it had the constitutional authority to make a declaration of incompatibility with regard to section 2(1) of the Suicide Act 1961, but that they should not do so in this case. It was held that Parliament should be given the opportunity to consider the issue first. The SC's main justification for an absolute prohibition on assisted suicide is to protect those who are vulnerable and most at risk. Lord Neuberger went further and states that if MPs and peers do not give serious consideration to legalising assisted suicide, there is a 'real prospect' a future legal challenge would succeed.

Ireland

In contrast to the UK, there has not been much case law in Ireland in the area of euthanasia and assisted suicide. In *RE a Ward of Court*,[232] the court adopted the unsatisfactory 'acts versus omissions' distinction that the UK courts had done in *Airedale NHS Trust v Bland.*[233] The ward in question had been in a persistent vegetative state for 23 years and the Supreme Court granted consent to discontinue artificial hydration and nutrition.[234]

In the recent landmark case of *Fleming v Ireland & Ors* (2013),[235] it was the first time that an Irish court was confronted unavoidably with the issue of euthanasia and assisted suicide. Marie Fleming was diagnosed with multiple sclerosis, a disease causing progressive neurological deterioration and eventually death. At the time of the hearing, Ms Fleming's condition had deteriorated to the stage that she had paralysed limbs, was confined to a wheelchair, and suffered acute pain.[236]

Ms Fleming contended that the absolute ban on assisted suicide in section 2 of the Criminal Law (Suicide) Act 1993 was unconstitutional. She argued that the ban violated her right to personal autonomy under Article 40.3.2 and was discriminatory, in violation of the equality guarantee contained in Article 40.1, and she sought to have the ban declared incompatible with the ECHR.[237] Furthermore, Ms Fleming relied heavily on *Purdy* in the UK, and argued that the DPP should issue guidelines in order to clarify the likelihood of prosecution of those who are subject to the discretion of the DPP.[238]

The Supreme Court found there was no constitutional right to die or to be assisted to do so.[239] It was held that the State's absolute ban on assisted suicide was proportionate, in particular having regard to the safety of others.[240] However, importantly, it did state that there was nothing to prevent the introduction of legislation to deal with cases such as that of Ms Fleming, once it conformed with the Constitution.[241] However, the Court also held that the Irish DPP had no comparative statutory obligation to issue prosecutorial guidelines.[242] Furthermore, it was held, given the harrowing circumstances of this case, the DPP would 'exercise her discretion in a humane and sensitive fashion'.[243] On one hand, the judiciary are constrained by existing law to proscribe acts of assisted suicide and euthanasia, yet the DPPs are encouraged to exercise their discretion in cases of compassion.[244]

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as a key factor in assessing culpability, with a subjective 'common sense' approach being stipulated as the method of determining what constitutes compassion in each given case; see for example, CPS/DPP, *Decision on Prosecution – The Death By Suicide of Daniel James* (9 December 2008).

[230] Alexandra Mullock, 'Overlooking the Criminality Compassionate: What are the Implications of Prosecutorial Policy on Encouraging or Assisting Suicide?' (2010) 18 Medical Law Review 44, 454.

[231] *Nicklinson and Lamb v Ministry of Justice* [2014] UKSC 38 – Tony Nicklinson was paralysed save for his head and eyes and wished to take his own life but was unable to do so because of his condition. Tony applied to the HC for a declaration that it would be lawful for a doctor to assist him in terminating his life, or failing that, for a declaration that the law breached his right to respect for private and family life under Article 8 of the ECHR.

[232] *Re a Ward of Court (No 2)* [1996] 2 IR 79.

[233] *Airedale NHS Trust v Bland* [1993] AC 789, 865.

[234] *Re a Ward of Court (No 2)* [1996] 2 IR 79; The medical profession in Ireland are of the view that it is not ethical for a doctor to withdraw artificial hydration or nutrition from a patient who is not dying and could live for many more years in his or his condition.

[235] *Fleming v Ireland & Ors* [2013] IESC 19 (29 April 2013).

[236] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 89.

[237] *Fleming v Ireland & Ors* [2013] IESC 19 (29 April 2013).

[238] Ibid.

[239] Ibid.

[240] Ibid.

[241] Ibid.

[242] Ibid.

[243] Ibid.

[244] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 92.

The area of euthanasia and assisted suicide is highly sensitive and controversial. Prior to *Fleming*, Ireland remained virtually silent on the issue other than proscribing assisted suicide legislatively and euthanasia judicially in *Re a Ward of Court*.[245] The High Court did not change the law, but it has rendered the English Policy hugely relevant in Ireland.[246] The illegality of euthanasia and assisted suicide has repeatedly been asserted in the UK, although a growing number of exceptions have emerged.[247] As with most controversial areas of law, the case law leaves much to be desired.
It is submitted that maintaining the current statutory framework obliges people to rely on convoluted judicial pronouncements and that legislating for the DPP to promulgate offence-specific guidelines would be unsatisfactory.[248] The scope of the Irish legislative reform should cover assisted suicide and limited cases of euthanasia.[249] As the High Court in *Fleming* suggested that parties should refer to the English Policy, this could possibly provide a rough template for any attempt at legislative reform in the area of euthanasia and assisted suicide in Ireland.

Other Jurisdictions

The Netherlands

Assisted suicide has been legalised in the Netherlands since 2001.[250] The legislation requires that:

1) the doctors be convinced that the patient's request was voluntary and well-considered;
2) the patient's suffering was lasting and unbearable;
3) the doctors have informed the patient about the situation he was in and his prospects;
4) the patient must hold the conviction that there was no other reasonable solution to the situation he was in.[251]

It should be noted that an independent physician must also be consulted.[252] There are approximately 10,000 requests per year for assisted suicide, of which 6,000 are not carried out either because the doctor declines or the patient dies from his illness.[253] A study was undertaken in the Netherlands since the introduction of the 2001 legislation and it concluded that it was 'followed by a moderate decrease in the rates of physician assistance in dying'.[254] This decrease after the introduction of the legislation supports the proposition that the introduction of legislation permitting euthanasia and assisted suicide in certain circumstances will not lead to a slippery slope.[255]

Belgium

Belgium legalised euthanasia in 2002,[256] and in 2014 it amended its euthanasia law to allow terminally ill children suffering constant and unbearable pain to die – it is the first country in the world to remove the age barrier to euthanasia.[257] In September 2016, a 17-year-old became the first minor to be euthanised since the country relaxed its laws which allows for doctor-assisted death for minors of all ages.[258] The Belgian legislation permitting euthanasia in certain circumstances provides that a physician will not be guilty of a criminal offence if a voluntary, well-considered and repeated request is made by a competent patient and that it was not the result of any external pressure.[259] Similarly to the Dutch legislation, external independent medical advice must also be sought.[260]

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[245] R*e a Ward of Court (No 2)* [1996] 2 IR 79.
[246] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 93.
[247] Ibid.
[248] Ibid, 99.
[249] Ibid, 100.
[250] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.
[251] Ibid, Article 2(1) (a)-(e).
[252] Ibid.
[253] Deirdre Madden, *Medicine, Ethics and the Law* (2nd edn, Bloomsbury 2011) 568.
[254] End-of-Life Practices in the Netherlands under the Euthanasia Act (May 10 2007) http://www.nejm.org/doi/full/10.1056/NEJMsa071143#t=articleTop accessed 31 October 2016.
[255] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 96
[256] The Belgian Act on Euthanasia 2002.
[257] Dan Buckley, 'Special Report: Euthanasia' *The Irish Examiner* (Dublin, 9 June 2014).
[258] 'First Minor Euthanised in Belgium After 2014 Law Change' *RTÉ News* (19 September 2016) http://www.rte.ie/news/2016/0917/817198-euthanasia/ accessed 21 October 2016.
[259] The Belgian Act on Euthanasia 2002, s3(1).
[260] Ibid, s2(3).

According to a recent study, there has been a significant increase in euthanasia cases in Belgium since it was legalised in 2002.[261] Euthanasia accounted for 1.7% of deaths in 2013, compared to only 0.2% in 2003, a total of 8,752 cases were reported during this period.[262] The study also found that there was evidence indicating that more vulnerable groups are being coerced into euthanasia.[263]
The High Court in *Fleming* was not persuaded by the empirical evidence from the Dutch and Belgian regimes as to the disproportionality of the ban on euthanasia and assisted suicide.[264] The Court was concerned over the risks inherent in those jurisdictions, despite the general decline of incidences of assisted suicide without an explicit request, and specific examples of abuse presented to the High Court.[265] Importantly, the Court also held that any risk of abuse or lack of compliance with essential safeguards in the Netherlands and Belgium was enough to highlight unavoidable risks in any liberalisation of the Irish regime.[266]

Assisted Human Reproductive Technologies

With the constant advances in scientific knowledge and capacity, a wide range of medically assisted human reproductive technologies (ART) can offer couples or single women a greater chance of achieving successful pregnancy and births.[267] ART includes the following: intrauterine insemination (IUI), gamete retrieval (sperm and ova), *in vitro* fertilisation (IVF), third-party ART which involves gamete donation or surrogacy, or techniques such as cryopreservation of gametes and embryos, pre-implantation genetic diagnosis (PGD) among other things.[268] Complex legal and ethical issues arise from these developments.

Background

The progress of research techniques on embryos, such as PGD, historically developed to address concerns related to major genetic disorders and disabilities, is increasingly being used for other purposes that can be achieved through genetic selection of offspring.[269] For example, in 2015, the UK became the first country to allow a controversial IVF technique that uses the DNA from two women and one man, called mitochondrial donation. In September 2016, the world's first baby to be born from this procedure in Mexico, was cared for by US fertility specialists and appears to be healthy. Other such purposes include sex selection of the future child according to personal preferences or socially determined choice.[270] Human rights in this area help to promote 'principles and norms that are not negotiable and cannot be compromised,'[271] such as the integrity of the human body and dignity.
The possibilities brought within reach by these technologies give rise to numerous ethical, religious, sociological, and legal issues that the legislators and courts throughout the world have sought to address and resolve.[272] Due to the advancement of technology, the field of bioethics has seen significant advances in the last few decades.[273] However, the rapid progress of such technologies has not been accompanied by advancements in the field of bioethics and law.[274]

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[261] Sigrid Dierickx, Lue Deliens, Joachim Cohen and Kenneth Chambaere, 'Euthanasia in Belgium: Trends in Reported Cases Between 2003 and 2013' (2016) Canadian Medical Association Journal 1 http://www.cmaj.ca/content/early/2016/09/12/cmaj.160202.full.pdf+html accessed 31 October 2016.
[262] Ibid.
[263] Sigrid Dierickx, Lue Deliens, Joachim Cohen and Kenneth Chambaere, 'Euthanasia in Belgium: Trends in Reported Cases Between 2003 and 2013' (2016) Canadian Medical Association Journal 1 http://www.cmaj.ca/content/early/2016/09/12/cmaj.160202.full.pdf+html accessed 31 October 2016; If the Federal Control and Evaluation Commission find that a euthanasia was not lawful, the case is turned over to the public prosecutor. To date, only one case in 10,000has been submitted for judicial review.
[264] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 97.
[265] *Fleming v Ireland* [2013] IEHC 70.
[266] Ibid, 104.
[267] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 341.
[268] Ibid, 341.
[269] Ibid,341.
[270] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 343.
[271] Henk Ten Have, 'Bioethics and Human Rights: Wherever the Twain Shall Meet' in Silja Vöneky, Britta Beylage-Haarmann and Anita Hofelmeier (eds), *Ethick Und Recht: Die Ethisierung des Rechts (Ethics and Law: The Ethicalisation of Law)* (Springer 2013) 168.
[272] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 343.
[273] Ibid, 344.
[274] Ibid.

Ethical and Legal Considerations

One of the core legal issues around ART is the very concept of the beginning of life, a concept where there is a lack of consensus at the European level. In most European countries there is no consensus on the moment an embryo becomes a human being, while only three countries consider that human life begins at conception: Germany, Malta and Switzerland.[275] This is significant as the right to life is not clearly articulated in relation to ART practices. Further legal conflict potentially emerge between ART and human rights with regard to human dignity, the integrity of the human body and the principle of non-discrimination, as well as the difficulty of balancing different rights and interest at stake with a focus on the rights of the (future) ART-born child.[276]

Balancing Conflicting Rights and Interests

The revolution of the institution of the family by the advances in ART creates different types of relations and conflicts of rights and interests as there are more than just the parents and the (future) ART-born child involved such as the ART industry specialists, donors and surrogates.[277] It is argued that there needs to be a more child-centred approach of legal frameworks regarding ARTS as the rights and best interests of the (future) ARTS child whose rights can often be in conflict with the rights and interests of the parents.[278] Adults can also find themselves in a vulnerable position where their rights are abused in the context of the transformation of ART into a mere profit-making business, where they are willing to sell their gametes or even offer their body for gestational purposes.[279] This clearly breaches the principles of respect for human dignity and integrity of the human body.

Genetic Selection of Offspring and Scientific Research on Human Embryos

The practice of genetic selection of offspring and scientific research on embryos, made possible by the progress of PGD, raises questions of ethics and conformity with the right for respect of human dignity, and of the principle of non-discrimination.[280]

In 1997, with the Oviedo Convention on Human Rights and Biomedicine, the Committee of Ministers of the Council of Europe adopted a framework Convention laying down the main principles and general standards to be observed for the respect of human rights and human dignity in the areas of biology and medicine.[281] Although the Convention lacks an enforcement mechanism, the ECtHR does mention it as a relevant source of European legal instruments when judging cases in this area.[282] The Oviedo Convention allows for the performing of predictive genetic tests to detect a genetic disposition or susceptibility to a disease for health purposes and for some forms of treatment, but prohibits sex-selection as it would contravene with the notion of inherent human dignity.[283]

It could be argued that genetic selection of offspring discriminates against the future of the ART-born child's rights as it increases stereotypes and discriminatory attitudes towards persons with disabilities.[284] It could also be argued that the selection of offspring for health purposes triggers the risk of a 'eugenics' with respect to persons with disabilities, incited by the ideal to create a 'perfect society'.[285]

The question remains as to what happens to undesired embryos. In some countries they are cryopreserved or used for scientific research. The different conceptual/definitions that countries have of human embryos and whether they consider them as human beings from a constitutional or legal

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[275] Ibid, 351.

[276] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 351.

[277] Ibid, 352.

[278] Maya Sabatello, 'Are the Kids Alright: A Child-Centred Approach to Assisted Reproductive Technologies (2013) 31(1) Netherlands Journal of Human Rights, 82.

[279] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 352.

[280] Ibid, 354.

[281] Oviedo Convention on Human Rights and Biomedicine, Art 1.

[282] For example: *Vo v France* App no 53924/00 (GC, 8 July 2004); *Evans v UK* App no 6339/05 (GC, 10 April 2007); *S v H and others v Austria* App no 57813/00 (GC, 3 November 2011).

[283] Oviedo Convention on Human Rights and Biomedicine, Articles 12, 13, 14 and 18.

[284] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 355.

[285] Margaret Sommerville, 'Law, Marching with Medicine but in the Rear and Limping a Little: Ethics as "First Aid" for Law'in Silja Vöneky, Britta Beylage-Haarmann & Anja Höfelmeier (eds), *Ethik und Recht: die Ethisierung des Rechts (Ethics and Law: The Ethicalisation of Law)* (Springer 2013) 78.

point of view clearly influences their position as regards scientific research on embryos.[286] The question of the moment when an embryo is considered a human being or whether it deserves legal protection is still a contentious issue with the EU, in fact, this issue is most of the time left unregulated.[287]

European Court of Human Rights

Since the chances for the adoption of a coherent European regulation able to offer solutions and avoid legal conflicts are slim, the ECtHR's case law presents an alternative approach through the application of the doctrine of balancing different human rights and the interests at stake.[288] It should be noted that although the ECHR does not provide for the right to health or for reproductive rights, nor any freedom of research, the Court has addressed questions in the area of ART.

Article 2 – The Right to Life

The question of the moment of when life begins has been addressed by the ECtHR in 2004 in *Vo v France,*[289] where a mix up with another patient's name resulted in the applicant's amniotic sack being punctured, making a therapeutic abortion necessary. The Court noted that there was no consensus on the nature and status of the foetus and held that there had been no violation of Article 2, and that it was not currently desirable or possible to rule on whether an unborn child was a person under Article 2.

The question of the moment of beginning of life was brought before the ECtHR again, in the context of *in vitro* embryos, in the case of *Evans v UK,*[290] which concerned the ability of a woman to use frozen embryos without her former partner's consent.[291] The applicant, who was suffering from ovarian cancer, underwent IVF treatment with her then partner before having her ovaries removed. Six embryos were created and placed in storage. When the couple's relationship ended, her ex-partner withdrew his consent for the embryos to be used, not wanting to be the genetic parent of the applicant's child. National law consequently required that the eggs be destroyed. The applicant complained that domestic law permitted her former partner effectively to withdraw his consent to the storage and use by her of embryos created jointly by them, preventing her from ever having a child to whom she would be genetically related.[292] The Grand Chamber followed the same reasoning as in *Vo,* reaffirming that the issue of when the right to life begins falls within the margin of appreciation on the member states, thus it could not be held that the embryos that were created had a right to life under Article 2 of the ECHR. The above two cases have been criticised as the ECtHR seems to apply both an attitude of judicial restraint and judicial activism throughout its case law.[293] The ECtHR allows members states to have a very broad margin of appreciation in order to respect pluralism and the principle of subsidiarity, while being judicially active when interpreting the ECHR as a 'living instrument' in the context of today's society and respective evolution of science.[294]

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[286] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 355.

[287] Ibid.

[288] Daniel Garcia San Jose, *European Normative Framework for Biomedical Research in Human Research in Human Embryos* (Cizur Menor, Thomas Reuters Aranzadi 2013) 123.

[289] *Vo v France* App no 53924/00 (GC, 8 July 2004).

[290] *Evans v UK* App no 6339/05 (GC, 10 April 2007).

[291] In 2016, in the US case of McQueen v Gadberry, the Court of Appeals of Missouri ruled that frozen pre-embryos, fertilised eggs that are not implanted in the uterus, are legally classified as marital property of a special character, and the consent of both parties is required before the pre-embryos can be implanted. The Court ruled in favour of Gadberry, affirming the trial court's decision that both Gadberry's and McQueen's fundamental rights to privacy and equal protection under the US Constitution would be violated if either party is forced to procreate against his or her wishes. The parties were awarded the frozen pre-embryos jointly and ordered that no transfer, release, or use of the frozen embryos shall occur without the signed consent of both parties.

[292] *Evans v UK* App no 6339/05 (GC, 10 April 2007); see also *Findley v Lee* - a judge in California ordered the destruction of five embryos, where a couple had participated in IVF and subsequently divorced. At the time they both signed an agreement stating that the embryos would be destroyed in such circumstances and this was upheld by the Superior court in order to give effect to the intentions at the time of the decision at issue.

[293] Paul Mahoney, 'Judicial Activism and Judicial Self-Restraint in the European Court of Human Rights: Two Side of the Same Coin' (1990) 11(1-2) Human Rights Journal 57 – 88.

[294] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 358.

Article 8 – The Right to Private and Family Life

In contrast, the ECtHR has developed interesting jurisprudence under Article 8 of the ECHR in relation to sexual and reproductive issues. The ECtHR considered the *Evans case* under Article 8, and analysed whether the woman's right to respect of her private and family life was infringed. The Court considered implicitly, whether there was a right to ART for the woman who wanted embryos to be implanted in her uterus despite the lack of consent of her previous partner in order to become a genetic parent. The Grand Chamber considered that, given the lack of European consensus and the fact that the domestic rules had been clear and brought to the attention of the applicant and that the national authorities had struck a fair balance between the competing interests, there had been no violation of Article 8 of the Convention.[295]

The ECtHR also addressed the right to access ART and to become genetic parents in the later case of *Dickson v UK,*[296] in 2007, the Grand Chamber held that the refusal of the domestic authorities to grant the prisoner's request for access to artificial insemination facilities to enable him to have a child with his wife was a violation of Article 8. The ECtHR held that a fair balance had not been struck between the competing public and private interests, because the authorities had not made a proportional assessment of the applicant's individual circumstances. As is illustrated from the above cases, access to ART not only falls within the scope of Article 8, but a right to access ART can be derived under certain circumstances.[297]

Although no violation of Article 8 was found, the ECtHR confirms the inclusion of a right to access ART in a more recent decision, *SH and others v Austria,*[298] in 2011. This case involved two Austrian couples wishing to conceive a child through IVF, one which needed the use of sperm from a donor, and the other a donated egg. Austrian law prohibits the use of sperm from a donor for IVF and ova donation in general. The ECtHR found 'that the right of a couple to conceive a child and to make medically assisted procreation for that purpose is also protected by Article 8.'[299] The ECtHR noted that, although there was a clear trend across Europe in favour of allowing gamete donation for *in vitro* fertilisation, the emerging consensus was still under development and was not based on settled legal principles.[300] It highlighted the importance of keeping legal and fast-moving scientific developments under in the field of artificial procreation under review.[301]

More recently in 2012, the ECtHR found in *Costa and Pavan v Italy*[302] that a parents' 'desire to conceive a child unaffected by a genetic disease of which they are healthy carriers (of cystic fibrosis in this case) and to use ART and PGD to this end attracts the protection of Article 8. It noted the inconsistency in Italian law (citing the new approach of ordinary courts) that denied the couple access to embryo screening but authorized medically assisted termination of pregnancy if the foetus showed symptoms of the same disease. The Court concluded that the interference with the applicants' right to respect for their private and family life had been disproportionate

Over the past few years, the scope of Article 8 for procreation has gradually been extended from a negative right to procreate without interference from third parties, to a positive right to access ARTs.[303] Until recently the ECtHR's interpretation of restrictive policies on ARTs have not often led to the conclusion that Article 8 was actually breached as the ECtHR deemed the interference with the Article 'necessary in a democratic society'.[304] The Court confines itself as much as possible to a case-by-case approach and 'the Court's task is not to substitute itself for the competent national authorities in determining the most appropriate policy for regulating matters of artificial procreation'.[305] Since *Evans,* it is clear that the ECtHR gives a wide margin of appreciation to member states in matters concerning ARTs as these technologies touch upon sensitive moral and ethical issues against a background of fast-moving medical technology developments; and there is often not yet a clear common ground among member states with regard to the issues that ARTs raise.[306]

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[295] *Evans v UK* App no 6339/05 (GC, 10 April 2007).
[296] *Dickson v the United Kingdom* App 44362/04 (GC, 4 December 2007).
[297] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 359.
[298] *SH and others v Austria* App no 57813/00 (GC, 3 November 2011).
[299] Ibid, para 82.
[300] Ibid.
[301] European Court of Human Rights, *Factsheet on Reproductive Rights* http://echr.coe.int/Documents/FS_Reproductive_ENG.pdf accessed 29 November 2016.
[302] *Costa and Pavan v Italy* App 54270/10 (ECtHR, 28 August 2012) para 50.
[303] Britta c Van Beers, 'Is Europe 'Giving in to Baby Markets?' Reproductive Tourism in Europe and the Gradual Erosion of Existing Legal Limits to Reproductive Markets' (2014) Medical Law Review.
[304] Ibid, 18.
[305] *SH and others v Austria* App no 57813/00 (GC, 3 November 2011) para 92.
[306] *SH and others v Austria* App no 57813/00 (GC, 3 November 2011) para 97; *Evans v UK* App no 6339/05 (GC, 10 April 2007) para 81.

Rights of Children Born Through Surrogacy Arrangements

It is clear from the case that the Strasbourg Court does not take under active consideration any future right of the future ART-born child and it is mostly the rights of the future parents that have been analysed with a view of granting protection under the ECHR.[307] It is evident in two cases brought against France (*Mennesson v France* and *Labasse v France*[308]) that the best interest of the child already born as a result of ART does represent a priority for the ECtHR. It was held in these two cases that the refusal by the domestic authorities to recognise a parent-child relationship in respect of the children born as a result of a foreign surrogacy arrangement meant there were violations of Article 8 in respect of the private lives of the children (not the biological fathers).

The ECtHR denied a violation of Article 8 ECHR in respect of the parents because the lack of recognition of the parental relationships had not prevented the parents from living with their children. However, the ECtHR noted that the French refusal to recognise the parental relationships established abroad 'undermined the children's identity within the French society'. Considering the principle that the best interests of the child must prevail, the ECtHR found France in breach of the right to the protection of privacy and family life of the children. In other words, not recognising the parental relationship between the children and their biological fathers, France 'had overstepped the permissible margin of appreciation'.[309]

The member states had a wide margin of appreciation since there is no European consensus on the lawfulness of surrogacy arrangements or on the question of whether a surrogacy arrangement concluded abroad can be legally recognised.[310] The Court relied on this judgment, and found a violation of Article 8 in respect of the right to respect for the private lives of the children concerned in the very recent case of *Foulon and Bouvet v France.*[311] This involved the refusal by French authorities to transcribe birth certificates issued in India in respect of children born as a result of foreign surrogacy arrangements.

A case similar to *Mennesson* was judged in 2015 (*Paradiso and Campanelli*).[312] This case concerned the placement in social service care of a nine-month-old baby who had been born in Russia following a gestational surrogacy; it subsequently transpired that the applicant's had no biological link with the child.[313] The applicants claimed that Italy had violated their rights by removing the child from them and by refusing to acknowledge the parent-child relationship established abroad by registering the birth certificate of their child in Italy. The Court held that there had been a violation of the right to respect for private and family life in regards to the couple, but rejected the complaint formulated in the name of the child because of the lack of standing of the applicants in this capacity.[314] It considered in particular that the public-policy considerations underlying Italian authorities' decisions could not take precedence over the best interests of the child, in spite of the absence of any biological link and the short period during which the applicants had cared for him.[315] Reiterating that the removal of a child from the family setting was an extreme measure that could be justified only in the event of immediate danger to that child, the Court concluded that, in the present case, the conditions justifying a removal had not been met.[316] The Court's judgment is not yet final, as the Italian Government has requested the case be referred to the Grand Chamber.[317]

Conclusion

There is no requirement for states to permit abortions where there is no risk to the life of the mother under the ECHR. As the ECtHR has held, provided there is an appropriate balance met between the

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[307] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 360.
[308] *Mennesson v France* App no 65192/11 (ECtHR, 26 June 2014) and *Labasse v France* App no 65941/11 (ECtHR, 26 June 2014).
[309] Giulia Dondoli, 'Paradiso and Campbell v Italy: Surrogacy and the Best Interests of the Child' (2016) Cork Online Law Review http://corkonlinelawreview.com/index.php/2016/02/22/paradiso-and-campanelli-v-italy/ accessed 30 November 2016.
[310] *Mennesson v France* App no 65192/11 (ECtHR, 26 June 2014) and *Labasse v France* App no 65941/11 (ECtHR, 26 June 2014).
[311] *Foulon and Bouvet v France* App nos 9063/14 and 1041/14 (ECtHR, 21 July 2016).
[312] *Paradiso and Campbell v Italy* App no 25358/12 (ECtHR, 27 January 2015).
[313] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 368.
[314] Ibid.
[315] *Paradiso and Campbell v Italy* App no 25358/12 (ECtHR, 27 January 2015).
[316] Ibid.
[317] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 368.

rights of the mother and the life of the unborn, states enjoy a broad margin of appreciation.[318] The political imperative to repeal the eighth amendment that upholds Ireland's restrictive abortion regime has been gaining momentum as Ireland's abortion law has been the subject of public and parliamentary debate to a degree unprecedented in the past. Although the narrow interpretation of terms in the 2013 Act ensured that women's reproductive rights could not emerge as a central concern, a discourse of reproductive autonomy is beginning to move from the margins to the centre of the abortion debate.

When people are faced with the prospect of death because of an illness, patient autonomy should not be violated for the sake of a theoretical 'sanctity of life' or conceptual 'slippery slope argument.[319] While the operation of assisted suicide in jurisdictions such as the Netherlands and Belgium are not perfect, this does not justify precluding this choice from someone like Marie Fleming. It is argued that the law should not place stringent limits on an individual's freedom of choice with regard to end of life decisions; any such limitation should be imposed and regulated by legislation.[320] As suggested above, the DPP's Policy in the UK following the Purdy case provides a valuable framework for any potential legislative reform in this jurisdiction.

The progress of research techniques on embryos, such as Pre-implantation Genetic diagnosis or PGD, historically developed to address concerns related to major genetic disorders and disabilities, is increasingly being used for other purposes that can be achieved through genetic selection of offspring.[321] The diversity in responses by EU member states to such advancements in reproductive technology derives from the fact that this subject lies within the states' sovereignty, and thus they enjoy a large margin of appreciation that results in a lack of consensus.[322] It has been argued with regard to research on human embryos that the present diverse approaches taken in Europe as regards regulation at national and international level is a reality with unknown consequences in the future.[323]

Identifying Topics for Future Challenges: for National Courts and the European Court of Human Rights

ART – Medically Assisted Reproductive Technologies
Property Rights in Embryos
Parenthood re-definitions
Surrogacy
Privacy – autonomy in health interventions and medical records confidentiality
Assisted Suicide and Euthanasia
Organ Transplant

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[318] *A, B and C v Ireland* App no 25579/05 (ECtHR, Grand Chamber, 16 December 2010).
[319] Nicholas Liddane. 'Abandoned to Principle: An Overview of the Law on Euthanasia in the UK and Ireland, & the Case for Reform' (2013) Cork Online Law Review 79, 102.
[320] Ibid.
[321] Elizabeth Steiner and Andreea Maria Rosu, ' Medically Assisted Human Reproductive Technologies (ART) and Human Rights – The European Perspective (2016) 2(2) Frontiers of Law in China 339, 341.
[322] Ibid, 348.
[323] I gratefully acknowledge and accredit the invaluable assistance and research of Ms Caitríona Donnellon LLB, LLM and PhD Candidate (NUIG) in the preparation of this paper.

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Member of the Constitutional Council (France)
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The outlook based on existing case law and national experience - in France

By establishing standards, the law is at risk of rigidifying a state of reflection and acceptability which is inevitably fluid. Two very different questions arise. Firstly, a possible shifting of the boundaries embodied in the legal rules: when, how and where to? Secondly, the question of the very substance of the principles governing this field, which may possibly be shaken up by developments in therapeutic means and methods.

In France the founding principle is the preservation of human dignity, which certain legal commentators have criticised as being "catch-all" and which the Constitutional Council has defined as follows: "a series of principles including the primacy of the human being, respect for human beings from the beginning of their lives, the inviolability and the integrity of the human body and the principle of non-ownership thereof, as well as the integrity of the human species". It is however clear that these notions do not always offer a precise basis for decisions. Moreover, as a matter of principle, the law does not answer all the questions, and there must be constant reflection on matters related to bioethics.

Some of the questions which legal specialists have to answer reveal tensions which have intensified over the last 20 years.

The first range of questions concerns the frame within which progress made by research must be considered.

A recent example is a provision of the law of 1 August 2013 which authorises, under certain conditions, research on embryos and embryonic stem cells, something previously prohibited subject to exceptions. This provision was challenged before the Constitutional Council, which confirmed its constitutionality. It is interesting to see the reasoning followed by the Constitutional Council in recognising this conformity, which it based on the principle of protection of human dignity while noting that the legislature had subjected the issuance of research authorisations to effective safeguards.
The latter are expressly laid down in the new wording of the Public Health Code: "1 The scientific relevance of research shall be established; 2 Research, whether basic or applied, shall have a medical purpose; 3 Given the state of scientific knowledge, it shall be impossible to conduct this research without using embryos or embryonic stem cells; 4 The project and the conditions under which the protocol is implemented shall respect ethical principles relating to research on embryos and embryonic stem cells." One can hardly be more explicit concerning the conditions under which scientific progress is to be taken into account in order to improve patient care, and therefore about the need for a periodic review.

The second range of questions concerns the dichotomy between the principle of non-ownership of the human body and personal freedom.

In this connection, reference can be made to a decision by the Constitutional Council in 2013 on the use of hematopoietic cells. The law lays down very strict conditions, which were challenged in the name of personal freedom. The response to the application lodged was worded as follows "the legislature's decision to make the harvesting of such cells dependent on the woman's written consent was not aimed at granting her rights over these cells, nor did it have that result." The European Court of Human Rights did not rule differently in its Parillo judgment of 2015.
This principle is clearly a limit on personal freedom, a notion which more or less corresponds to that of self-determination in other legal systems.

On the other hand, the need for consent is an application of personal freedom. Consent is also required for any form of treatment of course, but, especially in this case, there must naturally be consent to a donation by removal (in France anonymous and free donation is the general rule). All practices must therefore comply, but how can this be ensured in every case, and how can it be done when persons are deceased?

The third range of questions concerns the protection of health?

Without seeking to assess whether there is a scientific consensus on the subject, in the abovementioned decision the Constitutional Council gave the same answer as it had already given on several occasions in similar cases involving difficulties of scientific assessment: it is not for the Council to call into question provisions adopted by the legislature. I quote "in the absence of a proven and duly justified therapeutic need at the time of harvesting, transplants between family members of cells from umbilical or placenta blood or from the umbilical cord or placenta offer no established therapeutic advantage as compared with other transplants." The scientific (near) consensus must therefore outweigh an individual request.

The hope inspired by the use of products of the human body which have become therapeutic resources is sustained by the publicity surrounding discoveries.
Another type of question relating to health protection then arises: what is to be done with individual requests? This is probably, in practice, the area which can pose the most problems, notably for judges.

In the above-mentioned case, apart from the uncertainty surrounding the therapeutic potential of the cells in question, the need for solidarity in matters of health protection was advanced as an argument against granting such individual requests, in order to give precedence to the needs of the population as a whole.
(The question was admittedly raised in different terms for transplants, which needed to be managed due to the limited number of available transplant materials).

It was recently announced that a British judge had allowed the cyropreservation of a young woman. Should we accept such requests? And who should bear the cost of these techniques?

The fourth range of questions concerns adhesion to rules.

What is accepted here may not be allowed elsewhere. Will there not then be a temptation to adopt a "laissez-faire" approach (permitting trips abroad or scattered initiatives) with all the risks that entails?
One very telling example illustrates the ethical questions - that of pre-implantation genetic diagnosis, which has raised many hopes. Three risks have been identified: the risk of eugenics, the risk of manipulation and the risk of discrimination. Pre-implantation genetic diagnosis is authorised in France under strict conditions. It is prohibited in some countries and authorised in others. How do you ensure respect for French rules if a person can go elsewhere to obtain this diagnosis? Is it not a question of this nature which is behind the very violent dispute over the fate of children born through gestational surrogacy?

Some more food for thought.

The pressure is all the stronger in that some innovative techniques cause the emergence of a genuine market. In the example I gave a moment ago, this is the case with biobanking of autologous cells or tissues. But there is also a possibility that a form of "industrial" development, such as patent applications, may emerge. In a judgment delivered in 2001 the CJEU opposed this in matters relating to the use of stem cells, arguing on the basis of the principle of human dignity. But countries outside the European Union may not endorse this reasoning.

Biomedical activities in the research and medical fields are subject to controls, that is to say very often to authorisations, and will accordingly be restricted. But an authorisation cannot encapsulate an ethical principle, if only because authorisations may evolve according to scientific developments. At an international level it is clear that respect for these principles is all the more difficult in view of the movement of human beings, products and techniques.

We would like everything to do with bioethics to be shared. Ethics committees are trying to ensure this. The same does not hold true of legislators, who do not all make the same choices. Judges find themselves caught in the middle of the tensions between standards which have been accepted, but whose content may sometimes be unclear, and individual requests. At the international level in particular, the reconciliation which they seek to ensure is at risk of being founded on a precarious equilibrium.

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Aart Hendriks is a health and human rights lawyer, attached to Leiden Law School as professor in health law and to the Royal Dutch Medical Association as senior legal advisor. Besides that he is a member of the Board of Supervisors of two hospitals, surrogate judge and member of numerous scientific committees, editorial boards and advisory bodies. He regularly serves as consultant for regional and international organisations and teaches both nationally and internationally. He has extensively published on the right to health, patients' rights, medical secrecy, professional standards, biomedical issues and the case law of the European Court of Human Rights with respect to health issues.

Mr Justice Peter Jackson

Judge of the Family Division of the High Court (United Kingdom)

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Prof. Angelika Nußberger

Vice-President of the European Court of Human Rights

Prof. Dr. Dr. h.c. Angelika Nußberger M.A. is Judge at the European Court of Human Rights. She was elected on behalf of Germany in 2010 and took up office as of 1st of January 2011. From November 2012 until October 2015 she was vice-president of the fifth section of the Court; since 1 November 2015 she has been President of the fifth section.

She is professor at Cologne University where she used to teach public international law, German public law and comparative constitutional law. Before being elected Judge she had been Vice President of Cologne University, member of the Committee of Experts on the Application of Conventions and Recommendations of the International Labour Organisation (2004-2010) and substitute member to the Venice Commission (2006-2010). She was also one of the authors of the report of the Independent Fact Finding Mission on the Conflict in Georgia instituted by the EU under the leadership of the Swiss diplomat Heidi Tagliavini.

She has graduated in Slavic languages and literature (Magister Artium, Munich 1987) and law (first State exam Munich 1989, second State exam Heidelberg 1993, Diploma in comparative law at the University of Strasbourg in 1988, Doctor of Law at the University of Würzburg in 1993). From 1993 until 2001 she was research fellow at the Max-Planck-Institute for Foreign and International Social Law in Munich and from 1994 until 1995 visiting researcher Harvard University.

Closing Remarks

Dear Colleagues,

I have been given the challenging task of drawing the conclusions at the end of this seminar. Even though the subject matter of today's seminar was international case-law in bioethics, I found it very interesting that we did not discuss what we mean by the term "bioethics". The only, rather broad, definition was given by our Irish colleague Grainne McMorrow, who considered that bioethics was "the protection of the human being in the light of human dignity". I think it is indeed very difficult to provide an adequate all-embracing definition. Therefore I appreciated the approach taken by our British colleague Justice Peter Jackson, who considered that we are "standing in a river", giving us, at least, a metaphor for what we are doing in bioethics: We are standing in a river and the current is so strong that it is constantly driving us forward without giving us much time to reflect on what we are doing.

But even if we were not able (or did not want) to give an abstract definition of the term "bioethics", we singled out a considerable number of specific topics and problems falling within the scope of bioethics. The issue of surrogate motherhood, which appears to be one of the key questions, was frequently

raised, along with abortion and euthanasia, but also DNA testing for the purpose of establishing paternity.

I would like to summarise our discussions under three questions: The first question is, to my mind, the most intricate one: Who should decide on these issues? The second question is how (on what grounds) to decide and the third question: How much regulation do we need?

With regard to the first question, I think we should proceed from a narrow to a broader approach. The first person to take a decision is the person directly concerned. We then move on to the family, as the persons who are most intimately connected to the person affected by the decision. When we go further, we find the treating medical doctors and, as mentioned by our French colleague Claire Bazy Malaurie, the Ethics Committees. A further circle is formed by the courts, national courts as well as international courts, the latter being still further removed. The last relevant instance is the legislator, be it the national legislator or the international "legislators", that is, the standard setters in the international field.

Let us approach the issue by asking which question should be decided on which level, from the person concerned to the legislator. As to the person concerned by the medical treatment, I have detected a consensus among today's speakers that there should be, as far as possible, "informed consent" about all pertinent questions. That is where the problems start, because, as my Swiss colleague Judge Helen Keller showed in her presentation, when it comes to the most difficult questions concerning the beginning and the end of life, the person directly concerned cannot be asked directly. Neither the *nasciturus* nor the dying person can explain his or her wishes. The next step in the decision-making process is a very controversial one: Should it be the medical doctors and/or the family who assumes responsibility and is allowed to have the last word? This question was not so much discussed today, but it was at the very heart of the ECtHR Grand Chamber case of Lambert v. France, where the family was divided and could not agree on what measures should be taken to end or to allow to continue his life in a chronic vegetative state.

There was also consensus that the person concerned should have knowledge about medical data, as my colleague from Andorra, Judge Pere Pastor Vilanova explained. But, in as far as this knowledge concerns third persons, we can identify different approaches. An example which was frequently recalled was DNA analysis for the purpose of establishing paternity. There it is necessary to strike a balance between the potential father's rights and the child's rights. Our colleague from Britain Justice Peter Jackson presented the interesting case of *Spencer v. Anderson* where scientific testing of the DNA was granted for the purpose of providing evidence of paternity although the potential father had already died. We learned about the opposite approach taken in France. Following a controversial case concerning a paternity claim against the late Yves Montand, a law was introduced in order to ensure that those who were dead should be allowed to take their secrets with them ("les morts qui partent avec leurs secrets"). This demonstrates that the balancing of rights can lead to different results.

Moving on to the judicial level, we heard interesting views on national judges' experience with the use of European case-law. Justice Peter Jackson told us how he used the ECtHR Chamber case of Jäggi v. Switzerland as a source of inspiration for solving a similar problem at the domestic level, while our French colleague, Mme Bazy Malaurie, talked about the tensions between national legislation and the ECtHR's case-law on the legal status of children born following surrogacy treatment and the risk of circumvention by persons having recourse to surrogacy treatment abroad and subsequently claiming rights for their children on moral grounds.

The second question I would like to take up is how and on what grounds decisions should be taken. There are philosophical and ethical arguments, there are social arguments, and there are religious and historical arguments. All these approaches give an input into the dialogue within civil society. There is also the institutionalized legal decision making process. At the centre of the philosophical / ethical approach is the issue of human dignity. But even if we all agree that dignity is in the centre, we will not necessarily agree on what dignity is. So therefore the consensus already ends here. The controversy starts with the question who is the carrier of dignity. In this context we have addressed questions such as whether the embryo already carries human dignity and whether the dead body has still human dignity preventing the removal of parts of this body. A third example which appears to be quite far reaching in this context, was brought up by Grainne McMorrow, who referred to a recent opinion of the United Nations Human Rights Committee (UNHRC) which considered , *inter alia,* that

the Irish abortion law encroached on a woman's dignity by "forcing her to continue carrying a dying foetus". For me, being probably influenced by my national origin, the concept of "dignity" is most tangibly explained by Kant's saying that turning a person into an object is the negation of human dignity.

Not much has been elaborated on the religious dimension today, except for the reference to the Catholic Church's position in Ireland on the abortion issue. To my mind, there are religious concepts behind the different attitudes in different societies, and I think that religious traditions continue to be influential even if a society has lost the religion. We have the famous sentence in the bible "Be fruitful and multiply and replenish the earth and subdue it". If we take this literally, to be "fruitful and multiply" would also include recourse to surrogacy, and to "subdue the earth" would mean that there are no limits to what man is allowed to do. This is, as we know, not the understanding of the churches (and I use the plural deliberately here). The question remains where to draw the limits.

I found the two different approaches presented today on the question of surrogate motherhood - the Russian approach allowing surrogacy quite freely within certain limits on the one hand and the very prohibitive approach taken in France on the other hand - very interesting and wondered if there might be some underlying religious reasons for this.

Another important aspect of bioethical quesions is the social discourse. Especially the impact of money, an issue which has also been raised during the discussion, is, to my mind, underestimated. We tend to shy away from this material aspect in the context of ethical debate, but it appears to be fundamental. Let's take the example of abortion: Abortion cases arise frequently because of lack of money. In the ECtHR case of A, B and C v. Ireland (Grand Chamber), the applicants were very poor. Or take surrogacy motherhood: In the case of Paradiso and Campanelli v. Italy (pending before the Grand Chamber), a sum of 49,000 euros had been paid. We learned today that in Britain the payment of a sum of 150,000 GBP had been considered to be acceptable within the context of surrogacy agreements. Accordingly, it is a rich mother's right to have recourse to surrogacy. Surrogacy is frequently discussed in connection with the precarious financial situation of the surrogate mothers, but the other side of the coin, the fact that only money enables intended parents to travel abroad to a country where surrogacy is lawful and to pay for those services should also be taken in consideration. Financial interests are also behind the prohibition of financial gain, as alluded to by Prof. Michael O'Flaherty, and behind biobanks. If we want to have an in-depth discussion, this aspect must not be neglected. Let me just add briefly that even the ECtHR, when awarding just satisfaction, "commercializes" pain in a certain way by granting compensation for physical and/or moral suffering.
Historical reasons for different approaches in the bioethical debate were not brought up today. But, just to take one example, for me the issue of euthanasia would have to be considered in the light of the horrible experiences in Nazi Germany. This may be quite different for my colleagues coming from other countries.

As to the legal discourse, let me come to my third question on how much regulation is needed. This aspect touches upon the definition of the State's margin of appreciation within the framework of the European Convention on Human Rights. My colleague Judge Helen Keller has clearly shown that the arguments for a narrow and for a broad margin of appreciation are both relevant in cases of bioethics as, on the one hand, intimate aspects of personal life are touched upon, and, on the other hand, cultural differences matter and States often do not reach any consensus how to solve the questions raised. The main challenge therefore is the uncertainty on how to proceed. This leads me to another observation: We all agree on the fundamental importance of concepts such as personal autonomy and the best interests of a child, but we do not necessarily agree on how to define them. When it comes to the best interest of a child, we have the mother's, the father's and the doctor's perspective on what the child's best interest should be. Legal regulation does have its limits in this context as well.

Summing up, I think in the decision-making there is a general tension between the majority and the vulnerable ones. The majority construes answers to bioethical questions in the light of their ethical and religious conceptions. The most vulnerable ones are the individuals directly concerned, for example close relatives of a person who is dying or cannot die, couples unable to procreate who wish to have a child, as well as those who cannot express their wishes: the embryos, the new-born children, those who have arrived at the end of their lives. This tension between the majority opinion and the specific interests of the vulnerable ones has to be addressed within the context of democratic decision-making, which has to lead to results as precise as possible and with as much input from experts as possible.

The Human Rights jurisprudence has a corrective function and plays a subsidiary, but important role. Our British colleague, Justice Peter Jackson has given us a task, saying “the only thing I want from you is illumination”. I think that is quite a task.

Thank you.

Mr Christos Giakoumopoulos

Director of Human Rights, Directorate General of Human Rights and Rule of Law

Christos Giakoumopoulos was appointed Director of Human Rights in the Directorate General Human Rights and Rule of Law of the Council of Europe in 2011.

He was Director of Monitoring in the same Directorate General since 2006. Before joining the Directorate General of Human Rights, he was General Counsel and General Director for Legal and Administrative Affairs of the Council of Europe Development Bank (Paris).

Since joining the Council of Europe in 1987, he held posts in the Registry of the European Court of Human Rights, the Venice Commission and Director in the Office of the Commissioner for Human Rights, A. Gil Robles.

Closing Remarks

Judges,
Your Excellencies,
Ladies and Gentlemen,

This seminar is drawing to a close and I would like to thank Ambassador Constantinidou and Professor Constantinos Phellas, the Chairperson of the Cyprus National Bioethics Committee, for supporting this event. I would also like to thank the President and Judges Keller, Pastor Vilanova and Nußberger of the European Court of Human Rights for their welcome here, but above all for their contributions to this seminar. My very special thanks go to Judge Nußberger for presenting us with conclusions which reflect the quality and the diversity of the presentations and discussions.

For my part, I would like to share with you, by way of a closing message, some observations concerning what has been an outstanding event in terms of its ground-breaking nature, the high standard of the contributions and exchanges, and the lines of reflection it has opened up for future activities, particularly at intergovernmental level.

A ground-breaking event
As has been pointed out, this seminar dealt “for the first time at this level” with the case-law on protecting human rights in the biomedical field. As the President of the ECHR reminded us in his statement, the Court is “having to rule on cases involving issues of bioethics increasingly frequently”.

The presentations and discussions showed how significant these new issues have become in the judicial sphere at both national and international level, and how much more important they can be expected to become in future years.

Today's discussions provided an illustration, if any were needed, of how human rights are living rules and how the European Convention on Human Rights is and should be a living instrument, despite the observations and comments we sometimes hear in political (or, should I say, electoral?) debate, which are so far removed from the very point of human rights.

Both this seminar, which focuses on the judicial dimension, and the activities which may arise from it tie in with the work that the Council of Europe has been doing for over 20 years concerning the protection of fundamental rights in the biomedical field, providing guidance on new practices and following developments but always taking care and working actively to ensure that human rights are respected, ensuring in particular that human dignity, however it is understood and however far it extends, is preserved.

Next year, the Convention on Human Rights and Biomedicine (Oviedo Convention) will be 20 years old. This anniversary will provide an opportunity for a thorough investigation of the issues surrounding the Convention, and the aim of this seminar was to contribute to this investigation. I can say without hesitation that it has already succeeded brilliantly in doing so.

As the President of the Court pointed out, the Convention on Human Rights and Biomedicine was designed to clarify the European Convention on Human Rights in response to challenges posed by developments in medicine and science. As Judge Pastor Vilanova emphasised, the two texts are "closely interconnected". The Oviedo Convention has even become a point of reference outside Europe, and this anniversary will be an opportunity to insist on the need to examine the national legislation in this field regularly, as is required moreover by the Convention itself.

The high standard of the debate

This seminar was also an outstanding event because of the high standard of the contributions and the discussions. I would like to emphasise the importance of dialogue in this field.

Bioethical issues do indeed have a very wide field of application.
The varying contributions have shown the breadth of this field but they have also revealed the complexity and the sensitivity of these new questions to which national and international courts have to find answers. It is a field in which ethics, law and science are very closely linked.

Reference was already made to the importance of dialogue in the opening speeches. However, today's presentations and discussions have confirmed the need for such dialogue, particularly between the legal and the medical spheres, given that so many of the questions to be addressed lie at the interface between the two. The standard-setting work being carried out at intergovernmental level is an obvious context for such discussion, and dialogue is actively sought out in this area. This dialogue could be intensified still further, as has been suggested in our discussions.

However, an equally crucial aspect – as was illustrated today – is the dialogue between judges, as they are the key players where it comes to respect for the principles enshrined in the European Convention on Human Rights and the Convention on Human Rights and Biomedicine.
The Council of Europe will continue to promote this dialogue, as the Court does already, and to contribute to it in the course of its activities.

Pointers for future activities

I have just presented some ideas about the fields of inquiry for future activities. I would now like to highlight another aspect of this:

It seems to me that the interdisciplinary dialogue to which I have alluded should also include an element of education and training. In June 2015, at the annual conference of the HELP Network (for Human Rights Education for Legal Professionals), Dean Spielman, the former President of the European Court of Human Rights, talked of "the need for legal professionals to be given training on a number of national and international protective instruments, and not just the European Convention on Human Rights but also, in particular, the Convention on Human Rights and Biomedicine, which is the

first instrument to deal specifically with the protection of the dignity, rights and freedoms of human beings against any misapplication of biological and medical progress".

At this interface, where, as we have seen, the interdisciplinary dialogue between the legal and medical spheres is not just a matter of juxtaposing scientific opinions, there is probably a need to adopt an innovative multi-disciplinary approach to training aimed at both legal and health professionals. This is most certainly a major potential field of activity for 2017 and beyond, whose relevance has been confirmed by your discussions.

This seminar has also presented an opportunity to emphasise the place and the role of other aspects of intergovernmental work in dealing with the complex and sensitive questions which have been the main focus of our discussions. Reference was made on several occasions both to the Convention on Human Rights and Biomedicine and to the implementing tools arising from the activities of the Committee on Bioethics. The undoubted value of the DH-BIO's activities in the context of the Court's work was highlighted and the DH-BIO was encouraged to continue with this, taking its characteristic human-oriented approach and applying, as always, the highest technical standards.

The fields of enquiry identified at this seminar will be crucial when it comes to celebrating the 20th anniversary of the Convention on Human Rights and Biomedicine. They will help to trace out the lines of an action plan to meet the challenges posed to human rights by changes in medical practices and scientific and technological developments.

I would like to thank all the speakers, session chairs and participants – not forgetting the interpreters – for this intense yet highly rewarding and productive day.