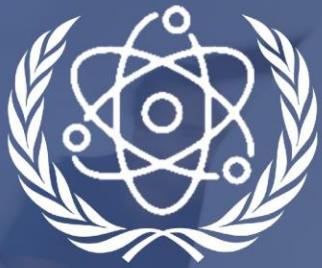


PacificMUN

Dare to Speak



IBC-Topic B
Backgrounder Guide



Right of Choice for Unresponsive Patients - IBC

Topic B

PacificMUN



Letter from the Director

Dear Delegates,

My name is Jessica Lin and I have the utmost pleasure of serving as the Director of the International Bioethics Committee 2019. I am currently a grade 11 student at Crofton House School and it has been four years since I stepped foot into my first committee room. Although I hardly raised my placard during my first conference, Model UN has not only allowed me to grow as a public speaker, but it has also given me the opportunity to discuss some of the most pertinent issues in the world with like-minded individuals. I hope that this conference, and Model UN as a whole, has the ability to do the same for you.

With the widespread development of new biomedical technology and its practices gaining traction, many of the ethical implications have yet to be addressed internationally. In this committee, we will be discussing the issues surrounding the advancing biological research field, specifically the Privacy Issues of Collecting Information for Big Data Projects and the Right of Choice for Unresponsive Patients. It is important to understand that bioethics is not a field that supplies absolute answers; the solutions you seek may evolve as quickly as the biomedical sector itself. While these topics may be challenging, research and reflection will greatly aid your understanding, and help you formulate both your own and your country's stance on these topics.

On behalf of your Chairs, Alexander Shojania and Jesse Hsieh, the dais team is excited to witness a



weekend of lively debate and fruitful discussion in February. In the meantime, please direct any questions regarding the committee, topics, or the backgrounder to ibc@pacificmun.org.

Best regards,

Jessica Lin
Director of IBC
PacificMUN 2019

Committee Overview

With the rapid developments in the medical and life science fields within the last half-century, many medical breakthroughs have occurred, yet a fair share of unethical behaviour have also occurred. The United Nations Educational, Scientific and Cultural Organization (UNESCO) therefore formed the Bioethics Programme to address the cultural, social, legal, and ethical implications brought forth by these developments.

Specifically within the Bioethics Programme, the International Bioethics Committee was formed in 1993 by the General Director of UNESCO, Dr. Federico Mayor Zaragoza. Comprised of a body of independent experts from various countries gathered to discuss legal and ethical issues involved in the application of life science. As the only international forum for reflection in bioethics, this body ensures human dignity and freedom is respected in the progress made in the life sciences field. In 1998, as part of the Statutes of the International Bioethics Committee (IBC), the Intergovernmental Bioethics Committee (IGBC) was created. This body of 36 Member States and their representatives meet at least once every two years to discuss the advice and recommendations placed forward by the IBC, and reports back to the IBC with opinions and proposals.

To ensure the healthy natural evolution of the human, care needs to be taken to prevent unsafe, unethical, or immoral practices from occurring, especially through the oversight of the IBC. The implementation of further regulation for the ethical development of medication and technology is important, and as such, the IBC is tasked with the mitigation of risks of medical exploration and usage of recently developed medical practices and medication. This mitigation of risks helps to ensure the safety and freedom of humanity while continuing to allow research into the human body to continue.



Through this committee, many ethical and moral issues will be discussed around how to prevent unethical usage of data, as well as the question of unresponsive patients.

Topic Introduction

The advancement of medical technology has allowed patients to attain an unprecedented level of control over their medical care. Patients of the 21st century not only have access to an ever-growing range of options for medical treatment, but also the right to refuse life-sustaining treatment. This control, however, becomes disputed when patients enter an unresponsive state. An unresponsive state – which encompasses vegetative states, brain death, and comas – renders patients incapable of dictating the course of their medical treatment.¹ Patients in such a state typically have severe neurological damage, which results in their organs functioning, but only through the assistance of automated devices. As such, the right of choice falls into the hands of the patient's immediate family; the family, or a legal trustee, gets to decide whether treatment should continue, in hopes of the patient's eventual return to a conscious state, or if treatment should be withdrawn and the patient's organs could then be donated. Thus, the state of an unresponsive patient is complicated by the patient's pre-existing wishes for the given situation (if any), the patient's organ donation status, and the patient's religious stance. On the family and decision-maker's part, these individuals may struggle to remain as objective as possible, given that there the human life in their hands is that of someone they have had a relatively intimate relationship with, and fail to consider the patient's expressed desires, the societal good that can come from organ donation, or the resources necessary to sustain a human life through mechanical life-support measures. Although well-intended, the decisions of these proxies may not honour the patient's right of choice or uphold the patient's desires because of the extensive emotional burden that accompanies such a decision.

Amongst even the most developed countries, governments have often overlooked the necessity of mechanisms that will effectuate a patient's right of choice when the individual is in an unresponsive state. Instead, many of the current mechanisms passively and ineffectively facilitate the upholding of the right of choice of patients; laws remain unclear as to what constitutes death, demand for organs grows while numbers on organ donor lists dwindle, and the public understanding of the opportunity cost of sustaining an unresponsive patient's life remains obscure.

Timeline

¹ <https://www.usatoday.com/story/news/nation/2014/01/09/brain-death-states-of-consciousness/4397515/>



1837 - An artificial nutrition and hydration mechanism (the feeding tube) is invented and used to deliver nutrients and hydrate patients who are unable to ingest solids and liquids in an automated manner. The tube is later categorized as an artificial means of life support.²

1928 - Mechanical ventilation is invented; although at this time mechanical ventilation is primarily used for life-sustaining purposes, mechanical ventilation is set to become the central device in keeping brain-dead patients alive.³

1954 - Joseph Murray performs the first successful organ transplant when he transplants Ronald Lee Herrick's liver to his identical twin brother.⁴

1974 - Credited as the origins of the Do Not Resuscitate (DNR) order, the American Heart Association noted that Cardiopulmonary resuscitation (CPR) left a select few with morbidities. Thus, it was recommended that patients who are negatively impacted by CPR are given the choice to forego revival and allow natural death to occur.⁵

November 1992 - Tony Bland, who is declared to be in a Persistent Vegetative State (PVS) after sustaining injuries from a head-trauma inducing accident, becomes the first patient in English legal history that has been "allowed to die" through the withdrawal of feeding tools and respiration assistance.⁶

June 25th, 1990 - In a landmark United States Supreme Court case, Nancy Cruzan's termination of life support is disputed. Upon entering a PVS, the court grants her parents the right to remove her life support and essentially grants Cruzan the right to die on the basis of evidence that she herself would have wanted life support to be removed.⁷

2005 - UNESCO adopts the Universal Declaration on Bioethics and Human Rights, part of which asserts that "the autonomy of persons to make decisions...is to be respected" but also that treatment

² <https://www.acls.net/information-and-ethics.htm>

³ Ibid.

⁴ <https://www.theguardian.com/society/2010/dec/30/first-organ-donor-dies-79>

⁵ <https://depts.washington.edu/bioethx/topics/dnr.html>

⁶ <http://www.life.org.nz/euthanasia/about-euthanasia/global-history-of-euthanasia12/Default.htm>

⁷ <https://www.nytimes.com/1990/12/27/us/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html>



"which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint"⁸

January 17th, 2006 - The Massachusetts Supreme Court rules that Haleigh Poutre, a young girl who is declared to have entered a PVS, could be removed off life support, as per the requests of her legal guardians. The following day, just as physicians prepared to remove life support, Poutre regains consciousness.⁹

Historical Analysis

Ethical issues surrounding medical treatments arise when technological advancements push the limitations of both mortality and morality. The technology that encompasses life support in the 21st century – mechanical ventilation, Cardiopulmonary resuscitation, and artificial nutrition and hydration – both revolutionized and complicated the world of bioethics. Mechanical ventilation has revived victims of drowning, trauma to the respiratory system, and electrocution.¹⁰ CPR has prevented millions of people from dying in the window of time between cardiac arrest and the availability of definitive cardiovascular treatment (eg. defibrillation). Feeding and hydration through artificial means have assisted patients, ranging from infants to the elderly, whose digestive systems' lack the ability to retain hydration and nutrition. Despite the well-regarded impact of these medical advancements, in their wake is also a throng of people who have been negatively affected by these treatments. Some argue that the use of life support technology has disrupted the natural cycle of life. With more concrete evidence, others argue that these technologies, implemented under the wrong circumstances, have the power to worsen the living standards of patients. A saved life is not necessarily the same life; patients have been left intubated for the remainder of their life and left to permanently rely on feeding tubes for nutrition and hydration. As such, the pain and discomfort that may accompany attempts to save or prolong an individual's life must be weighed against the choice of foregoing treatment altogether. Weighing this decision, however, must be done with consideration to religious perceptions, ethical definitions, and legal implications.

In 1957, Pope Pius XII addressed resuscitation, citing "the alleviation of pain – not mere prolongation of life—[as the] the ultimate end of medical treatment."¹¹ Pursuits of indefinite extensions of life,

⁸ <https://unesdoc.unesco.org/ark:/48223/pf0000146180>

⁹ <https://www.bostonglobe.com/2014/08/02/timeline-the-case-haleigh-poutre/9j3BhnkLrA8AxIYo4PZWoN/story.html>

¹⁰ https://www.atsjournals.org/doi/abs/10.1164/ajrccm/140.2_Pt_2.S2?journalCode=arrd

¹¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3157529/>



interpreted as idolatry, are strongly opposed by the Catholic church. The prolongment of life, thus constitutes the grey area between saving a life and the unnecessary pursuit of the prolongment of life. Religious perspectives such as those of the Catholic church have exacerbated the bioethical issues surrounding the use of life support. Through the hierarchical diffusion of stances on such ethical issues, religious institutions have influenced public perception on the morality behind life support.

In the 1980s, the debate surrounding bioethics progressed to the inclusion of patient rights and the duty to respect patient autonomy.¹² The general consensus was that a patient of sound mind had the right to refuse medical treatment and it was the right of physicians to respect this right of choice. Under these newfound principles of patient care, new controversy surfaced: is life-extending *simply* medical care? Or does it constitute its own category, one that does not allow for patient refusal? Advocates for the right of choice claimed that life-prolonging medical treatments are no different from other procedures while those with pro-life values claimed that terminating life-sustaining medical treatment is not only insensitive to the value of a human life, but also burdensome to the physicians who are thereby responsible for what is a near parallel to 'murder'. In this climate, the legal status of refusing life-sustaining treatments was relatively ambiguous, leaving room for states and provinces to deal with each dispute on a case-by-case basis.

By the late 1990s, a greater consensus had been reached with the advent of greater legal clarity. The 1990 US Supreme Court decision on the Cruzan case sided with the view that life-sustaining medical could be terminated under the right conditions. As more research was conducted to determine the extent of futility behind administering life-sustaining treatment to the terminally ill, the new debate of bioethics would become increasingly centred around what exactly constitutes 'the right conditions'.

Current Situation

In considering the state of unresponsive patients, there are both medical and legal definitions to understand. Although perceived by many to be interchangeable when used colloquially, comas, vegetative states, and brain death constitute markedly different medical states. First and foremost, brain death is no different from any other form of death – someone who is brain dead is no longer alive, the term only describes how the death was determined.¹³ Like all other forms of death, brain death is defined as the "irreversible cessation of circulatory and respiratory functions" or the

¹² Ibid.

¹³ https://www.huffingtonpost.com/2014/01/10/ethics-brain-dead_n_4577116.html



"irreversible cessation of all functions of the entire brain, including the brain stem."¹⁴ As the patient is, medically speaking, a corpse, the only complicating factor in 'unplugging' someone who is brain dead is the emotional attachment of family members. Comas and vegetative states, on the other hand, are altered states of consciousness. Comas are temporary states of depressed consciousness and can be distinguished from brain death by responsiveness from the brain stem. Typically lasting no more than a few weeks, patients in comas may either recover consciousness, progress to brain death, or progress into a vegetative state. Vegetative states, when a patient is deemed to be alive but with severely impaired consciousness, are defined by a lack of awareness for one's surroundings. Although generally referred to as a persistent vegetative state, the patient can more specifically be described by the length of time the patient fits the criteria of a vegetative state; after four weeks in this state the patient is described to be in a prolonged vegetative state and after a year of non-responsiveness a patient is described to be in a permanent vegetative state, with a minuscule chance of recovering consciousness.

Law and medicine are typically separate entities and legal systems have not always stayed up to date with research from the medical sector. If a patient is clinically declared to be dead, most legal systems simply regard the individual as dead. There are no ethical implications of removing a brain-dead individual from life-support, as life-support only stretches out the amount of time before the body deteriorates on its own, and hospitals are typically not legally obligated to keep these patients on life support. Unless the diagnosis of brain death is disputed, in which a court order can be obtained for the continuation of life support for a limited amount of time, life support will immediately be terminated. As mentioned above with the Haleigh Poutre case, the sufficiency of current medical procedures in determining the appropriateness of life support removal is questionable. Furthermore, on several occasions, physicians have been accused of inappropriately advising for the removal of life-support for registered organ donors; because of the growing demand and dwindling supply of healthy organs, inter-patient opinions may cloud a physician's judgement. Persistent vegetative states, however, are an even more complicated legal matter. Under most legal systems, hospitals are obligated to keep patients on life-support unless a DNR has been or is signed. Otherwise, hospitals must await the family of the patient's decision to seek a court order to remove the patient from life-support. Many families, thoughts clouded by the emotional attachment to the patient and the hope of recovery, choose to forego the removal of life-support, even if it undermines the professional opinion of physicians. Understandable for the emotional burden that accompanies the decision to withdraw life-support, the decision irrationally considers the implications of maintaining life-support. The chance of survival for patients is minimal and even if a patient recovers consciousness, he or she will likely never be able to attain the

¹⁴ <http://www.aopo.org/state-brain-death-laws/>



same standard of living. The social good, in such a situation, is difficult to recognize and rarely ever considered. A patient on life-support absorbs the scarce resources of Intensive Care Units (ICUs) that may be needed for patients with injuries that retain a greater rate of survival. Furthermore, the potential for a patient in a PVS to save the lives of individuals who await organ transplants is often overlooked. Without the emotional complications associated with being a family member in this situation, it is easy to look at delaying the removal of life-support for patients in PVS in an objective light. It is essential, however, to consider the mindsets of family members and how looking at patients in PVS objectively as resource drains and organ donors may promote the treacherous idea that one has a duty to die.

The right of choice for unresponsive patients is thus complicated by the aforementioned issues. Very few individuals have Advance Decisions – living wills that express refusal of certain treatments – or DNRs, and prior to entering such a state, very few express a preference for dying a natural death. The lack of Advance Decisions, however, is not indicative of the population's perception of the medical treatments one would wish to, or not to, receive in such a situation. Rather, the lack of DNRs points to the lack of conversation surrounding decisions in the case of brain death or admittance into a PVS. With insufficient amounts of knowledge advising the decisions of family members, it is difficult for decision-makers to honour an individual's opinion if they knew so little about what he or she would want in the situation. Legally speaking, if there is no DNR, there needs to be a sufficient amount of evidence indicating that if the individual were conscious, he or she would want life-support to be removed. If there is no indication of an end of life choice, there is also unlikely to be an explicit declaration of the individual's stance on organ donation. In most countries, unless the individual is a registered organ donor, the decision rests on the family or appointed decision makers. With their judgement clouded by the emotional aspects of death, families rarely opt to donate organs at such a time, a decision that may not align with the desires of the patient. Religious alignment may point to the direction one may have wished for, yet it is imprudent to simply assume that the presented stance of a religion is the stance of the individual, especially with the personal and individualistic nature of the issue. The preservation of patient autonomy is the end goal of ensuring unresponsive patients retain their right of choice, yet unless a patient explicitly expresses their stance at some point in their life, it is next to impossible to accurately gauge what exactly a patient's choice would have been.

United Nations Involvement

The greatest issue on executing bilateral action in securing the right of choice of unresponsive patients is the lack of uniformity of patient rights in different countries and in different jurisdictions.



Much of this inconsistency results from the prevailing cultural and social norms of a given region. The few documents delineating the ethical principles of physicians, including but not limited to the Declaration of Geneva (The Hippocratic Oath) and the International Code of Medical Ethics, do not promote patient autonomy as a self-standing concept, but rather, the result of physicians' obligations to patients.¹⁵ The development of such documents have been perceived by many healthcare professionals as a threat to their professional autonomy. It is essential that new documents, if any, strike a balance between patient and professional autonomy to ensure that such declarations consider both the interests of parties at length.

The United Nations has been more actively involved in the regulation of organ transplants because of the emergence of illicit organ trades. Although this is a subordinate aspect of retaining the right of choice of unresponsive patients, it is essential to understand how increasing the documentation or expression of a patient's choice before they are in an unresponsive state can aid the UN's efforts with the unregulated organ trade. When the decision to donate organs no longer falls in the hands of emotionally affected family members, the number of organs available for transplants may rise significantly. As such, it is not only in the best interests of the IBC to implement initiatives that provide unresponsive patients with the appropriate right of choice, but also in the best interest of all the organs of the UN to facilitate such an effort.

Seeking Resolution

Public Awareness

A root cause of the lack of respect for an unresponsive patient's wishes is the lack of conversation that has occurred prior to that given moment. With the advent of the automobile, the number of car accidents has grown and so has the number of trauma-induced comas. Yet few people expect to ever encounter such a situation and even fewer people realize that there are implications for remaining on life support beyond an individual's family members. Furthermore, the media has inaccurately portrayed and almost romanticized the idea of being in coma, leading to false and overly hopeful perceptions from family members. Oftentimes, individuals will only discuss their desires or make efforts to have their wishes recorded if they themselves go through the experience second-hand as a decision maker or trustee. If a better sense of awareness, or at least attempts to correct misconceptions, can be achieved, then it is more likely that people will engage in conversations with family members about end of life decisions, communicate their stance on what is to be done in such a situation, or even pursue

¹⁵ <https://www.wma.net/wp-content/uploads/2016/11/Patient-rights-20160118.pdf>



Advance Decisions that delineate what their wishes are in such a situation. Creating greater clarity for the individuals entrusted with the decision to remove life-support allows the patient's right of choice to be better respected, the emotional burden of family members and legal trustees to be alleviated, and resources to be more appropriately allocated.

Opt-out System

Consent is necessary for an individual's organs to be taken and transplanted upon death, but the definition of consent becomes difficult to discern when the patient is incapable of giving such consent. In most countries, individuals can consent by registering to be an organ donor while they are still capable of such, yet for those who have not, about 25% of possible donors' family members choose not to at the time of death.¹⁶ While most countries have opt-in systems, where individuals have to give explicit consent by opting to register to be an organ donor, the efficacy behind such a system is questionable as many who are willing to donate never get around to registering. An alternative approach, the opt-out system, has been implemented by countries such as Austria and Belgium. In this system, consent is presumed and citizens are presumed to be organ donors unless they opt to register out of the system as an individual who is unwilling to consent to organ donation. Although this is hardly an all-encompassing solution to preserving the right of choice of unresponsive patients, if paired with other solutions, the opt-out system may mitigate the lack of organ donations that occur when family members are proxies for an individual's end of life decisions. An opt-out system may appear to be the solution with the absolute advantage, but delegates must evaluate the legal and political climates of their countries before considering the opt-out system. Between the UK, Germany, and Austria, the opt-out system and a general public perception of organ donation has been met with differing levels of hostility. Geographical neighbours, Austria and Germany have experienced discrepancies between public perception of organ donation. Austria's implementation of the opt-out system has engendered a 99% organ donation consent rate while Germany's opt-in system retains an organ donor list that consists of only 12% of its population.¹⁷ Britain, who tried to adopt the opt-out system, was opposed by portions of its Muslim population, who objected to organ removal on religious grounds. In seeking any solution, countries must be mindful of the social and cultural ties that inhibit solutions from taking effect.

Mandated Choice

If the opt-out and opt-in systems of organ donation are viewed as diametric ends of a spectrum, mandated choice is a concept that lies in the region between the two. The principles of mandated

¹⁶ <https://journals.sagepub.com/doi/abs/10.7182/pit2013801>

¹⁷ <https://www.nytimes.com/2009/09/27/business/economy/27view.html>



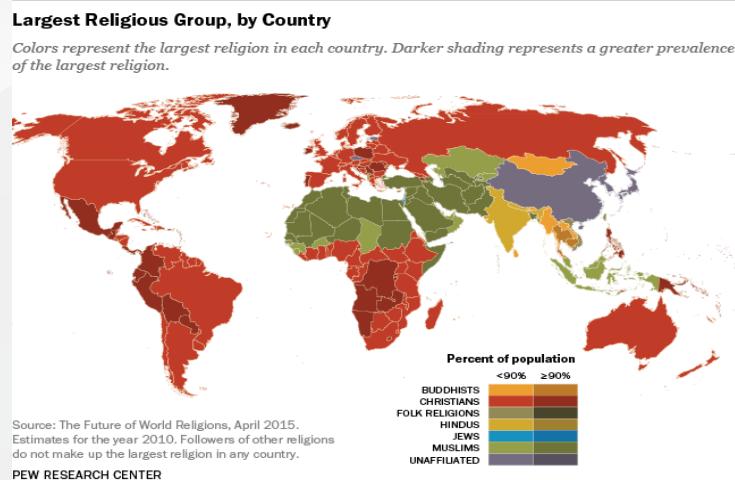
choice necessitate that all citizens indicate their preference for organ donation. Citizens are asked whether or not they wish to be an organ donor when a driver's license is renewed, making organ donation registration convenient, but still in a legally binding manner. Unlike the opt-out system, individuals avoid upsetting individuals who object to have their choice presumed. Although this is far from ubiquitous explicit statements of whether or not individuals would want life-support to be removed if he or she enters a permanent vegetative state, mechanisms similar to the mandated choice of organ donation can be employed to respect the right of choice of unresponsive patients. Delegates may use the structure of this system as an exemplar that can be reproduced to help facilitate a greater degree of patient autonomy whilst in an unresponsive state.

Bloc Positions

Western Liberal Democracies

For the most part, Western Liberal Democracies such as the United States, the United Kingdom, and Canada will pursue greater patient autonomy whilst in unresponsive states. With respect to the rights of patients and the right of an individual to act in a manner that he or she deems appropriate, it is in the best interests of these countries to implement greater preemptive measures that facilitate the vocalization or documentation of a patient's choice pertaining to life-support removal and organ donation. Although serviceable towards the rights of citizens as patients, these governments are also mindful of the resource drain that results from sustaining the lives of unresponsive patients. Furthermore, in these countries, the technology necessary to perform organ transplants is readily available. As such, organs are in high demand and the low supply of them only gives more reason for governments to seek a patient's end of life decisions before the choice falls in the hands of emotionally driven family members.

Countries with Religious Affiliations



Largest Religious Group by Country (Pew Research Center)

Countries that are influenced by a heavily religious population tend to have legislation that favours these religious views. For example, in Italy, where Catholicism is the dominant religion, DNRs are not recognized and physicians are legally obliged to attempt resuscitation on any patient, regardless of the expressed beliefs of the patient or family members. Thus, in these countries where legislation is swayed by a religion's beliefs on the value of a life, delegates need to carefully weigh patient autonomy against the religious beliefs of the majority. Furthermore, some Orthodox Jews, Buddhists, and Muslim groups object to brain death as a determinant of death, believing that the cardiopulmonary standard is the only indicator of death. Hospitals serving large populations of such religions must then consider the religious views of the patients and the family in determining the appropriateness of removing life-support. Although the legal system may override these objections, it is necessary for countries to consider the social and cultural implications of new policies regarding the removal of life-support. These countries must search for solutions that fit the cultural and religious values of the majority, while ensuring that minorities are still entitled to the right of choice in all forms of medical treatment.

Discussion Questions

1. What fundamental implications are there if the right of choice for all patients is not honoured?
2. Which of the current practices and policies are harmful and/or helpful to preserving a patient's right of choice?
3. What can be done to lessen the emotional burden of families and legal trustees?
4. How can there be less ambiguity in rules and procedures, but still allow for outstanding situations to be dealt with on a case-by-case basis?



5. How can there be a greater consensus and sense of uniformity between the legal and medical systems in regards to unresponsive patients?
6. In what ways may both the professional autonomy of physicians and the personal autonomy of patients be honoured?
7. How can solutions be catered to the social, cultural, and religious needs of countries?

Further Reading

Ethics of Artificial Nutrition and Hydration:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3157529/>

Uniform Determination of Death Act:

http://www.lchc.ucsd.edu/cogn_150/Readings/death_act.pdf

Declaration of Geneva:

<https://www.wma.net/wp-content/uploads/2018/07/Decl-of-Geneva-v1948-1.pdf>

International Code of Medical Ethics:

<https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/>

Universal Declaration on Bioethics and Human Rights:

<http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/>



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