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Sector for Social and Human Sciences
Division of Ethics of Science and Technology
Secteur des sciences sociales et humaines
Division de l'éthique des sciences et des technologies
.....

BIOETHICS CORE CURRICULUM

SECTION 2: STUDY MATERIALS

ETHICS EDUCATION PROGRAMME

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INTRODUCTION

Background

On 19 October 2005, the 33rd Session of the General Conference of UNESCO adopted the *Universal Declaration on Bioethics and Human Rights* (hereafter referred to as the Declaration). The Declaration embodies a set of bioethical principles that has been agreed upon by 191 Member States of UNESCO after an intense elaboration and consultation process involving independent and governmental experts from all regions of the world. This set of bioethical principles provides a common global platform by which bioethics can be introduced and strengthened within each Member State, and UNESCO is mandated to promote, disseminate and elaborate these principles for practical purposes.

The core curriculum consists of two sections. Section 1 provides the core contents with objectives, syllabus and teacher manual for each unit of the curriculum. Section 2 (this document) contains the proposed study materials for each unit of the curriculum.

Justification

The UNESCO Bioethics Core Curriculum sets out to introduce the bioethical principles of the *Universal Declaration on Bioethics and Human Rights* to university students. Bioethics teaching has not been introduced in many universities in many countries. This UNESCO Bioethics Core Curriculum can provide an incentive to start introducing such teaching. Its contents are based on the principles adopted in UNESCO. It therefore does not impose a particular model or specific view of bioethics, but articulates ethical principles that are shared by scientific experts, policy-makers and health professionals from various countries with different cultural, historical and religious backgrounds.

The UNESCO Bioethics Core Curriculum furthermore presents a core: it defines what should be regarded as the minimum (in terms of teaching hours and contents) for appropriate bioethics teaching. It allows flexible application. It also invites teachers and students to expand its contents and approaches in diverse directions.

Focus of this section

While Section 1 provides a common framework that can be used in different settings, the focus of Section 2 is more heterogeneous. The bioethics principles need to be applied in different contexts and cultural settings. In these contexts and settings, specific value systems and ethical views need to be taken into account. Also, problems and cases will differ in various health care systems and national and regional conditions. This section will therefore offer a range of materials that should be regarded as suggestions and proposals, to be further specified and adapted by teachers. It should also be noted that the materials included in this section are primarily from UNESCO and other international organizations; however, teachers are encouraged to seek out other resources, especially from their own countries.

Work in progress

Efforts have been made to ensure that the references in this section cover a wide spectrum of opinions and materials so as to provide teachers with a broad and balanced menu to select from, and to avoid promoting any particular perspective. An extensive consultation process was also carried out to ensure the cultural sensitivity of the materials included in this section. However, it is recognized that there are other culturally and contextually relevant materials that could still be included. Teachers are invited to provide additional materials to be considered for inclusion in this section.

It is anticipated that Section 2 will be frequently revised to include additional study materials submitted from around the world.

Feedback

As they adapt the curriculum to their teaching styles and contexts, teachers are invited to submit additional modules they have developed around the core units of the syllabus as well as additional study materials that are deemed useful. Teachers are also encouraged to provide feedback on the core curriculum to enable UNESCO to improve the product.

Please submit all feedback and materials to:

Ethics Education Programme (Bioethics Core Curriculum)
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COURSE LEARNING OBJECTIVES

General Objective:

- Students should be able to identify ethical issues in medicine, health care and life science
- Students should be able to provide rational justification for ethical decisions
- Students should be able to apply the ethical principles of the *Universal Declaration on Bioethics and Human Rights*

UNIT 1	
Title	What is ethics?
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to recognize and distinguish an ethical issue from other issues 2. Students should be able to reason about ethical issues 	
Study Materials	
Cases	<p>Case 1: <u>Ethics and law</u> A 17 year old young woman is brought to the emergency room with a septic abortion. She is living separately from her parents, from whom she is estranged and who live in a distant town. Local law requires parental consent if there is an abortion in a minor. The patient is septic, blood pressure is stable, and antibiotics are started. The patient does not want her parents informed, but the practitioner is concerned about legal consequences if the patient is treated without parental consent.</p> <p>Case 2: <u>Conflict of interests</u> A seventy-six year old very wealthy woman is affected with mild dementia. Her children call on her doctor complaining of her spending habits of giving liberally to members of a church cult, whom they think are scheming to deprive her of her wealth. They are worried about their rights to her inheritance and request from the doctor to declare her incompetent to manage her financial affairs. The doctor dutifully advises his patient about the visit from her children and tells her that he does not think that a psychiatric consultation is in order. The doctor himself is a member of the same church cult.</p>
Readings	
Video/Movie	<p>Movie: <u>12 Angry Men (1957, Director: Sidney Lumet)</u></p> <ul style="list-style-type: none"> • 12 Angry Men is the gripping, penetrating, and engrossing examination of a diverse group of twelve jurors (all male, mostly middle-aged, white, and generally of middle-class status) who are uncomfortably brought together to deliberate after hearing the “facts” in a seemingly open-and-shut murder trial case. They retire to a jury room to do their civic duty and serve up a just verdict for the indigent minority defendant (with a criminal record) whose life is in the balance. • The jury of twelve “angry men,” entrusted with the power to send an uneducated, teenaged Puerto Rican, tenement-dwelling boy to the electric chair for killing his father with a switchblade knife, are literally locked into a small, claustrophobic rectangular room on a stifling hot summer day until they come up with a unanimous decision - either guilty or not guilty. The film examines the jurors’ deep-seated personal prejudices, perceptual biases and weaknesses, indifference, anger, personalities, unreliable judgments, cultural differences, ignorance and fears that threaten to taint their decision-making abilities, cause them to ignore the real issues in the case, and potentially lead them to a miscarriage of justice. • Fortunately, one brave dissenting juror votes “not guilty” at the start of the deliberations because of his reasonable doubt. Persistently and persuasively,

	<p>he forces the other men to slowly reconsider and review the shaky case (and eyewitness testimony) against the endangered defendant. He also chastises the system for giving the unfortunate defendant an inept “court-appointed” public defense lawyer who “resented being appointed” - a case with “no money, no glory, not even much chance of winning” - and who inadequately cross-examined the witnesses. Heated discussions, the formation of alliances, the frequent re-evaluation and changing of opinions, votes and certainties, and the revelation of personal experiences, insults and outbursts fill the jury room.</p> <ul style="list-style-type: none"> • This movie is based on a 1954 play by Reginald Rose, entitled “Twelve Angry Men”. • Running time: 96 minutes <p>Movie: <u>12 (2007, Director: Nikita Mikhailov)</u></p> <ul style="list-style-type: none"> • This is a partial remake of 12 angry men in Russian, about a juror blocking a near unanimous guilty verdict. The film is designed to explore society through twelve characters, telling the same story but from a different view point, bound together as they must solve the problem of a life that is unknown to them. That life is an orphaned Chechen youth accused of murdering his father, an officer in the Russian army. • Running time: 159 minutes
Role play	<p><u>Talk in Pairs</u></p> <ul style="list-style-type: none"> • Use this game to help students get to know one another and increase participation. Ask the students to talk to the person next to them using the following as possible topics: <ul style="list-style-type: none"> ◦ The legal system always leads to the most ethical outcome. ◦ To kill someone is always wrong no matter what. ◦ Positive discrimination for minorities improves our society. • Adapted from Game 5 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
Group discussion	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Divide into groups of 6 people with the goal of analyzing Case 1 following the procedures described in the Teacher’s Manual. <p><u>Group Discussion on Movie:</u></p> <ul style="list-style-type: none"> • After watching the video, a general discussion of its content will take place. The teacher should organize and conduct the debate. The goal of the discussion will be to see this movie as a process of deliberation, in order to take a wise decision about the case. One important point to be stressed is the difficulty of deliberating correctly, due to many constraints and biases, some psychological, other educational, characterological, etc. The first question to be asked is why these twelve men are so “angry”. And the answer is because they have anguish. Anguish is the general reaction against psychological

	<p>aggression. And we consider, in general, that everyone who argues against our opinions is assaulting us. This is the most important difficulty in the deliberation process: to assume that our own point of view is not absolute, that our reasons about something can't exhaust the matter and that the others, giving different or, even, opposite reasons, are not necessarily wrong, and can help us to progress in the analysis of problems. In order to take part in a true process of deliberation, it is necessary to have some intellectual modesty or humility, that is, the Socratic wisdom of "knowing that one does not know". This is the only way to be capable of listening to the others and progress all together in searching the truth. Deliberation is a rational process of interaction, in order to take wise decisions. And it works well when the final decision is wiser than that we were prone to take at the beginning of the process. In the movie the change of opinion of almost all the participants is evident; and the last opinion is also wiser than the first. This is the true test of consistency of a deliberation process.</p>
Other	<ul style="list-style-type: none"> UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs

UNIT 2	
Title	What is bioethics?
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the difference between medical ethics and bioethics 2. Students should be able to differentiate bioethics, law, culture, and religion 3. Students should be able to explain the principles of bioethics and how to balance these principles in practice 	
Study Materials	
Cases	<p>Case 1: <u>Medical professionalism</u> Dr. DL is the only doctor serving a small suburban community. Dr. DL is treating JT, the 22 year old son of the T family, for active venereal infection, which JT says he probably contracted in his relationship with a person in a nearby town. On testing JT, Dr. DL has found no evidence that he has contracted HIV infection. When Dr. DL's patient, Mr. MA, is in the doctor's office for treatment, he informs Dr. DL that his daughter, aged 17, is to marry JT in two months' time, and asks Dr. DL whether there is any health information about JT, who MA knows is a patient of Dr. DL's, which his daughter should know.</p> <p>Case 2: <u>Double loyalty of the psychiatrist</u> A child psychiatrist agrees to provide an expert opinion with regard to allegations of sexual abuse made by a six-year-old child. She submits her report to the judge after 3 months. During this work she notices that the child is the victim of great physical suffering, and so agrees to continue seeing the child, at the mother's request, for psychotherapy sessions. Six months later, she is summoned to court to give testimony regarding the affair for which she provided an expert opinion. She then realizes that she is, at that point, both expert witness and consulting doctor.</p> <p>Case 3: <u>Conflict of interests</u> A fifty year old psychiatrist hires a patient to clean her apartment. At the same time she is treating the patient for phobias with hypnosis after returning home in the evenings. The arrangement for her cleaning work was intended to provide a kind of 'payment' for the treatment she could not afford otherwise.</p>
Readings	<ul style="list-style-type: none"> • Ethics and Medical Professionalism, World Medical Association (WMA) - references to codes of ethics and other policies of the WMA and national medical associations and to recent statements on medical professionalism: http://www.wma.net/e/ethicsunit/professionalism.htm (English) http://www.wma.net/f/ethicsunit/professionalism.htm (French) http://www.wma.net/s/ethicsunit/professionalism.htm (Spanish) • <i>Guide No. 1: Establishing Bioethics Committees</i>, UNESCO, Paris, 2005: http://portal.unesco.org/shs/en/ev.php-URL_ID=7771&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>Guide No. 2: Bioethics Committees at Work: Procedures and Policies</i>,

	<p>UNESCO, Paris, 2005: http://portal.unesco.org/shs/en/ev.php-URL_ID=8767&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages)</p> <ul style="list-style-type: none"> • <i>WMA Medical Ethics Manual</i>, World Medical Association (WMA), 2005: http://www.wma.net/e/ethicsunit/resources.htm (English) http://www.wma.net/f/ethicsunit/resources.htm (French) http://www.wma.net/s/ethicsunit/resources.htm (Spanish)
Video/Movie	<p>Movie: <u>Wit (2001, Director: Mike Nichols)</u></p> <ul style="list-style-type: none"> • Vivian Bearing is a professor of English literature, who is known for her intense knowledge of metaphysical poetry, especially the Holy Sonnets of John Donne. Her life takes a turn when she is diagnosed with metastatic Stage IV ovarian cancer. Her oncologist, Dr. Harvey Kelekian, prescribes various chemotherapy treatments to treat her disease. As she suffers through the various side-effects (such as fever, chills, vomiting, and abdominal pain), she attempts to put everything in perspective. The story periodically flashes back to previous moments in her life, including her childhood, her graduate school studies, and her career before her diagnosis. During the course of the film, Vivian continually looks into the camera to narrate her feelings. As she grows increasingly ill, she agrees to undergo more tests and experimental treatments, even though she learns that the doctors treating her, including a former student in her class, Jason Posner, see her less as someone to save and more as a guinea pig for their treatments. The only person who seems to have any care for Vivian is Susie Monahan, one of the nurses. Late in Vivian's sickness, the only visitor she receives in the hospital is her graduate school professor, Dr. EM Ashford. Towards the end of her life, Vivian realizes that kindness is something she should have exhibited to more people. In her time of greatest need, she learns that human compassion was of more profound importance than intellectual wit. • The movie is based on a 1998 play of the same name by Margaret Edson. • Running time: 98 minutes <p>Movie: <u>The Doctor (1991, Director: Randa Haines)</u></p> <ul style="list-style-type: none"> • Dr. Jack MacKee has it all: friends, success, money, and no worries - that is, until he is diagnosed with throat cancer. He then experiences life as a patient, including the coldness and detachment of his former colleagues. He begins to empathize with the patient, which is a new experience for him. Eventually, he returns to work, and begins immediately to drill into the incoming interns (whom he has charge of) the perspective of the patient and the patient's experiences by making the new interns spend 72 hours as patients. • The movie is based on the 1988 memoir of real-life surgeon Ed Rosenbaum, entitled "A Taste of My Own Medicine". • Running time: 122 minutes
Role play	<p><u>Small Groups</u></p> <ul style="list-style-type: none"> • Have the students break into small groups of four. Give them one of the

	<p>following cases to discuss, ultimately making an ethical decision that affects clinical outcome (like a hospital ethics committee might):</p> <ul style="list-style-type: none"> ○ A young woman is 16 weeks pregnant and arrives at the hospital to request a termination of the pregnancy because she is in a violent relationship. She will be unable to leave the relationship if she has the child as she has no financial means to support herself and no family. In this country abortion is only legal if there is “significant risk of harm to the mother”. The doctor approaches you, the ethics committee, and asks for advice. ○ An eminent doctor who makes a lot of money for the hospital in research and brings in much prestige has admitted to you that he has been drinking small amounts of alcohol at work for many years. This doctor has never been accused of negligent practise or been reported for unprofessional behaviour in the past. As his employer, what is the appropriate course of action? <ul style="list-style-type: none"> • Adapted from Game 8 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
<p style="text-align: center;">Group discussion</p>	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Should the doctor inform Mr. MA of JT’s previous venereal infection? What are the competing ethical principles? <p><u>Group Discussion on Case 2:</u></p> <ul style="list-style-type: none"> • Is this a conflict of interest? Justify your answer. <p><u>Group Discussion on Case 3:</u></p> <ul style="list-style-type: none"> • Present an argument that justifies this arrangement. Now contrast that with the argument against this arrangement. What is the balance of benefit and harm? <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Discussion about the description of the field of bioethics in Article 1 Paragraph 1 of the <i>Universal Declaration on Bioethics and Human Rights</i>: “Ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions.” • Discussion about the definition of health stated by the World Health Organization (WHO). It states “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946).
<p style="text-align: center;">Other</p>	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 3	
Title	Human dignity and human rights (Article 3)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain and apply the concepts of human dignity and human rights 2. Students should understand the relevance of these concepts in the context of bioethics 	
Study Materials	
Cases	<p><u>Case 1: Protecting a prisoner’s dignity</u></p> <p>B is a prisoner serving a 20-year sentence handed down in 1996. The jury convicted B of the offense of conspiring to commit an act of terrorism, and he is considered a high-risk prisoner. In August 2006, B was referred for medical treatment after being diagnosed with testicular cancer. B was handcuffed on the way to and from the hospital for treatments. On several occasions prison officers were present at B’s medical consultations and treatment despite the sensitive nature of his condition. B had an operation to remove one of his testicles. He was handcuffed when he went into surgery, and still handcuffed when he awoke from the anaesthetic. He was also handcuffed on his way back to prison. Moreover, B has allegedly been required to supply samples, including semen samples, while in the presence of prison officers. On other occasions, he allegedly had to provide semen samples with one hand handcuffed. B claims that during his various medical consultations and treatments, he felt humiliated and demeaned and suffered from pain and discomfort. His privacy was invaded at a time he was feeling vulnerable.</p> <p><u>Case 2: Prolonging the life of infants</u></p> <p>Baby J was born very prematurely on May 28, 1990 after 27 weeks of gestation. He weighed only 1.1 kg at birth. During his short life, he has suffered almost every conceivable misfortune. He was not breathing at birth and almost immediately was placed on a ventilator. He was administered intravenous antibiotics to counteract infection. His pulse rate frequently dropped very low, and for the first ten days of his life his survival was touch and go. By September 1990, when J was only three months old, he had already been ventilated on two occasions for a total of six weeks. J’s current status is that he is severely brain damaged due to oxygen deprivation and impaired blood supply around the time of his birth. This damage is permanent, and the brain tissue lost is irreplaceable. It is debatable whether he will ever be able to sit up or hold his head upright. J appears to be blind, although he may possibly regain some degree of sight. He is likely to be deaf as well. He may be able to make sounds that reflect his mood, but he is unlikely ever to be able to speak. It is highly unlikely that he will develop even limited intellectual abilities. Most unfortunate of all, he is likely to be able to feel the same extent of pain as a normal baby because pain is a very basic response. He may achieve the ability to smile and cry. Finally, as one might expect, his life expectancy has been considerably shortened; at most he will live into his late teens, but will probably die long before then.</p> <p>J is not terminally ill, and he is not at the point of death or of dying. At the moment J appears to be stable and is breathing independently. In some ways his condition has slightly improved. Nevertheless, this improvement is fragile and a crisis could occur</p>

	<p>again at any time.</p> <p>The doctors responsible for J’s care have unanimously agreed that they do not wish to give J further prolonged ventilation and intensive care if and when such need should arise. One doctor, however, thought that a situation might arise in which very short-term ventilation might be appropriate. The other doctors stressed that such treatment is very unpleasant and distressing to J. The position of J’s parents is not consistent. At first, they accepted the doctors’ recommendations, but now they want J to be given any chance possible.</p> <p>Case 3: Claim of “wrongful life”</p> <p>Prior to her marriage, A consulted a genetic counsellor. She wanted to know whether her future descendants were at risk of developing a particular heredity syndrome known as Hunter’s disease, which ran in her family. If she were to discover that her descendents were at risk, she was determined not to give birth to boys as the disease primarily affects males. Due to negligence in carrying out the tests or in interpreting the results, the genetic counsellor determined that there was no risk of A’s descendants being afflicted with the disease. Based on the consultant’s opinion, A became pregnant and gave birth to a baby boy with Hunter’s disease. The disease severely damaged his physical and mental development.</p> <p>It should be noted that there were only two possibilities for A’s son: to be born with this disease or not to be born at all. There was no other medical option to enable him to be born without this heredity disease.</p>
Readings	<ul style="list-style-type: none"> • UNESCO, 2011. <i>Casebook on Human Dignity and Human Rights</i>, Bioethics Core Curriculum Casebook Series, No. 1, UNESCO: Paris, 144pp.: http://unesdoc.unesco.org/images/0019/001923/192371e.pdf • Andorno, R. 2009. ‘Article 3: Human Dignity And Human Rights’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 91-98: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>Universal Declaration of Human Rights</i>, UN General Assembly Resolution 217 A (III) of 10 December 1948: http://www.un.org/Overview/rights.html (multiple languages) • <i>Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine</i>, Council of Europe CETS No.164, 4.IV.1997: http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm (English) http://conventions.coe.int/Treaty/fr/Treaties/Html/164.htm (French) • “Human Dignity”, The President’s Council on Bioethics: http://www.bioethics.gov/topics/human_dignity.html • Bioethics and Human Rights Links: http://www1.umn.edu/humanrts/links/bioethics.html • <i>Declaration on Patient-Centred Healthcare</i>, International Alliance of Patients’ Organizations (IAPO): http://www.patientsorganizations.org/showarticle.pl?id=712&n=312

	<ul style="list-style-type: none"> • <i>The Barcelona Declaration on Policy Proposals to the European Commission on Basic Ethical Principles in Bioethics and Biolaw</i>, European Commission funded BIOMED-II Project, 1998: http://www.ethiclaw.dk/publication/THE%20BARCELONA%20Dec%20Ene%20lsk.pdf (English) http://www.ethiclaw.dk/publication/barcelonaFratxtFinal9909.pdf (French)
Video/Movie	<p>Movie: <u>My Sister's Keeper (2009, Director: Nick Cassavetes)</u></p> <ul style="list-style-type: none"> • Anna is not sick, but she might as well be. By age thirteen, she has undergone countless surgeries, transfusions, and shots so that her older sister, Kate, can somehow fight the leukemia that has plagued her since childhood. The product of preimplantation genetic diagnosis, Anna was conceived as a bone marrow match for Kate - a life and a role that she has never questioned ... until now. Like most teenagers, Anna is beginning to question who she truly is. But unlike most teenagers, she has always been defined in terms of her sister - and so Anna makes a decision that for most would be unthinkable ... a decision that will tear her family apart and have perhaps fatal consequences for the sister she loves. <i>My Sister's Keeper</i> examines what it means to be a good parent, a good sister, a good person. Is it morally correct to do whatever it takes to save a child's life ... even if that means infringing upon the rights of another? Is it worth trying to discover who you really are, if that quest makes you like yourself less? • This movie is based on a 2004 book of the same name by Jodi Picoult. • Running time: Not available at time of writing <p>Movie: <u>The Doctor (1991, Director: Randa Haines)</u></p> <ul style="list-style-type: none"> • Dr. Jack MacKee has it all: friends, success, money, and no worries - that is, until he is diagnosed with throat cancer. He then experiences life as a patient, including the coldness and detachment of his former colleagues. He begins to empathize with the patient, which is a new experience for him. Eventually, he returns to work, and begins immediately to drill into the incoming interns (whom he has charge of) the perspective of the patient and the patient's experiences by making the new interns spend 72 hours as patients. • The movie is based on the 1988 memoir of real-life surgeon Ed Rosenbaum, entitled "A Taste of My Own Medicine". • Running time: 122 minutes
Role play	<p><u>Debate</u></p> <ul style="list-style-type: none"> • The concept of a Socratic debate in philosophy is one that has developed in many countries over a long time. Divide the students into two groups of three; allocate one group representing the "affirmative" and one the "negative". One person should also be allocated "chair" and be advised that they shall be enforcing the rules (i.e. only one person speaking at a time and time limits). • Ask the students to consider the following question and the two corresponding statements: <ul style="list-style-type: none"> ○ Are criminals whose prefrontal cortex is damaged responsible for their criminal behaviour?

	<ul style="list-style-type: none"> ▪ Criminals with prefrontal cortex damage should not be punished in jail but should be rehabilitated ▪ If we have methods to modify the behaviour of these criminals by brain surgery and/or drugs, we should do that, even if they do not agree <ul style="list-style-type: none"> • Depending on their group, they shall have to argue for or against each of the statements, regardless of their personal beliefs. It is a good idea to give the students the question and statements the week prior to give them time to prepare. • Adapted from Game 11 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Haifa: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
Group discussion	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Should a physician interfere in situations in which a patient is handcuffed or is unable to obtain privacy during medical treatments? • How should individual rights be weighted in comparison to the need to protect society? • Does being a criminal remove a person’s right to respect for their dignity? <p><u>Group Discussion on Case 2:</u></p> <ul style="list-style-type: none"> • Should the doctors put J on a mechanical ventilator and subject him to the intensive care associated with this treatment if in the future he suffers another collapse and cannot continue breathing unaided? <p><u>Group Discussion on Case 3:</u></p> <ul style="list-style-type: none"> • Is it possible to have a situation in which not existing at all (as distinguished from death) is better than living? <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • What does human dignity mean in your culture?
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages) • Tolstoy, L. 1886. <i>The Death of Ivan Ilyich</i> (Novel), Russia: http://www.pallcare.ru/en/?p=1175101312 (English) http://az.lib.ru/t/tolstoj_lew_nikolaewich/text_0136.shtml (Russian)

UNIT 4	
Title	Benefit and harm (Article 4)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to identify harms and benefits in health care settings 2. Students should be able to evaluate harm and benefit in health care settings 3. Students should be able to justify decisions taking harms and benefits into account 	
Study Materials	
Cases	<p>Case 1: <u>Treatment through a 3rd party</u></p> <p>A 43 year old patient has had schizophrenia since he was 20. At the moment, he has a chronic form of schizophrenia, marked by chronic deficits, dominant negative symptoms, and the constant presence of delusions.</p> <p>The patient's condition is known from reports by the patient's mother because he refuses to consult a doctor. He has never been aggressive to others and has never met the criteria for compulsory hospitalization.</p> <p>Recently, his mother has noticed a worsening in his condition, including intensified positive symptoms that impair his social functioning. She asked for compulsory treatment. The psychiatrist, acting in the best interests of the patient, prescribed risperidone in liquid form to be added to his soup by the mother.</p> <p>This treatment has had a good result. The patient began walking his dog for the first time in six years.</p> <p>Case 2: <u>Confidentiality of HIV/AIDS patients</u></p> <p>PD went to the Medical Centre with her future husband FH to have pre-marital blood tests to ensure that neither of them carried any sexually transmitted disease. At the time of their joint consultation, PD and FH were not living together, though they engaged in sexual relations and practised protected sex. FH came to the Centre for testing at PD's request. She was concerned about her future husband's STD status because he came from a country where the prevalence of sexually transmitted diseases was significantly higher than usual.</p> <p>The doctor was aware of the purpose of the test and of PD's concerns. Yet he did not inform either PD or FH that, in the absence of their consent, he was legally prohibited from disclosing any information concerning the HIV or AIDS status of one partner to the other. They did not discuss how the test results were to be dealt with. PD believed she would have FH's results and he would have hers, but the topic was not specifically raised.</p> <p>PD and FH each answered intrusive questions about their sexual behavior in the presence of the other.</p> <p>Both PD and FH gave blood at the joint consultation in the presence of the other, and then left the surgery. The doctor told them to return to his surgery in about a week's time when the pathology tests would be available.</p> <p>A week later, the doctor received PD's pathology report, which was negative for both hepatitis B and HIV. The following day, he received FH's pathology report, which was positive for hepatitis B and HIV.</p>

	<p>PD returned to the Centre sometime between one and two weeks after the initial consultation. The receptionist gave her a copy of the pathology report relating to her. She asked for a copy of FH’s pathology report, but was told that it was confidential and could not be given to her. The receptionist did not make any mention that if FH gave his consent, she could be given FH’s pathology report.</p> <p>The doctor informed FH by telephone that he had tested positive but did not inform PD of FH’s results. Furthermore, the doctor did not take any steps to ensure that FH inform PD of his test results. The doctor also did not try to get FH to consent that the clinic or himself disclose this information to PD.</p> <p>FH mislead PD and told her he had tested negative.</p> <p>A few years later, PD became aware that she was HIV positive.</p> <p>Case 3: “Therapeutic” amputation</p> <p>A middle aged man has had since childhood an all consuming sense that one of his legs does not belong to him. He has long had the desire to “lose” it and is adamant that it is not his.</p> <p>A reputable surgeon considers operating on the patient, and requests a psychiatric assessment of the patient. This assessment concludes that the patient is not psychotic but suffers from “body dysmorphic disorder” and truly believes that his leg does not belong to him. The report, however, does not recommend amputation.</p> <p>The surgeon performs the amputation. Following this the patient describes himself as “complete”.</p> <p>Case 4: Cosmetic surgery on a teen minor</p> <p>S is a 17-year-old boy with a condition known as bilateral gynaecomastia, or enlarged breast tissue. To avoid great embarrassment and the suffering caused by ridicule from his peers, S never swam, never went to the beach, and never engaged in any activities that might expose his chest to view.</p> <p>Gym days at school were particularly difficult for S. Although he eventually lost a significant amount of weight and went down eight clothing sizes, S’s gynaecomastia was not dispelled. S thus continued to avoid situations where his condition would be apparent to others. Moreover, although he was accepted for admission to an out-of-state university, he decided not to attend as he did not want to live in a dormitory where he anticipated being subjected to ridicule.</p> <p>Dr. G, S’s paediatrician, recommended surgery to eliminate S’s “deformity” and its consequent emotional pain. According to Dr. G, the procedure was medically necessary.</p>
Readings	<ul style="list-style-type: none"> • UNESCO, 2011. <i>Casebook on Benefit and Harm</i>, Bioethics Core Curriculum Casebook Series, No. 2, UNESCO: Paris, 140pp.: http://unesdoc.unesco.org/images/0019/001923/192370e.pdf • Pellegrino, E.D. 2009. ‘Article 4: Benefit And Harm’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 99-109: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E

	<ul style="list-style-type: none"> • <i>World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects</i>, WMA, 2008: http://www.wma.net/e/policy/b3.htm (English) http://www.wma.net/f/policy/b3.htm (French) http://www.wma.net/s/policy/b3.htm (Spanish) • <i>International Ethical Guidelines for Biomedical Research Involving Human Subjects</i>, Council for International Organizations of Medical Sciences (CIOMS), 2002: http://www.cioms.ch/frame_guidelines_nov_2002.htm
Video/Movie	<p>Video: <u>Obedience (The Milgram Experiment, 1962)</u></p> <ul style="list-style-type: none"> • This video documents the work of Stanley Milgram, a psychologist who tested the willingness of subjects to follow direct orders to inflict pain on other humans. This experiment raises many ethical issues because the study's subjects were deceived about the true intention of the experiment and were put under more pressure than many believe was necessary. • Running time: 45 minutes • The video is available for purchase from Penn State Media Sales (University of Pennsylvania) at: http://mediasales.psu.edu/ <p>Video: <u>Stanford Prison Experiment (1971)</u></p> <ul style="list-style-type: none"> • This video documents the 1971 experiment of Stanford psychologists who set up a mock prison, with subjects acting as guards and as prisoners. It shows the willingness of the guards to persecute the prisoners when in role play, as well as the prisoners increasing tolerance to persecution. • Running time: 50 minutes • The video is available for purchase from the Stanford Prison Experiment's official website at: http://www.prisonexp.org/. The website also contains a slide show providing details about the experiment.
Role play	<p><u>Moral Continuum</u></p> <ul style="list-style-type: none"> • A statement is made and the students are asked to stand in a U-shaped line facing each other to form a continuum based on their view between two extremes along a moral continuum. Students are then asked to give explanations as to why they are standing on that point in the line. Then students will move to the appropriate point in the moral continuum so that they are more positive or negative than their immediate neighbours according to side. • Start with a general question, then give a modified question and students can move up the continuum to new positions. Use situations where benefit and harm must be weighed against each other like the cases above. • Adapted from Game 4 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
Group discussion	<p><u>Group Discussion on Case 1:</u></p>

- Should the psychiatrist have been allowed to collaborate with the mother by assisting her in administering medication to the patient without his knowledge?

Group Discussion on Case 2:

- Should the doctor, in his position as physician for both PD and FH, have disclosed to PD that FH was HIV positive because of the joint consultation?

Group Discussion on Case 3:

- Can this amputation be referred to as “therapeutic”?
- Do the psychological benefits in this case outweigh the harm incurred by amputating a healthy limb?

General Group Discussion: Discuss the case of infertility

- Formulate an answer to the following questions:
 - Is infertility a health need?
 - Are the benefits afforded by such treatment health benefits?
 - Should scarce health funds be used for providing treatments for infertility?
- Background:
 - For centuries the inability of couples to produce their own children was blamed on the female partner who was described as barren. We now know that in at least half of the cases of infertility the problem lies with the male partner rather than the female, and is usually connected to an inadequate production of sperm. This knowledge has come as a great relief to many women who suffered irrational guilt, anxiety and social disapproval for not being able to become mothers. But such a relief is a small comfort to them when nothing can be done to address the issue of their childlessness except artificial insemination.
 - In limited numbers of cases women with disease conditions which caused their infertility could be treated for those diseases, or the results of them, and their fertility could be restored. Tubal surgery is still performed for this purpose. Such treatments enjoy limited success. But they also leave unhelped couples whose infertility is not explained and those whose infertility is due to their male partner’s problems. The technological breakthrough of *in vitro* fertilisation (IVF) in the late 1970s afforded clinical hope for these couples. Professor Robert Edwards (United Kingdom) has reported that by the year 2002 more than a million children had been born as a result of the use of this technology and that by 2012 he estimates that ten million people will be alive who were born by these means. But the provision of these services has been the subject of continued dispute amongst health care providers in numerous parts of the world.
 - The problems can be seen to arise from the difficulties presented by

	<p>the temptation to assume that health is fundamentally constituted by the absence of disease. This is clearly demonstrated in a comparison of the behaviour of a number of health providing authorities in the United Kingdom (in 1993). Half of them refused to purchase IVF treatments whilst the other half did purchase them. The reasons for their choices are illuminating. The predominant reason given by the non-purchasers of IVF services was that couples with unexplained infertility were not ill and that their infertility was not a disease. Even some of the purchasers gave reasons which also embodied the assumption of the need to relate the treatment to disease in that they purchased the services as a prophylactic designed to ward off the onset of stress and mental illnesses which often arise from infertility.</p> <ul style="list-style-type: none"> ○ Others paid lip service to the importance of social aspects of the condition but in such a way as to bar it from treatment. The view was that the condition of childlessness was a social rather than a health need. It is the case that the use of IVF does not really constitute a treatment of infertility as such but rather that of childlessness. This is because the treatment leaves the couple as infertile as they were before that condition was circumvented to achieve a pregnancy. But to disengage such physiological conditions from the context in which they occur, as these non-purchasers did, is a sure way to misidentify health needs and benefits. ○ It is not difficult to make a case for regarding infertility as a health need in certain circumstances and, hence, to regard its clinical circumvention as a health benefit. It is acknowledged by all that the condition is a source of much unhappiness and stress causing suffering for many couples. It is also clear that it constitutes a physiological dysfunction. The function of procreation is a fundamental physiological function at the species level. But it is also an extremely important function at the personal level for the vast majority of people for whom living in and rearing families is a major constituent of emotional wellbeing. For the infertile couple who long for a child the dysfunction is socially debilitating. We have already noted that other dysfunctions such as the loss of limbs are standardly treated by health care professionals because of their socially significant consequences. So why not infertility or, rather, childlessness? Until the advent of IVF and the subsequent research on the early stages of human development and reproduction there was little that could be done to address the condition for most couples. Thus they could not then be said to have any need for clinical treatment. But now that we do have clinical means to circumvent their infertility and enable them to achieve a pregnancy in many cases they can be said to have a clinical need. This is tantamount to saying that they have a health need and that the successful bringing to birth of a child constitutes a health gain. ○ It now begins to look as though the amended WHO definition of health does, after all, serve the purpose of identifying what shall count as a health benefit if we add the rider that where a clinical intervention can achieve the possibility of a socially productive life then it achieves
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	<p>a health benefit. Nevertheless this is not quite so. One might be tempted to read it as suggesting that wherever infertility is found then it represents a physiological dysfunction which calls for treatment. But this would be a mistake. It is possible to argue that no physiological condition in itself constitutes a health need. That is, until the condition is cast in the context of the life of the person or persons concerned we cannot know whether it is a health need or not. This is easily demonstrated in the case of infertility or childlessness. It is ironic that in many areas where IVF services are not accessible to patients contraceptive and sterilisation services are available. Of course in some cases sterilisation, for example, is thought to be an important clinical treatment to avoid the possibility of diseases unrelated to reproduction. But in most cases it is offered in order to produce a desirable biological dysfunction for the patient concerned. This is because for those patients their fertility is seen as constituting a health need and the state of childlessness, whether temporary or permanent, is seen to be a desirable condition. Thus in the process of identifying possible health benefits it is important to consider the particular circumstances of each patient in question in order to see whether the apparently general rule in fact applies.</p>
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 5	
Title	Autonomy and individual responsibility (Article 5)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the concepts of autonomy and individual responsibility and to understand their significance for the health care provider-patient relationship 2. Students should understand the relationship between autonomy and individual responsibility 	
Study Materials	
Cases	<p>Case 1: <u>Autonomy and genuine decision-making</u></p> <p>A 25 year old man goes to see a psychiatrist for the first time. He is accompanied by his father, who says that his son has been acting strangely for the last three weeks. He is seen on his own by the psychiatrist, and the young man describes the aural hallucinations that he has been having for three weeks. His discourse reveals an intense, invasive mystical delusion, with no signs of being dangerous. The psychiatrist diagnoses an acute psychotic episode and fears that it marks the beginning of schizophrenia. He wants to start neuroleptic treatment as soon as possible and tells the patient so. He explains the benefit of swift treatment and the possible side effects of the medicine. The patient refuses the treatment, fearing that his intellectual capacities will be harmed. The psychiatrist then sees the patient again in the presence of his father, to explain the situation. At this point, the patient agrees to the treatment as he thinks that his father is the “emissary of God” and he must obey him.</p> <p>Case 2: <u>Informed consent</u></p> <p>A 42 year old Aboriginal woman with a diagnosis of residual schizophrenia is functioning well and is symptom free for many years. She was admitted with suicidal ideation in the context of an unplanned and unwanted pregnancy. She has two adult children, both of whom were removed from her care at an early age. She considered termination of pregnancy, although with overwhelming feelings of guilt: the thought of a new baby was reprehensible for her. Pregnancy was the result of a casual encounter with her cousin who is regarded as an elder in the Aboriginal community. The father of the unborn baby was unaware of pregnancy. She continued to think about termination and time became critical. The patient’s mental health deteriorated, initially with depression, then psychosis. Her capacity to give informed consent became impaired as her mental state deteriorated. Pharmacotherapy was required, but the issue of safety in pregnancy prevailed. She is pressured by elders to give the baby to a childless, schizophrenic, younger sister (age 32). As she had an idealized transference towards her consultant, she refused to speak with nursing staff or with registrar. She wanted the consultant to make the decision for her: “I will do whatever you say”.</p>
Readings	<ul style="list-style-type: none"> • Evans, D. 2009. ‘Article 5: Autonomy And Individual Responsibility’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 111-121: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>World Medical Association Declaration on the Rights of the Patient</i>

	<p>(<i>Declaration of Lisbon</i>), WMA, 2005: http://www.wma.net/e/policy/14.htm (English) http://www.wma.net/f/policy/14.htm (French) http://www.wma.net/s/policy/14.htm (Spanish)</p> <ul style="list-style-type: none"> • <i>The Barcelona Declaration on Policy Proposals to the European Commission on Basic Ethical Principles in Bioethics and Biolaw</i>, European Commission funded BIOMED-II Project, 1998: http://www.ethiclaw.dk/publication/THE%20BARCELONA%20Dec%20Ene%20lsk.pdf (English) http://www.ethiclaw.dk/publication/barcelonaFratxtFinal9909.pdf (French)
Video/Movie	<p>Movie: <u>EXIT: The Right to Die (2005, Director: Fernand Melgar)</u></p> <ul style="list-style-type: none"> • No one knows the day or the hour. When illness strikes, accompanied by pain and physical decline, there we are, faced with death. The outlook on what remains of life appears dismal and full of anguish. How to spare oneself, and one's closest family, painful agony? Switzerland is the only country in the world where associations, such as EXIT, quite legally provide suicide assistance to people at the end of their lives. For over twenty years volunteers have accompanied sick and handicapped people towards a death of their choice that seems more dignified to them. In this documentary, these escorts and the people they accompany tackle death head-on. Not like a taboo or an unacceptable end, but like a release. In a society tending to control everything, they refer us back to this quintessential, intimate question: Is choosing our death not our ultimate freedom? • Running time: 75 minutes • Official website of the documentary: http://www.climage.ch/qsPortal/Home.asp?C=593&N=716 <p>Movie: <u>Whose Life Is It Anyway? (1981, Director: John Badham)</u></p> <ul style="list-style-type: none"> • The movie revolves around Ken Harrison, a sculptor who is left a quadriplegic after a car accident. Ken feels that he is now useless as an artist and human being, and is determined that he should be allowed to die. The movie presents arguments for and against euthanasia, scrutinizing the moral and ethical dilemmas of this practice. It also examines the legal obstacles to a patient's ability to exercise the right to die. • The movie is adapted from the 1972 television movie and play of the same name. • Running time: 119 minutes <p>Movie: <u>The Sea Inside (2004, Director: Alejandro Amenabar)</u></p> <ul style="list-style-type: none"> • The movie is based on the real-life story of Ramón Sampedro, a Spanish ship mechanic left quadriplegic after a diving accident. Sampedro fought a 28-year campaign in support of euthanasia and his right to end his own life. • Running time: 125 minutes
Role play	<u>Small Groups</u>

	<ul style="list-style-type: none"> • Have the students break into small groups and discuss the following questions: <ul style="list-style-type: none"> ○ What is autonomy? ○ How has each student in the group expressed her/his autonomy to make herself/himself look different from other persons? What have each person done to look the same? ○ Are there limits to the expression of autonomy that people have? • Adapted from Game 8 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html <p><u>Mapping Social Networks</u></p> <ul style="list-style-type: none"> • Individuals and small groups can make social network maps. First they need to agree on which person to map, and then on any limits to the relationships to map. For example, the relationships of the person drawn at the centre of the map may be limited to human beings, or include ecosystems and the environment, or just sentient animals. The group should then draw other people (or items) with whom they have important relationships on the map. Use lines and arrows to indicate relationships. Use different coloured lines to show different kinds of relationships, e.g., ‘helping’ relationships, friendships, business relationships, ecological relationships, and so on. Use distance between people (or items) and the central person on the map to show the importance of the relationship – the closer to the person, the more important. • Divide the class into small groups of 3 to 5 students. Ask for a volunteer within each group to be the central figure for whom the social network map is to be created. Each group is to create a social network map based on the following questions: <ul style="list-style-type: none"> ○ If you visit a doctor, do you make treatment decisions on your own or in discussion with other family members, and the doctor? Who else affects your treatment decisions? • Discuss what is shown on the map, and let the whole class compare the different maps made in each small group. • Adapted from Game 34 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
<p style="text-align: center;">Group discussion</p>	<p><u>General Group Discussion: Discuss the following case</u></p> <ul style="list-style-type: none"> • Case description: <ul style="list-style-type: none"> ○ A patient is bleeding profusely post-operatively. He is sedated and partially unaware of his surroundings. The patient, who has strong religious convictions, informed the doctor prior to the operation that he did not want a blood transfusion under any circumstances, stating that this is a “fate worse than death” according to his religion. The doctor predicts that without blood he will die and gives three units of blood to

	<p>the patient, plus multiple blood products designed to aid clotting. Three weeks later the patient is discharged with his spouse and three children, fully recovered from his operation. The patient is never informed of the transfusions given whilst he was sedated.</p> <ul style="list-style-type: none"> • Discuss the following questions based on the case above: <ul style="list-style-type: none"> ○ Keeping in mind that a blood transfusion is a “fate worse than death” for this patient, did the end justify the means? ○ What is good about paternalism? ○ What is bad about autonomy? <p><u>General Group Discussion</u></p> <ul style="list-style-type: none"> • Discuss the following statements and provide arguments for a positive as well as negative reply: <ul style="list-style-type: none"> ○ Every competent adult has the right to refuse unwanted medical treatment. ○ Is this right valid in a case of a pregnant woman who is refusing medical treatment for an illness that might impact the foetus? ○ Does a soldier have the right to refuse medical treatment that would render him/her to return to active duty? • There are several groups of people who are unable to exert their autonomy when making decisions about their health. How should decisions be made for the following groups of people and who should make them? <ul style="list-style-type: none"> ○ A child lives in an area where polio is prevalent but her parents refuse vaccination as they believe it is poison. ○ A 24 year old immigrant man with Guillain-Barre syndrome is trapped in his body, unable to speak or move. There is a very good chance he will improve with treatment but this will take months to years. His mother wishes to take him back to his home country as she is convinced he is going to die. However, you suspect that this country will not have the resources to provide adequate treatment.
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 6	
Title	Consent (Article 6)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the meaning of “consent”, “informed”, and “informed consent”; they should be able to define the principle of “informed consent” 2. Students should be able to explain what the process of informed consent requires 3. Students should be able to explain how the principle of consent is applied in different interventions, research, and teaching 4. Students should be able to explain how exceptions to the principle can be justified 	
Study Materials	
Cases	<p>Case 1: <u>Explanation needed</u></p> <p>A 72 year old male farmer with three children has been suffering from colon cancer. He described his illness as a “mass in the intestine” but he did not know what kind of a treatment modality would be needed. The day after the surgery, the assistant surgeon on duty visited the patient for routine inspection and treatment of the surgical wound. The patient, expecting to see a closed wound, was scared when he saw the opening of his colostomy. He asked the surgeon about “the hole in his abdomen”. The surgeon, in a serious manner, replied: “The end of the intestine that was operated on was sutured to your abdomen. You are now to defecate through this hole and into the bag I will place at the end of it”. Surprised and angered by the response, the patient asked: “Whom did you ask before opening that hole?” The surgeon told the patient that they had informed his son about the procedure. The patient shouted in anger: “Who was to be operated on and have a hole in his abdomen? Is it me or my son? How dare you perform that without asking me? I will sue all of you!” The surgeon, unprepared for such a reaction, slowly started to explain the reason why colostomy had been performed and referred to the patient’s disease as a “bad” one. After the explanation, the patient said: “If you had told me this earlier, I would not have shouted at you. I am not that illiterate, you know! I could understand”.</p> <p>Case 2: <u>Treatment without consent</u></p> <p>Mrs. ED is a 69 year old retired bank manager. She has been suffering from poorly controlled diabetes for the last 18 years. For the last 6 months she has needed hemodialysis twice a week for end-stage renal disease. Three days ago, she was hospitalized because of an infected non-healing wound at the amputated stump of her left leg. Two days later gangrene set in. Following a meeting of her diabetologist, infectious disease specialist, surgeon, and family it was decided to amputate. Her eldest son, a physician, agreed to the amputation but announced that no one should tell her about it. She would only be told that the wound would be “surgically cleaned”. Last year when the foot was to be amputated, Mrs. ED refused to give her consent. They did it without her consent and after her initial anger for a few days she appeared to understand the need and no longer blamed them. Her son anticipates the same reaction and feels informing her will only add more stress. Her husband and other children agree to the plan.</p>

Case 3: Informing the patient

Mr. SR is a 28 year old former graduate academic scholar at a prestigious Catholic university who left school to work full time with the poorest of the poor. He engaged in carrying heavy sacks of rice for some time in his new task. Eventually he developed moderate to severe low back pains which could not be relieved by resting and medications. He consulted an orthopedic surgeon who investigated him and discovered a protruding disc and suggested surgical correction but he informed SR that the operation carried a risk of permanent disability. SR was unhappy, apprehensive and decided to forgo the procedure and confined himself to chiropractic treatment. There was no benefit. SR consulted a second orthopedic surgeon who told him that under a skilled surgeon's hands the risk of surgery would be minimal. The second surgeon urged Mr. SR to ask him all the questions he wanted. But SR did not ask anything about the risk of permanent disability. As SR was an obviously anxious patient, the second surgeon held back information about this possibility; he did not go any further into the description of the risks.

Case 4: The right not to know

Mr. DA is a 55 year old salesman, married, with 3 children. He has been a heavy smoker for the last 30 years. He has a chronic productive cough, with moderate exercise dyspnea, both of which led to medical tests that resulted in a diagnosis of COPD 5 years ago. He has no other known medical disorders and does not take any regular treatment. During the last month, he has been suffering from hemoptysis. After some hesitation, he told this to his family, and they persuaded him to inform his family physician, who knew him well. Upon meeting with his family physician, he agreed to be referred to a pulmonologist and to undergo tests, such as a chest roentgenogram, but he requested that if a severe disorder was found, such as lung cancer, he should not be informed. He explained this request as due to his preference to be spared the heartbreak involved in such bad news, and he was not willing to discuss related treatment, such as surgery, radiation therapy or chemotherapy. The family physician explained to him the variability of prognosis of different types of lung cancer and the importance of the patient knowing the diagnosis, as he can then decide in an informed and perhaps more rational manner on treatment, but Mr. DA persisted in his request to waive the breaking of bad news.

Case 5: Refusal of treatment

A couple attended a fertility clinic wishing to conceive a child, and needed IVF treatment. In the female history, the woman reported that her father had Huntington's chorea, an autosomal dominant condition which presents in the fourth decade of life, and leads to dementia and an early death. The woman was in her early 30s. She had chosen not to be tested for the condition (she has a 50% chance of having it), as to find out that she has the condition would be psychologically too much to bear, and has implications for insurance purposes.

Case 6: Incompetent patients

A woman, 28 years of age, attends an occupational therapy day program at a local psychiatric hospital. She has mild mental retardation (IQ 65) and for the past month

has been diagnosed with AIDS. According to her psychiatrist, she was able to give informed consent for HIV testing after proper counselling had taken place. She has proven herself to be very promiscuous and in spite of ongoing psycho-education about her illness, the availability of condoms and her promises to practise safe sex, she just cannot act according to her knowledge. At the day program it is possible to ‘shadow’ her, but according to her mother her promiscuous behaviour poses a threat to herself and others in the community. Efforts to curb her sexual behaviour by means of an SSRI (Serotonin Reuptake Inhibitor) have failed. She is verbally quite strong, commutes to the hospital on her own by train, has many friends and lives with her mother and siblings within the community. The mother contacts her therapist and asks whether her daughter should not be institutionalized for the sake of her own safety and the safety of others.

Case 9: Minors

JB, a 5 year old girl, is brought to hospital by her parents with symptoms of fever and weakness. Upon further examination acute lymphocytic leukemia (ALL) is suspected, but a bone biopsy is required to confirm the diagnosis. The parents are informed of the procedure for the “bone marrow pin-prick” and give their consent. When a diagnosis of ALL is confirmed, the standard chemotherapy treatment is explained to the parents as well as the probable prolongation of life for a few years. On realizing the cost involved in this treatment and that “success” is not guaranteed, the parents are distraught and feel it is not worth continuing treatment.

Case 10: Unwitting Patient Participation in Research

Shortly after JM learned he had hairy-cell leukemia, he underwent treatment for the disease at the University Medical Center.

Dr. G, the physician who diagnosed the disease, was aware that certain blood products and blood components were of great value in a number of commercial and scientific efforts and that access to a patient whose blood contained these substances could offer competitive, commercial, and scientific advantages.

Dr. G recommended that JM’s spleen be removed, informing JM that his life was in danger and that the proposed splenectomy operation was necessary to slow down the progress of the disease. Based upon Dr. G’s representations, JM signed a written consent form authorizing the splenectomy.

Prior to the operation, Dr. G and Dr. Q made a decision to obtain portions of JM’s spleen following its removal and made arrangements to take these portions to a separate research unit. These research activities were not intended to have any impact upon JM’s medical care. However, neither Dr. G nor Dr. Q informed JM of their plans to conduct this research or requested his permission. JM’s spleen was removed.

After the surgery, JM returned to the University Medical Center several times at Dr. G’s direction. On each of these visits, Dr. G took additional samples of blood, blood serum, skin, bone marrow aspirate, and sperm.

Dr. G established a cell line from JM’s T-lymphocytes and a patent was issued for this cell line, naming Dr. G and Dr. Q as the inventors.

Readings	<ul style="list-style-type: none"> • Kollek, R. 2009. ‘Article 6: Consent’, in <i>The UNESCO Universal Declaration</i>
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	<p><i>on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 123-138: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E</p> <ul style="list-style-type: none"> • <i>Report of the International Bioethics Committee (IBC) of UNESCO on Consent</i>, UNESCO, Paris, 2008: http://portal.unesco.org/shs/en/ev.php-URL_ID=12581&URL_DO=DO_TOPIC&URL_SECTION=201.html • Carmi, A. (ed.) 2003. <i>Informed Consent</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=9210&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • Dickens, B.; Cook, R.; Kismodi, E. (eds.) 2006. <i>Medical ethics in reproductive health: Case studies</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=10667&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • Carmi, A.; Moussaoui, D.; Arboleda-Florez, J. (eds.) 2005. <i>Teaching Ethics in Psychiatry: Case-Vignettes</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=9211&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects</i>, WMA, 2008: http://www.wma.net/e/policy/b3.htm (English) http://www.wma.net/f/policy/b3.htm (French) http://www.wma.net/s/policy/b3.htm (Spanish) • <i>International Ethical Guidelines for Biomedical Research Involving Human Subjects</i>, Council for International Organizations of Medical Sciences (CIOMS), 2002: http://www.cioms.ch/frame_guidelines_nov_2002.htm
Video/Movie	<p>Video: <u>Informed Consent in Developing Countries (Dr. Asad Jamil Raja)</u></p> <ul style="list-style-type: none"> • Informed Consent in Developing Countries is a documentary filmed in Rehri Goth, a small fishing village outside Karachi where poverty and illiteracy are rife and medical care scarce. The film centres around a research project performed on pregnant women and premature infants, examining both community attitudes and those of the researchers to aspects of informed consent. It explores the concept of communal consent, the influence of gender and the impact of paternalistic attitudes on achieving true informed consent. • Special thanks to Dr. Asad Jamil Raja for granting permission to use this video as part of the UNESCO Bioethics Core Curriculum. Copyright and credit belongs to Dr. Asad Jamil Raja, Professor of Surgery, Department of Surgery, King Khalid University, P.O. Box 641, Abha, Kingdom of Saudi Arabia (Email: araja@kku.edu.sa; Tel: +966530984450). • Use of this video is strictly for educational purposes only, and the proper acknowledgement of credit and copyright must be given. • Running time: 28 minutes 11 seconds

	<ul style="list-style-type: none"> • Available for video streaming at: mms://stream.unesco.org/vod/informedconsentcomplete.wmv <p>Video: <u>Code of Silence - Medicine at the Crossroads Series, Vol. 2 (1993, Director: Stefan Moore and Martin Freeth)</u></p> <ul style="list-style-type: none"> • From the earliest times, the doctor-patient relationship has been central to the healing process, but medical technology has erected a barrier between patients and doctors who often cloak themselves in a code of silence. What is the role of communication in the healing process? Code of Silence takes a close-up look at two societies: Japan, where patients are routinely lied to, and the United States, where informed consent is the rule. • This documentary is produced for PBS by Thirteen/WNET, New York, NY, and BBC-TV, England, in association with Televisión Española, SA, and the Australian Broadcasting Corporation and WETA, Washington, DC. • Running time: 56 minutes • Please check your local university library or British Council for a copy of the video.
Role play	<p><u>Role Play: How to inform patients/subjects?</u></p> <ul style="list-style-type: none"> • Ask students to adopt the roles in the scenarios below: <ul style="list-style-type: none"> ○ A doctor informing a 40 year old patient that she has breast cancer, with one student as the doctor, one as the patient and one as the patient's aggressive husband. The patient needs to decide between mastectomy (surgical removal of the breast) and lumpectomy (surgical removal of the lump). ○ A psychiatrist informing a patient that she has a psychotic illness and that she needs to be started on long term medication. This patient is a highly intelligent university student who is paranoid and believes she is being monitored 24 hours a day but is otherwise continuing to function quite well. ○ A researcher seeking consent to trial a new drug on a patient with HIV and a predicted life expectancy of 3 years. The drug has multiple possible side effects, all remote but previously documented in preliminary trials. The side effects include renal failure, liver failure, cardiomyopathy and possibly hastened death. In most cases however, the drug proved safe and increased life expectancy by 10 years. ○ A doctor informing a subject that he has suffered a significant side-effect from a medication (i.e. an antibiotic), so severe as to suggest impending liver failure and likely long term liver dysfunction. The doctor needs to obtain consent from this patient to carry out a liver biopsy for further investigation. Patient is clearly distressed and angry at the physician. • Students should identify that if a patient is highly distressed (i.e. in the first case above) he/she is often not capable of providing informed consent. If a decision is not immediately required it should be postponed. • Adapted from Game 23 of Macer, D. 2008. <i>Moral Games for Teaching</i>

	<p><i>Bioethics</i>, UNESCO Chair in Haifa: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html</p>
Group discussion	<p><u>Group Discussion on Case 10:</u></p> <ul style="list-style-type: none"> • Should Dr. G, as JM’s physician, be involved in medical research that was not known to JM and that had no therapeutic value for JM?
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 7	
Title	Persons without the capacity to consent (Article 7)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the meaning of “capacity to consent” 2. Students should be able to explain the criteria of capacity to consent 3. Students should be able to explain how the criteria for consent are applied in different circumstances of treatment and research 	
Study Materials	
Cases	<p><u>Case 1: Medical treatment of teenagers</u></p> <p>A government body has issued guidelines on family planning services for young people. These guidelines state or imply that, at least in certain cases which are described as ‘exceptional’, a doctor can lawfully prescribe contraception for a girl under the age of 16 without her parents’ consent.</p> <p>The guidelines further state that a doctor should proceed on the assumption that advice and treatment on contraception should not be given to a girl under the age of 16 without parental consent and that the doctor should try to persuade the girl to involve her parents in the matter. Nevertheless, the principle of confidentiality between doctor and patient applies to a girl under 16 seeking contraceptives. Therefore in exceptional cases a doctor can prescribe contraceptives without consulting the girl’s parents or obtaining their consent if, in the doctor’s clinical judgment, prescribing contraceptives is desirable.</p> <p>Mrs. G, the mother of five daughters under the age of 16, objected to the guidelines and sought assurance from her local area health authority that her daughters would not be given advice and treatment regarding contraception without her prior knowledge and consent while they were under the age of 16.</p> <p><u>Case 2: Forced treatment of demented persons</u></p> <p>R, an 80 year old holocaust survivor living alone in her home, was born in Country P and was in a concentration camp until the age of 22. She lost her entire family during the war. After the war, she married and moved to Country A with her husband, but they had no children and only a few friends. Her only relative is an 84 year old sister who suffers from dementia and lives in a nursing home. R became depressed after the death of her husband from a stroke two years previously. She is also experiencing significant anxiety and difficulty in coping on her own. She has no previous mental history, but suffers from hypertension. While on treatment at home, she experienced severe nausea and vomiting from the antidepressants making it necessary to admit her, involuntarily, to a psycho-geriatric unit. A case manager was appointed with a view to organizing support at home. The patient was considered to be seriously depressed with persistent low mood, lack of energy and motivation, poor self-esteem, obsessive rumination, but no suicidal thoughts or psychotic symptoms were elicited. Minimental state was assessed at 27/30. The organic work-up was unremarkable. The neuro-psychology report showed a borderline to low-average range for executive function and memory. Although she reacted better to new medications and responded well to the support in the clinic, even participating in group activities, she continued to experience significant anxiety and suffered a relapse with deterioration of her</p>

mental state when advised that a guardian had been appointed. Although she accepted this decision, she objected to being placed in a nursing home, wishing to return home on her own and, yet, acknowledging that she would not be able to manage. Worsening depressive symptoms, severe agitation, expression of suicidal thoughts and deterioration in self-care occurred despite the current treatment with medications. On consultation, two psychiatrists recommended electroshock therapy (ECT), or adding another anti-depressant medication. She reluctantly accepted to take the new medication, but refused consent for ECT. Her guardian agreed that her doctor should go ahead and treat her with ECT.

Case 3: Forced treatment of persons permanently unable to make their own decisions

A is a 24 year old unemployed man, who used to live independently in a home adjacent to his parents' large property. He associated largely with "alternative" and "green" groups. He was referred to psychiatric services by the community outreach workers who had concerns about his physical and mental state. He had been subsisting on a skimpy vegetarian diet and appeared malnourished and emaciated. He could barely walk and had collapsed several times. At 184 cm and 44kg, his body mass index was only 13. His mother reported that he began to lose weight approximately four years earlier when he became interested in alternative medicine and dieting. He had read alternative nutrition materials and was convinced that fruitarians were happier people. He believed that non-organic foods were toxic to the vital organs and manufactured as part of food and drug "conspiracies". He claimed that dairy products were "mucous forming" around the throat, which interfered with absorption. He also believed that eating root vegetables meant "killing" the vegetable and that his fasting would make him live longer. Three years earlier he had moved into a van and isolated himself, was dishevelled, and walked around town with only a blanket on, becoming verbally aggressive when confronted. Eventually he began to suffer from urinary incontinence. On admission, despite his life threatening physiological changes, he insisted that his weight was adequate and maintained that if he had survived on his diet thus far, his food intake must have been adequate. He felt that people come in different shapes and sizes and commented that people who are obese are not locked up. He did not accept the abnormal results of his X-rays, blood tests, electrocardiogram, etc. He had no interest in contact with psychiatric services and he was generally mistrusting of doctors. A proved a difficult diagnostic and management problem. He required urgent nasogastric re-nutrition against his will as an involuntary patient. In undergoing such treatment, he felt that doctors were "fascist" and that, as a free citizen, he had the right to eat what he wanted and not have to adhere to conventional westernized ideals. He did not view himself as a mental patient, and accused the system of being intolerant of alternative lifestyles and beliefs.

Case 4: Experimental medical treatment of persons permanently unable to make their own decisions

JS is an 18 year old boy and JA is a 16 year old girl. Both suffer from variant Creutzfeldt-Jakob disease (vCJD). Although JS and JA are from separate and unrelated families, each has been afflicted by this appalling and fatal disease and each

	<p>is at a similar stage in the disease.</p> <p>Each one of them has changed from a normal, energetic teenager into a helpless invalid who lies in bed and whose ability to enjoy life is severely limited. JS and JA are cared for in their respective homes. Their families are extraordinarily dedicated and are providing their children a high standard of care.</p> <p>For each patient, the experts are in agreement about the state of the disease and its inevitable outcome in the absence of any new treatment. There is no cure, and to date no recognized effective drugs have been able to prolong life or arrest the continuing neurological deterioration. Both JS and JA are bound to die prematurely. Once the symptoms appear, the average patient lives for 14 months. Fifteen months have passed since JS began to show symptoms, while JA’s symptoms appeared three years ago. The fact that both young people are still alive is a tribute to the outstanding care they receive at home.</p> <p>The proposed treatment for both patients is identical and known as P. This treatment is new and so far has not been tested on human beings. Both families are very well informed about the disease and the proposed treatment, including its risks and possible benefits. Both families are strong advocates of the proposed treatment.</p> <p>The risks posed by P infusions are dose-dependent. At high doses P is toxic, and a balance must be achieved between effectiveness and potential toxicity. With the cautious dosage suggested in the trial protocol, the risk does not appear great, though the effects upon humans are of course unknown. The benefits to be gained from P infusion are less tangible and more difficult to assess. There might not be any obvious benefit or any benefit at all. At best, there might be some improvement. Another possibility is that the otherwise inevitable deterioration of the nerve cells would be arrested. The third possibility would be prolonging the life of the patient in his or her present state.</p> <p>Undisputedly, neither JS nor JA is competent to make decisions about this proposed treatment.</p>
Readings	<ul style="list-style-type: none"> • Martin, J.F. 2009. ‘Article 7: Persons Without The Capacity To Consent’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 139-153: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>Report of the International Bioethics Committee (IBC) of UNESCO on Consent</i>, UNESCO, Paris, 2008: http://portal.unesco.org/shs/en/ev.php-URL_ID=12581&URL_DO=DO_TOPIC&URL_SECTION=201.html • Carmi, A. (ed.) 2003. <i>Informed Consent</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=9210&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • Dickens, B.; Cook, R.; Kismodi, E. (eds.) 2006. <i>Medical ethics in reproductive health: Case studies</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=10667&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages)

	<ul style="list-style-type: none"> • Carmi, A.; Moussaoui, D.; Arboleda-Florez, J. (eds.) 2005. <i>Teaching Ethics in Psychiatry: Case-Vignettes</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=9211&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>Convention of the Rights of the Child</i>, UN General Assembly Resolution 44/25 of 20 November 1989: http://www2.ohchr.org/english/law/crc.htm (English) http://www2.ohchr.org/french/law/crc.htm (French) http://www2.ohchr.org/spanish/law/crc.htm (Spanish) • <i>Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine</i>, Council of Europe CETS No.164, 4.IV.1997: http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm (English) http://conventions.coe.int/Treaty/fr/Treaties/Html/164.htm (French) • <i>Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research</i>, Council of Europe CETS No.195, 25.I.2005: http://conventions.coe.int/Treaty/EN/Treaties/Html/195.htm (English) http://conventions.coe.int/Treaty/FR/Treaties/Html/195.htm (French) • <i>World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects</i>, WMA, 2008: http://www.wma.net/e/policy/b3.htm (English) http://www.wma.net/f/policy/b3.htm (French) http://www.wma.net/s/policy/b3.htm (Spanish) • <i>International Ethical Guidelines for Biomedical Research Involving Human Subjects</i>, Council for International Organizations of Medical Sciences (CIOMS), 2002: http://www.cioms.ch/frame_guidelines_nov_2002.htm
Video/Movie	<p>Video: <u>Informed Consent in Developing Countries (Dr. Asad Jamil Raja)</u></p> <ul style="list-style-type: none"> • Informed Consent in Developing Countries is a documentary filmed in Rehri Goth, a small fishing village outside Karachi where poverty and illiteracy are rife and medical care scarce. The film centres around a research project performed on pregnant women and premature infants, examining both community attitudes and those of the researchers to aspects of informed consent. It explores the concept of communal consent, the influence of gender and the impact of paternalistic attitudes on achieving true informed consent. • Special thanks to Dr. Asad Jamil Raja for granting permission to use this video as part of the UNESCO Bioethics Core Curriculum. Copyright and credit belongs to Dr. Asad Jamil Raja, Professor of Surgery, Department of Surgery, King Khalid University, P.O. Box 641, Abha, Kingdom of Saudi Arabia (Email: araja@kku.edu.sa; Tel: +966530984450). • Use of this video is strictly for educational purposes only, and the proper acknowledgement of credit and copyright must be given. • Running time: 28 minutes 11 seconds • Available for video streaming at:

	mms://stream.unesco.org/vod/informedconsentcomplete.wmv
Role play	<p><u>Head or Heart</u></p> <ul style="list-style-type: none"> • Give the students a question and ask them to make a choice. After they have made their decision, ask them to indicate whether they used their head or their heart or both by placing their hand on the head or over their heart. Ask the students to explain their decision making process. This can lead to a discussion about how we make decisions and what are our different influences. Example questions are: <ul style="list-style-type: none"> ○ Your sibling has meningitis and is currently on a ventilator. Even if they survive they will certainly be severely disabled, both physically and mentally. Your parents ask you if you think continuing treatment is appropriate and demand an answer. What do you say? ○ Your mother has kidney failure and the only compatible donor is your mentally handicapped sister who is terrified of doctors and hospitals. You have to consent or decline on her behalf. ○ You are offered a full genetic screen on your child, including diseases they may not actually develop but have a predisposition for. Do you say yes? • Adapted from Game 37 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Haifa: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
Group discussion	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Should a doctor ever, under any circumstances, give contraceptive advice or treatment to a girl under the age of 16 without her parents' consent? <p><u>Group Discussion on Case 4:</u></p> <ul style="list-style-type: none"> • Should JA and JS be treated with the proposed experimental treatment?
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 8	
Title	Respect for human vulnerability and personal integrity (Article 8)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the principle of respect for human vulnerability 2. Students should be able to analyse the interrelationship between present-day scientific medicine and human vulnerability and to illustrate the difficulties in this relationship with examples 3. Students should be able to specify the connections of the principle of respect for human vulnerability with the notion of personal integrity and with care ethics 	
Study Materials	
Cases	<p><u>Case 1: Bone marrow donation by a mentally ill patient</u></p> <p>Y, a 25 year old woman who is severely mentally and physically handicapped from birth, lives in a community home. Until the age of 10 she lived with her parents and three sisters in a close-knit family, and since moving to the home she has been visited regularly by her mother and sisters. Those visits are very important to Y, particularly because they maintain her link with the outside world, which is helpful to her and would otherwise be lost.</p> <p>Her eldest sister, B, aged 36, is married and has one daughter, E, aged 6. B suffers from a pre-leukaemic bone marrow disorder known as myelodysplastic syndrome. Her only realistic prospect of recovery is a bone marrow transplant from a healthy, compatible donor. Furthermore, bone marrow transplanted from a sibling is superior to a transplant from a stranger. Preliminary investigations show that of the three sisters, only Y would be a suitable donor. Without a transplant, B's prospects of survival are very poor and are deteriorating fast.</p> <p>Due to her disabilities, Y is unaware of her sister's illness and unable to consent to the tests and surgical procedure entailed in donating bone marrow. Y understands her own basic needs but cannot understand the needs of others.</p> <p>The disadvantages to Y from the harvesting procedure are very small.</p> <p><u>Case 2: Commercial organ selling</u></p> <p>An 18 year old boy sells his kidney for several times his family's yearly income to a wealthy, elderly foreigner. He has a post-operative wound infection that requires treatment with IV antibiotics. However, once this is resolved he is discharged from hospital with no apparent health problems. There is no plan for long term health care; this will be his responsibility. With the money he is able to complete technical college and help his family financially to enable his brother to finish high school.</p> <p><u>Case 3: Respect for the dignity of the deceased</u></p> <p>In 1995 Mrs. H became pregnant. Ten weeks into her pregnancy she was diagnosed as diabetic. At 20 weeks she and her husband learned that their baby was likely to suffer from a rare condition known as arthrogryposis. They were strongly advised to terminate the pregnancy. They rejected that advice, and on October 6, 1995, when she</p>

	<p>was in her 28th week of pregnancy, Mrs. H was admitted to hospital as an emergency patient. Her baby daughter R was delivered by caesarean section.</p> <p>Baby R weighed 686 grams and was born with severe multiple abnormalities. Baby R lived for three days and died on October 9, 1995. A post-mortem examination was carried out, during which Baby R’s brain, heart, lungs and spinal cord were removed. These organs were retained at the University Hospital where the post-mortem had been carried out.</p> <p>On October 16 Baby R was cremated without these organs being returned to her body. On May 31, 2001 Mr. and Mrs. H received a letter from the University Hospital and learned for the first time that Baby R’s organs had been removed at the time of the post-mortem examination and retained at the hospital.</p> <p>The parents were subsequently told that the organs had been disposed of. Mr. and Mrs. H complained that they have not consented to the removal of those organs and their retention at the hospital. They further claimed that when they were asked to give their permission for the post-mortem examination, they gave specific instructions that all removed organs must be returned so that Baby R could be buried or cremated whole.</p>
Readings	<ul style="list-style-type: none"> • Patrão Neves, M. 2009. ‘Article 8: Respect For Human Vulnerability And Personal Integrity’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 155-164: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>The Barcelona Declaration on Policy Proposals to the European Commission on Basic Ethical Principles in Bioethics and Biolaw</i>, European Commission funded BIOMED-II Project, 1998: http://www.ethiclaw.dk/publication/THE%20BARCELONA%20Dec%20Ene%20lsk.pdf (English) http://www.ethiclaw.dk/publication/barcelonaFratxtFinal9909.pdf (French) • Chenje, M.; Tata, T.; de Villiers, C. 2002. ‘Chapter 3: Human Vulnerability To Environmental Change’, in <i>Africa Environment Outlook: Past, present and future perspectives</i>, eds. Bird, G.; Medina, S. African Ministerial Conference on the Environment (AMCEN)/United Nations Environmental Programme (UNEP): http://www.grida.no/aeo/234.htm (English) http://www.grida.no/aeo/french/234.htm (French)
Video/Movie	<p>Video: <u>Organ Sales in the Philippines (CNN, November 2007)</u></p> <ul style="list-style-type: none"> • CNN reporter Hugh Riminton examines the current practice in the Philippines, where a legal loophole permits the donation of kidneys in return for “gifts”, and a controversial new plan authorities say will protect donors - the legalisation of commercial organ trade. • Running time: 3 minutes 22 seconds • Available on the Internet at: http://edition.cnn.com/video/#/video/world/2007/11/05/riminton.philippines.kidney.sale.cnn?iref=videosearch

	<p>Video: <u>Singapore debates legalising the organ trade (Al Jazeera, August 2008)</u></p> <ul style="list-style-type: none"> • One of Singapore’s wealthiest businessmen is on trial on charges of illegally trying to buy a kidney from an impoverished Indonesian man. This stirs debate in Singapore about legalising organ trading. The case has stirred debate in Singapore, and the government has confirmed to Al Jazeera that it is thinking about legalising organ trading. Step Vaessen reports. • Running time: 2 minutes 57 seconds • Available on the Internet at: http://english.aljazeera.net/news/asia-pacific/2008/08/200882751451479389.html <p>Video: <u>Organ trafficking controversy (Al Jazeera Inside Story, February 2008)</u></p> <ul style="list-style-type: none"> • A doctor has been remanded in custody in Delhi in connection with an alleged international organ transplant racket which has gripped the nation. Amit Kumar is said to have sold the kidneys of more than 500 labourers who claim they were operated on illegally under the pretext of medical tests. Trafficking in human organs is of course nothing new. There are countless stories in India alone of desperate donors who agree to sell a kidney illegally in an attempt to fend off poverty. Many are never paid the price they were promised and end up too sick to work again, leaving them worse off than ever before. In contrast, desperate recipients at home and abroad - in the US and Gulf states, for example - pay extraordinary prices for illegal organs as they fight to prolong their lives. Just what is the global scale of the trade? Can it be policed internationally when legal donations are so often governed by local laws, customs and ethics? And what of those who say the black market can only be brought under control by legalising the sale of human organs? <i>Inside Story</i>, with presenter Hashem Ahelbarra, investigates. • Running time: 22 minutes 4 seconds • Available on the Internet at: http://english.aljazeera.net/programmes/insidestory/2008/02/20085251918442645.html
<p>Role play</p>	<p><u>Debates</u></p> <ul style="list-style-type: none"> • The concept of a Socratic debate in philosophy is one that has developed in many countries over a long time. Divide the students into two groups of three; allocate one group representing the “affirmative” and one the “negative”. One person should also be allocated “chair” and be advised that they shall be enforcing the rules (i.e. only one person speaking at a time and time limits). • Give the students one of the case scenarios above, then a corresponding statement. Depending on their group, they shall have to argue for or against the statement, regardless of their personal beliefs. It is a good idea to give the students the case and statement the week prior to give them time to prepare. • The statement for each of the cases above are: <ul style="list-style-type: none"> ○ Case 1: The benefits to Y of helping her sister far outweigh the negatives. ○ Case 2: My organs are my own and I may sell them as I wish.

	<ul style="list-style-type: none"> ○ Case 3: A person who is deceased is not vulnerable. • Adapted from Game 11 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Haifa: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
Group discussion	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Should Y be a bone marrow donor for her sister despite the fact that she is incapable giving her consent? <p><u>Group Discussion on Case 2:</u></p> <ul style="list-style-type: none"> • Should the hospital have informed Baby R’s parents about the removal of her organs during the post-mortem examination?
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 9	
Title	Privacy and confidentiality (Article 9)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain why patient privacy and confidentiality should be respected 2. Students should be able to recognise legitimate exceptions to confidentiality 	
Study Materials	
Cases	<p>Case 1: <u>Informing the wife?</u></p> <p>Mr. S is married and the father of two school children. He is treated in your clinic for a rare form of pneumonia that is often associated with AIDS. His blood test results show that he is indeed HIV-positive. Mr. S says that he wants to decide himself if and when he will tell his wife about the infection. You indicate that it could be life-saving for his wife to protect herself from infection. Besides, it would be important for her to have an HIV test herself. In case of a positive test result she would then have the opportunity to take drugs to slow down the outbreak of the disease and thereby prolong her life. Six weeks later, Mr. S comes into your clinic for a control investigation. Answering your question he says that he hasn't informed his wife yet. He doesn't want her to know about his homosexual contacts because he fears that she would end their relationship and the family would shatter. But to protect her he has had only "safer sex" with her. As the treating physician, you wonder whether you should inform Mrs. S of the HIV status of her husband against his will so that she would have the opportunity to start treatment if needed.</p> <p>Case 2: <u>Prison events</u></p> <p>As part of your medical duties you spend one day every two weeks seeing inmates in a nearby prison. Yesterday you treated a prisoner with multiple abrasions on his face and trunk. When you asked what caused the injuries, the patient replied that he had been attacked by prison staff during interrogation when he refused to answer their questions. Although this is the first such case you have experienced, you have heard of similar cases from your colleagues. You are convinced that you should do something about the problem but the patient refuses to authorize you to disclose information about himself for fear of retaliation from the prison authorities. Furthermore, you are not certain that the prisoner has told you the truth; the guard who brought him to you said that he had been in a fight with another prisoner. You have a good relationship with the prison staff and do not want to harm it by making unsubstantiated accusations of mistreatment of prisoners. What should you do?</p> <p>Case 3: <u>Warning the friend?</u></p> <p>A 45 year old rich, handsome, sociable and elegant man, a member of the jetset society, had an amorous relationship with an equally elegant and beautiful 35 year old woman. Due to some bouts of jealousy on the part of the man (possibly of morbid dimensions), the young woman decided to put an end to the relationship. Following this, the man visited a psychiatrist, whom he had been seeing for some time, informed him that he was carrying a gun and that his next visit would be to his ex-girlfriend because he intended to kill her. He added that this information was</p>

confidential from patient to doctor and that any breach in confidentiality would not remain unnoticed. The psychiatrist decided that a breach of confidentiality was necessary in this case and informed the lady and the police. When asked by the police, the man denied that he had bad intentions. A heated discussion among professionals followed, which was re-fuelled by the fact that this man eventually managed to kill his ex-friend with the very gun he carried when he visited the psychiatrist's office.

Case 4: The politician

A 68 year old powerful politician was affected with Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis) and given no more than one year of life. She prohibited her doctor to ever mention her condition even to her husband or her family because of the sensitive political situation that such a revelation might entail or to seek further consultations. As her condition worsened, pressures mount on her doctor to refer her to another physician or to hospitalize her. Following the expressed directions of his patient he refused, but her family insists on consultation and possible hospitalization.

Case 5: The bus driver

A 46 year old man, married and father of three children, is a bus driver on an inter-urban line on difficult roads across the mountains. In a consultation with a doctor, his main complaint is that he has started to experience episodes of acute tachycardia during the past five months, following the death of his mother. It happened first when he was in the street, where he thought that he was taking leave of his senses and was about to die. In the emergency room of the hospital to which he was rushed he was diagnosed as having a heart that was in good shape, but owing to his stress, he was advised to take a holiday. Upon return from his vacation he began to suffer the same episodes especially when he was driving across the mountains. He also began to believe that his driving might become careless and cause him to drop into the ravine. He insisted that this was exclusively a heart disease, refusing to consider that he was suffering from any kind of panic disorder which might be complicated by agoraphobia. Refusing to accept any psychotropic medication or psychotherapy, he demanded treatment by a cardiologist. He asserted that he would refuse to take "the same kind of medication as his mother", who had been treated for years as a person with schizophrenia. At the same time he continued working on his arduous bus route, since he had contracted debts which he had to repay.

Case 6: Publishing a case

Dr. X published a paper based on two dreams from psychotherapeutic treatments (without any identifying clues), making detailed diagnostic and prognostic comments. A brief version was published in a magazine dedicated to Human Sciences Updating. As Dr. X was a prestigious colleague, I used to include his name in my list of professional references. When my hospital workmate asked me for a therapist, I gave her three names, including Dr. X. She categorically rejected him because she considered that he badly harmed her sister, when she was his patient. The problem originated from the above mentioned paper. The patient had bought the Human Sciences magazine at a newspaper and magazine stand, precisely because she

	<p>saw her therapist’s name as an author. She was deeply upset when she recognized her own dream printed in the magazine, and when she realized (even if nobody else could recognize her as the patient), that the theoretical comments were about her personality and her psychological conflicts. She discontinued her treatment and rejected any meeting with her former therapist.</p>
Readings	<ul style="list-style-type: none"> • Stiennon, J.-A. 2009. ‘Article 9: Privacy And Confidentiality’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 165-171: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • ‘Chapter Two – Physicians and Patients’, in <i>WMA Medical Ethics Manual</i>, World Medical Association (WMA), 2005: http://www.wma.net/e/ethicsunit/pdf/manual/chap_2.pdf (English) http://www.wma.net/f/ethicsunit/pdf/manual/chap_2.pdf (French) http://www.wma.net/s/ethicsunit/pdf/manual/chapitre_2.pdf (Spanish) • <i>Confidentiality as part of a bigger picture: A discussion paper from the BMA</i>, British Medical Association (BMA), 2005: http://www.bma.org.uk/ethics/confidentiality/ConfidentialityBiggerPicture.jsp • <i>European Guidance for Healthcare Professionals on Confidentiality and Privacy in Healthcare</i>, European Commission funded European Standards On Confidentiality and Privacy In Healthcare Among Vulnerable Patient Populations (EuroSOCAP) Project, 2006: http://www.eurosocap.org/Downloads/European-Guidance-for-Healthcare-Professionals-on-Confidentiality-and-Privacy-in-Healthcare.doc (English) http://www.eurosocap.org/eurosocap-standards.aspx (multiple languages) • Article 14, <i>International Declaration on Human Genetic Data</i>, UNESCO General Conference 32 C/Resolution 22 on 16 October 2003: http://portal.unesco.org/shs/en/ev.php-URL_ID=1882&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages)
Video/Movie	
Role play	<p><u>The personal physician</u></p> <ul style="list-style-type: none"> • Consider the following real events: <ul style="list-style-type: none"> ○ President Francois Mitterrand of France died on 8 January 1996, at the age of 79. Dr. Claude Gubler, the general practitioner who treated him from 1969 to 1994, published a book, <i>The Great Secret</i>, jointly written with a journalist, immediately after the death of the president. The book went on sale on 17 January having been featured, with excerpts and unofficial photographs of the president, the previous day by the popular weekly magazine Paris-Match. The book stated that the president was diagnosed with cancer of the prostate and bone metastases as early as 1981 but that the diagnosis was kept as a “state secret” despite President Mitterrand’s promise of transparency regarding his health. The cancer was revealed to the public only late in 1992, and Dr. Gubler asserted that “In November 1994, I considered Francois Mitterrand no longer capable of carrying out his duties.”

	<p>(French officials denied that he had been incapacitated, and even the prime minister, Alain Juppe, who served as foreign minister under the Socialist president, said: “I never found him in a state of impairment.”). Dr. Gubler said that he started his book in August 1995 because he wanted to reveal the truth behind the incomplete medical bulletins issued in his name over several years. He said that he and Dr. Adolphe Steg, an urologist, had regularly given President Mitterrand radiation and chemotherapy since 1982, when the already advanced stage of cancer led to the pessimistic prognosis of a survival time of about three years. In November 1994, wrote Dr. Gubler, the president came to work at about 9.30 or 10 a.m. and spent most of his days in bed. “He was not working because nothing interested him except his disease.” At the end of 1994, after voicing doubts about the president’s capabilities, Dr. Gubler was dismissed, and President Mitterrand was treated by a doctor specialising in homoeopathy and by Dr. Jean-Pierre Tarot, a pain specialist, who became his personal physician and stayed with him until his death.</p> <ul style="list-style-type: none"> ○ The book was an instant success; the first day of its publication about 40.000 copies have been sold. • Make 4 sub-groups and discuss separately in each group whether any actions are appropriate. The four groups are all meeting in the afternoon of January 17: <ul style="list-style-type: none"> ○ The family of the deceased president ○ The Medical Association ○ Paris judges ○ Journalists • Exchange the views of the 4 groups and discuss what will be the best strategy to respond to this event.
Group discussion	<p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Discuss the question: Are privacy and confidentiality specifically ‘Western’ concepts or are they universal? • Identify the most influential Medical Code of Ethics in your country <ul style="list-style-type: none"> ○ analyse the statements in the Code in regard to privacy and confidentiality ○ identify for which situations the provisions in the Code for privacy and confidentiality apply ○ review when breaches of confidentiality are justified according to the Code
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 10	
Title	Equality, justice and equity (Article 10)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to identify and deal with the ethical issues involved in allocating scarce health care resources 2. Students should be able to recognize conflicts between the health care professional's obligations to patients and to society and identify the reasons for the conflicts 	
Study Materials	
Cases	<p>Case 1: <u>Shopping patients</u> Dr. S works in a region where healthcare is entirely state funded. She is becoming increasingly frustrated with patients who come to her either before or after consulting another health practitioner for the same ailment. She considers this to be a waste of health resources as well as counter-productive for the health of the patients. She decides to tell these patients that she will no longer treat them if they continue to see other practitioners for the same ailment. She intends to approach her national medical association to lobby the government to prevent this form of misallocation of health care resources.</p> <p>Case 2: <u>Sex selection</u> An infertility clinic is considering whether or not it wants to include sex selection in its offerings. A long debate has been going on between the staff members on the issues of selection of embryos based on genetic characteristics that do not influence the health of the child. One side maintains that all such selection is discrimination and usually against females. The other side maintains that there should be no discrimination if selection is offered only for a second or later child when couples are seeking the sex different from that of the first child or previous children. The other fertility centre in town has been offering sex selection without regard to whether there is a first child or "family balancing".</p> <p>Case 3: <u>Equality in providing health services</u> Mr. S is a 41 year old unemployed male. He is diabetic and suffers from ischemic heart disease and cerebrovascular disease, causing him to have a stroke in 1996. That year, his kidneys failed as well. His condition is irreversible, and he is now in the final stages of chronic renal failure. His life could be prolonged by regular renal dialysis treatment. He has sought such treatment from the renal unit of the public hospital; however they can only provide dialysis treatment to a limited number of patients. Because of the shortage of resources, the hospital follows a set policy regarding the use of its dialysis resources. Only patients suffering from acute renal failure that can be treated and remedied by renal dialysis are given automatic access to renal dialysis at the hospital. Those patients who, like Mr. S, suffer from irreversible chronic renal failure are not automatically admitted to the renal dialysis program. Access to dialysis treatments for patients like Mr. S is given only to those eligible for a kidney transplant. Mr. S suffers from ischemic heart disease and cerebrovascular disease,</p>

	<p>and is therefore not eligible for a kidney transplant. Therefore, the hospital has been unable to provide Mr. S with the treatment he has requested.</p> <p>Mr. S has arranged to receive dialysis treatment from private hospitals and doctors, but his finances have been depleted and he claims he is no longer able to afford such treatments.</p>
Readings	<ul style="list-style-type: none"> • d’Empaire, G. 2009. ‘Article 10: Equality, Justice And Equity’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 173-185: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • ‘Chapter 3 – Physicians and Society’, in <i>WMA Medical Ethics Manual</i>, World Medical Association (WMA), 2005: http://www.wma.net/e/ethicsunit/pdf/manual/chap_3.pdf (English) http://www.wma.net/f/ethicsunit/pdf/manual/chap_3.pdf (French) http://www.wma.net/s/ethicsunit/pdf/manual/chapitre_3.pdf (Spanish) • <i>The right to the highest attainable standard of health</i>, UN Economic and Social Council’s Committee on Economic, Social and Cultural Rights (CESCR) General Comment E/C.12/2000/4 on 11 August 2000: http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/32/PDF/G0043932.pdf?OpenElement (Arabic) http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/33/PDF/G0043933.pdf?OpenElement (Chinese) http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/34/PDF/G0043934.pdf?OpenElement (English) http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/35/PDF/G0043935.pdf?OpenElement (French) http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/36/PDF/G0043936.pdf?OpenElement (Russian) http://daccessdds.un.org/doc/UNDOC/GEN/G00/439/37/PDF/G0043937.pdf?OpenElement (Spanish) • ‘Chapter 8 – A Practical Framework for Setting Priorities in Health Research’, in <i>10/90 Report on Health Research 1999</i>, Global Forum for Health Research, 1999: http://www.globalforumhealth.org/filesupld/1090_report_99/109099CHPT8.PDF • <i>Guidance on Ethics and Equitable Access to HIV Treatment and Care</i>, World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS), 2004: http://www.who.int/hiv/pub/advocacy/en/guidanceethics_en.pdf (English) http://www.who.int/hiv/pub/guidelines/guidanceethics_fr.pdf (French)
Video/Movie	
Role play	<p><u>Choosing core health services</u></p> <ul style="list-style-type: none"> • Suppose that your government invites you to be a member of a State Committee that should make recommendations concerning a new system of health care services, distinguishing core services and other services. The Committee should make a proposal for these essential (“core”) services that

	<p>should be included in the basic health care package, open to all citizens. You are specifically invited to study the following list of services, and identify those that should be regarded as essential services:</p> <ul style="list-style-type: none"> ○ in vitro fertilisation ○ contraceptive medicines ○ organ transplantation ○ alternative medicine ○ relaxation therapy (Spa treatment) ○ aesthetic surgery ○ physiotherapy ○ screening for breast cancer ○ screening for hypertension ○ home nursing care ○ medical-technical devices (prosthesis, wheelchair) ○ dental care ○ optician’s prescriptions
<p>Group discussion</p>	<p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Is there a right to health care in your country? What does it mean in practice? <ul style="list-style-type: none"> ○ Does your country have a state funded health system? To what extent? ○ How are resources distributed? Is there disparity between regions, socioeconomic status or racial groups? ○ Is there a “safety-net” for those who cannot afford health care? ○ Are there any groups of people who would be denied treatment? On what grounds?
<p>Other</p>	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 11	
Title	Non-discrimination and non-stigmatization (Article 11)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the concepts of discrimination and stigmatization in the context of bioethics 2. Students should be able to identify different contexts and bases of discrimination and stigmatization and their implications 3. Students should be able to identify and deal with situations where exceptions to the principle can be justified 	
Study Materials	
Cases	<p>Case 1: <u>Stigmatization</u> YL, aged 18, has come to Dr. NG for contraceptive care and testing of her status for sexually transmitted infections, explaining that her father’s friend has been sexually abusing her, including by non-consensual intercourse. She further explains that, when she complained to her parents, they angrily denied the possibility, and accused YL of flirting and being sexually provocative. The family lives in a small community and has few means, so she is not able to leave home and be self-supporting. The community is also religiously devout, so any sexual scandal involving police or other authorities would be very stigmatizing. YL asks that her parents not be informed that she is receiving contraceptive care, because this would confirm their suspicions of her immorality.</p> <p>Case 2: <u>Discrimination on moral grounds</u> In Village A, any sex outside marriage is very strongly condemned, particularly for women. Furthermore, the Village delivery suite has very limited resources and is both poorly staffed and equipped. One evening, two women, Ms. AC and Mrs. BD came for delivery, with Ms. AC arriving shortly before. At triage, the regulatory identity check showed that Ms. AC, known in the Village as a sex worker, is a single mother and she does not know the father of her child. Given the lack of delivery rooms, the medical team decided to give priority to Mrs. BD; while Ms. AC is referred to another maternity ward, approximately two hours drive on non-asphalted road from Village A.</p> <p>Case 3: <u>Positive discrimination</u> In a multiethnic country with limited health and economic resources, the government decided to give priority for primary healthcare to poor minorities. For instance, specific funds will be allocated for the prevention, diagnosis and care of tuberculosis and infantile diarrhoeal diseases.</p> <p>Case 4: <u>Positive discrimination</u> The national programme for early detection of breast and cervical cancer in Country A was designed to reduce disparities in mortality due to cancer by targeting primarily low income and uninsured women. The programme has delivered notable improvements in access to screening for minority groups that lagged behind in the</p>

	<p>1990s with an over representation of women originating from poor minorities. This result was obtained at the expense of an under-representation of other women.</p>
<p>Readings</p>	<ul style="list-style-type: none"> • Rivard, G. 2009. 'Article 11: Non-Discrimination And Non-Stigmatization', in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 187-198: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>Universal Declaration of Human Rights</i>, UN General Assembly Resolution 217 A (III) of 10 December 1948: http://www.un.org/Overview/rights.html (multiple languages) • <i>Universal Declaration on the Human Genome and Human Rights</i>, UNESCO General Conference 29 C/Resolution 16 on 11 November 1997: http://portal.unesco.org/shs/en/ev.php-URL_ID=1881&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>International Declaration on Human Genetic Data</i>, UNESCO General Conference 32 C/Resolution 22 on 16 October 2003: http://portal.unesco.org/shs/en/ev.php-URL_ID=1882&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>Convention on the Elimination of All Forms of Discrimination against Women</i>, UN General Assembly Resolution 34/180 of 18 December 1979: http://www.un.org/womenwatch/daw/cedaw/cedaw.htm (multiple languages)
<p>Video/Movie</p>	<p>Movie: <u>The Elephant Man (1980, Director: David Lynch)</u></p> <ul style="list-style-type: none"> • Based on the true story of Joseph Merrick, a 19th-century Englishman afflicted with a disfiguring congenital disease. With the help of kindly Dr. Frederick Treves, Merrick attempts to regain the dignity he lost after years spent as a side-show freak. • Running time: 124 minutes <p>Movie: <u>Miss Evers' Boys (1997, Director: Joseph Sargent)</u></p> <ul style="list-style-type: none"> • In 1932 Macon County, Alabama, the federal government launched into a medical study called The Tuskegee Study of Untreated Blacks With Syphilis. The study selected 412 men infected with the disease and faked long term treatment, while really only giving them placebos and liniments. The premise of the action was to determine if blacks reacted similar to whites to the overall effects of the disease. The experiment was only discontinued 40 years later when a Senate investigation was initiated. At that time, only 127 of the original study group were left alive. The story is told from the point of view of Nurse Eunice Evers, who was well aware of the lack of treatment being offered, but felt her role was to console the involved men, many of whom were her direct friends. In fact the movie's name comes from the fact that a performing dancer and three musicians named their act for her – "Miss Evers' Boys". All had the disease. A romance with one goes unrequited even after he joins the army during World War II and is treated and cured by penicillin. As the result of the Senate investigation, medical experimentation on humans has

	<p>been curbed. The survivors of the study did receive treatment and financial compensation after the Senate Investigation.</p> <ul style="list-style-type: none"> • The movie is adapted from the 1992 stage play by David Feldshuh. • Running time: 118 minutes
<p>Role play</p>	<p><u>Courage to change</u></p> <ul style="list-style-type: none"> • Indicate a line on the ground with one end representing “easy” and the other representing “hard”. Give the students a problem and a solution (or have them come up with it themselves) in relation to addressing stigma and discrimination in the community. Have the students discuss why they are at that point on the line. For example: <ul style="list-style-type: none"> ○ Women earn less money than men. We should introduce a law that mandates equal pay between the sexes. ○ There are community minorities that have far lower university attendance than other members of the community. We should create places specifically for them. ○ Hate-crimes against minorities are rife in a community. The penalties for such crimes should be drastically increased to act as a deterrent. • Adapted from Game 21 of Macer, D. 2008. <i>Moral Games for Teaching Bioethics</i>, UNESCO Chair in Haifa: http://portal.unesco.org/shs/en/ev.php-URL_ID=12631&URL_DO=DO_TOPIC&URL_SECTION=201.html
<p>Group discussion</p>	<p><u>Group Discussion on Case 3:</u></p> <ul style="list-style-type: none"> • Discuss: Positive discrimination (or affirmative action) provides extra help to a particular group. A common argument in favour of such actions is that it can correct deep inequalities, while some claim against because it can create dependence and a sense of entitlement. Moreover, it can create a sense of discrimination for those who are excluded from the programs <p><u>Group Discussion on Case 4:</u></p> <ul style="list-style-type: none"> • Discuss and share your understanding of the context that makes affirmative action in medicine necessary <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Discuss the following cases and determine whether or not exceptions to the principle can be justified. If an exception to the principle is justified, what are the arguments? Which other principles are overriding the principle of non-discrimination? <ul style="list-style-type: none"> ○ <i>Affirmative action</i> in medical practice, e.g. in the case of pandemics and natural catastrophes, priority of access to scarce medical resources should be given to: <ul style="list-style-type: none"> ▪ Young vs. elderly people ▪ Health professionals, politicians and key security persons ○ <i>“Negative action”</i> situations where the public interest imposes

	<p>restrictions on the non discrimination principle</p> <ul style="list-style-type: none"> ▪ Cases of violent patients in the hospital: can they be refused future access to the hospital? ▪ Quarantining of infected patients due to public health risks (e.g. SARS) ▪ Non priority access of obese persons to healthcare services in some countries
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 12	
Title	Respect for cultural diversity and pluralism (Article 12)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the meaning of ‘culture’ and why it is important to respect cultural diversity 2. Students should be able to explain the meaning of pluralism and why it is important in the field of bioethics 3. Students should be able to deal with cultural diversity and take into consideration cultural specificities (appropriate approach, positive inputs and limits) with respect to the fundamental principles of bioethics and human rights 	
Study Materials	
Cases	<p>Case 1: <u>Treatment without consent</u> Treating Mrs. TP for complications late in her pregnancy, Dr. RR diagnoses placenta previa and concludes that, by following Mrs. TP’s intention of natural delivery, the fetus would not be born alive and the life of Mrs. TP herself would be in serious peril. Mrs. TP rejects the advice of Dr. RR that she delivers by caesarean section, however, stating her religious conviction that, if the diagnosis is correct, the condition will be resolved by divine intervention, and she will safely deliver a healthy baby.</p> <p>Case 2: <u>Circumcision of girls</u> Mrs. BE brings her six year old daughter to Dr. GH asking that she be safely “circumcised”. Mrs. BE explains that she wants the procedure done for fear that the daughter will not be eligible for marriage in the rather isolated community where the family lives if it is not done, and for fear that her daughter will be considered negatively by members of her wider family and by her young peers. The mother further explains that she wants Dr. GH to undertake the procedure because such procedures performed on her two older daughters by a traditional birth attendant resulted in their severe bleeding and infection. Mrs. BE adds that, unless Dr. GH performs the procedure, her mother-in-law, who lives with the family, will insist on undertaking the procedure herself by customary means, or on taking the daughter to a traditional birth attendant. There are no legal prohibitions in the jurisdiction that ban the practice.</p> <p>Case 3: <u>Unnecessary treatment</u> A 26 year old woman contacts a psychiatrist because she is perplexed by a situation which she does not know how to handle. She was born of immigrant parents, and has been brought up in a Western European country. With respect to norms and values in the sphere of women’s behaviour she feels that her personality has been split by two cultures. She has had sexual relations without the knowledge of her parents who are arranging for her marriage to a young man from her country of origin. She knows that her prospective bridegroom’s parents are traditional and will accept only a virgin as their daughter-in-law. She reluctantly contacts her family doctor for hymen repair in order to “restore her virginity”. She is met with a refusal since he cannot recommend that a tradition be upheld that does not provide a woman with freedom to choose her</p>

	<p>sexual partner. The young woman is distressed by the fact that the date of the marriage is approaching and she believes that her family will be disgraced and she will become the object of contempt.</p> <p>Case 4: <u>Expert testimony</u></p> <p>A 29 year old immigrant worker, who had moved to Country X four years before, stabbed his wife and wounded her severely. Her life was saved only because he rushed her to the hospital for emergency surgery. In court both claimed that they had a quarrel before the stabbing in their car. She accused him of adultery and told him that she was going to make love to his best friend and that his friend would do a better job than the husband. The defendant remembered that he stabbed once, although the victim was wounded twice, and he had a blurred memory which could be a sign of profound disturbances of consciousness, a reason to mitigate punishment according to the law of Country X. The couple had meanwhile been reconciled and wanted to continue their marriage. After the psychiatric examination, which did not reveal any disturbances, the defendant wanted to talk to the psychiatrist under the privilege of confidentiality, which was denied. At that moment the defendant started to tremble, cry, and sweat and almost collapsed. He then claimed that he had been the victim of sexual abuse in his country of origin and had seen a doctor at that time but had not told him about his victimization. The only persons who knew about it were his brother who had prevented the defendant from shooting his molester, and now the psychiatrist. If anyone in his community were to learn about it, he would lose all self respect; and his wife would leave him because he could not be master of his own house. This opinion was supported by an expert on his culture. The defendant preferred a harsher sentence over the disclosure of his secret to the court.</p>
Readings	<ul style="list-style-type: none"> • Revel, M. 2009. ‘Article 12: Respect For Cultural Diversity And Pluralism’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 199-209: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>UNESCO Universal Declaration on Cultural Diversity</i>, UNESCO General Conference 31 C/Resolution 25 on 2 November 2001: http://unesdoc.unesco.org/images/0012/001271/127160m.pdf (multiple languages) • <i>International Declaration on Human Genetic Data</i>, UNESCO General Conference 32 C/Resolution 22 on 16 October 2003: http://portal.unesco.org/shs/en/ev.php-URL_ID=1882&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • Dickens, B.; Cook, R.; Kismodi, E. (eds.) 2006. <i>Medical ethics in reproductive health: Case studies</i>, UNESCO Chair in Bioethics: http://portal.unesco.org/shs/en/ev.php-URL_ID=10667&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages)
Video/Movie	
Role play	

<p style="text-align: center;">Group discussion</p>	<p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • For each case below, determine if the principle of respect for cultural diversity and pluralism should be applied. If not, which other principle(s) of the Declaration should be applied instead? <ul style="list-style-type: none"> ○ A woman consults the physician in order to have a prescription for contraceptives. The physician only wants to make a prescription if the husband consents in order, as he argues, “to respect the cultural customs of the country” ○ A clinical trial has been started in the hospital. In order for adult women to be included, a male consent (usually the husband or the father) is requested instead or in addition of the woman’s consent ○ In a traditional community, researchers have set up a trial to study the incidence of specific diseases. Because individual autonomy is not highly appreciated in this community, they have asked the chief of the community to give permission to include all adult members of his community in the trial ○ In a society in which the family is very important, medical doctors are used to communicate the diagnosis of a patient’s terminal condition to the family instead of to the patient himself or herself ○ In order to respect cultural diversity, a hospital has made the rule that male patients will only be received by male doctors, and female patients only by female doctors ○ In a particular country, long-standing systems of alternative healing and medication are practised and commonly used by the population. An advertisement campaign has started to call on AIDS patients to use these traditional medicines “because they are very efficient in our culture” <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Some argue that the principle of voluntary informed consent would be difficult to implement in societies where the norms of decision-making emphasize the community rather than the concerned individual. Moreover, the proponents of this argument claim that imposing individual consent can exclude some persons/groups from the benefit of the research and stigmatize those who have chosen individual consent over communal consent. Others argue that applying the principle of voluntary informed consent in human subjects’ research in communal culture could serve as an effective measure to protect vulnerable subjects from possible abuses or exploitations. Discuss the pros and cons of each opinion
<p style="text-align: center;">Other</p>	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 13	
Title	Solidarity and cooperation (Article 13)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the development of the notion of solidarity in different societies 2. Students should be able to describe the difference between solidarity as an instrumental and a moral value 3. Students should be able to give examples of solidarity in the context of health care and research 	
Study Materials	
Cases	<p>Case 1: <u>Organ donation</u></p> <p>Organ donation programs are an example of solidarity among citizens of a nation, with organs from a deceased person allowing another citizen to live. In many countries this is achieved by people voluntarily joining a register. Some countries however have adopted an “opting out” policy for organ donation - in that all citizens are presumed to be willing organ donors unless they apply to “opt-out”.</p> <p>Mr. X is a middle aged man who has suffered a large stroke and is declared brain dead whilst on mechanical ventilation. His family request a further 24 hours to wait for a miracle which is granted by the doctors. There is no change in his condition and his organs are becoming less viable by the day, with some already unusable because of the delay.</p> <p>His family request a further 24 hours to wait for some sign of improvement; his mother is particularly distressed. The hospital authorities say that this will make his organs unusable and he is taken to surgery for organ harvesting whilst the family are distraught. The country has an opting out policy and the authorities say they are respecting Mr. X’s choice to not opt out by harvesting his organs whilst still viable.</p> <p>This “opting out” policy has dramatically increased organ transplants in this country and has saved many lives.</p> <p>Case 2: <u>Unnecessary hospitalization</u></p> <p>A 58 year old male, diagnosed with paranoid schizophrenia in full remission, is placed in a psychiatric hospital for 8 months, as he has no private place to reside in. The patient has no official guardian. His brother, who sold the patient’s home without permission, refuses to take him from the hospital and take care of him. The patient has to stay in the hospital, where he has only the minimal basic needs for existence.</p> <p>Case 3: <u>Unnecessary hospitalization</u></p> <p>A 47 year old, unemployed female, diagnosed with schizophrenia several times was treated at a psychiatric hospital. She had lived with her husband and all contacts with other relatives were lost. During remissions she used to do laundering at a country house. For the last few years, she lived alone, as her husband left her.</p> <p>For two years she heard voices which issued commands to her. Under their influence she destroyed her own house by fire and was arrested by police and hospitalized.</p>

	<p>After a few years her mental status was stabilized; she now sincerely regrets what she had done. At the same time, she has no place to live after discharge. There is no assisted residency in the country, which is why she is still kept at the hospital. She has no prospects of improving her domiciliary status in the foreseeable future.</p>
Readings	<ul style="list-style-type: none"> • Elungu, A. 2009. ‘Article 13: Solidarity And Cooperation’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 211-217: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • Müller, H. 2005. <i>Towards an ethics of solidarity</i>, News article from the Fifth World Social Forum, Porto Alegre, Brazil on the SpiritHit Website (Religious and Spiritual Portal): http://news.spirithit.com/index/south_america/more/towards_an_ethics_of_solidarity/ • <i>Ethics and SARS: Learning Lessons from the Toronto Experience</i>, Report by the Joint Centre for Bioethics SARS Working Group, University of Toronto Joint Centre for Bioethics, Toronto, 2006: http://www.yorku.ca/igreene/sars.html • <i>Report of the IBC on solidarity and international co-operation between developed and developing countries concerning the human genome</i>, UNESCO, Paris, 2001: http://portal.unesco.org/shs/en/ev.php-URL_ID=2295&URL_DO=DO_TOPIC&URL_SECTION=201.html (English) http://portal.unesco.org/shs/fr/ev.php-URL_ID=2295&URL_DO=DO_TOPIC&URL_SECTION=201.html (French)
Video/Movie	
Role play	
Group discussion	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Does the benefit of a life-saving organ transplant outweigh the distress caused to Mr. X’s family? <p><u>Group Discussion on Case 2:</u></p> <ul style="list-style-type: none"> • Should the patient be discharged from the hospital? <p><u>Group Discussion on Case 3:</u></p> <ul style="list-style-type: none"> • Should the patient be discharged from the hospital? <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Discuss the following statements and determine whether or not you agree that solidarity requires what is expressed. Explain the arguments for your agreement or disagreement. <ul style="list-style-type: none"> ○ Solidarity between generations: the younger age groups should

	<p>contribute to the expenditures required to meet the needs of the older generations and the older generations should also take care of the younger generations</p> <ul style="list-style-type: none"> ○ Solidarity between the rich and the poor: the rich should contribute to provide health care for the poor ○ Solidarity for disadvantaged persons: for examples homeless people and addicted persons should receive preferential treatment to ameliorate their condition ○ Solidarity requires that all citizens contribute to (and pay taxes to allow) health care for all other citizens, regardless of their own health status; thus men pay for obstetric care, and everybody pays for psychiatric care, even if they are sure they will never need it themselves ○ Solidarity requires that the system of explicit consent to organ donation should be replaced by a system of presumed consent
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 14	
Title	Social responsibility and health (Article 14)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should become acquainted with the shared responsibilities of the state and various sectors of society in regard to health and social development 2. Students should understand the requirements of global justice and the notion of the highest attainable standard of health care as a right 3. Students should be able to explain that health status is a function of social and living conditions and that the attainment of the highest attainable standard of health care depends upon the attainment of minimum levels of social and living conditions 4. Students should be able to appreciate the urgent need to ensure that progress in science and technology facilitates access to quality health care and essential medicines as well as the improvement of living conditions and the environment, especially for marginalized segments of the population 5. Students should be able to analyze potentially exploitative social practices or arrangements affecting public health and recommend possible solutions 	
Study Materials	
Cases	<p>Case 1: <u>Tenofovir trials in Cambodia</u></p> <p>The proposed study is a double blind placebo-controlled trial. It involves using <i>Tenofovir</i>, an Anti-Retroviral drug, among HIV-negative female sex workers. The objective of the study is to assess if the drug has a protective effect in reducing the risk of HIV infection. One of the reasons for the initiation of the trial is that behavioural measures in the prevention of HIV infection are not adequately effective since the use of highly efficacious and readily available means such as condoms is not always guaranteed for one reason or another. Therefore, chemo-prophylactic means, if proven effective, would provide a wider range of options for people to choose according to their own convenience.</p> <p>The study would recruit up to 960 female sex workers in both arms, and they will take a daily dose of <i>Tenofovir</i> or <i>placebo</i> up to one year with regular follow-ups during which blood testing and counselling will be performed. Before the recruitment of the participants a series of community meetings will be conducted to explain the objective of the study, the procedures, the possible risks and benefits.</p> <p>A test of understanding will be administered to all potential participants; only those who fully understand the procedures and risk of the study will be asked to consent. The participation will be completely voluntary and participants have all the rights to withdraw from the study at any time without giving reasons and with no punishment or penalty.</p> <p>The study has been criticized over several aspects:</p> <ol style="list-style-type: none"> 1. The use of <i>placebo</i> would subject participants to greater risk of infection than they would have if they are not participating in the study. It has been suggested that participants in the control arm be given best proven substance instead of <i>placebo</i>. The researchers argued that there have not been any best proven chemo-prophylactic measures available yet. The only effective preventive measure is

	<p>the condom; and the participants will be encouraged to use a condom as much as they can during the course of the study. Therefore, this would justify the use of <i>placebo</i>.</p> <p>2. The question of why Cambodia has been selected as a site for the study is very much debated. There has been fear that a poor country like Cambodia is easily exploited by pharmaceutical companies to test their products that sometimes cannot be done in rich countries where ethical and legal systems are stricter.</p> <p>In response to the concern, the researchers argued that Cambodia is not the only site for the project. It has been done elsewhere including the United States. One of the reasons why Cambodia is included is the burden of HIV/AIDS the country is bearing. The country has a critical need for effective preventive measures to tackle the spread of the disease.</p> <p>3. The future availability and affordability of the drug to the Cambodian people are also questioned. It is argued that the Cambodian people who participate in the study would not benefit from the study as the cost of the drug is not expected to be at an affordable level.</p> <p>Although unable to give specific assurance, the researchers believe that the price of the drug would drop and continue to drop as generic drugs can be produced locally, just like in the case of other ARV drugs which are now produced in many developing countries with the price affordable to a reasonably good number of AIDS patients.</p> <p>Case 2: <u>Unnecessary hospitalization</u></p> <p>A 47 year old, unemployed female, diagnosed with schizophrenia several times was treated at a psychiatric hospital. She had lived with her husband and all contacts with other relatives were lost. During remissions she used to do laundering at a country house. For the last few years, she lived alone, as her husband left her. For two years she heard voices which issued commands to her. Under their influence she destroyed her own house by fire and was arrested by police and hospitalized. After a few years her mental status was stabilized; she now sincerely regrets what she had done. At the same time, she has no place to live after discharge. There is no assisted residency in the country, which is why she is still kept at the hospital. She has no prospects of improving her domiciliary status in the foreseeable future.</p>
Readings	<ul style="list-style-type: none"> • Martínez-Palomo, A. 2009. 'Article 14: Social Responsibility And Health', in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 219-230: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>Report of the International Bioethics Committee (IBC) of UNESCO on Social Responsibility and Health</i>, UNESCO, Paris, 2010: http://unesdoc.unesco.org/images/0018/001878/187899e.pdf (English) http://unesdoc.unesco.org/images/0019/001900/190054f.pdf (French) • <i>Universal Declaration of Human Rights</i>, UN General Assembly Resolution 217 A (III) of 10 December 1948: http://www.un.org/Overview/rights.html (multiple languages)

	<ul style="list-style-type: none"> • <i>Universal Declaration on the Human Genome and Human Rights</i>, UNESCO General Conference 29 C/Resolution 16 on 11 November 1997: http://portal.unesco.org/shs/en/ev.php-URL_ID=1881&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>International Declaration on Human Genetic Data</i>, UNESCO General Conference 32 C/Resolution 22 on 16 October 2003: http://portal.unesco.org/shs/en/ev.php-URL_ID=1882&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • <i>Constitution of the World Health Organization</i>, International Health Conference, New York, Off. Rec. Wld Hlth Org., 2, 100, 22 July 1946: http://www.who.int/governance/eb/who_constitution_ar.pdf (Arabic) http://www.who.int/governance/eb/who_constitution_zh.pdf (Chinese) http://www.who.int/governance/eb/who_constitution_en.pdf (English) http://www.who.int/governance/eb/who_constitution_fr.pdf (French) http://www.who.int/governance/eb/who_constitution_ru.pdf (Russian) http://www.who.int/governance/eb/who_constitution_sp.pdf (Spanish) • <i>Public health, innovation and intellectual property rights</i>, World Health Organization (WHO) Commission on Intellectual Property Rights, Innovation and Public Health, 2006: http://www.who.int/intellectualproperty/documents/thereport/en/index.html (multiple languages) • <i>2005 World Summit Outcome</i>, UN General Assembly Resolution A/RES/60/1 on 16 September 2005: http://daccessdds.un.org/doc/UNDOC/GEN/N05/487/58/PDF/N0548758.pdf?OpenElement (Arabic) http://daccessdds.un.org/doc/UNDOC/GEN/N05/487/59/PDF/N0548759.pdf?OpenElement (Chinese) http://daccessdds.un.org/doc/UNDOC/GEN/N05/487/60/PDF/N0548760.pdf?OpenElement (English) http://daccessdds.un.org/doc/UNDOC/GEN/N05/487/61/PDF/N0548761.pdf?OpenElement (French) http://daccessdds.un.org/doc/UNDOC/GEN/N05/487/62/PDF/N0548762.pdf?OpenElement (Russian) http://daccessdds.un.org/doc/UNDOC/GEN/N05/487/63/PDF/N0548763.pdf?OpenElement (Spanish)
Video/Movie	<p>Video: <u>Medical tourism goes global (CNN, March 2009)</u></p> <ul style="list-style-type: none"> • CNN Chief Medical Correspondent Dr. Sanjay Gupta examines how medical tourism is a growing phenomenon as more people go abroad to get affordable care. • Running time: 7 minutes • Available on the Internet at: http://edition.cnn.com/video/#/video/health/2009/03/26/medical.tourism.gupta.cnn?iref=videosearch

	<p>Video: <u>Organ Sales in the Philippines (CNN, November 2007)</u></p> <ul style="list-style-type: none"> • CNN reporter Hugh Riminton examines the current practice in the Philippines, where a legal loophole permits the donation of kidneys in return for “gifts”, and a controversial new plan authorities say will protect donors - the legalisation of commercial organ trade. • Running time: 3 minutes 22 seconds • Available on the Internet at: http://edition.cnn.com/video/#/video/world/2007/11/05/riminton.philippines.kidney.sale.cnn?iref=videosearch <p>Video: <u>Africa’s Deadly Brain Drain (CNN, March 2008)</u></p> <ul style="list-style-type: none"> • CNN World Untold Stories examines the struggle of doctors in Malawi, especially the brain drain of African medical professionals from Africa to developed countries (medical migration). Aaron Lewis reports. • Running time: 21 minutes 34 seconds • Available on the Internet at: http://edition.cnn.com/video/#/video/international/2008/03/14/wus.africa.brain.drain.bka.cnn?iref=videosearch (Part 1) http://edition.cnn.com/video/#/video/international/2008/03/14/wus.africa.brain.drain.bkb.cnn?iref=videosearch (Part 2) <p>Movie: <u>The Constant Gardener (2005, Director: Fernando Meirelles)</u></p> <ul style="list-style-type: none"> • British diplomat Justin Quayle marries impulsive activist Tessa and they are deployed to Kenya. Whilst there Tessa starts working with a local doctor and the pair uncover a system of researchers testing drugs on locals that provides large sums of money to pharmaceutical companies and the government, at the cost of the health and the dignity of the local population. She is brutally murdered and it is set up to look like a crime of passion. Her quiet and polite husband sets out to uncover the truth and complete Tessa’s work however he is persecuted for his efforts. • Running time: 124 minutes
<p>Role play</p>	<p><u>Resource Allocation</u></p> <ul style="list-style-type: none"> • Students are provided with a budget, and asked to prioritise allocation of resources, as well as provide justifications of their decisions (the following is only an example – an exercise more specific to your area may be useful). • You are working for an NGO and are asked to set up a rural health service with 100,000 USD a year. You have a population of 20,000 that comprises 20% elderly, 30% adult and 40% children. It is a tropical area and the main health problems are gastrointestinal disease in children requiring IV rehydration and perinatal mortality. The rate of HIV infection is approximately 10%. Other STDs are rife as there is no access to condoms and very poor education. The funds have been raised by a community group of local men. However, there are no conditions placed on allocation by the contributors. <ul style="list-style-type: none"> ○ To set up a standard maternity ward will cost 60,000. However, you

	<p>can reduce this to 40,000 by only treating those who can afford to pay a partial fee, approximately three quarters of the women in the community. Alternatively you can set up a transport service to the nearest hospital, 4 hours away, for 10,000.</p> <ul style="list-style-type: none"> ○ A childhood vaccination schedule that covers all infections will cost you 50,000. To cover only TB and polio (both present in the region) will cost you 20,000. ○ A paediatric ward will cost you 30,000 for ten beds, nurses, IV fluids and some antibiotics. ○ A malarial treatment program including nets and antibiotics will cost 50,000. Nets only will cost 5,000. ○ A sexual health clinic will cost you 15,000. If this includes an HIV treatment program for all the citizens it will cost 100,000. Treating only children will cost 65,000. An education program about HIV and condom distribution will cost you 10,000. <ul style="list-style-type: none"> • How will you allocate your funds? • Can you think of any other effective public health measures that may be cost-effective in this population? • What other demographical information would be useful? • Is it fair to allocate all the funds to a maternity ward and children’s health if a men’s group has raised the money?
<p style="text-align: center;">Group discussion</p>	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • What social responsibilities do you think the researchers have to the research subjects? • What about the pharmaceutical company that manufactures the drug – what responsibilities do they have to the research subjects? • Given those social responsibilities, what do you think of the issues raised in 1 to 3 above? <p><u>General Group Discussion</u></p> <ul style="list-style-type: none"> • Medical Migration and its implications for the provision of health services in developing countries. <ul style="list-style-type: none"> ○ Is it acceptable for a developed country to actively recruit health professionals from developing nations? ○ Should a doctor be allowed to “sell her/his wares” like other professionals? • Organ donation – avoiding the exploitation of vulnerable populations <ul style="list-style-type: none"> ○ Discuss “I have the right to sell my kidney as it is mine alone” ○ Discuss “Criminalising commercial organ selling is paternalism” • International Health Research – Standard of Care and the Protection of Vulnerable Subjects <ul style="list-style-type: none"> ○ Is it acceptable for drug companies to test their drugs against placebo rather than the best available treatment when conducting trials in an

	<p>impoverished nation where there would otherwise be no treatment available?</p> <ul style="list-style-type: none"> ○ If the results of a trial may challenge traditional beliefs of a society (i.e. identifying a genetic cause for a physical condition previously thought to be sacred) then communal consent is required in addition to individual consent. Discuss ○ Discuss “Spending vast quantities of money on HIV research in nations where there is inadequate access to basic necessities is unethical”
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 15	
Title	Sharing of benefits (Article 15)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to understand the need for ensuring that scientific knowledge contributes to a more equitable, prosperous and sustainable world 2. Students should be able to explain that scientific knowledge has become a crucial factor in the production of wealth, but at the same time has perpetuated its inequitable distribution 3. Students should be able to explain the reality that most of the benefits of science are unevenly distributed among countries, regions and social groups, and between the sexes 4. Students should be able to analyse efforts that have been undertaken at various levels to promote the sharing of the benefits of scientific knowledge and research and to explore novel initiatives that may be undertaken 5. Students should be able to identify and assess potentially undue or improper inducements in different research settings/situations 	
Study Materials	
Cases	<p>Case 1: <u>The San people and the hoodia plant</u></p> <p>The San have used the hoodia plant as an appetite suppressant for many centuries, especially during hunting expeditions where little food was available for many days. In 1963, CSIR became aware of the plant's traditional uses, from a 1937 paper by a Dutch ethnobiologist, and from San trackers who had worked for the South African military. In the 1980s, the South African Council for Scientific and Industrial Research (CSIR) isolated the plant's active ingredient, a compound called P57, which it then patented in 1995.</p> <p>In 1997 the CSIR licensed P57 to a small British biotech company, Phytopharm, which then sub-licensed the product to Pfizer for \$21 million.</p> <p>A lawyer representing the San people in contemporaneous land negotiations with the South African government found out about the license to Phytopharm of the CSIR P57 patents. He communicated the news of the patents to the newly established San political organization, which decided to challenge the lack of compensation for their traditional knowledge.</p> <p>The San did not challenge the patent itself (which could have resulted in loss of profitability as the commercial knowledge then became public) but rather demanded some form of benefit from the commercial development process. In response the CSIR immediately acknowledged that some form of compensation was appropriate and began negotiations with the indigenous people's representatives. As a result, the San Council and the CSIR entered into a memorandum of understanding in February 2002 recognizing the San contribution in the form of traditional knowledge, and providing for benefits to be shared not only with the South African San but also with San peoples in other countries in the region: Namibia, Botswana, Angola, Zambia and Zimbabwe.</p> <p>Under the terms of the agreement reached between CSIR and the San, CSIR will pay 6% of all milestone payments (estimated to be \$0.9 to \$1.4 million) it receives from Phytopharm, and 8% of all royalties from products developed from P57. Payments were to be made to a trust fund established for the San, the San Hoodia Benefit-</p>

Sharing Trust. The Trust includes representatives of CSIR, the regional San Councils, WIMSA, and an observer from the South African Department of Science and Technology. The trust fund can then be used for local development projects in the community. The San planned to use the money for education, jobs, and preservation of their language. As described in a press release, the trust is set up “to use income received from the CSIR for general upliftment, development and training of the San Community as approved by the Board of Trustees.”

Case 2: Genetic research in Tonga

The Autogen agreement

In November 2000, through negotiations with the government of Tonga, and in particular, the minister of health, Autogen announced an agreement to conduct genetic research for the purpose of discovering disease-related genes in the relatively isolated and homogeneous Tongan population. The Tongan population seemed well suited to genetic studies of factors relating to diabetes and obesity, since the island community had had relatively little immigration, was genetically isolated, and in recent years has had a high incidence of the diseases in question. Autogen made a commitment to donate a certain amount of financial support to the ministry of health, including plans for construction of a new research center in the country, and to share some portion of royalties of any commercial products subsequently developed from the Tonga project. The Autogen CEO stated that “This major research initiative will benefit Tonga as well as Autogen’s gene discovery program. The establishment of a research center will create many new job opportunities in scientific research and provide opportunities for Tongan graduates overseas to return to the country and participate in world-class scientific research.

Reactions in Tonga

The Autogen/Tonga agreement was immediately the target of strong criticism from Tongan community groups. The head of the Tonga human rights and democracy movement stated several objections (see: <http://planet-tonga.com/HRDMT>), among them a) lack of public discussion of the project in Tonga; b) lack of transparency on the part of the Tongan government about its actions; c) lack of consideration of privacy concerns for families whose members might participate in the project on the basis of individual consent; there was particular concern about stigmatization and discrimination against individuals in the relatively small and insular Tongan society; d) opposition to the notion of patenting DNA and other ‘life forms’; e) no guarantees of any benefit for the Tongan people and f) colonial appropriation of resources of the Tongan people. The human rights and democracy leader remarked that the benefits were “a drop in the bucket” for the Tongan people compared to the material gain that might be realized by the biotech company in attracting new capital and producing successful products. He also pointed out that at the time Tonga or other Pacific Forum countries (Cook Islands, Fiji, Kiribati, Marshall Islands, Federal States of Micronesia, Nauru, Nieu, Papua New Guinea, Solomon Islands, Samoa, Tonga, Tuvalu and Vanuatu) had no existing intellectual property law or regulation of biologic research, and thus limited ability to protect its own IP interests.

The Tonga National Council of Churches published a statement in the Journal of Medical Ethics in 2001, stating opposition to the Autogen project based on religious beliefs, namely, that patenting of ‘life forms’ was a violation of respect for the

sanctity of life and fundamental religious principles. Moreover, this patenting was not in the interest of the Tongans: “The conversion of lifeforms, their molecules or parts into corporate property through patent monopolies is counter-productive to the interests of the [people] of the Pacific.” The statement also affirmed the Tongans desire to control research conducted in their country: “The peoples of the Pacific have the right to manage their own biological resources, to preserve their traditional knowledge and to protect these from expropriation and exploitation by scientific, corporate or governmental interests.”

Shortly after the protests by Tongan groups, Autogen withdrew its plans for the project and pursued agreements to gather samples elsewhere. Autogen did not collect or analyze samples and instead formed new agreements with Polynesian groups on other islands to gather genetic information.

Governance and Benefit-Sharing

Commercial benefits of genetic research are difficult to predict, especially in the short term. In cases where benefit-sharing agreements are constructed around potential commercial profits, these benefits may not emerge at all in the short- or medium-term. There are also questions about the form and disbursal of benefits to populations, for example as up-front payments or percentage of future royalties that may be dedicated to projects or programs, or as free provision of commercial products of research resulting from the genetic information.

Case 3: The Maya ICBG

Introduction

In 1996, a project was initiated to collect ethnobotanical information in Chiapas, Mexico, set up as a joint project with four partners: a US university research team, a Mexican teaching and research center, a biotech company, and a non-profit organization set up by the project to represent the interests of the Mayan communities. The multiple aims of the project included preservation of local medicinal plant knowledge and its use to discover new therapies for a range of local and internationally important diseases, as well as the development of local economic and scientific capacity. Controversy erupted as some local and external groups charged that the project was exploitative, while the project partners defended it as mutually beneficial and socially responsible. Collection of plant materials for bioprospecting was never initiated, and the disputes led to withdrawal of the local public research center partner, cessation of funding, and termination of the project.

Background on Chiapas

The Chiapas region in southern Mexico is a region of extreme poverty, well below national averages for Mexico in important indicators such as child survival, per capita GDP, and educational levels. Approximately one third of the population is Maya speaking, belonging to one of eight language groups.

While rich in natural resources, there are few economic opportunities for Chiapas residents, many of whom farm small plots of land. The economic situation for small farmers in the Chiapas region during the 1990's was bad, and it was getting worse, due to changes in prices and trade policies, as well as accelerated degradation of natural resources. Struggles for land reform in the region had been ongoing for many decades, and had led to the formation of many local peasant resistance groups, including, in 1983, the Zapatista Army of National Liberation (EZLN). In 1994, the

indigenous peoples of Chiapas gained world attention in an armed uprising of the EZLN, and became international symbol of ethnic resistance to globalization and the struggle for social equality and indigenous rights.

In Chiapas, governance was structured at the municipal level; indigenous land ownership had traditionally, and under Mexican law known as the ejido system, been communal. In the early 1990s, government policies protecting communal land ownership in the ejido system was eroding, but in response to the Zapatista uprising, the San Andres accords of 1996 established local indigenous communities as legitimate land owners. The accords were supposed to support indigenous peoples' rights in several areas: control of their traditional natural resources; participation in decision-making regarding public expenditures; control of their own judicial and administrative affairs. Subsequently there was disagreement and controversy regarding the implementation of the accords, which were not translated into legislative action or implementation by the Mexican government, creating further bitterness and disillusionment among indigenous communities.

Mayan traditions of healing

The highland Maya had a long tradition of use of medicinal plants for healing. These herbal traditions were not seen as a distinct class of medicine, but were part of a systemic view of health and healing that involves spiritual healers, prayer, rituals, and herbal preparations, although healers have become aware of the attractiveness of the use of medicinal plants to outside groups. Herbal preparations continue to be an important source of primary health care for the vast majority of Maya residents of Chiapas. The researchers in the ICBG project had studied the degree to which knowledge of herbal remedies was held by community members generally, and planned to study only those herbal preparations used by the community at large. Also, a large proportion of the herbal preparations are based on plants and knowledge that are shared with other communities outside of the region. However, the local healers group was concerned that specialized knowledge was being appropriated by outsiders.

Background on bioprospecting

Most bioprospecting agreements do not result in economic gain for industrial partners in the short and medium term due to the low chances of developing a successful, marketable drug from plant or microbial sources; long-term benefits may vary, depending on whether products become commercially successful. Some bioprospecting efforts involve use of traditional knowledge in indigenous communities to focus on plants with known medicinal value, while some do not. Companies frequently view other strategies, such as combinatorial chemistry, as more efficient means of screening compounds with potential activity. However, there is a fairly widespread public perception that multinational drug companies can easily make millions from appropriation of natural resources of countries with rich biodiversity. The Convention on Biological Diversity (CDB) 1992 arose in part, out of concerns about appropriation or exploitation of biological resources in countries without adequate policies or regulations to protect natural resources or their local users. In the Bonn guidelines, which emerged from the CBD, it is recognized that indigenous groups should be able to share in benefits from their traditional knowledge (2002), and Prior Informed Consent (PIC) should be sought in communities where biological resources or traditional knowledge is utilized in

research.

Under Mexican law, permits for collecting biological specimens need to be obtained from a national ministry, and in addition, permission from the owner of the land is needed for any collection destined for commercial purposes. However, the law does not address intellectual property or bioprospecting *per se*.

The International Cooperative Biodiversity Program (ICBG), started in 1993 and sponsored by 3 US government agencies aims to promote research programs that incorporate a commitment to conservation and biodiversity, as well as local economic development, in bioprospecting research

(<http://www.fic.nih.gov/programs/oecdub.html>). The intent of ICBG projects is that they be contracted as fair partnerships among organizations including research organizations, industrial partners, and community organizations, and to develop outcomes that benefit not only the partners, but also larger social goods locally and internationally.

Story of the Maya ICBG

The Maya ICBG project involved collecting and cataloguing botanical species of the Chiapas highlands, including development of ethnobotanical gardens for conserving plants, evaluating traditional remedies, compiling monographs in several languages (including local languages) which would describe botanical and medicinal findings. The project's principal investigators had been investigating ethnobotany in the region for almost 30 years. Through the ICBG and other efforts they had begun to publish handbooks on traditional remedies for diarrhea, respiratory conditions, infectious diseases, and contraception in native languages with translations to Spanish and English.

The ICBG project involved four partners: a US university; a local Mexican public research center with a long history of multidisciplinary, sustainable development-oriented research activities in the region; a small biotech company based in Wales, whose mission was to identify promising new plant-based compounds that could then potentially be developed by larger pharmaceutical companies for clinical applications; and the Mayan communities themselves. The more than 250,000 Maya people potentially involved were not grouped in a single overarching organization, but had formed complex, diverse and dispersed political, religious and production-oriented organizations. Given that there was no overarching organization representing Mayan communities, the ICBG project leaders proposed instead PROMAYA: a trust fund initially promoted and governed by regional and national political figures sympathetic with the concerns of indigenous people; this governance was selected by the non-indigenous partners in the project.

The project never reached the stage of collections for research with commercial development potential. However, the participating organizations had begun drafting agreements regarding intellectual property. The draft ICBG-Maya Joint Ownership agreement stipulated that Maya communities would receive 1/4 of any royalties and co-ownership of any licenses that emerged from the research – the other shares were divided in equal fourths among the US university, the biotech company, and the Mexican research institution. The Maya share was to be paid to the NGO/Trust fund PROMAYA. Decisions taken regarding use of PROMAYA funds were to be made by representatives from each of the participating communities. However, funds could also be used for projects that benefited other local communities that declined to

	<p>participate in the research.</p> <p>Prior informed consent was sought in local villages using Tzeltal and Tzotzil language theatre, in order to meet the current legal requirements established by the Mexican government to provide collecting permits. The informed consent process emphasized that the chances of substantial financial benefits from the project were slim, and that other non-monetary benefits were more significant, such as conservation of traditional knowledge, creation of ethnobotanical gardens, and use of plant-based pest control agents. A consent form was signed, usually by elected community leaders, in each of the 46 villages that decided to participate (out of the 47 villages approached).</p> <p>Twelve percent of the project budget was allocated to salaries for 24 Maya field assistants, who received training in transcription in their own languages, field botanical survey techniques, computer literacy, lab techniques, plant propagation, marketing and IP issues.</p> <p>From the beginning of negotiations regarding the project, the local indigenous healers group, was not involved; they had been informed of the project informally by the Mexican research partner during the grant-writing stage. They did not join in the planning or grant-writing stages of the project, although they did attend a public workshop about the project after the grant was obtained.</p> <p>In challenges to the informed consent process, a consortium of healers' groups, which included the local healers' group, and an NGO advocating widely against bioprospecting activities alleged that the consent of the participating villages was insufficient, and that national level policies regarding protection of indigenous right and resources would be necessary before any collection could begin. In 1999 the healers' consortium directed a letter to local and federal authorities called for a halt to the project. Denunciations of the ICBG project were published on numerous websites, and gathered increasing media attention, and support from observers unconnected to the case or to the region.</p> <p>In 2001 the Mexican research institution withdrew from the project, citing the difficulties arising from the challenges of the healer's consortium and the NGO, the need for a self-organized indigenous partner, and for national level regulation to provide some resolution of the impasse. Without a local research partner, the project was no longer eligible for US government grant support, and in November 2001 the project folded.</p>
Readings	<ul style="list-style-type: none"> • Galjaard, H. 2009. 'Article 15: Sharing Of Benefits', in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 231-241: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>Declaration on Science and the Use of Scientific Knowledge</i>, UNESCO-ICSU World Conference on Science on 1 July 1999: http://www.unesco.org/bpi/science/content/docum/declare.htm (multiple languages) • <i>Universal Declaration on the Human Genome and Human Rights</i>, UNESCO General Conference 29 C/Resolution 16 on 11 November 1997: http://portal.unesco.org/shs/en/ev.php-

	<p>URL_ID=1881&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages)</p> <ul style="list-style-type: none"> • <i>International Declaration on Human Genetic Data</i>, UNESCO General Conference 32 C/Resolution 22 on 16 October 2003: http://portal.unesco.org/shs/en/ev.php-URL_ID=1882&URL_DO=DO_TOPIC&URL_SECTION=201.html (multiple languages) • Secretariat of the Convention on Biological Diversity (2002). <i>Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization</i>. Montreal: Secretariat of the Convention on Biological Diversity: http://www.biodiv.org/programmes/socio-eco/benefit/bonn.asp • <i>Declaration on the TRIPS Agreement and Public Health</i>, World Trade Organization (WTO) Ministerial Conference, Doha, Qatar, WT/MIN(01)/DEC/2 adopted on 14 November 2001: http://www.wto.org/english/thewto_e/minist_e/min01_e/mindecl_trips_e.htm (English) http://www.wto.org/french/thewto_f/minist_f/min01_f/mindecl_trips_f.htm (French) http://www.wto.org/spanish/thewto_s/minist_s/min01_s/mindecl_trips_s.htm (Spanish) • TRIPS and public health, World Trade Organization (WTO) – references to all news, briefings and official texts on Trade-Related Aspects of Intellectual Property Rights (TRIPS), patents, and pharmaceuticals and public health: http://www.wto.org/english/tratop_e/trips_e/pharmpatent_e.htm (English) http://www.wto.org/french/tratop_f/trips_f/pharmpatent_f.htm (French) http://www.wto.org/spanish/tratop_s/trips_s/pharmpatent_s.htm (Spanish)
Video/Movie	
Role play	
Group discussion	<p><u>Group Discussion on Case 1:</u></p> <ul style="list-style-type: none"> • Is the benefit-sharing agreement reasonable in terms of amount and type of benefit distributed to the San? How can it be determined that distribution of monetary gains through the San Trust fund is reasonable and genuinely beneficial to the San people? • In this case, the San were able to negotiate for benefits with CSIR after a patent had already been established. In some cases indigenous groups have been unsuccessful in making claims for benefit sharing. What kind of oversight could be exercised more generally on the part of the government of South Africa or other nations to provide for benefits to indigenous communities that share traditional knowledge? • In this case, indigenous political organizations had already been formed for land claims issues. How can legitimacy of such organizations be determined, especially when the prospect of large financial gain enters the picture? <p><u>Group Discussion on Case 2:</u></p>

	<ul style="list-style-type: none"> • What ethical concerns arise concerning the ability of national governments to negotiate and decide agreements for genetic research concerning their populations? Can decision-makers be unduly swayed by the potential for commercial profit or valuable collaboration with scientific groups? The islands of Tonga have a history of relationships with colonial powers, including current economic dependence on more industrialized nations. Is this an interesting footnote, or a substantive concern in the negotiation of agreements with foreign companies? • Would it have made any difference if the genetic research project were carried out by a non-profit entity, as opposed to a for-profit commercial entity? Non-profits can also acquire patents to DNA sequences or products derived from research on specific genes. Do the overall goals of the research matter? • Are risks of research and potential benefits characterized adequately and analyzed as part of the decision-making process at the national level? Was there sufficient public discussion of potential risks or benefits in the two cases? How can benefit-sharing arrangements be evaluated in terms of fairness, transparency, and responsiveness to national needs? How can it be determined that benefits that may accrue to a body or governmental organization in the country can serve the interests of the population? <p><u>Group Discussion on Case 3:</u></p> <ul style="list-style-type: none"> • Discuss and determine what particular ethical issues are most critical in this case: <ul style="list-style-type: none"> ○ Is it primarily about the need to define informed consent at the community level? ○ The potential for exploitation of indigenous knowledge for the benefit of others? ○ The capacity of these endeavours to actually make a difference in community development? ○ The need to respect cultural norms in disadvantaged communities? ○ The interference of external private organizations in agreements between researchers and community members? ○ The degree of protection provided under current Mexican national law or under international contract law?
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 16	
Title	Protecting future generations (Article 16)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain the principle of protecting future generations 2. Students should be able to evaluate the possibilities and difficulties in the application of the principle in practical settings 	
Study Materials	
Cases	<p><u>Case 1: Commission for Future Generations</u></p> <p>A country created a Commission for Future Generations according to Parliamentary Law. The idea at the base of the Commission was to create an inner-parliamentary entity, which would have a comprehensive sight of the legislative picture. The Commission would oversee the legislative process with special regards to long-term issues and would attempt to prevent potentially damaging legislation from passing in Parliament.</p> <p>The Commission was given the authority to initiate bills that advance the interests of future generations and to advise Members of Parliament and Parliamentary Committees in regards to the legislative process. Furthermore, the Commissioner had the authority to delay the legislative process in case it was necessary to seek more time to formulate its position on a matter. In addition, the Commissioner had the authority to retrieve information from all governmental entities, such as ministries, public companies, state institutions, enterprises and more.</p> <p>The purpose of the Commission was to preserve the resources of this country and create sustainable infrastructures for coming generations. According to the law, the Commission’s authority concentrated on the following areas: environment, natural resources, science, development, education, health, state economy, demography, construction, quality of living, technology and law.</p> <p>The Commission was entitled to:</p> <ol style="list-style-type: none"> 1. Present its position on bills brought before the Parliament of interest to future generations. 2. Present its stand on sub-legislations and regulations, brought by the government before the Parliament’s different Committees of interest to future generations. 3. Provide the Parliament, from time to time, with recommendations on any matter the Commissioner considers being of importance regarding future generations. 4. Advise the Members of the Parliament on matters that are of special interest to future generations. <p>The opinions and the recommendations given by the Commissioner had to carry a scientific character, be detailed and include comparative research.</p> <p><u>Case 2: Genetically modified plants</u></p> <p>A civil action is brought by the Center for Food Safety against the Federal Department of Agriculture, concerned that approvals for conducting trials on</p>

	<p>genetically engineered crops had been granted without proper environmental reviews. The Center was concerned that the long term consequences of contamination of the natural environment with genetically modified plants had not been properly evaluated.</p> <p>The Center argued that genetic alteration has the potential to spread through reproduction with sexually compatible wild plants and then persist in the environment, the consequences of which are unknown.</p> <p>The judge found in favour of the Center for Food Safety and deemed the permits that had been issued illegal. The further issuing of permits was to halt until more rigorous environmental review had been undertaken.</p> <p>Case 3: <u>Deforestation</u></p> <p>Written into the constitution of a country is that “the State shall protect and advance the right of the people to a balanced and healthy ecology in accord with the rhythm and harmony of nature”.</p> <p>On the basis of this statement, the Secretary of the Department of Environmental and Natural Resources was petitioned by minors (represented by their parents), claiming to represent both themselves and unborn generations, to cancel all existing timber licenses and to desist from processing new ones. The petitioners claimed that “the ... archipelago ... is endowed with rich, lush and verdant rainforests in which varied, rare and unique species of flora and fauna may be found: these rainforests contain a genetic, biological and chemical pool which is irreplaceable; they are also the habitat of indigenous ... cultures which have existed, endured and flourished since time immemorial”. The plaintiffs list many environmental disasters that have been directly contributed to by deforestation and claim that only 2.8% of the land mass of the entire archipelago remains as old growth rainforests. They claimed that at the current rate of deforestation the nation will be bereft of forest resources within the decade.</p> <p>The court granted the petitioners permission to go to trial, stating that “the forest cover of our territory is of extreme importance to the country”.</p> <p>However the timber industry provides many jobs from the level of harvesting upwards.</p>
Readings	<ul style="list-style-type: none"> • Morisaki, T. 2009. ‘Article 16: Protecting Future Generations’, in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 243-245: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • <i>The Precautionary Principle</i>, UNESCO World Commission on the Ethics of Scientific Knowledge and Technology (COMEST), UNESCO, Paris, 2005: http://unesdoc.unesco.org/images/0013/001395/139578c.pdf (Chinese) http://unesdoc.unesco.org/images/0013/001395/139578e.pdf (English) http://unesdoc.unesco.org/images/0013/001395/139578f.pdf (French) http://unesdoc.unesco.org/images/0013/001395/139578s.pdf (Spanish) • <i>Declaration on the Responsibilities of the Present Generations Towards Future Generations</i>, UNESCO General Conference 29 C/Resolution 44 on 12 November 1997: http://unesdoc.unesco.org/images/0011/001108/110827ab.pdf (Arabic)

	<p>http://unesdoc.unesco.org/images/0011/001108/110827eb.pdf (English) http://unesdoc.unesco.org/images/0011/001108/110827fb.pdf (French) http://unesdoc.unesco.org/images/0011/001108/110827sb.pdf (Spanish)</p> <ul style="list-style-type: none"> • Agius, E. 2006. 'Environmental ethics: towards an intergenerational perspective', in <i>Environmental Ethics and International Policy</i>, ed. ten Have, H.A.M.J. UNESCO Publishing, Paris, pp. 89-115: http://publishing.unesco.org/details.aspx?Code_Livre=4510 (English) http://publishing.unesco.org/details.aspx?Code_Livre=4551 (French) • <i>Our Common Future</i>, United Nations World Commission on Environment and Development (WCED), Oxford University Press, Oxford/New York, 1987: http://www.un-documents.net/wced-ocf.htm • Daar, A.S.; Chapman, L.E. 2006. 'Xenotransplantation', in <i>Ethics of Science and Technology: Explorations of the frontiers of science and ethics</i>, UNESCO, Paris, pp. 101-128: http://unesdoc.unesco.org/images/0014/001454/145409e.pdf • ten Have, H.A.M.J. (ed.) 2007. <i>Nanotechnologies, Ethics and Politics</i>. UNESCO Publishing, Paris: http://publishing.unesco.org/details.aspx?Code_Livre=4539 (English) http://publishing.unesco.org/details.aspx?Code_Livre=4650 (French)
Video/Movie	
Role play	
Group discussion	<p><u>Group Discussion on Case 2:</u></p> <ul style="list-style-type: none"> • Based on this case and on the reading of <i>The Precautionary Principle</i> (UNESCO, 2005), discuss what is meant by the Precautionary Principle • Discuss how the Precautionary Principle should be applied in the context of the principle of protecting future generations <p><u>Group Discussion on Case 3:</u></p> <ul style="list-style-type: none"> • How can the principle of protecting future generations be balanced with the economic needs of a country and its individual citizens? • What is "intergenerational justice"? <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Nanotechnology is expected to be a massive industrial reality by 2015; some applications may take another 10, 15 or 20 years of research and development. Although it is difficult to distinguish realistic hopes from fantasy, real risks from forecasts, there are still significant uncertainties about potential environment and health impacts, and concerns for long term non-ethical applications • How should legislation deal with risk? • What is acceptable risk in view of: <ul style="list-style-type: none"> ○ significant scientific uncertainty (precautionary principle, security

	<p>margins)</p> <ul style="list-style-type: none"> ○ large scale applications (in particular environmental exposure) • Is science based risk assessment sufficient or is there a need for mechanisms for ethical assessment of advanced nanomedicine applications in order to protect future generations?
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: http://www.unesco.org/shs/ethics/geobs (multiple languages)

UNIT 17	
Title	Protection of the environment, the biosphere and biodiversity (Article 17)
Unit Learning Objectives	
<ol style="list-style-type: none"> 1. Students should be able to explain how bioethics is related to environmental issues 2. Students should be able to analyse environmental issues from anthropocentric, biocentric and ecocentric ethical perspectives 3. Students should be able to describe sustainable development 	
Study Materials	
Cases	<p>Case 1: <u>Biocentrism vs Anthropocentrism</u></p> <p>Diabetes is a global problem; the World Health Organization (WHO) estimates indicate that more than 180 million people worldwide have diabetes and that this number is likely to more than double by 2030.</p> <p>Diabetes is a chronic illness that affects multiple organs and may develop in different ways. Type 1 diabetes is caused by a diminished production of insulin by the pancreas; Type 2 diabetes occurs when the body cannot effectively utilize the insulin that it produces. The potential consequences of diabetes are serious, particularly if it is not adequately treated, and include blindness, renal damage, cardiovascular disease, neuropathy and peripheral vascular disease. The combination of the last two may necessitate lower limb amputation.</p> <p>Modern treatment for people with Type 1 diabetes is the daily delivery of insulin by injection or a pump, without which they would not survive. People with Type 2 diabetes may also be insulin dependent, without which their uncontrolled diabetes could lead to serious physical side effects and hasten organ damage.</p> <p>In 1922 medical scientists Frederick Banting and Charles Best discovered the pancreatic hormone insulin and extracted it from pancreatic tissue, later proving it to be an effective treatment for diabetes. Until 1982 insulin was produced exclusively from animal pancreas however further developments resulted in genetically-engineered human insulin becoming commercially available. Currently the vast majority of insulin (over 90%) used world-wide is recombinant human insulin.</p> <p>Whilst most of the insulin used is genetically-engineered, all products are toxicity tested on laboratory mice or rats. In addition, a significant amount of diabetes research is performed on animals as there is a large demand for the treatment of diabetes to be improved. There is a large range of research performed on animals including surgical removal of the pancreas to artificially induce diabetes, an irreversible procedure. Because of the experimental nature of the work, death may occur as a direct result of the interventions performed.</p> <p>In different countries, animal rights groups protest against animal exploitation in insulin toxicity tests and diabetes medical research. Medical scientists argue that today there is still no alternative to the use of animals in this field and for the benefit of such a large cohort of patients this activity should be sustained.</p> <p>Case 2: <u>Right to a healthy environment</u></p> <p>A case was brought to the court by a concerned citizen in a very large and crowded</p>

	<p>city regarding the authorities' inadequacy in dealing with sanitation and environmental preservation. They cited the health effects on the denizens as a result of environmental degradation, in particular water pollution, poor sewerage treatment, inadequate rubbish disposal and overcrowding. The claim was based on constitutional law, which guarantees a "right to life" for its citizens and that the "state shall endeavour to improve the environment and to safeguard the forests and wild life of the country"; it will "protect and improve the natural environment including forests, lakes, rivers and wild life and to have compassion for living creatures".</p> <p>The Supreme Court ruled in favour of the plaintiff and the authorities were given strict directions to implement policy that addressed the environmental concerns. This decision has sometimes been seen as a reaffirmation of the "right to a healthy environment", as far as its role in enabling the "right to life".</p> <p>Case 3: <u>Climate change</u></p> <p>The Kyoto Protocol is an international agreement linked to the United Nations Framework Convention on Climate Change. The major feature of the Kyoto protocol is that it sets binding targets for 37 industrialised countries and the European community for reducing greenhouse gas emissions. These amounts to an average of five percent against 1990 levels over the five-year period 2008-2012.</p> <p>Recognising that developed countries are principally responsible for the current high levels of greenhouse gas emissions in the atmosphere as a result of more than 150 years of industrial activity, the Protocol places a heavier burden on the developed nations under the principle of "common but differentiated responsibilities".</p> <p>Case 4: <u>Population control</u></p> <p>A "one-child policy" is introduced in a densely populated country. This policy is largely enforced by regional governments and is known to include mandatory contraception in the form of intrauterine devices (IUDs) and sterilization. Severe punishments (to both the woman and her extended family) are enacted for violation of this law. Termination is strongly recommended and by ending the pregnancy the punishment is avoided. The government aims for sustainable development through population control. Since the implementation of the policy, there has been significant economic growth throughout the region and life expectancy has increased. However, there is now a serious imbalance in the male-female distribution of the population.</p>
Readings	<ul style="list-style-type: none"> • Tandon, P.N. 2009. 'Article 17: Protection Of The Environment, The Biosphere And Biodiversity', in <i>The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles and application</i>, eds. ten Have, H.A.M.J.; Jean, M.S. UNESCO, Paris, pp. 247-254: http://publishing.unesco.org/details.aspx?&Code_Livre=4657&change=E • ten Have, H.A.M.J. (ed.) 2006. <i>Environmental Ethics and International Policy</i>, UNESCO Publishing, Paris: http://publishing.unesco.org/details.aspx?Code_Livre=4510 (English) http://publishing.unesco.org/details.aspx?Code_Livre=4551 (French) • <i>Our Common Future</i>, United Nations World Commission on Environment and Development (WCED), Oxford University Press, Oxford/New York, 1987:

	<p>http://www.un-documents.net/wced-ocf.htm</p> <ul style="list-style-type: none"> • <i>Johannesburg Declaration on Sustainable Development</i>, adopted at the 17th plenary meeting of the World Summit on Sustainable Development on 4 September 2002: http://www.un.org/esa/sustdev/documents/WSSD_POI_PD/English/POI_PD.htm (English) http://www.un.org/esa/sustdev/documents/WSSD_POI_PD/French/POI_PD.htm (French) http://www.un.org/esa/sustdev/documents/WSSD_POI_PD/Spanish/WSSDsp_PD.htm (Spanish) • <i>Rio Declaration on Environment and Development</i> (Principles of Sustainable Development), United Nations Conference on Environment and Development (UNCED/Earth Summit), Rio de Janeiro, Brazil, adopted on 14 June 1992: http://www.un.org/documents/ga/conf151/aconf15126-1annex1.htm • <i>Agenda 21. Programme of Action for Sustainable Development</i>, United Nations Conference on Environment and Development (UNCED/Earth Summit), Rio de Janeiro, Brazil, adopted on 14 June 1992: http://www.un.org/esa/sustdev/documents/agenda21/index.htm (multiple languages) • <i>United Nations Millennium Declaration</i>, UN General Assembly Resolution A/RES/55/2 of 8 September 2000: http://daccessdds.un.org/doc/UNDOC/GEN/N00/559/49/PDF/N0055949.pdf?OpenElement (Arabic) http://daccessdds.un.org/doc/UNDOC/GEN/N00/559/50/PDF/N0055950.pdf?OpenElement (Chinese) http://daccessdds.un.org/doc/UNDOC/GEN/N00/559/51/PDF/N0055951.pdf?OpenElement (English) http://daccessdds.un.org/doc/UNDOC/GEN/N00/559/52/PDF/N0055952.pdf?OpenElement (French) http://daccessdds.un.org/doc/UNDOC/GEN/N00/559/53/PDF/N0055953.pdf?OpenElement (Russian) http://daccessdds.un.org/doc/UNDOC/GEN/N00/559/54/PDF/N0055954.pdf?OpenElement (Spanish) • <i>State of World Population 2007: Unleashing the Potential of Urban Growth</i>, United Nations Population Fund (UNFPA), New York, 2007: http://www.unfpa.org/public/publications/pid/408 (multiple languages)
Video/Movie	<p>Movie: <u>An Inconvenient Truth (2006, Director: Davis Guggenheim)</u></p> <ul style="list-style-type: none"> • Humanity is sitting on a ticking time bomb. If the vast majority of the world's scientists are right, we have just ten years to avert a major catastrophe that could send our entire planet into a tail-spin of epic destruction involving extreme weather, floods, droughts, epidemics and killer heat waves beyond anything we have ever experienced. • If that sounds like a recipe for serious gloom and doom -- think again. From director Davis Guggenheim comes the Sundance Film Festival hit, <i>An Inconvenient Truth</i>, which offers a passionate and inspirational look at one man's fervent crusade to halt global warming's deadly progress in its tracks

	<p>by exposing the myths and misconceptions that surround it.</p> <ul style="list-style-type: none"> • Running time: 94 minutes • Official website: http://www.climatecrisis.net/aboutthefilm/
Role play	
Group discussion	<p><u>Group Discussion on Case 2:</u></p> <ul style="list-style-type: none"> • Discuss the concept of a “right to a healthy environment”. Do you think this right should exist? Justify your answer • Is there such a right enshrined in the Constitution of your country? <p><u>General Group Discussion:</u></p> <ul style="list-style-type: none"> • Discuss the 17 Principles of Environmental Justice <ul style="list-style-type: none"> ○ Analyse the statement of the First National People of Colour Environmental Leadership Summit, issued in 1991: <ul style="list-style-type: none"> http://www.ejnet.org/ej/principles.html http://www.ejrc.cau.edu/princej.html ○ Develop policy recommendations on the basis of the principles of environmental justice <ul style="list-style-type: none"> ▪ at individual level ▪ at national level ▪ at international level ○ Point out what will be the practical implications of such policies ○ Indicate which implications you yourself currently bring into practice
Other	<ul style="list-style-type: none"> • UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics: <ul style="list-style-type: none"> http://www.unesco.org/shs/ethics/geobs (multiple languages)

GENERAL RESOURCES

- **UNESCO Global Ethics Observatory (GEObs) Database on Resources in Ethics**
(<http://www.unesco.org/shs/ethics/geobs>)

The GEObs Database on Resources in Ethics is designed to reinforce ethics teaching, especially in regions where such activities are absent or minimal. The database contains links to resources such as ethics websites, ethics journals, ethics events, UNESCO publications, case materials and specific study materials for the UNESCO Bioethics Core Curriculum. Some of the resources listed are as shown below:

Ethics Websites (please check database for complete and most recent list):

- *BioEdge: bioethics news from around the world*
 - <http://www.bioedge.org/index.php/site/>
- *Bioethics and Human Rights Links, Human Rights Library, University of Minnesota*
 - <http://www1.umn.edu/humanrts/links/bioethics.html>
- *Bioethics, Council of Europe*
 - http://www.coe.int/T/E/Legal_affairs/Legal_co-operation/Bioethics/
 - http://www.coe.int/T/F/Affaires_juridiques/Coop%E9ration_juridique/Bio%E9thique/
- *bioethics.gov, The President's Council on Bioethics (USA)*
 - <http://bioethics.gov>
- *bioethics.net, Alden March Bioethics Institute*
 - <http://www.bioethics.net>
- *Bioethics, Pan American Health Organization*
 - <http://www.paho.org/Spanish/bio/home.htm>
 - <http://www.paho.org/english/bio/home.htm>
- *Bioethics Resources on the Web, National Institutes of Health (USA)*
 - <http://bioethics.od.nih.gov/>
- *Bioethics, UNESCO*
 - <http://www.unesco.org/shs/bioethics>
 - <http://www.unesco.org/shs/fr/bioethics>
- *Bioética.org, Cuadernos de Bioética*
 - <http://www.bioetica.org>
- *Center for Ethics & Professionalism, American College of Physicians*
 - http://www.acponline.org/running_practice/ethics/
- *CODEX, The Swedish Research Council*
 - http://www.codex.uu.se/codex_eng/codex/index.html
 - <http://www.codex.uu.se/index.html>
- *Ethics and Health, WHO*
 - <http://www.who.int/ethics/en>
- *Ethics of Science and Technology, UNESCO*
 - www.unesco.org/shs/est
 - www.unesco.org/shs/fr/est

- *Ethics Unit, The World Medical Association*
 - <http://www.wma.net/e/ethicsunit/index.htm>
 - <http://www.wma.net/f/ethicsunit/index.htm>
 - <http://www.wma.net/s/ethicsunit/index.htm>
- *Ethics Updates, Values Institute, University of San Diego*
 - <http://ethics.sandiego.edu/>
- *European Group on Ethics in Science and New Technologies, European Commission*
 - http://europa.eu.int/comm/european_group_ethics/index_en.htm
 - http://ec.europa.eu/european_group_ethics/index_fr.htm
- *German Reference Centre for Ethics in the Life Sciences (Deutsches Referenzzentrum fuer Ethik in den Biowissenschaften)*
 - <http://www.drze.de/?la=en>
 - <http://www.drze.de/?la=de>
 - <http://www.drze.de/BELIT/thesaurus?la=en>
 - <http://www.drze.de/BELIT/thesaurus?la=fr>
 - <http://www.drze.de/BELIT/thesaurus?la=de>
- *Human Dignity, The President's Council on Bioethics*
 - http://www.bioethics.gov/topics/human_dignity.html
- *International Medical and Dental Ethics Commission*
 - <http://www.imdec.org/>
- *Multilingual Ethics Resources, UNESCO Bangkok*
 - <http://www.unescobkk.org/rushsap/ethics-resources/multilingual-material/>
- *National Bioethics Advisory Commission (USA)*
 - <http://bioethics.georgetown.edu/nbac>
- *National Consultative Bioethics Committee (France)*
 - <http://www.ccne-ethique.fr>
 - <http://www.ccne-ethique.fr/?langue=2>
- *National Reference Center for Bioethics Literature (NRCBL), Kennedy Institute of Ethics, Georgetown University*
 - <http://bioethics.georgetown.edu>
- *Nuffield Council on Bioethics*
 - <http://www.nuffieldbioethics.org>
- *Online Ethics Center, The National Academy of Engineering (USA)*
 - <http://www.onlineethics.diamax.com/>
- *SciDev.Net, Science and Development Network*
 - <http://www.scidev.net/en/>
 - <http://www.scidev.net/fr/>
 - <http://www.scidev.net/es/>
 - <http://www.scidev.net/zh/>
- *The Bioethics and Society Research Register*
 - <http://www.ihs.ox.ac.uk/perl/ethox/us60.pl>
- *TRIPS and public health, World Trade Organization (WTO)*
 - http://www.wto.org/english/tratop_e/trips_e/pharmpatent_e.htm

- http://www.wto.org/french/tratop_f/trips_f/pharmpatent_f.htm
- http://www.wto.org/spanish/tratop_s/trips_s/pharmpatent_s.htm

UNESCO Publications (please check database for complete and most recent list):

- *Allgemeine Erklärung über Bioetik und Menschenrechte* (Deutsche UNESCO-Kommission e.V. (DUK))
 - <http://portal.unesco.org/shs/en/files/9409/11430234511Bioethik-Erklärung-2006.pdf/Bioethik-Erklärung-2006.pdf>
- *Avicenna and the ethics of science and technology today*
 - <http://unesdoc.unesco.org/images/0013/001344/134475e.pdf>
 - <http://unesdoc.unesco.org/images/0013/001344/134475f.pdf>
 - <http://unesdoc.unesco.org/images/0013/001344/134475s.pdf>
 - <http://unesdoc.unesco.org/images/0013/001344/134475r.pdf>
- *Best ethical practices in water use*
 - <http://unesdoc.unesco.org/images/0013/001344/134430e.pdf>
 - <http://unesdoc.unesco.org/images/0013/001344/134430fo.pdf>
- *Bioethics: International Implications*
 - <http://unesdoc.unesco.org/images/0013/001309/130976e.pdf>
 - <http://unesdoc.unesco.org/images/0013/001309/130976f.pdf>
- *Bioetika: voprosy i otvety (Bioethics: Questions and Answers)*
 - <http://www.unesco.ru/files/docs/shs/Bioethics%20brochure.pdf>
- *Casebook on Benefit and Harm* (UNESCO Bioethics Core Curriculum Casebook Series)
 - <http://unesdoc.unesco.org/images/0019/001923/192370e.pdf>
- *Casebook on Human Dignity and Human Rights* (UNESCO Bioethics Core Curriculum Casebook Series)
 - <http://unesdoc.unesco.org/images/0019/001923/192371e.pdf>
- *Classroom Communication: Use of emotional intelligence and non-verbal communication in ethics education at medical schools* (UNESCO Chair in Bioethics, Haifa, Israel)
 - <http://medlaw.haifa.ac.il/index/main/4/CLASSROOM%20COMMUNICATION.pdf>
 - <http://medlaw.haifa.ac.il/index/main/4/communicationspanish.pdf>
- *Declaration on Science and the Use of Scientific Knowledge* (1999)
 - <http://unesdoc.unesco.org/images/0012/001207/120706e.pdf#121033>
- *Declaration on the Responsibilities of the Present Generations towards Future Generations* (1997)
 - <http://unesdoc.unesco.org/images/0011/001108/110827eb.pdf>
 - <http://unesdoc.unesco.org/images/0011/001108/110827fb.pdf>
 - <http://unesdoc.unesco.org/images/0011/001108/110827sb.pdf>
 - <http://unesdoc.unesco.org/images/0011/001108/110827ab.pdf>
- *Draft Report of the Working Group of IBC on Human Cloning and International Governance* (2009)
 - http://portal.unesco.org/shs/en/files/12761/12396540721Draft_Report_Human_Cloning_March_2009.pdf/Draft%2BReport%2BHuman%2BCloning%2B%2BMarch%2B2009.pdf

- http://portal.unesco.org/shs/fr/files/12761/12396542931Draft_report_Human_Cloning_March_2009_FR.pdf/Draft%2Breport%2BHuman%2BCloning%2B%2BMarch%2B2009%2BFR.pdf
- *Environmental Ethics and International Policy* (UNESCO Publishing)
 - http://publishing.unesco.org/details.aspx?Code_Livre=4510
- *Ethics in Asia-Pacific*
 - <http://unesdoc.unesco.org/images/0013/001359/135911e.pdf>
- *Ethics of Science and Technology: Explorations on the frontiers of science and ethics*
 - <http://unesdoc.unesco.org/images/0014/001454/145409e.pdf>
- *Guide No. 1: Establishing Bioethics Committees*
 - <http://unesdoc.unesco.org/images/0013/001393/139309e.pdf>
 - <http://unesdoc.unesco.org/images/0013/001393/139309f.pdf>
 - <http://unesdoc.unesco.org/images/0013/001393/139309s.pdf>
 - <http://unesdoc.unesco.org/images/0013/001393/139309a.pdf>
 - <http://unesdoc.unesco.org/images/0013/001393/139309r.pdf>
 - <http://unesdoc.unesco.org/images/0013/001393/139309c.pdf>
- *Guide No. 2: Bioethics Committees at Work: Procedures and Policies*
 - <http://unesdoc.unesco.org/images/0014/001473/147392e.pdf>
 - <http://unesdoc.unesco.org/images/0014/001473/147392f.pdf>
 - <http://unesdoc.unesco.org/images/0014/001473/147392s.pdf>
 - <http://unesdoc.unesco.org/images/0014/001473/147392r.pdf>
 - <http://unesdoc.unesco.org/images/0014/001473/147392c.pdf>
- *Guide No. 3: Educating Bioethics Committees*
 - <http://unesdoc.unesco.org/images/0015/001509/150970e.pdf>
 - <http://unesdoc.unesco.org/images/0015/001509/150970f.pdf>
 - <http://unesdoc.unesco.org/images/0015/001509/150970s.pdf>
 - <http://unesdoc.unesco.org/images/0015/001509/150970a.pdf>
 - <http://unesdoc.unesco.org/images/0015/001509/150970r.pdf>
 - <http://unesdoc.unesco.org/images/0015/001509/150970c.pdf>
- *Human Cloning: Ethical issues*
 - <http://unesdoc.unesco.org/images/0013/001359/135928e.pdf>
 - <http://unesdoc.unesco.org/images/0013/001359/135928f.pdf>
 - <http://unesdoc.unesco.org/images/0013/001359/135928s.pdf>
 - <http://unesdoc.unesco.org/images/0013/001359/135928a.pdf>
 - <http://unesdoc.unesco.org/images/0013/001359/135928r.pdf>
 - <http://unesdoc.unesco.org/images/0013/001359/135928cb.pdf>
- *Informed Consent* (UNESCO Chair in Bioethics, Haifa, Israel)
 - <http://unesdoc.unesco.org/images/0014/001487/148713e.pdf>
 - <http://medlaw.haifa.ac.il/index/main/4/Informed%20consent%20-%20french.pdf>
 - <http://medlaw.haifa.ac.il/index/main/4/consentimientoinformado.pdf>
 - <http://medlaw.haifa.ac.il/index/main/4/ConsentArabic.pdf>
 - <http://medlaw.haifa.ac.il/index/main/4/informedConsentChinese.pdf>
 - <http://medlaw.haifa.ac.il/index/main/4/ConsentRussian.pdf>

- <http://medlaw.haifa.ac.il/index/main/4/ConsentTurkish.pdf>
- http://medlaw.haifa.ac.il/index/main/4/consent_romanian.pdf
- <http://medlaw.haifa.ac.il/index/main/4/consentslovak.pdf>
- <http://medlaw.haifa.ac.il/index/main/4/InformedPolish.pdf>
- *International Declaration on Human Genetic Data* (2003)
 - http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html
 - http://portal.unesco.org/fr/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html
 - http://portal.unesco.org/es/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html
 - <http://unesdoc.unesco.org/images/0013/001331/133171a.pdf#page=50>
 - <http://unesdoc.unesco.org/images/0013/001331/133171r.pdf#page=48>
 - <http://unesdoc.unesco.org/images/0013/001331/133171c.pdf#page=48>
 - http://portal.unesco.org/shs/en/files/9193/11387255151DECLARATION_PORTUGAL.pdf/DECLARATION%2BPORTUGAL.pdf
 - http://portal.unesco.org/shs/en/files/9192/11387254601DECLARATION_TURC.pdf/DECLARATION%2BTURC.pdf
 - <http://unesdoc.unesco.org/images/0013/001361/136112HEB.pdf>
- *Legal and ethical framework for astronauts in space sojourns*
 - <http://unesdoc.unesco.org/images/0013/001397/139752m.pdf>
- *Medical ethics in reproductive health: Case studies* (UNESCO Chair in Bioethics, Haifa, Israel)
 - <http://medlaw.haifa.ac.il/index/main/4/ReproductiveHealth.pdf>
 - <http://unesdoc.unesco.org/images/0014/001499/149913F.pdf>
- *Moral Games for Teaching Bioethics* (UNESCO Chair in Bioethics, Haifa, Israel)
 - <http://unesdoc.unesco.org/images/0016/001627/162737e.pdf>
- *Nanotechnologies and Ethics: Policies and Actions* (COMEST Policy Recommendations)
 - <http://unesdoc.unesco.org/images/0015/001521/152146E.pdf>
 - <http://unesdoc.unesco.org/images/0015/001521/152146F.pdf>
 - <http://unesdoc.unesco.org/images/0015/001521/152146A.pdf>
 - <http://unesdoc.unesco.org/images/0015/001521/152146S.pdf>
 - <http://unesdoc.unesco.org/images/0015/001521/152146R.pdf>
- *Nanotechnologies, Ethics and Politics* (UNESCO Publishing)
 - http://publishing.unesco.org/details.aspx?&Code_Livre=4539&change=E
- *Psychiatric Ethics and the Rights of Persons with Mental Disabilities in Institutions and the Community* (UNESCO Chair in Bioethics, Haifa, Israel)
 - <http://medlaw.haifa.ac.il/index/main/4/psychethicsperlin.pdf>
- *Report of the IBC on Ethics, Intellectual Property and Genomics* (2002)
 - http://portal.unesco.org/shs/en/files/2139/10541304201FinalReportIP_en.pdf/FinalReportIP_en.pdf
 - http://portal.unesco.org/shs/fr/files/2139/10541303171FinalReportIP_fr.pdf/FinalReportIP_fr.pdf
- *Report of the IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention* (2003)

- http://portal.unesco.org/shs/en/files/2397/10554294261ReportfinalPGD_en.pdf/ReportfinalPGD_en.pdf
 - http://portal.unesco.org/shs/fr/files/2397/10554295391ReportfinalPGD_fr.pdf/ReportfinalPGD_fr.pdf
- *Report of the IBC on Solidarity and International Co-operation between Developed and Developing Countries concerning the Human Genome* (2001)
 - http://portal.unesco.org/shs/en/files/2295/10541325861Solidarity_en.pdf/Solidarity_en.pdf
 - http://portal.unesco.org/shs/fr/files/2295/10541324521Solidarity_fr.doc/Solidarity_fr.doc
- *Report of the International Bioethics Committee (IBC) of UNESCO on Consent* (2008)
 - http://portal.unesco.org/shs/en/ev.php-URL_ID=12581&URL_DO=DO_TOPIC&URL_SECTION=201.html
- *Report of the International Bioethics Committee (IBC) of UNESCO on Social Responsibility and Health* (2010)
 - <http://unesdoc.unesco.org/images/0018/001878/187899e.pdf>
 - <http://unesdoc.unesco.org/images/0019/001900/190054f.pdf>
- *Teaching Ethics in Psychiatry: Case-vignettes* (UNESCO Chair in Bioethics, Haifa, Israel)
 - <http://medlaw.haifa.ac.il/index/main/4/teaching%20ethics%20in%20psych%20new.pdf>
 - http://portal.unesco.org/shs/en/files/9212/11395853611Teaching_Ethics_in_Psychiatry_AR.pdf/Teaching_Ethics_in_Psychiatry_AR.pdf
 - <http://medlaw.haifa.ac.il/index/main/4/psychiatry%20hebrew%20complete.pdf>
- *The Ethics and Politics of Nanotechnology*
 - <http://unesdoc.unesco.org/images/0014/001459/145951e.pdf>
 - <http://unesdoc.unesco.org/images/0014/001459/145951f.pdf>
 - <http://unesdoc.unesco.org/images/0014/001459/145951a.pdf>
 - <http://unesdoc.unesco.org/images/0014/001459/145951c.pdf>
- *The Ethics of Energy*
 - http://portal.unesco.org/shs/en/files/1944/10485193631Ethics_of_Energy_Report.pdf/Ethics%20of%20Energy%20Report.pdf
- *The Ethics of Space Policy*
 - <http://unesdoc.unesco.org/images/0012/001206/120681e.pdf>
 - <http://unesdoc.unesco.org/images/0012/001206/120681f.pdf>
- *The Precautionary Principle*
 - <http://unesdoc.unesco.org/images/0013/001395/139578e.pdf>
 - <http://unesdoc.unesco.org/images/0013/001395/139578f.pdf>
 - <http://unesdoc.unesco.org/images/0013/001395/139578s.pdf>
 - <http://unesdoc.unesco.org/images/0013/001395/139578c.pdf>
- *The Teaching of Ethics*
 - <http://unesdoc.unesco.org/images/0013/001345/134552mb.pdf>
- *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application*
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- *The Universal Declaration on the Human Genome and Human Rights* (1997)
 - http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html
 - http://portal.unesco.org/fr/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html
 - http://portal.unesco.org/es/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html
 - <http://unesdoc.unesco.org/images/0011/001102/110220ab.pdf#page=50>
 - <http://unesdoc.unesco.org/images/0011/001102/110220rb.pdf#page=61>
 - <http://unesdoc.unesco.org/images/0011/001102/110220cb.pdf#page=61>
 - <http://unesdoc.unesco.org/images/0012/001229/122990por.pdf>
 - http://portal.unesco.org/shs/en/files/9191/11387252331GENOME_HUMAIN_Turc.pdf/GENOME%20HUMAIN%20Turc.pdf
 - <http://unesdoc.unesco.org/images/0012/001229/122990HEB.pdf>
- *Towards Knowledge Societies: UNESCO World Report*
 - <http://unesdoc.unesco.org/images/0014/001418/141843e.pdf>
 - <http://unesdoc.unesco.org/images/0014/001418/141843f.pdf>
 - <http://unesdoc.unesco.org/images/0014/001418/141843s.pdf>
 - <http://unesdoc.unesco.org/images/0014/001418/141843a.pdf>
 - <http://unesdoc.unesco.org/images/0014/001418/141843r.pdf>
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