Human Subjects Protection based ETD’s in the OATD Resource Discovery Service

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Objective

To present characteristics and publication patterns of theses and dissertations on human subject protection accessible in Open Access Theses and Dissertations (OATD) resource discovery service, a tool developed by Wake Forest University in the United States.
Background

- Human Subjects Suffer
  - Poor provision of basic amenities like unsafe drinking water, unhygienic living conditions, occupational hazards-poisoning due to chemicals
  - Inadequate supply of food
  - Unequal distribution of resources

Research

- Nazis’ experimentation on prisoners during World War II in concentration camps
- Tuskegee Syphilis experiment in 1932 where the rural American African men were denied treatment to study natural progression of syphilis
Human Subject Protection Measures

- Declarations and Guidelines
  - Nuremberg Code
  - Belmont Report
  - Hastings Report

- Universal Declaration of Human Rights in 1948

- Meetings and deliberations - WMA expert meets

- Committees – Institutional Ethics Committee

- NGO’s – Amnesty International

- Agencies & Commissions – Global & Local-
  National Human Rights Commission

- Publications: Human Development Report, ETD’s
About OATD

- Open Access Theses and Dissertations (OATD) resource discovery service, a tool developed by Wake Forest University in the United States.

- OATD facilitate access to ETD’s from over 1100 colleges, universities and research institutions across the world. It has over 3.5 million records and has advanced search options available.

- OATD is the best possible resource for finding open access graduate ETDs.
Search Strategy

- abstract: (human AND research AND protection) AND abstract: (bioethics OR compliance OR regulation) AND pub_dt:[2000-01-01T00:00:00Z TO *].
- The search was limited to thesis published in the year 2000 and onwards.
- Search was conducted on OATD website during February 2017.
Methodology

- Systematic observational approach followed
- Relevant fields recorded in Google sheet
- Duplicate records removed from the list
- Data analysis using MS-Excel
- Results represented as Graphs
Observations

- Records obtained from the search in OATD after removal of duplicate entries were 129.
- After the deletion of irrelevant abstracts not pertaining to human protection 102 theses abstract met the inclusion criteria.
Data Analysis is done on the basis of

- year of publication
- country
- language
- degree obtained
- discipline of study
- accessibility
Year-wise distribution of Human Subject Protection based ETD’s in OATD
n=102
Country-wise distribution
n=102

- United States: 19.6%
- United Kingdom: 14.7%
- Brasil: 12.7%
- South Africa: 11.8%
- Australia: 10.8%
- Canada: 6.9%
- Lithuania: 3.9%
- Canada: 3.9%
- Norway: 2.9%
- Finland: 2.9%
- Netherlands: 2.9%
- Denmark: 1%
- Ethiopia: 1%
- Italy: 1%
- China: 1%
- United Kingdom: 1%
Educational Degree
n=102

- Bachelor: 7%
- Masters: 34%
- Doctoral: 58%
- Unspecified: 1%
Subject-wise distribution
n=102

- Social Science: 26%
- Business: 9%
- Engineering: 2%
- Environmental Science: 13%
- Law: 30%
- Bioethics: 20%
Language-wise distribution
n=102
Accessibility of ETDs

N=102

- 82.4% Open Access
- 11.8% Closed Access
- 4.9% Error
- 1% Embargo
Major Themes

Student research on human subjects’ protection includes

- Legal human rights of a stateless person
- Child rights on child born by egg donor insemination
- Ethical and legal aspects of research on human embryo
- Stem cell research in understanding diseases
- HIV vaccination practices
- Privacy, and confidentiality of research subject participants
The ethics in genetics - The legitimacy and application of stem cell research

De Vries, Len

URI: http://hdl.handle.net/2263/27105
Date: 2007-02-07

Abstract:
This dissertation provides an in-depth analysis of the practical application and judicial framework pertaining to stem cell research in South Africa. In the realisation of the above-mentioned analysis, and ultimate critique on the current and proposed legal position, focus is placed on aspects of Medical Law, Legal Philosophy and Human Rights. These include concerns on the procurement of informed consent from stem cell donors, ethical and religious influences on the regulation of biomedicine in general as well as the impact of socio-economic indicators in the realisation of the effective implementation of stem cell research. Focus is firstly placed on the medical aspects surrounding the research, whereafter an examination of the current legal position and its practical application is made. Following the discussion of the current legal position, with reference to the array of influences and concerns pertaining thereto, the newly proposed regulative measures are examined within the current international framework. These regulative measures are placed within context of the private and public sector with their different benefits and disadvantages. In a further discussion of the realisation of the private sector’s interests, focus is placed on the role that Intellectual Property Rights play in the protection of monetary incentives to conduct stem cell research. All of the above ultimately leads the author to provide an informed set of recommendations in which the proposed regulative measures can be adapted to ensure the legitimate and practically sound implementation of stem cell research in South Africa.

http://repository.up.ac.za/handle/2263/27105
Understand the environmental fate, behaviour, effects and risks associated with contaminants of emerging concern (CECs) with the goal of protecting environmental and human health

Each and every one of us is exposed to chemicals on a daily basis and contributes to the global issue of chemical pollution. Humankind has become heavily dependent on the use of man-made chemicals in order to sustain the increased quality of life that is generally seen globally. There is however a price to pay in that we generally live in a world that is polluted by anthropogenic chemicals. From the water we drink to the food we eat there will be some trace of chemical residues; you just need to look closely enough and/or know what you’re looking for. With many hundreds of thousands of man-made chemicals approved within Europe for use in various ways, it is no surprise that we are exposed to these substances.
The South African legal framework for the conservation of biodiversity

South Africa is ranked as one of the most biologically diverse countries in the world. In comparison it has more species of vascular plants, amphibians, reptiles, birds and mammals per 1000 km² than Africa and the rest of the world. Unfortunately, statistics indicate that this biological diversity is becoming increasingly threatened by various anthropocentric activities in South Africa. It can be concluded that South Africa has the highest number of red data species in the world, as well as the second highest number of endemic taxa. The numbers of extinct, endangered, rare, and vulnerable species have increased exponentially over the past 10-15 years. South African legislation provides directives to ensure measures are taken to provide for biodiversity conservation and sustainable use. However, the trends in the conservation status of various South African species have raised the question of whether this legislation can adequately sustain biodiversity for future use. Biodiversity needs to be preserved for sustainable future use due to the instrumental and intrinsic value it holds for society. Various criteria should be complied with to ensure that biodiversity is sustained for future generations. In this research project a consortium of criteria was identified relevant to ensuring sustainable use of biodiversity and its conservation. These criteria pertain to the...
This thesis aims to analyse the influence of human rights concerns on recent revisions of mental health legislation in England and Ireland (Mental Health Act 2001), and the extent to which human rights concerns assist in promoting human rights through legislation. The thesis demonstrates that human rights standards, as reflected in the European Convention on Human Rights and publications by the World Health Organisation (WHO), played a critical role in shaping revisions of mental health law in England (where public safety was not a central issue and human rights concerns dominated single-handedly). Mental health legislation in England meets 92 (55.4%) of the 166 relevant standards set by the WHO; mental health legislation in Ireland meets 81 (48.8%). Areas of high compliance include definitions of mental disorder and clarity regarding offences. Areas of medium compliance relate to capacity and consent (with a particular deficit regarding review procedures (which exclude long-term voluntary patients and lack robust complaint procedures), and rules governing compliance relate to economic and social rights, voluntary patients (especially non-protesting, incapacitated patients), and treatment. Overall, mental health legislation provides substantial protection for some rights (e.g. liberty) but not others. Additional protection is provided by mental health policy, social policy or other areas of law (e.g. human rights law). For example, the outcome of mental health legislation in the lives of the mentally ill; the relevance of the “third wave” of human rights, analysis of the role of health-care and social-care actors affecting the mentally ill; and values underpinning increased trans-national influence (Council of Europe, European Union, WHO).
The main research issue of this master thesis is problem-oriented approach of privacy and data protection regulation in EU member states, with a particular emphasis on international level. Nevertheless, privacy is numbered as one of the fundamental human rights and should be protected by national and international law norms concerning privacy and data protection. Also, to reveal and discuss main threats to modern society, this paper deals with challenges of technological, social and economical reality. In this final paper author discusses personal data protection and supplemented with new norms which should be up to date considering nowadays reality. It is also noted that some problematic aspects are discussed in master’s thesis concerning privacy violations, legal norm regulation etc. to his research. These methods are linguistic, comparative, systematic analysis and others. Final paper consists of three chapters. At the end of the paper there are personal conclusions and proposals for better protection of this value in the future.
Proteção da vida humana embrionária e repercussão no campo jurídico e ambiental
Kempf, Denise Fátima

URI: https://repositorio.ucs.br/handle/11338/604
Orientador(es): Brauner, Maria Claudia Crespo
Defesa: 2011-04-29
Instituição: Universidade de Caxias do Sul
Programa/Curso: Programa de Pós-Graduação de Mestrado em Direito
Tipo de Obra: Dissertation

Resumo:
O avanço da ciência, em especial na área da reprodução humana, permitiu a ocorrência de concepção humana de forma extracorpórea através do processo de fecundação in vitro a ser feita em laboratório especializado em reprodução humana assistida. Os embriões não implantados em útero materno são criopreservados. Este trabalho busca trazer os questionamentos da bioética, do biodireito, a cerca deste tema e das questões nele envolvidas.
Women for sale/eggs needed: Is the market for egg donation developing without oversight that protects organ donors?

by Petty, Elaine G., M.A.L.S., Georgetown University, 2008, 114; 1471588

Abstract (Summary)

Human organ donation is generally viewed as an altruistic endeavor in which a donor saves the life of a recipient by donating part of his or her body. Organ transplantation is strictly controlled at the state and federal level. Allocation of organs, medical oversight, and strict prohibition of selling organs are governed by clear, ethical guidelines. The more recent past, however, is surprisingly different. The regulations giving oversight for organ donations do not apply to egg donations. Young women are recruited by ads promising to always clearly explained to potential donors, and many remain unknown. The market-driven dimension of the fertility industry raises ethical concerns about them becoming more than a $3 billion business. The problem is that egg donation is different from organ donation in legislative treatment, in medical oversight and in young donors in harm’s way.

This paper documents the similarities and differences between organ and egg donation, related to the risks that donors are required to take. The comparative values issues drive and maintain the differences by answering the question, "Is the growing market for human eggs developing without the medical and legislative protection of an organ donor at risk?" The results indicate that the egg donor has less protection, less oversight and greater vulnerability to exploitation than the organ donor. She does not yet take known and unknown risks to her health in order to do so. After her eggs are harvested, future problems are neither tracked by the health system conceived.

Ethical concerns are being voiced by those calling for change in this industry where donors are too often exploited and exposed to injury. Robust discussions must occur about the risk of harm and provide for the health of donor and recipient alike. If not, it is the egg donor who is at risk of being sold to the highest bidder.
DE JURE STATELESSNESS IN SERBIA - A Critical Analysis of the Legal Framework with Regards to Combating Statelessness and the Protection of Stateless Persons

Permanent link
http://hdl.handle.net/10037/5307

Author
Nikolic, Natasa

Abstract
Abstract In the age of proclamation of universalism of human rights, the interrelation between citizenship and human rights still raises concerns. Statelessness, a condition of having no nationality, affects more than 12 million people worldwide causing a legal limbo in which those who are denied a political membership are deprived of access to basic human rights. Being in the shadow of refugee and migration issues, statelessness has not only been neglected on the international arena but in academia, as well. In light of political changes in Eastern Europe during the ‘90s, statelessness came into the...
Institutional review boards: Politics, power, purpose and process in a regulatory organization.

Alternatives are offered for consideration: (1) use of more precise terminology to distinguish between participant/patient, doctor/researcher, and therapist; (2) developing different rules for social research, particularly qualitative research, that do not consider no treatment and/or "minimal risk"; (3) insisting regulators focus on the impacts of research decisions and contemplating rules; (4) developing realistic attitudes about what regulation of any kind can do; and (5) engaging in and encouraging scrutiny of the regulatory processes when studies involve only "minimal risk."
Published thesis and dissertation scholarship that focuses on human subject protection is a societal barometer that maintain attention of readers and researchers. The open access to the scholarship on such areas are essential for human resource development as it allows:

- Easy discoverability of ETDs in IR
- Visibility on different search platforms and search engines
- Greater impact
- Higher citations
- Enhances research and efficiency
- Bridges inequalities
- Moral consideration
Discussion

Different platforms for accessing ETDs

- NDLTD global ETD search,
- ProQuest Dissertations & Theses Global,
- ProQuest PQTD Open
- OpenDOAR

Difficulties

- NDLTD - limited search options
- ProQuest Dissertations & Theses - subscription-based service.
- OpenDoar - directory of open access repositories
Conclusion

- Limited sample on human subjects’ protection.
- The OATD resource discovery service continues to grow in size and coverage.
- Human subjects’ protection theses will expose important research and provide more support for safe human participation in research trials.
Thank you for your attention
Questions?