

A Right to Health Perspective on Embryo Research: Synergies, Gaps and Opportunities

Giulia Perrone*

A RIGHT TO HEALTH PERSPECTIVE ON EMBRYO RESEARCH: SYNERGIES, GAPS AND OPPORTUNITIES

ABSTRACT: *The significant progress made in biology research has revealed the key role of human stem cells in the discovery of medical treatments. What has emerged, in particular, is the revolutionary capability of human embryonic stem cells (hESCs) to differentiate into any other specialised cell of the human body. The capability to be pluripotent makes these cells as an essential and invaluable resource for both the analysis of the embryos themselves and the discovery of new therapies for untreated diseases. However, because hESCs are derived from the inner mass of a blastocyst – a very early embryo – some ethical concerns arise about the need to destroy a human embryo to extract the cell lines. In some States, including Italy, such concerns have led to legal restrictions at the national level, such as the absolute ban to donate supernumerary embryos left over after fertility treatments and no more intended for implantation, for research purpose.*

Attention is dedicated to the relevant synergies and worrying gaps that exist between embryo research and the right to the enjoyment of the highest attainable standard of health. The final goal is to identify potential opportunities to maximise the benefits of scientific progress and ensure compliance between embryo research and the right to health. It is worth noting that, although the right to the benefits of science and its applications and the right to life are addressed throughout the research, this work primarily focuses on the right to health.

KEYWORDS: Embryo Research; Health; Human Rights; Stem Cells; Regenerative Medicine

SOMMARIO: 1. Introduction. – 2. The absence of a legal definition for the embryo: regional instruments and different perspectives. – 3. The right to the enjoyment of the highest attainable standard of health and its underlying determinants. – 4. Towards the progressive realisation of the right to health: embryos unsuitable for implantation and the maximum available resources of a State. – 5. The right to prevention, treatment and control of diseases. The duty to fulfil the right to health. – 6. Understanding the benefits of science for human health: monitoring, accountability and a participative approach to embryo research and the right to health. – 7. Concluding observations.

* LL.M. in International Human Rights and Humanitarian Law, University of Essex. Mail: giuliperone90@gmail.com. The article was subject to a double blind peer review process.



1. Introduction

Historically, scientific research has largely proved to be key for the extraordinary advancement in the prevention, treatment and care of human diseases. One of the brightest chapters in the history of science is the discovery of vaccines against illnesses that used to be fatal for humans and that were defeated by humans, eventually. Thanks to the hard work of some scientists, several diseases have been eradicated and some others, such as influenza, are now far from representing a threat for people's life¹.

However, a number of devastating illnesses, including cancer, diabetes, Parkinson's Disease and Alzheimer's Disease are still untreated and continue to affect persons' health and life, sometimes leading to death². The significant progress made in biology has revealed the key role of human stem cells in the discovery of medical treatments. What has emerged, in particular, is the revolutionary capability of human embryonic stem cells (hESCs) to differentiate into any other specialised cell of the human body³. The capability to be *pluripotent* makes these cells as an essential and invaluable resource for both the analysis of the embryos themselves and the discovery of new therapies for untreated diseases.

What is at the centre of the debate, however, is the way in which such cell lines are obtained, considering that hESCs might be extracted from either supernumerary embryos left unused after an *In Vitro Fertilization* (IVF), embryos no more intended for implantation or embryos rendered unsuitable for reproductive purpose because of arrested or abnormal growth. The fact that hESCs are derived from the inner mass of a blastocyst – a very early embryo – gives rise to some ethical issues about the need to destroy a human embryo to extract the cell lines⁴. In some States, including Italy, similar concerns have led to legal restrictions on embryo research at the national level, including the absolute ban to donate any embryos left over after fertility treatments for research, even when they are not intended to be implanted anymore.

In recent years, there has been a growing interest in the unique properties of human stem cells and their potential for medical progress whereas less attention has been paid to the connections between embryo research, human health and human rights.

The present article aims to examine some of these connections and to identify potential synergies, gaps and opportunities in the analysis of embryo research from the right to health perspective. In particular, the study elaborates on some potential understandings of articles 2(1) and 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR)⁵ and poses questions on

¹ S. PLOTKIN, *History of vaccination*, in *Proc. Natl. Acad. Sci. U.S.A.*, 111, 34, 2014, pp. 12283-12287.

² A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL, *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, in *American Association for the Advancement of Science and Institute for Civil Society*, 1999, Preface.

³ A. BONGSO, M. RICHARDS, C.Y. FONG, *From Human Embryos to Clinically Compliant 14 Embryonic Stem Cells: Blastocyst Culture, Xeno-free Derivation and Cryopreservation, Properties and Applications of Embryonic Stem Cells*, in A. BONGSO, E.H. LEE, *Stem Cells: From Bench to Bedside*, Singapore, 2005, p. 23.

⁴ American College of Obstetricians and Gynecologists, Committee on Ethics, *Opinion 347: Using Preimplantation Embryos for Research*, 2006.

⁵ UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, Treaty Series (TS), vol. 993, 16 December 1966.

what States are required to do or should refrain from doing to ensure compliance between internal policies and the international human rights standards on health. Also, the research tackles the important issue of providing effective monitoring mechanisms to check progress in the implementation of the right to health and hold those responsible accountable for their actions. Finally, attention is paid to the role played by the civil society in the development of national programmes and regulation.

2. The absence of a legal definition for the embryo: regional instruments and different perspectives

When James Thomson derived hESCs from an embryo in 1998, he introduced a technique which involved the destruction or disaggregation of the embryo from which the cell lines were extracted⁶. The need to destroy the embryo, however, continues to cause ethical concerns, arriving to be banned by the national legislations of certain countries. Those who consider the embryo as a potential human being, identify it as a human rights holder to be protected on the same level of a person. In their view, the destruction of an embryo can be compared to the killing of a human being⁷. However, it is argued that the exceptional capability of hESCs to differentiate into any other type of human cell makes them as a primary resource for the treatment of diseases caused by the loss of cells and tissues that are still cause of human mortality and that, because of their ability to renew themselves, hESCs might represent an endless source of biological resources to be used by scientists for medical progress⁸.

At the basis of the debate there is the difficulty to identify the legal status of the embryo. International human rights instruments do not define the moment when life begins and the absence of a clear position in this regard has relevant consequences in determining whether or not an embryo can be entitled with human rights. However, significant jurisprudence has been developed at the regional level, especially in the Inter-American system and in Europe, where Courts have been accessed in a good number of cases to clarify whether or not the embryo is entitled with human rights.

⁶ J.A. THOMSON, M.A. WAKNITZ, J.J. SWIERGIEL, V.S. MARSHALL, *Embryonic Stem Cell Lines Derived from Human Blastocysts*, in *Science*, 282, 1998, pp. 1145 -1147.

⁷ M. FARLEY, *Roman Catholic Views on Research Involving Human Embryonic Stem Cells*, in S. HOLLAND, K. LEBACQZ, L. ZOLOTH, *The Human Embryonic Stem Cell Debate: Science, Ethics, and Public Policy*, Cambridge (Massachusetts), 2001, pp. 115-117.

⁸ Although the present article mainly focuses on the legal issues, the moral status of the embryo has been highly debated by scholars. Broadly on this topic, please consider reading: A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL, *op. cit.*; ETHICS COMMITTEE OF THE AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE, *Donating embryos for human embryonic stem cell (hESC) research: a committee opinion*, in *Int J Fertil Steril*, 100, 4, 2013, pp. 935-939; J. SAVULESCU, J.PUGH, T. DOUGLAS, C. GYNGELL, *The moral imperative to continue gene editing research on human embryos*, in *Protein & Cell*, 6, 7, 2015, pp 476-479; S.D. PATTINSON, *Some Comments on Developmental Thresholds and their Moral and Policy Significance*, in *Human Embryo Culture*, Nuffield Council on Bioethics, 2017, pp. 81-83.

2.1. The Inter-American System

Article 4 of the American Convention on Human Rights recognises the right to life «in general, from the moment of conception»⁹, where the word conception is defined by the Inter-American Court of Human Rights (IACHR) as «the moment when the embryo becomes implanted in the uterus»¹⁰. What seemed to identify the embryo as entitled with the right to life has therefore been excluded by the Court which, in its judgment on the *Artavia Murillo case*, specifies: «Before this event, Article 4 of the Convention would not be applicable»¹¹. Also, the words *in general* give rise to broader interpretations where the protection of the right to life under Article 4 walks together with the social conscience, in accordance with the political and legal developments on this issue. It follows that the Inter-American Court has never recognized an absolute right to life of the embryo, leaving space for exceptions to the general rule, instead¹². A similar perspective had already been held by the Inter-American Commission of Human Rights in the *Baby Boy* case in 1981¹³, when the judges pointed out that they could not recognise the right to life of the embryo since the drafters of the American Declaration of Human Rights (Bogotá, 1948) had chosen «not to adopt language which would clearly have stated that principle»¹⁴.

2.2. The European Framework

The European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) states in its Article 2(1) that «Everyone's right to life shall be protected by law»¹⁵. However, to whom the word *everyone* refers specifically and who the subjects entitled with such right are, is controversial. The question about the beginning of life has been addressed by the European Court of Human Rights (ECtHR) in a good number of cases where the legal status of either the foetus or the embryo was at stake. However, because of the acute sensitivity of the political, moral and ethical issues raised, the Court has often preferred to act cautiously, leaving the legal definition of the embryo to the margin of appreciation of each State.

*Vo v. France*¹⁶ and *Tysiac v. Poland*¹⁷ represent two good examples of such approach. Arguably, although they refer to the foetus and not to the embryo, the position of the Court is still applicable to hESCs research as the embryo is biologically less developed than a foetus.

⁹ Organization of American States (OAS), *American Convention on Human Rights, "Pact of San Jose"*, 22 November 1969, art. 4 (Right to Life).

¹⁰ *Gretel Artavia Murillo y. Otros ("Fecundacion in Vitro") v. Costa Rica*, Inter-American Court of Human Rights (IACHR), 28 November 2012, para. 264.

¹¹ *Gretel Artavia Murillo y. Otros ("Fecundacion in Vitro") v. Costa Rica*, cit., para. 264.

¹² *Gretel Artavia Murillo y. Otros ("Fecundacion in Vitro") v. Costa Rica*, cit., paras. 188, 221–222.

¹³ *Gretel Artavia Murillo y. Otros ("Fecundacion in Vitro") v. Costa Rica*, cit., para. 264.

¹⁴ *White and Potter v. United States*, IACHR, 6 March 1981, para. 14(a).

¹⁵ Council of Europe, *European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14*, European Treaty Series (ETS) 5, 4 November 1950, art. 2.

¹⁶ *Vo v. France*, European Court of Human Rights (ECtHR), 26 November 2003.

¹⁷ *Tysiac v. Poland*, ECtHR, 21 September 2005.

In *Vo v. France*, the applicant was forced to undergo a therapeutic abortion because of a fatal mistake committed by a medical doctor. Since the woman was almost 21 weeks pregnant and her foetus was healthy before the abortion, she lodged a criminal complaint for homicide against her unborn child. However, the ECtHR did not consider it necessary to answer the question on whether the foetus has the right to life¹⁸ and ruled that, in absence of a European consensus about the legal determination of the beginning of life, such issue had to be left to the margin of appreciation of single States¹⁹. Similar conclusions were reached by the ECtHR in the *Tysiack v. Poland* case, where a pregnant woman was denied the right to abortion, even though she was at risk of blindness because of that pregnancy. She was forced to continue with her pregnancy and she became blind as a result²⁰. Again, the Court avoided to address the question about the beginning of life directly, but it did recognise the lack of clarity of Polish law about abortion. Also, the ECtHR did not ignore the high pressure under which the applicant was and the impact of such pregnancy on her health; hence, it recognised the violation of article 8 ECHR²¹.

Direct attention to the embryo was paid in *Evans v. UK*²², instead., where the Grand Chamber held that, in the circumstances described, the embryo was not to be considered as entitled with the right to life under Article 2 ECHR²³. Such conclusion was reached by the Chamber on the basis of what the Grand Chamber had already established in *Vo v. France*: in absence of any European consensus on the legal definition of the beginning of life, any decision about this issue comes with the margin of appreciation of the single State. Under the legislation of the United Kingdom, the embryo does not have any independent rights or interests recognised. Hence, it is not considered as entitled with the right to life²⁴. Finally, the *Parrillo v Italy*²⁵ case is of interest in this regard. Here, the applicant claimed that a blanket ban imposed by the Italian Law No. 40/2004²⁶ had prevented her from donating embryos produced *in vitro* and no more intended for implantation to scientific research. The case highlighted the urgent need for a legal definition of the embryo as to determine to what extent a person is free to decide upon its destiny and scientists can conduct embryo research. However, no indication was provided by the Court²⁷.

¹⁸ *Vo v. France*, cit, paras. 76-80.

¹⁹ *Vo v. France*, cit, para 82.

²⁰ *Tysiack v. Poland*, cit., para. 65.

²¹ *European Convention for the Protection of Human Rights and Fundamental Freedoms*, cit., art. 8. (Right to respect for private life and family life).

²² *Evans v. the United Kingdom*, ECtHR, 10 April 2007.

²³ *European Convention for the Protection of Human Rights and Fundamental Freedoms*, cit., art. 2 (Right to life).

²⁴ *Evans v. the United Kingdom*, cit., paras 54-56.

²⁵ *Parrillo v. Italy*, ECtHR, 27 August 2015.

²⁶ Act No. 40 of February 19, 2004, *Rules on Medically Assisted Procreation*, Official Gazette, No. 45 (Feb. 24, 2004).

²⁷ *Parrillo v. Italy*, cit.

3. The right to the enjoyment of the highest attainable standard of health and its underlying determinants

From a human rights perspective, the definition of health goes far beyond the mere idea of building hospitals and accessing health care²⁸. Rather, health is to be considered as interdependent and interrelated with the respect, protection and fulfilment of other human rights²⁹, including the right to enjoy the benefits of scientific progress and its applications. The impact of the indivisibility of human rights against vulnerabilities or ill health has been clearly recognised by the Declaration of Commitment on HIV/AIDS, adopted by the United Nations General Assembly in 2001, which states that «the full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic, including in the areas of prevention, care, support and treatment, and that it reduces vulnerability to HIV/AIDS and prevents stigma and related discrimination against people living with or at risk of HIV/AIDS»³⁰.

This universal and inclusive right is made up of freedoms and entitlements aimed at protecting the inherent dignity and equity of every human being. Among its freedoms, there is the right to be free from non-consensual medical treatment whereas the entitlements include, *inter alia*, the right to prevention, treatment and control of diseases; the provision of health-related education and information; the participation of the population in health-related decision-making at the national and community levels³¹.

Also, underlying determinants of health and ill health are not purely connected with the biological or medical field but comprehend a wide range of political, social, economic and cultural factors which protect and promote the right to health beyond health services, goods and facilities³². The Committee on Economic, Social and Cultural Rights lists, among others, health-related education and information³³. A rights perspective is therefore perfectly compatible with work in epidemiology that has identified social determinants as key causes of disease³⁴.

²⁸ L.P. FREEDMAN, *Achieving the MDGs: Health Systems as Core Social Institutions*, in *Development*, 48, pp. 19, 20 2005; P. HUNT, G. BACKMAN, *Health Systems and the Right to the Highest Attainable Standard of Health*, in *Health & Human Rights*, 10, 2008, pp. 81-92; A.E. YAMIN, *Toward Transformative Accountability: A Proposal for Rights-Based Approaches to Fulfilling Maternal Health Obligations*, in *SUR – Int'l J. On Hum Rts*, 7, 12, 2010, p. 95.

²⁹ UN General Assembly, Vienna Declaration and Programme of Action, A/CONF.157/23, 12 July 1993, para. 11.

³⁰ UN General Assembly, *Declaration of Commitment on HIV/AIDS*, A/RES/S-26/2, 2 August 2001, para. 16.

³¹ Office of the United Nations High Commissioner for Human Rights United Nations Office (OHCHR), *The Right to Health*, 2008, pp. 3-4.

³² A.E. YAMIN, *Transformative combinations: women's health and human rights*, in *J Am Womens Assoc.*, 52, 1997, pp. 169-173.

³³ UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, E/C.12/2000/4, 11 August 2000, para. 11.

³⁴ B.G. LINK, J. PHELAN, *Social conditions as fundamental causes of disease*, in *J Health Soc Behav*, Spec No, 1995, pp. 80-94; M. MARMOT, R.G. WILKINSON, *Social Determinants of Health*, 1999; L. BERKMAN, I., KAWACHI, *A historical framework for social epidemiology*, in L. BERKMAN, I. KAWACHI, *Social Epidemiology*, New York, NY, 2000, pp. 3-12; S. MARKS, *The new partnership of health and human rights*, in *Hum Rights Dialogue*, 2, 2001, pp. 21-22. A.E. YAMIN, *The Right to Health Under International Law and Its Relevance to the United States*, in *Am J Public Health*, 95, 7, 2005, pp. 1156-1161.

The first notion of a right to health under international law is enshrined in the Preamble of the WHO Constitution, adopted in 1946 which states that the «enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition»³⁵. Two years later, article 25(1) of the 1948 Universal Declaration of Human Rights laid the foundations for the international legal framework for the right to health and set forth the right to a «standard of living adequate for the health and well-being of himself and his family, including (...) medical care and (...) the right to security in the event of (...) sickness, disability (...) or other lack of livelihood in circumstances beyond his control»³⁶.

Since then, a wide range of international, regional and domestic instruments have codified the right to health.

Article 12 of ICESCR³⁷ introduces legally binding provisions and provides a cornerstone protection of the right to health for all individuals of the 166 ratifying States³⁸. Additional protections for specific groups are provided by group-focused international treaties. Women's right to health is addressed by the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), in particular articles 11(1)f, 12 and 14(2)b³⁹. The Convention on the Right of the Child (CRC) provides extensive protection to the child's right to health (article 25), including the most vulnerable groups of children (articles 3(3), 17, 23, 25, 32 and 28)⁴⁰. Article 5(e)(iv) of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) protects «the right to public health (and) medical care» of racial and ethnic groups⁴¹. Persons with disabilities find several provisions on their right to health in the Convention on the Rights of Persons with Disabilities (CRPD) which stresses the importance of protecting such right «without discrimination on the basis of disability» (article 25)⁴². Interestingly, the treaty bodies that monitor the ICESCR, the CEDAW and the CRC have adopted general comments on the right to health. They are not legally binding instruments but provide an authoritative interpretation of the provisions enshrined in the treaties⁴³.

³⁵ Constitution of the World Health Organization, adopted 22 July 1946 and entered into force 7 April 1948, 14 UNTS 185, preamble.

³⁶ UN General Assembly, *Universal Declaration of Human Rights*, 217 A, 10 December 1948, art. 25(1).

³⁷ UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, Treaty Series, vol. 993, p. 3, 16 December 1966, art. 15(1)(b).

³⁸ www.indicators.ohchr.org (last visited 09/01/2018).

³⁹ UN General Assembly, *Convention on the Elimination of All Forms of Discrimination Against Women*, Treaty Series, vol. 1249, 18 December 1979, p. 13.

⁴⁰ UN General Assembly, *Convention on the Rights of the Child*, Treaty Series, vol. 1577, 20 November 1989, p. 3.

⁴¹ UN General Assembly, *International Convention on the Elimination of All Forms of Racial Discrimination*, Treaty Series, vol. 660, 21 December 1965, p. 195.

⁴² UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106.

⁴³ Office of the United Nations High Commissioner for Human Rights United Nations Office, *The Right to Health*, Geneva, Switzerland, 2008, p.10.

At the regional level, the right to health is addressed by a wide range of instruments, including the African Charter on Human and Peoples' Rights (article 16)⁴⁴; the American Convention on Human Rights (paras 83-91)⁴⁵ and its Additional Protocol in the Area of Economic, Social and Cultural Rights, "Protocol of San Salvador" (article 10)⁴⁶; the European Social Charter (article 11)⁴⁷.

Finally, over eighty States have explicitly recognised the right to health or the right to health care in their national constitutions⁴⁸.

4. Towards the progressive realisation of the right to health: embryos unsuitable for implantation and the maximum available resources of a State

The ICESCR represents a cornerstone treaty in the protection of ESC rights, including the right to the enjoyment of the benefits of scientific progress and its applications and the right to the highest attainable standard of health. In article 2(1), this legally binding instrument poses a duty on each State party to «take steps (...) to the maximum of its available resources» towards the *progressive realisation* of the rights recognised in the Covenant⁴⁹. Similar provisions are also enshrined in article 4 of CRC and article 4(2) CRPD⁵⁰.

What these treaties do not clarify, however, is the definition of *resources* within the scope of their articles. Scholars have thoroughly discussed on whether the concept of resources purely refers to a financial commitment of the State or should be interpreted more broadly, instead⁵¹. As Chapman pointed out, the assessment of progressive realisation within the context of resource availability «considerably complicates the methodological requirements for monitoring»⁵². Two are the practical issues in evaluating State compliance with the full use of the maximum available resources. First, the definition of what resources are *available* to a State⁵³, to identify the precise content of

⁴⁴ Organization of African Unity (OAU), *African Charter on Human and Peoples' Rights ("Banjul Charter")*, CAB/LEG/67/3, 1981, rev. 5, 21 I.L.M. 58, 1982.

⁴⁵ Organization of American States (OAS), *American Convention on Human Rights, "Pact of San Jose"*, Costa Rica, 22 November 1969.

⁴⁶ Organization of American States (OAS), *Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights ("Protocol of San Salvador")*, A-52, 16 November 1999.

⁴⁷ Council of Europe, *European Social Charter (Revised)*, ETS 163, 3 May 1996.

⁴⁸ National Constitutions Database available at: www.globalhealthrights.org/constitutions/constitution-region/page/2/ (last visited 09/01/2018).

⁴⁹ UNGA, *International Covenant on Economic, Social and Cultural Rights*, cit., art. 2(1).

⁵⁰ See UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant)*, E/1991/23, 14 December 1990, para. 9; UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 13: The Right to Education (Art. 13 of the Covenant)*, E/C.12/1999/10, 8 December 1999, para. 44; UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, E/C.12/2000/4, 11 August 2000, para. 31.

⁵¹ M. SSENYONJO, *Economic, Social and Cultural Rights in International Law*, Portland, 2016, pp. 95-98.

⁵² A. CHAPMAN, S. RUSSELL, *Introduction*, in A. CHAPMAN, S. RUSSELL, *Core Obligations: Building a Framework for Economic, Social and Cultural Rights*, 2002, p. 23.

⁵³ See R. ROBERTSON, *Measuring state Compliance with the Obligation to Devote the "Maximum Available Resources" to Realising Economic, Social and Cultural Rights*, in *Human Rights Quarterly*, 16, 1994, pp. 693-694.

the obligation and any potential breaches of it⁵⁴. Second, the evaluation on whether the State has concretely used its available resources to the *maximum*.

During the drafting process of the Covenant, the word *resources* was understood as including «budgetary appropriations and also technical assistance, international cooperation and other elements»⁵⁵ available at the domestic and international level⁵⁶. More recently, the Committee on the Rights of the Child has suggested that «resources are also to be understood in qualitative terms and not solely quantitative» and that they should be given a broader interpretation which includes «not only financial resources, but also other types of resources relevant for the realization of economic, social and cultural rights»⁵⁷. Therefore, the State has the progressive obligation to use all available financial, natural, human, cultural and scientific/technological resources, as well as information resources, to achieve ESC rights⁵⁸.

The capability of hESCs to specialise into any other cells of the human body makes them represent an essential resource in the development of regenerative medicine. Because of their pluripotency, the use of hESCs in biomedicine might be crucial for treating untreated diseases, including nervous

⁵⁴ S. JOSEPH, M. CASTAN., *The International Covenant on Civil and Political Rights: Cases, Materials and Commentary*, New York, NY, 2013, p. 7.

⁵⁵ E/CN.4/SR/271, 14 MAY 1952, 5 (Mr Azkoul, Lebanese representative to the UN Human Rights Commission).

⁵⁶ CESCR, *Statement: An Evaluation of the Obligation to Take Steps to the 'Maximum of Available Resources' Under an Optional protocol to the Covenant*, UN Doc E/C.12/2007/1, 10 May 2007, para 5.

⁵⁷ Committee on the Rights of the Child (CRC Committee), *Resources for the Rights of the Child - Responsibility of States, Investments for the Implementation of Economic, Social and Cultural Rights of Children and International Cooperation* (CRC article 4), CRC/C/GC/19, 21 September 2007, para 24.

⁵⁸ See S. SKOGLY, *The requirement of Using the "Maximum of Available Resources" for Human Rights Realisation: A Question of Quality as Well as Quantity?*, in *Human Rights Law Review*, 12, 3, 2012, p. 393.

system diseases⁵⁹, cancer⁶⁰, diabetes⁶¹, immunodeficiency diseases⁶², retinal repair⁶³ and bone diseases⁶⁴. Also, there is evidence that although the generation of iPSCs from adult stem cells can lead to good medical progress⁶⁵, this technology is limited by two factors: first, most mature tissues usually contain small quantity of stem cells; second, because of their tendency to maintain their molecular identity, the development of iPSCs into other cell types can be sometimes problematic⁶⁶. It follows that hESCs – and therefore the supernumerary embryos from which they can be extracted – represent the main and most suitable source of material for making progress in the discovery of therapies for untreated diseases.

In the light of these considerations, it might be reasonable to consider those human embryos which are no more suitable for implantation as part of the *available resources* that a State must use for the realisation of the right to health.

⁵⁹ A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL, *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, American Association for the Advancement of Science, 1999, p. 2; E.A. KIMBREL, R. LANZA, *Current status of pluripotent stem cells: moving the first therapies to the clinic*, in *Nature*, 14, 2015, pp. 681-692; O. LINDVALL, *Treatment of Parkinson's disease using cell transplantation*, in *Phil. Trans. R. Soc.*, 370, 1680, 2015; W. LI, E. ENGLUND, H. WIDNER, B. MATSSON, D. VAN WESTEN, J. LÄTT, S. REHNCRONA, P. BRUNDIN, A. BJÖRKLUND, O. LINDVALL, J.Y. LI, *Extensive graft-derived dopaminergic innervation is maintained 24 years after transplantation in the degenerating parkinsonian brain*, in *PNAS*, 113, 23, 2016, pp. 6544-6549; O. LINDVALL, *Clinical translation of stem cell transplantation in Parkinson's disease*, in *Journal of Internal Medicine*, 279, 2016, pp. 30-40.

⁶⁰ A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, cit., Preface; Y. RAPHAEL, *Cochlear Pathology, Sensory Cell Death and Regeneration*, in *British Medical Bulletin*, 63, 2002, p. 25.

⁶¹ A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, cit., Preface; F.K. GORUS, B. KEYMEULEN, P.A. VELD, D.G. PIPELEERS, *Predictors of progression to Type 1 diabetes: preparing for immune interventions in the preclinical disease phase*, in *Expert Rev. Clin. Immunol.*, 9, 12, 2013, pp. 1173-1183. See also: G.C. WEIR, S. BONNER-WEIR, *Scientific and Political Impediments to Successful Islet Transplantation*, in *Diabetes*, 1997, pp. 1247-1256; D. PIPELEERS, B. KEYMEULEN, L. CHATENOU, C. HENDRIECKX, Z. LING, C. MATHIEU, B. ROEP, D. YSEBAERT, *A View on Beta Cell Transplantation*, in *Diabetes*, Ann. N.Y. Acad. Sci. 958, 2002, pp. 69-76.

⁶² A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, cit., Preface.

⁶³ L. CRUZ, F.K. CHEN, A. AHMADO, J. GREENWOOD, P. COFFEY, *RPE transplantation and its role in retinal disease*, in *Prog. Retin Eye Res.*, 26, 6, 2007, pp. 598-635; A. LANE, R. PHILIP LISSA, L. RUBAN, K. FYNES, M. SMART, A. CARR, C. MASON, P. COFFEY, *Engineering Efficient Retinal Pigment Epithelium Differentiation From Human Pluripotent Stem Cells*, in *Stem Cells Translational Medicine*, 3, 11, 2014, pp. 1295-1304; M.J. RADEKE, C.M. RADEKE, Y.H. SHIH, J. HU, D. BOK, L.V. JOHNSON, P.J. COFFEY, *Restoration of mesenchymal retinal pigmented epithelial cells by TGFβ pathway inhibitors: implications for age-related macular degeneration*, in *Genome Medicine*, 7, 2015, p. 58.

⁶⁴ A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, cit., Preface.

⁶⁵ K. TAKAHASHI, S. YAMANAKA, *Induction of pluripotent stem cells from mouse embryonic and adult fibroblast cultures by defined factors*, in *Cell*, 126, 2006, pp. 663-676; K. TAKAHASHI et al., *Induction of pluripotent stem cells from adult human fibroblasts by defined factors*, in *Cell*, 131, 2007, pp. 861-872; J. YU et al., *Induced pluripotent stem cell lines derived from human somatic cells*, in *Science*, 318, 2007, pp. 1917-1920.

⁶⁶ United Nations Educational, Scientific and Cultural Organization (UNESCO), *Human Cloning*, Paris, France, 2005, pp. 973-974; S. REARDON, D. CYRANOSKI, *Japan stem-cell trial stirs envy: researchers elsewhere can't wait to test iPSC cells in humans*, in *Nature*, 513, 2014, pp. 278-288.

What is worth noting in the wording of article 2(1) ICESCR is the choice of the verb used to define the responsibility of States. They are required to *take steps* to ensure the progressive realisation of ESC rights to the maximum of their resources. This means that the Covenant «does not make the absurd demand that a comprehensive, integrated health system be constructed overnight»⁶⁷ but that States have «a specific and continuing obligation to move as expeditiously and effectively as possible»⁶⁸ towards the realisation of the rights recognised by the Covenant. In the case of the right to health, this includes making cryopreserved embryos not suitable for implantation available for properly regulated scientific research. In other words, because embryo research is a health-related issue falling within both articles 2(1) and 12 ICESCR, the application to take steps to progressively realise the right to health includes taking at least certain steps that would permit research on otherwise unusable embryos. An absolute prohibition to donate human embryos to research would be inconsistent with that⁶⁹.

5. The right to prevention, treatment and control of diseases. The duty to fulfil the right to health

The definition of the right to health provided by the constitution of the World Health Organization builds in a reasonableness standard. This means that the State is called on to create the political, civil, social, economic and cultural conditions for ensuring the highest attainable standard of health but that some factors are beyond the State's control⁷⁰.

General Comment 14 points out that the provision contained in article 12(1) ICESCR must be read taking also into account that there is a number of factors, including unhealthy lifestyle or individual susceptibility to ill health, that might play an impactful role in people's health. «Good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health»⁷¹. The obligation of the State does therefore not extend to ensuring the complete absence of diseases but it consists in realising the right to enjoy of a wide range of facilities, goods and services for the prevention, treatment and care of adverse health conditions⁷².

Similarly, although the realisation of the right to the highest attainable standard of health is strongly connected with medical progress, the outcomes of scientific research remain unpredictable and do not fall within the obligations of the State, nor affects them in any way. The opportunity to being open to new knowledge is at the heart of science itself. Where General Comment 14 mentions

⁶⁷ P. HUNT, G. BACKMAN, *Health Systems and the right to the highest attainable standard of health*, in *Health and Human Rights*, 10, 1, 2008, pp. 81-92.

⁶⁸ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit., para. 31.

⁶⁹ G. PERRONE, *Interview with Professor Paul Hunt, 2002-2008 UN Special Rapporteur on the Right to the Enjoyment of the Highest Attainable Standard of Health*, 7 August 2017.

⁷⁰ E. KINNEY, *The international right to health: what does this mean for our nation and our world?*, in *Indiana Law Rev.*, 34, 2001, 34, pp. 1457-1475; B. TOEBES, *The Right to Health as a Right in International Law*, Oxford, England, 1999.

⁷¹ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit., para. 9.

⁷² United Nations Educational, Scientific and Cultural Organization (UNESCO), *Human Cloning*, cit.

human immunodeficiency virus, acquired immunodeficiency syndrome (HIV/AIDS) and cancer as samples of diseases that, because of their increasing presence among the world population, should be taken into account when interpreting article 12 ICESCR, it calls on States to include biomedical research within their national health plan and use all the available resources to their maximum to ensuring the highest attainable level of health services, goods and facilities for all. A broader interpretation of article 2(1) ICESCR as to include left over embryos within the notion of available resources would be crucial for the development of preventive measures against certain non-communicable diseases and for the discovery of new therapies in the field of regenerative medicine. It follows that a denial of such interpretation would lead to the absurd circumstance in which those biological resources that are available within a State cannot be used in properly regulated research towards improvements in medical progress and the realisation of right to health. Although research outcomes are still unpredictable, the right to health – with its related obligations – is not only concerned with the provision of essential medicines for everyone but it encompasses the processes underlying such provision, including the creation of a national health plan, transparency, participation and non-discrimination factors⁷³.

A very important distinction to make is between the inability and the unwillingness of a State to comply with its duties under article 12 and 2(1) ICESCR. If a worrying scarcity of resources makes it impossible for the State to take steps towards the realisation of ESC rights, the State has the burden of justifying that all possible measures have nevertheless been taken to prioritise the satisfaction of its obligations by using all resources at its disposal. By contrast, the unwillingness of a State to allocate the maximum of its available resources for the realisation of the highest attainable standard of health represents a violation of the duties outlined in the two articles above⁷⁴.

An absolute ban on the donation to research of existing embryos no more suitable or intended for reproductive purpose, hinders the development of preventive measures and medical treatments for fatal diseases that today still result in mortality. Arguably, this might be interpreted as the unwillingness of a State to use all the resources at its disposal towards the realisation of the *highest attainable standard of health*.

A duty to guarantee the right to «prevention, treatment and control of epidemic, endemic, occupational and other diseases»⁷⁵ is placed on States party by article 12(2)(c) ICESCR.

According to General Comment 14, the *control of diseases* should be interpreted as including States' efforts to «make available relevant technologies, using and improving epidemiological surveillance and data collection on a disaggregated basis»⁷⁶. This means that States have an obligation to adopt strategies aimed at gathering reliable information and analysing them properly on a systematic basis. The provision of evidence on embryo research is a fundamental step for the monitoring process on how experimentations are conducted and what their impact on health might be. Also, it helps strengthen *accountability*, which does not only refer to the identification of who is responsible for

⁷³ P. HUNT, G. BACKMAN, *op. cit.*

⁷⁴ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), *cit.*, para. 47.

⁷⁵ UNGA, *International Covenant on Economic, Social and Cultural Rights*, *cit.*, art.12(2)(c).

⁷⁶ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), *cit.*, para. 16.

what, but goes beyond and provides useful understanding of what worked and can be repeated and what did not work and should thus be changed in the implementation of ESC rights⁷⁷.

The necessity to take positive steps for ensuring compliance with articles 12 and 2(1) emerges also from the obligation of State parties to *fulfil* the right to health. This includes, *inter alia*, the «promotion of medical research and health education» and the adoption of a «national health policy with a detailed plan for realizing the right to health»⁷⁸. Each State party has a duty to provide evidence on its progress in the field of medical research and health, wherein experimentation on embryonic stem cells plays a fundamental role. This means that reliable and disaggregated data on embryonic stem cells analysis should be provided by public institutions and made accessible for all. Proper information about the quantity of available embryos in the State and the conduct of research on hESCs would make every individual fully aware of how the State manages its resources, for what purpose and with what results. Such health plan should be also revised and implemented periodically to ensure up-to-date information and help people make informed choices about their health.⁷⁹ The failure or omission to adopt a detailed national health policy including all information on embryonic stem cells research might amount to a breach of the ICESCR.

Unfortunately, the collection of data represents a point of significant weakness in the realisation of human rights, including the right to enjoy the benefits of scientific progress and its applications and the right to health. Although embryo research is highly discussed at both national and international level, States are often unwilling to provide clear information about its conduct within their territory. This might happen, *inter alia*, when a government not monitored by any independent authority tries to contrast the pressure coming from public campaigns against a legal ban to donate embryos to research. Arguably, the presence of an external body with control functions would help the monitoring of implementation of the right to health, also ensuring that authorities are accountable for their actions.

However, because biomedical research is a fragmented, highly specialised, sectorial activity, problems with an effective communication and consultation between biologists and professionals focused on different disciplines – e.g. policy makers, health professionals, the public – might easily occur. The creation of a public platform for effective communication among different players might be an opportunity for providing a more integrated and coordinated, systems perspective⁸⁰.

⁷⁷ L.P. FREEDMAN, *Human rights, constructive accountability and maternal mortality in the Dominican Republic: a commentary*, in *Int J Gynaecol Obstet*, 82, 1, 2003, pp. 111-114.

⁷⁸ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 36.

⁷⁹ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 37.

⁸⁰ T. PANG et al., *Knowledge for better health - a conceptual framework and foundation for health research systems*, in *Bulletin of the World Health Organization*, 81, 11, 2003, pp. 815-820.

6. Understanding the benefits of science for human health: monitoring, accountability and a participative approach to embryo research and the right to health

The implications of introducing new drugs and medical technologies for human health are not easy to estimate, nor the advancement of scientific progress is immediately accessible to persons with low education in such field. However, to enjoy the benefits of such studies, we need to understand what these benefits are.

The entire process of hESCs research – from the donation of embryos, to experimentations, to the management of data and results – involves concluding agreements based on the provision of *informed consent*⁸¹, that is an act of will depending on the understanding of related legal and moral issues. It follows that a complete knowledge of hESCs research involves awareness of the political, social, economic, civil and cultural issues around human embryos and health.

What is therefore to be done by a State for ensuring that every person can enjoy the benefits of scientific progress for human health? First, guarantee access for all to a clear and complete information and make sure that no forms of discrimination occur⁸².

Transparency in scientific research is a prerequisite to maintain the trust of the public, especially those who have to dispose of their embryos. There is evidence that people's willingness to donate their embryos for scientific purpose is largely influenced by their perception of science and scientists⁸³. Thus, it is essential to provide all individuals – including researchers and potential donors – with proper tools to take reasonable decisions about the development of new technologies and their application in health care.

A particular initiative by the Belgian Federal Commission for medical and scientific research on embryos *in vitro* can be taken as an example in this regard. The Commission has in fact developed a system of data collection where information concerning the conduct of embryo research are properly disaggregated according to established criteria. By providing clarifications on the meaning of basic terms – including *embryo* and *research* – and explaining the actual practice of handling

⁸¹ Broadly on informed consent and embryo research: COMMITTEE ON PEDIATRIC RESEARCH AND COMMITTEE ON BIOETHICS, *Human Embryo Research*, in *Pediatrics*, 108, 5, 2001, pp. 813-816; B. LO, V. CHOU, M.I. CEDARS, E. GATES, R.N. TAYLOR, R.M. WAGNER, L. WOLF, K.R. YAMAMOTO, *Informed consent in human oocyte, embryo, and embryonic stem cell research*, in *Fertility and Sterility*, 82, 3, 2004, pp. 559-563; D. HILL, A. JAEGER, *Informed consent in embryo research*, in *Reproductive Biomedicine Online*, 10, Suppl. 2, 2005, p. 40; T. CAULFIELD, U. OGBOGU, R.M. ISASI, *Informed consent in embryonic stem cell research: Are we following basic principles?*, in *CMAJ*, 176, 12, 2007, pp. 1722-1725; E. NELSON, R. MYKITIUK, J. NISKER, J. CHRISTILAW, J.A. COREY, M. HEAMAN, A. LIPPMAN, S. RODGERS, J. SHAPIRO, S. SHERWIN, *Informed consent to donate embryos for research purposes*, in *J. Obstet. Gynaecol. Can.*, 30, 9, 2008, pp. 824-836; THE ETHICS COMMITTEE OF THE AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE (American Society for Reproductive Medicine, Birmingham, Alabama), *Informed consent and the use of gametes and embryos for research: a committee opinion*, in *Fertility and Sterility*, 101, 2, 2014, pp. 332-335.

⁸² UNGA, *International Covenant on Economic, Social and Cultural Rights*, cit., art. 2(2); UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 12(b).

⁸³ V. PROVOOST, G. PENNING, P. DE SUTTER, J. GERRIS, A. VAN DE VELDE, M. DHONT, *Patients' reflections regarding the option to donate leftover embryos for science*, in *Reprod Biomed Online*, 20, 2010, pp. 880-891; C. SAMORINHA, M. SEVERIO, H. MACHADO, B. FIGUEIREDO, C. DE FREITAS, S. SILVA, *Couples' willingness to donate embryos for research: a longitudinal study*, in *Acta Obstet. Gynecol. Scand.*, 95, 2016, pp. 912-919.

embryos in IVF clinics and laboratories, this data collection aims to answer the many questions raised by the public and policy makers as to clarify which procedures are used for researching and what benefits might derive from the experimentations⁸⁴.

However, because in pluralistic societies it is difficult to reach large consensus on issues that involve ethical considerations, States should be committed to ensure that, in circumstances innervated with socio-ethical sensibility, persons can feel free to act in conformity with their own moral. Nevertheless, biomedical progress might be of benefit for public health and the respect for opposing views, especially based on religious grounds, must be consistent with the protection and promotion of public safety and health⁸⁵.

Clear evidence of embryo research would also help with the monitoring of compliance between national legislations and the 4A-scheme. The 4A-scheme is a quartet of elements – Availability, Accessibility, Acceptability and Adaptability – which sets the conditions under which ESC rights should be enjoyed.⁸⁶ Such framework has been applied in several General Comments, including the one on the right to health in which the word *Adaptability* has been changed into *Quality*⁸⁷.

The following considerations might help with the understanding of how medical research would impact on the realisation of the right to health. In particular:

Availability refers to the fact that health facilities, goods and services must be available for everyone in sufficient quantity. According to General Comment 14, this includes the underlying determinants of health⁸⁸, to which biological material for health treatments might belong⁸⁹. It follows that States should provide proper information in public registries about the quantity of embryos available within their territory but no more destined for reproductive purpose. The goal is to (1) enable scientists to better evaluate the opportunity of using such embryos for research and (2) make the public aware of what resources can be accessed for the development of potential therapies for untreated diseases. Also, a detailed information concerning the quantity of biological material would help those who have to dispose of their embryos make their final decision.

Accessibility: health facilities, goods and services have to be accessible by everyone without discrimination of any kind. This means that they have to be physically and economically accessible

⁸⁴ G. PENNING, S. SEGERS, S. DEBROCK, B. HEINDRYCKX, V. KONTOZOVA-DEUTSCH, U. PUNJABI, H. VAN DE VELDE, A. VAN STEIRTEGHEM, H. MERTES, *Human embryo research in Belgium: an overview*, in *Fertility and Sterility*, 108, 1, 2017, pp. 96-107.

⁸⁵ A.R. CHAPMAN, M.S. FRANKEL, M.S. GARFINKEL *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*, cit., Preface.

⁸⁶ Y. DONDER, *The right to enjoy the benefits of scientific progress: in search of state obligations in relation to health*, in *Med Health Care Philos.*, 14, 4, 2011, pp. 371–381.

⁸⁷ UN Committee on the Elimination of Discrimination Against Women, 1999. General Recommendation No. 24 on Article 12: Women and Health, paras 6-13; UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 12; UN Sub-Commission on the Promotion and Protection of Human Rights, *Norms on the responsibilities of transnational corporations and other business enterprises with regard to human rights*, E/CN.4/Sub.2/2003/12/Rev.2, 2003, para. 12.

⁸⁸ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 12(a).

⁸⁹ Cf para. 1, above.

(affordability) for all and that individuals should be properly educated and informed about what alternative solutions involving human embryos and hESCs therapies might be at their disposal to treat certain diseases. Good knowledge of the possible consequences of accessing hESCs therapies is included. However, information accessibility does not affect the right to have personal health data kept with maximum confidentiality⁹⁰.

Acceptability: all health treatments, goods and services must comply with the cultural context in which they are used⁹¹. A proper collection of data about the procedures used to treat human embryos would have triple advantage in this regard. First, it could demonstrate that embryos might be treated in compliance with the ethical sensibility of the population. Second, the information provided by public registries might help scientists develop working methods more compatible with the social, political and ethical issues of a particular context. Third, a clear and complete information about research procedures might encourage governments to adopt proper regulations concerning the conduct of experimentations, also providing funding for research that seek to identify mechanisms to, for example, extract hESCs without necessarily destroying the human embryo⁹².

Quality: health facilities, goods and services must be scientifically and medically appropriate and of a good quality⁹³. The donation of human embryos to research provides scientists with the opportunity to do clinical trials with human cells, not animal cells, to generate drugs and treatments thus obtaining much more effective, safe and faster results⁹⁴.

6.1. Monitoring and Accountability

Monitoring and accountability are crucial elements of the right to highest attainable standard of health. Because right-holders are entitled to access information about the benefits of embryo research on health and because governments have a duty to release all relevant material, the results of monitoring should be released publicly. Meaningful evidence plays a dual role in relation to accountability. On the one hand, it provides governments with essential information for the development of a national health plan⁹⁵ and for the equal distribution of available resources. On the other hand, it provides right-holders with the information they need to claim their right and hold the

⁹⁰ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 12(b).

⁹¹ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 12(c).

⁹² J. SHAND, J. BERG, C. BOGUE, *Human Embryonic Stem Cell (hESC) and Human Embryo Research*, Committee for Pediatric research and Committee on Bioethics, in *Pediatrics*, 130, 5, 2012, p. 976.

⁹³ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 12(d).

⁹⁴ S. SOLOMON, *The promise of research with stem cells*, Ted Talk, available at: www.ted.com/talks/susan_solomon_the_promise_of_research_with_stem_cells/details (last visited 09/01/2018).

⁹⁵ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 55.

government to account when obligations are not satisfactorily fulfilled⁹⁶. There are multiple ways available to governments for the release of relevant information. For example, many countries have established independent institutions responsible for reporting on the health status of the population with regard to embryo research. These include the *Human Fertilisation and Embryology Authority* in the United Kingdom and the above mentioned *Belgian Federal Commission for medical and scientific research on embryos in vitro*. The data gathered from monitoring activities may also be released in the annual report to Parliament on the implementation of national health plans with the information made available at the regional and international levels.

However, there is a significant number of cases in which the same body is responsible for regulating health-related services and for holding those responsible to account at the same time. From the right to health perspective, States have an obligation to ensure equal access for all to integrated, responsive, effective health systems which are of good quality. Hence, the overlap of functions is problematic⁹⁷.

While in the past the notion of accountability was primarily linked to judicial courts and remedies, new techniques have been developed in recent years. Accountability is now interpreted in broader sense as a «constructive accountability» which is no more to be intended as a *naming and blaming* system but as a way to find out what worked and can be repeated and what did not work and should be revised in the implementation of the right⁹⁸.

This includes an increasing number of forms such as national human rights institutions, public enquiries, local health councils, regional health conferences with grassroots participation, public audits or reviews⁹⁹ and the use of indicators, benchmarks, impact assessments, budgetary analysis and so forth¹⁰⁰. There is a large number of indicators that health policy makers can use to evaluate progress in implementation of the right to health¹⁰¹. Also, and because accountability establishes a link between duty-bearers and right-holders, participation of individuals and groups in the development, implementation and review of health policy of the right to health is present throughout the process of accountability¹⁰². Paragraph 42 of General Comment 14 specifies that «While only States are parties to the Covenant and thus ultimately accountable for compliance with it, all mem-

⁹⁶ H. POTTS, *Accountability and the right to the highest attainable standard of health*, Human Rights Centre, University of Essex, Colchester, England, 2008; UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 59.

⁹⁷ G. BACKMAN, P. HUNT, R. KHOSLA, C. JARAMILLO-STROUSS, B.M. FIKRE, C. RUMBLE et al., *Health systems and the right to health: an assessment of 194 countries.*, in *Lancet*, 13, 372, 9655, 2008, pp. 2047-2085.

⁹⁸ P. HUNT, *Missed opportunities: human rights and the Commission on Social Determinants of Health*, in *Global Health Promotion*, 16, 36, 2009; L. FREEDMAN, *Achieving the MDGs: health systems as a core social institution*, in *Development*, 48, 2005, pp. 19-24.

⁹⁹ H. POTTS, *Accountability and the right to the highest attainable standard of health*, cit.; UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 59.

¹⁰⁰ G. BACKMAN, P. HUNT, R. KHOSLA, C. JARAMILLO-STROUSS, B.M. FIKRE, C. RUMBLE et al., *op. cit.*

¹⁰¹ S. HARMAN, F. LISK, *Governance of HIV/AIDS: Making Participation and Accountability Count*, New York, NY, 2009, p. 70.

¹⁰² A. SCHEDLER, *Conceptualizing Accountability*, in A. SCHEDLER, L. DIAMOND, AND M. PLATTNER (eds.) *The Self-Restraining State*, Boulder, Colorado, 1999, p. 15.

bers of society – individuals, including health professionals, families, local communities, intergovernmental and non-governmental organizations, civil society organizations, as well as the private business sector – have responsibilities regarding the realization of the right to health»¹⁰³. It follows that indicators might help a proper evaluation of such participation, together with the protection of the right to seek, receive and impart information on the right to health¹⁰⁴.

Taking steps from the section of General Comment 14 where accountability is linked to judicial remedies for those victims of abuses¹⁰⁵, and in light of the above-mentioned considerations, a broader interpretation of the concept of accountability should be taken into account in the analysis of the obligations placed by the ICESCR on States parties. Human rights accountability, including the right to health, must be integrated into all stages of the domestic policy-making, from planning, to budgeting, implementing, monitoring and assessing, taking also into account the role played by regional and international accountability systems¹⁰⁶.

Arguably, this might lead to the reasonable assumption according to which the establishment of independent bodies aimed to effectively monitor progress and hold duty-bearers accountable in relation to the right to health is required by General Comment 14 and thus by the ICESCR. Because the ICESCR applies to all health issues falling within article 12 and because there are reasonable arguments for which embryo research may be located within article 12, it might be advanced that such legally binding requirement may be extended to embryo research when analysed in relation to the right to health. Certainly, governments should be left discretion to decide which body would better suit the needs of the State, whether a court, an ombudsman or other types of institution. Nevertheless, an independent mechanism should be put in place¹⁰⁷.

7. Concluding observations

The present research aimed to analyse embryo research from the right to health perspective with the goal to demonstrate that certain restrictions to such biomedical studies may need a thorough review to comply with international human rights standards. Particular attention was dedicated to the relevant synergies and worrying gaps existing between the mentioned fields with the view to identify the potential opportunities of approaching embryo research from the right to health perspective.

¹⁰³ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, para. 42.

¹⁰⁴ Broadly on how to address deficiency in health indicators: P. HUNT, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, E/CN.4/2006/48, 2006.

¹⁰⁵ UN CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), cit, paras. 59-62.

¹⁰⁶ V. GAURI, D.M. BRINKS, *Courting Social Justice: Judicial Enforcement of Social and Economic Rights in the Developing World*, Cambridge, England, 2008.

¹⁰⁷ G. PERRONE, Interview with Professor Paul Hunt, cit.

It is worth noting that, although the right to enjoy the benefits of science and its applications and the right to life were addressed in this article, the research primarily focused on the right to health. Concluding observations are as follows:

Synergies: biomedical progress in the field of embryo research has revealed the enormous potential of hESCs for new possible developments in regenerative medicine. Because of their capability to differentiate into any type cell of the human body, hESCs represent an essential resource for the introduction of new therapies for diseases that are still cause of mortality or morbidity. Examples of diseases for which hESCs treatments might be relevant include those resulting from loss or damage of human cells, such as Parkinson's Disease, Alzheimer's Disease, spinal cord injuries, diabetes, retinal diseases and cancer.

Gaps: at the basis of the open debate concerning embryo research there is the absence of consensus over the legal status of the embryo. Because of the ethical sensibility of the issue, international human rights treaties and bodies prefer to leave the definition of the embryo to the margin of appreciation of single States, thus leading to confusion on whether the embryo can be entitled with human rights. Although significant jurisprudence has been developed in this regard, the lack of a clear regulation adversely affects the development of scientific research on hESCs with negative implications for the right to health. A second relevant gap lies in the fact that States are sometimes unwilling to provide clear information about the quantity of supernumerary embryos no more intended for implantation and potentially suitable for research purpose. This might happen, inter alia, when a government not monitored by any independent authority tries to contrast the pressure coming from public campaigns against a legal ban to donate human embryos to research. However, the lack of a proper collection of data hinders the effectiveness of any monitoring mechanisms and makes it difficult to hold authorities accountable when violations of human rights occur.

Opportunities: article 2(1) ICESCR poses a duty on each State party to «take steps (...) to the maximum of its available resources» towards the progressive realisation of the rights recognised by the Covenant, including the right to the enjoyment of the benefits of scientific progress and its applications and the right to the highest attainable standard of health. Building on (a) the studies of excellent scholars, (b) the understanding of *available resources* during the drafting process of the Covenant and (c) the suggestions provided by Committee on the Rights of the Child, it seems reasonable and advantageous to include supernumerary embryos no more suitable for reproductive purpose within the available resources of a State for the realisation of the right to health.

In addition, because health research is a fragmented, highly specialised, sectorial activity, problems with an effective communication and consultation between biologists and professionals focused on different disciplines – e.g. policy makers, health professionals, the public – might easily occur. The creation of a public platform for effective communication among different players would represent an opportunity to provide a more integrated and coordinated, systems perspective¹⁰⁸.

¹⁰⁸ PANG T et al., *Knowledge for better health - a conceptual framework and foundation for health research systems, op. cit.*, pp. 815-820.

With this view, governments may take the following steps:

- Create a platform for researchers to exchange country experiences on embryo research and ensure that proper information is available and accessible for all, including policy makers and the public.
- Elaborate proper guidelines to regulate scientific research on embryos in compliance with human dignity and rights. In particular, ensure that persons feel free to act in conformity with their own moral and that the respect for opposite views is consistent with the protection of public safety and health.
- Identify available resources and set priorities on new research.
- Establish an effective monitoring and accountability mechanism, also introducing an independent body responsible for checking progress and holding duty-bearers accountable if violations of human rights occur.
- Ensure that the population is well educated about embryo research and the right to health and that everyone is allowed and encouraged to participate in the relating decision-making process concerning policies, programmes, practises and legislation.

Biomedical research has largely proved to be impactful for the extraordinary advancement in the prevention, treatment and care of human diseases. By approaching embryo research from the right to health perspective, enormous opportunities might arise for treating major diseases that are still cause of human mortality.