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At the CPME Board Meeting in Brussels on 13 June 2009, CPME adopted the following document: “**Medical Ethics Core Curriculum on Consent, Confidentiality and Human Rights**” (CPME 2008/159 final EN/Fr)” (referring to CPME 2008/159 EN/Fr)

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### **Medical Ethics Core Curriculum On Consent, Confidentiality and Human Rights**

#### **ETHICS EDUCATION PROGRAMME**

The health policy of every nation seeks to control the use of its medical knowledge and resources so as to optimise the resulting benefits and minimise any resulting harms. Ethics provides a bridge between health policy and values and doctors have individual and collective responsibility both to inform health policy and to pursue medical practice in ways that maintain and improve the quality of health care, respect human rights and conform to ethical standards that promote people’s health in the sense of their physical mental and social wellbeing.

This document considers three core aspects of medical ethics- consent, confidentiality and human rights- in the light of these objectives. It is closely modelled on relevant parts of the UNESCO bioethics curriculum and thanks are due to UNESCO for permitting the CPME to use the UNESCO curriculum as the basis of its own curriculum while modifying it so as to reflect the concerns of an organisation representing European *doctors* and concerned with *medical* ethics. Thus whereas the UNESCO document is concerned with the entire spectrum of bioethics- a field of study which it describes at p 17 c below to be ‘as wide as the facts of life’- the CPME is concerned with *medical* ethics- that subclass of bioethics that encompasses ethical issues relevant to the practice of medicine in all its branches.

This document furthermore presents only a core: it provides a basis for appropriate medical ethics teaching concerning consent confidentiality and human rights. It allows flexible application and it invites teachers and students to expand its contents and approaches in diverse directions. This core curriculum should not be treated as a comprehensive curriculum even for the areas it covers let alone for medical ethics as a whole. The CPME recognizes that the content of this core curriculum does not cover all aspects of medical ethics and traditional issues that have not been included could be incorporated within the curriculum’s framework.



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## Introduction

### Background

On 19 October 2005, the 33<sup>rd</sup> Session of the General Conference of UNESCO adopted the [Universal Declaration on Bioethics and Human Rights](#) (hereafter referred to as the Declaration)[UNESCO 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 , not yet available, contains the proposed study materials for each unit of the curriculum.

[The UNESCO Bioethics Core Curriculum](#) sets out to introduce the bioethical principles of the *Universal Declaration on Bioethics and Human Rights* to university students. These principles are especially relevant to those studying and working in the health care sector, and their teachers. Use of the UNESCO principles 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 the world with different cultural, historical and religious backgrounds , yet agreeing on the principles articulated in the Declaration.

The UNESCO Bioethics Core Curriculum 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. The CPME initial curriculum presents only slightly more than half of this UNESCO core, with the objective of encouraging relevant medical education authorities in member countries to integrate it within their own teaching and learning programmes and to inform CPME and UNESCO on the results of such use. If the initial CPME curriculum is found to be helpful in European medical education, including especially postgraduate medical education, the CPME will address the more complex issues covered in units 10-17 of the UNESCO Bioethics core curriculum.

### Objectives

Each unit starts with specific learning objectives. These demarcate the contents of the unit and also form the basis for assessment of the programme and evaluation of the students.

### Target groups



Although the primary target group of the UNESCO core curriculum is medical students, the CPME considers its content relevant to all practising doctors, many of whom have not had much analytical medical ethics education in their own undergraduate studies. In addition many doctors are involved in teaching undergraduate and postgraduate students, and in continuing medical education and much of the UNESCO curriculum is in the form of 'teacher manual' which serves both to guide the teaching and where necessary the teachers. Thus the CPME recommends that doctors use the curriculum primarily as a guide to their own teaching of medical students and junior colleagues. In so doing they will refresh and sometimes augment their own knowledge.

Students engaged in research with human beings should partake in additional training beyond the core curriculum.

### Structure of the curriculum and possible uses

- Units based on principles

The first thing a teacher will notice about the syllabus is its innovative and unconventional structure. Typically, ethics courses in medical schools are organized around specific medical dilemmas such as beginning of life and end of life issues. The UNESCO core curriculum, however, is designed around the bioethical principles of the UNESCO Declaration, with each unit of the syllabus (except for the first two units) elaborating one of the principles. The primary rationale for this design is firmly rooted in the fact that 191 UNESCO Member States, including all those belonging to the CPME, have achieved consensus on these bioethical principles, thus establishing an essentially uncontroversial core curriculum for the teaching of bioethics in all Member States.

- Not a complete course but source of inspiration

However, the core curriculum should not be treated as a comprehensive curriculum in bioethics. It is recognized that the content of the core curriculum does not necessarily cover all aspects of bioethics. Traditional issues that have not been included could be incorporated as examples that are pertinent to one or several of the Declaration's principles within the curriculum's framework. Furthermore, the number of hours proposed for each unit should be considered as the minimum amount of time to be dedicated to the material. It is preferred that teachers do not deem the proposed time allotment as sufficient, and they should strive to build more hours into their teaching. Although UNESCO has taken measures to ensure that the curriculum is sensitive to various social, cultural and economic contexts, it is emphasized that teachers using the curriculum must still exercise discretion on the methods employed to convey the content of the curriculum, selecting contextually relevant materials provided or sourcing other available materials. Therefore, the core curriculum is intended to be a minimum teaching programme in bioethics with the possibility of further innovation, expansion and flexible application in different contexts. It is not intended to impose a particular model of teaching but rather to provide a source of ideas and suggestions on how to approach bioethics teaching.



- Flexibility

Teachers are encouraged to build additional modules focusing on traditional and other relevant issues around the units of the syllabus, bearing in mind that all units should be covered, dedicating at least the minimum recommended time. The proposed order of units could and should be adjusted according to the teaching style of the teacher. However, it should also be noted that the following units should be taught in conjunction to maintain a logical flow of the syllabus: Units 1 and 2; Units 5, 6 and 7; Units 13, 14 and 15; and Units 16 and 17.

#### Wider scope of bioethics

Teachers should keep in mind that the core curriculum is meant to provide them a way of getting students to reflect upon the ethical dimensions and human rights considerations of medicine, health care and science, and that the UNESCO Declaration approaches bioethics by going beyond individualistic perspectives of ethics, widening the scope to include social and community issues. Finally, it is stressed that although a bioethics course is important and a prerequisite, ethics needs to be taught as much as possible throughout the entire university curriculum, including undergraduate and postgraduate and continuing education medical curricula.

#### Methods of assessment

As with other courses in university education, bioethics teaching should be evaluated. Two types of evaluation will be necessary.

- Course evaluation

After completion of the core curriculum the teaching should be evaluated. Students as well as teachers are invited to provide feedback on the implementation of the curriculum. The purpose of this evaluation is to identify how the course and the teaching can be improved. In order to obtain comparable data about the implementation, UNESCO will develop a standardized questionnaire for the evaluation of the course. CPME member institutions are encouraged to feed back their evaluations both to UNESCO and to the CPME.

- Student evaluation

The purpose of this evaluation is to assess whether the teaching of the course has accomplished its objectives in each student. This evaluation is therefore focused on assessing the impact of the course in individual students. Various methods can be used: a written test, a multiple choice test, paper assignments, case analyses, presentations, essays, oral examinations.

In the future, on the basis of the outcome of the evaluation of the core curriculum, other assessment methods can be suggested.



### 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. The CPME is keen to participate in such feedback and to encourage participating medical education authorities both to submit feedback and materials to:

Standing Committee of European Doctors  
Rue Guimard 15, B-1040 Brussels, Belgium

Email: [secretariat@cpme.eu](mailto:secretariat@cpme.eu)

And to copy such feedback to:

Ethics Education Programme (Bioethics Core Curriculum)

Division of Ethics of Science and Technology

Sector for Social and Human Sciences

UNESCO, 1, rue Miollis, Paris 75732, France

Email: [eep@unesco.org](mailto:eep@unesco.org)



## CORE CURRICULUM CONTENT

Units	Title	Hours (60 mins)
1	What is ethics?*	2
2	What is bioethics?*	2
3	Human dignity and human rights (Article 3)	2
4	Benefit and harm (Article 4)	[2]
5	Autonomy and individual responsibility (Article 5)**	1
6	Consent (Article 6)**	2
7	Persons without the capacity to consent (Article 7)**	2
8	Respect for human vulnerability and personal integrity (Article 8)	1
9	Privacy and confidentiality (Article 9)	2
10	Equality, justice and equity (Article 10)	2
11	Non-discrimination and non-stigmatization (Article 11)	2
12	Respect for cultural diversity and pluralism (Article 12)	2
13	Solidarity and cooperation (Article 13)***	2
14	Social responsibility and health (Article 14)***	2
15	Sharing of benefits (Article 15)***	2
16	Protecting future generations (Article 16)****	1
17	Protection of the environment, the biosphere and biodiversity (Article 17)****	1
<b>TOTAL HOURS</b>		<b>30 [UNESCO] 14 [CPME]</b>

### Content Note

- \* Units 1 and 2 are tied together.  
 \*\* Units 5, 6, and 7 are tied together.  
 \*\*\* Units 13, 14, and 15 are tied together.  
 \*\*\*\* Units 16 and 17 are tied together.

### COURSE LEARNING OBJECTIVES

#### General Objective:

- Students should be able to identify ethical issues in medicine, health care and life sciences
- 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*



<b>UNIT 1</b>	
<b>Title</b>	<b>What is ethics?</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>1. Students should be able to recognize and distinguish an ethical issue from other issues</li> <li>2. Students should be able to reason about ethical issues</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. The moral point of view               <ol style="list-style-type: none"> <li>a. What is ethics?</li> <li>b. The world of ethics</li> <li>c. The universal experience of duty</li> <li>d. Moral experience is universal, but some moral perceptions and judgements vary</li> <li>e. Universality and variability of human morality</li> <li>f. Moral statements</li> </ol> </li> <li>2. The nature of moral judgements               <ol style="list-style-type: none"> <li>a. Three types of sentences</li> <li>b. Surface grammar and depth grammar</li> <li>c. Moral criteria and moral judgements</li> </ol> </li> <li>3. An ethical method of reasoning               <ol style="list-style-type: none"> <li>a. First step: Fact deliberation                   <ol style="list-style-type: none"> <li>i. The case</li> <li>ii. Deliberation about the facts</li> </ol> </li> <li>b. Second step: Value deliberation                   <ol style="list-style-type: none"> <li>i. Identification of the moral problems</li> <li>ii. Choice of the main problem</li> <li>iii. The values at stake</li> </ol> </li> <li>c. Third step: Duty deliberation                   <ol style="list-style-type: none"> <li>i. Reflecting on the most challenging cases</li> <li>ii. Reflecting on other cases</li> </ol> </li> <li>d. Fourth step: Testing consistency</li> <li>e. Fifth step: Conclusion</li> </ol> </li> </ol>	
<b>Teacher Manual</b>	
<ol style="list-style-type: none"> <li>1. The moral point of view               <ol style="list-style-type: none"> <li>a. What is ethics?                    Morality is a unique feature of the life of human beings. It is deeply influenced by several cultural factors, such as history, traditions, education, religious beliefs, etc. The intellectual analysis of this human dimension in all of its complexity is the goal of the discipline called Ethics. Ethics does not create morality or moral behaviour. The goal of ethics is much more modest: to explore the nature of moral                 </li> </ol> </li> </ol>	





experience, its universality and its diversity. Ethics and morality are generally taken as synonyms, because they originally had the same meaning: the study of the disposition, character, or attitude of a specific person, group of people or culture, and ways of promoting or perfecting it.

b. The world of ethics

In its development through history, the discipline called Ethics has known different approaches. None of them have obtained, to this moment, a general agreement. There are ethical systems ordered around the ideas of law, duty, obligation, virtue, happiness, principles, consequences, etc. In an effort to capture the valuable insights of each of these approaches it will be useful to begin by analyzing the universal moral experience of human beings. Proceeding this way, two concepts emerge as basic: one is “value” and the other is “duty”. Values can be identified amongst all peoples and societies and they often provide unique identifiers of those cultures. Values therefore predate the discipline called ethics, being promoted by religions, cultural traditions, history, etc. Values are the background of many other moral concepts derived from them, like principles, norms, laws, virtues, etc. One of the most important goals of ethics is the intellectual analysis of values and value conflicts, in order to define our duties. And duties always involve the values at stake in each specific situation, promoting them as much as possible.

c. The universal experience of duty

We all consider that some things ought to be done and others avoided. We have a duty to act in certain ways rather than others. The experience of duty is one of the most universal characteristics of human life. There is no human language without the so-called “duty-verbs”, such as “must”, “ought”, “shall”, or without imperative moods, in order to express commands, like: “do no harm!”, “fulfil your promises!”, “do not steal!”, “do not lie!”. Similarly, there is no human society without some rules of conduct, either “prohibitions” or “obligations”.

d. Moral experience is universal, but some moral perceptions and judgements vary

For instance, morality has been changing all over human history. Moral values are different depending on the place in which one is living, the language one speaks, the culture, the religions practised. Ask the students to provide examples.

e. Universality and variability of human morality

It follows from the previous statements that there are some universal and unchangeable elements in human morality, but others are historically conditioned and particular. Structurally, morality is always the same, but the contents are, at least to some extent, variable. In fact, moral values are constantly evolving. But at the same time, some moral duties remain unchanged, reflecting the logical limits of what counts as part of moral discourse. For instance, do not harm others, or tell the truth are universal moral norms only to be breached for overriding moral justifications.

f. Moral statements

Human beings express, communicate, and exchange human experiences through language. Statements are judgements, propositions or assertions that attribute some predicates to subjects.



## 2. The nature of moral judgements

### a. Three types of sentences

- i. Mahatma Gandhi was 1.5 metres tall.
- ii. Mahatma Gandhi was nice.
- iii. Mahatma Gandhi was good.

### b. Surface grammar and depth grammar

The words surface grammar refers to the construction of the sentences in terms of subject, verb and complement. The sentences are identical in this respect. As the first sentence ascribes a property to a subject we might expect the others to do the same. However when we look at the way we handle the sentences in the case of apparent disagreements about their truth we see that they behave very differently. This shows that the depth grammar or the logical character of the sentences varies.

- i. How do we resolve a disagreement about the first sentence? It is a matter of measurement. Though we might not be in a position to make the measurement we certainly know what it would be like to make it. Our understanding the sentence depends on such knowledge. If two people disagree about the claim made by the sentence one of them must be wrong. It is a question of objective fact, an empirical claim.
- ii. How do we resolve an apparent disagreement about the truth of this sentence? Each speaker might be able to give a reason for their statement. But they do not have to be able to do so and might simply say that they just like him. There is no logical limit to what people may like or dislike. The lesson is that the sentence is not in fact about Gandhi at all but about the speaker who is simply expressing a feeling he has about Gandhi. This is not therefore a statement about Gandhi at all but an expression of the speaker's feeling towards Gandhi. The speaker might be trying to deceive us but he cannot be mistaken.
- iii. How do we resolve a disagreement about the truth of the final sentence? No-one can say that they have no reason for the claim as it is not a matter of whim. Further there are limits to the kind of consideration which can count as a proper reason. It has to be a moral reason. Thus the fact that Gandhi was a man of peace who supported non-violent protest would be a justification of the claim. But another observer might consider that opting for non-violent protest is a sign of weakness which hinders the quest for justice. This would be a reason for disagreeing with the claim. Thus the same consideration can count either for or against the judgement. It follows that relevant criteria are called for but they might not guarantee agreement.

### c. Moral criteria and moral judgements

In the history of ethics we can find two groups of thinkers who have taken different views of moral statements depending on which of sentence i or ii most resembles sentence iii.

One group have seen passions or emotions as the key element of moral sentences which makes them much like sentence ii. This takes seriously the



possibility of no agreement being reachable by the application of reason. However it ignores the fact that there are logical limits to the feelings relevant to moral statements. It has been pointed out that we cannot simply experience feelings like pride by just trying hard. Rather we have to remember some achievement or relation to the object of pride in order to experience pride. Similarly we cannot experience the moral feeling of shame without recalling some unworthy event in our lives.

It has also been pointed out that no rule of behaviour can count as a moral principle except it is related to a family of concepts like respect, truthfulness, pride, ostentation, harm, benefit and so on. These logical limits make moral statements appear to be akin to sentence i. But to overemphasise this similarity suggests that all moral disagreements can be resolved by appeal to these principles and criteria. But if it were not for moral values there would be no moral problems for these are created by tensions between those values in specific situations. Nevertheless reason has its role to play in moral deliberation for the logical limits we have referred to have to be respected. In many cases reasonable reflection will facilitate agreement but it simply cannot be guaranteed to do so.

### 3. An ethical method of reasoning

#### *Decision-making and ethics*

Ethics is both a theoretical and a practical discipline. The language of ethics refers to duties and values. One goal of ethics is to determine right decisions, and in order to do that, it is necessary to go step by step, analyzing, first, the facts of the case, second, the values at stake, and third, the duties.

#### a. First step: Fact deliberation

##### i. The case

The deliberation process begins always in the same way, with the presentation of a problem or a case, which is often difficult from the moral point of view. This difficulty is perceived as a conflict, generally called "moral conflict". Conflicts appear when a decision should be taken, and it is difficult to identify the best course of action, because in all possible actions important values are at stake, and selecting one implies the infringement of other compelling values. The goal of the ethical method of reasoning is always the same, to help people to resolve these kinds of problems, taking wise decisions.

##### ii. Deliberation about the facts

In order to resolve a moral conflict, the first thing we must do is to make a careful analysis of the facts of the case, lowering the uncertainty in this field as much as possible and also correcting misperceptions. This is not an easy task, and it usually takes a lot of time. But at this point, the careful analysis of facts is basic if we want to do things well. For instance, a careful analysis of medical facts is essential in medicine in order to know the situation of the patient, the diagnosis, prognosis, and treatment. This is a very difficult task. We must reduce uncertainties as much as possible, through the process of individual or collective deliberation. Nobody knows all possible facts involved in a situation. Our perception of facts is influenced by our education, cultural



background, personal expertise and experience. We might have been trained to perceive some facts, for instance, the medical ones, but we might not have the same sensitivity to perceive others, such as the patient's socio-economic situation, which other people, with other training, perceive more readily. Therefore, we should analyze facts carefully, considering the advice of other people when things are difficult. For instance, in medicine so-called "clinical rounds" often take place, in which members of the health care team discuss the facts of a clinical case, in order to reduce their uncertainty about its diagnosis, prognosis, and treatment. However their considerations should range more widely than the medical facts and should take account of the patient as a whole.

b. Second step: Value deliberation

i. Identification of the moral problems

The analysis of a case starts when somebody thinks that he or she has a problem and thinks it is a moral problem. Such cases are often more complex than they at first appear. People ask about a problem, but this does not mean that this is the only problem the case presents. It is necessary, therefore, to identify and describe the different moral problems we are able to find in the case, to enable full and unambiguous discussion.

ii. Choice of the main problem

After the identification of all ethical problems at stake in the case, we must choose one among them, which is to be discussed in the next steps of the analysis. Problems should be discussed one by one. Only after the discussion of one can we begin the debate about another, and so on. If we mix different problems, reaching a conclusion will be impossible. In any case, we consider that the problem to be discussed first is, of course, that conveyed by the person who presented the case in step 1. This is the main problem, at least for him or her, and our duty now is to help him or her to reach a wise decision. The problem identified by the questioner might be insignificant compared to other moral problems the case involves. The solution of the major problems might remove the original problem from the scene altogether. For example a doctor might perceive the problem of whether to choose a more expensive form of treatment for a patient or not when the major problem might be that he has not enquired whether the patient wants to be treated at all. Therefore, we should analyse the problem conveyed by the person who presented the case, and the problems on which it is dependent, if they exist.

iii. The values at stake

We have been talking until now of "problems", and "moral problems". We have not given a precise definition of this expression. "Moral problems" are always concrete, specific. They are not abstract. When someone has a moral problem, it is because he or she does not know which moral value should be respected in the situation. We say that the person has a "conflict of values". Therefore, the specific language of "moral problems" can be translated into the abstract and universal language of "values" and "conflict of values". Values are special qualities. For instance, justice and truthfulness are values. Values are qualities that human beings think important. If we think of a world without



justice, or truthfulness, we can realize that these are important or positive values. There are, of course, opposite values to them, as injustice. Our duty is always and necessarily to implement positive values, promoting them in our world. And moral conflicts appear when the attempt to implement a specific value infringes the fulfilment of another. In order to solve this conflict, the first thing to do is to identify the different values at stake; that is, to translate “moral problems” into the language of values and “conflict of values”.

c. Third step: Duty deliberation

A conflict of values can be solved in different ways, and our duty is to identify and choose the best one, that is, that which promotes best the fulfilment of positive values, or that infringes least upon the values at stake. Therefore, we must identify the different possible courses of action of the case. And the easiest way of doing that is identifying first the extreme courses of action.

i. Reflecting on the most challenging cases

It is important for the doctor to be sensitive to the whole range of ethical values in dealing with clinical cases. Such sensitivity, however, will often present challenges which would otherwise not occur. These challenges are ethical in nature in that it is the tensions between respect for various values which make it difficult to decide what should be done. There will be more and less demanding challenges of this kind. The most problematic for the doctor to deal with will be those where it seems that whichever alternative course of action is taken he will be doing wrong by failing to respect an important value. These situations are called dilemmas and are rarer than might at first appear. More often than not careful consideration of all aspects of the case will show that the dilemma is only apparent. The following example is such a case.

A Jehovah Witness refuses a blood transfusion for himself in line with his sincere religious beliefs but at the same time asks for help in saving his life. The two main values at stake here are respect for his spiritual wellbeing on the one hand, and respect for his physical wellbeing on the other. We might at first think that we cannot maintain respect for both of these values in this situation. If we are correct then we shall have to choose between the extremes and sacrifice one value for the other believing that we are doing wrong whichever option we take. This would constitute a moral dilemma. Our view might be that the best outcome of the treatment is the survival of the patient whereas his view might be that surviving at the cost of being damned forever would be the greatest possible personal disaster.

Our first moral duty is to endeavour to respect all values at stake as much as possible. Ideally we need to find a way of saving the life of the patient without ignoring his religious beliefs. That is, we need to carefully examine our initial belief that we have a genuine dilemma on our hands. There are numerous possible ways of respecting both values in such cases. For example, around 12% of Jehovah's Witnesses do not fully agree with the Watchtower's blood doctrine. One intermediate course of action is, therefore, to evaluate individual beliefs in respect to blood among Jehovah's Witnesses patients. Some of them accept some form of blood or blood products. If we find that our patient is firmly opposed to this option there are other possibilities. One is the use of



bloodless surgery techniques. Another is the use of transfusion alternatives, like volume expanders, and oxygen therapeutics. And yet another course of action is avoiding the use of blood or any substitute unless the need really arises. Thus in the case under discussion the apparently contradictory ethical demands on the clinician can both be satisfied. Failure to reflect on these matters could result in serious harms to the patient whichever of the two apparent options is taken.

ii. Reflecting on other cases

Most moral problems which face doctors in treatment decisions are less dramatic than the apparent dilemmas such as the case cited above. They usually take the form of numbers of ethical values calling for attention and making demands on practitioners. These call for careful consideration but do not suggest that the practitioner is presented with an impossible task to find an acceptable solution. We might call these moral problems rather than dilemmas. Nevertheless considerable harms can be caused if the doctor fails to take the various issues into account. The reflection should involve weighing the various values against each other in the specific situation to facilitate the wisest decision. That decision will be the one which is least morally objectionable, or, to put it another way, involves least disrespect for the values which figure in the case. These reflections can be complex and different cases might involve details which tip the balance one way or the other to give priority to a particular value. Sadly neat solutions are not always available but there are a number of possible outcomes. There are those where each value is compromised somewhat but at no great moral cost, and others where one value or set of values will be seen to outweigh the others in the specific set of circumstances. In the latter cases that value or set of values will win out over the other at no moral cost for the duty to act in that situation becomes clear.

d. Fourth step: Testing consistency

It is important that moral reflection is consistent. Special pleading involves giving undue weight to one or more consideration because it is in the interest of the decision maker so to do. This will always prejudice the decision and undermine the proper role of reason in ethical reflection. We can use a number of techniques to guard against such inconsistency.

- i. We can avoid such bad practice by referring to some external measures such as the Law. Though the law does not solve ethical problems it does usually reflect the moral values of citizens. On some occasion laws might be unjust and not serve us in this way.
- ii. We can also ask ourselves the question: Would I behave in this way if it was to become generally known that I had done so? An honest appraisal in these terms would draw our attention to our disregard for the principle which has been extremely important in the history of ethics, namely to act in such a way as to be able to wish that mode of behaviour be a universal law.
- iii. We should not be hasty in drawing conclusions in moral reflection. Once presented with moral problems in practice doctors experience a considerable injection of emotions. Such feelings are not unimportant but they might cloud any immediate judgement and stimulate rash decisions. Using the time that is



available, which might also involve consulting with colleagues, allows these emotional rushes to recede somewhat and facilitate wiser decisions.

e. Fifth step: Conclusion

The desired outcome of all these reflective activities is to arrive at wise decisions. Practical wisdom, the art of making well-thought decisions is the moral virtue par excellence. Well-thought decisions are not necessarily universally agreed decisions. Serious and responsible people can disagree on ethical matters. However it has been said that the unexamined life is not worth living and in medicine it is certainly true that the morally unreflective life is to be deplored.



<b>UNIT 2</b>	
<b>Title</b>	<b>What is bioethics?</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>1. Students should be able to explain the difference between medical ethics and bioethics</li> <li>2. Students should be able to differentiate bioethics, law, culture, and religion</li> <li>3. Students should be able to explain the principles of bioethics and how to balance these principles in practice</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. The birth of bioethics <ol style="list-style-type: none"> <li>a. The coining of the word “bioethics”</li> <li>b. Bioethics as bridge between facts and values</li> <li>c. Bioethics versus medical ethics</li> <li>d. The idea of Potter</li> <li>e. Bioethics as global ethics</li> </ol> </li> <li>2. Health and disease as values <ol style="list-style-type: none"> <li>a. Health and disease are facts as well as values</li> <li>b. Health identified with wellbeing</li> </ol> </li> <li>3. Principles of bioethics <ol style="list-style-type: none"> <li>a. Health care decisions include facts and values</li> <li>b. The principles of the <i>Universal Declaration on Bioethics and Human Rights</i></li> <li>c. Many principles have not been respected throughout history</li> <li>d. Paternalism and “informed consent”</li> <li>e. Conflicts between bioethical principles. Limits to the autonomy of patients</li> <li>f. Limits of justice and resource allocation</li> <li>g. Limits to paternalism</li> </ol> </li> <li>4. Ethics committees <ol style="list-style-type: none"> <li>a. Previously, moral conflicts were scarce</li> <li>b. Nowadays, many principles need to be respected and they are often in conflict</li> <li>c. The occurrence of conflicts is not negative</li> <li>d. The main goal of bioethics is to manage moral conflicts</li> <li>e. To accomplish this goal, bioethics uses deliberation</li> <li>f. “Bioethics committees” are platforms for deliberation</li> <li>g. Different types of committees</li> <li>h. Ethics committees are not legal tribunals</li> </ol> </li> <li>5. Medical professionalism <ol style="list-style-type: none"> <li>a. Professional ethics</li> <li>b. Changes in medical ethics</li> <li>c. The unchanging goal of professional ethics</li> </ol> </li> </ol>	





- d. Professionals strive for excellence

### Teacher Manual

#### 1. The birth of bioethics

- a. Bioethics is a relatively new word coined by a biochemist, Van Rensselaer Potter, in 1970 in an endeavour to draw attention to the fact that the rapid advances in science had proceeded without due attention being paid to values. For some time the word referred to the attempt to link scientific facts and values in the area of environmental concerns. Nowadays it has taken on a more general meaning which includes medical, or more generally, health care ethics. Though there are examples of reflection on ethics in medicine through the ages the subject of bioethics has mushroomed into a sub-discipline of ethics in the past decades. This growth was stimulated both by abuses of human beings in the course of medical research, especially during the Second World War, and by the emergence of medical technologies which have challenged various widely held public values.
- b. Potter conceived this new discipline, bioethics, as a “bridge” between “facts” and “values”. During the second half of the twentieth century, he said that biological sciences had been increasing their knowledge and technical power continuously, but reflection about the values at stake has not progressed in the same proportion. Potter said that he coined the word bioethics using two Greek words, *bíos*, life, representing the facts of life and life sciences, and *éthos*, morals, referring to values and duties.
- c. One profession dealing with life during centuries and millennia, especially with human life, has been medicine. But today there are many sciences and professions working in this field. Therefore, bioethics should not be conflated with medical ethics, which is only one of its branches. The field of bioethics is as wide as the facts of life, and its study is divided in many branches, each one with its specificity: Ecological or environmental bioethics, Medical bioethics, Clinical bioethics. Medical ethics is the study of ethical issues relevant to the practice of medicine in all its branches.
- d. The idea of Potter, and in general of bioethics, is that not all that is technically possible is morally right, and that some control of our intervention in nature and the environment, on animals and on human beings, is needed. The future of life and of humankind is at stake.
- e. Bioethics is the first attempt of thinking “globally” in ethics. In fact, one of the books written by Potter is titled *Global Bioethics* (1988). Throughout its history, ethics has not had a global dimension. The widest criterion introduced in ethics was the Kantian principle of “universality”: “Act only according to that maxim whereby you can at the same time will that it should become a universal law”. But the German philosopher Immanuel Kant (1724-1804) probably understood “universal” in a very narrow way, as comprising only all the actual human beings. On the contrary, the idea of “globalization” includes not only all actual human beings, but also future generations (called “virtual” human beings), all other living organisms, and also



nature, the environment.

- f. Global bioethics includes, therefore:
    - i. All actual human beings (see Units 5-15)
    - ii. Future human beings (see Unit 16)
    - iii. All living organisms and the environment (see Unit 17)
2. Health and disease as values
- a. Health and disease, like life and death, are not bare facts, but also embody values. Usually health and life are valued and disease and death disvalued. It is also true that values can determine what counts as health itself. Many physicians, especially in the West, think that health and disease can only be understood as bare facts. Diseases, they say, are due to the alteration of some tissues or parts of the human body, which can be determined scientifically. Therefore they conclude that disease is a scientific fact, the same as the usual facts in physics or in chemistry.
  - b. We think of health as positive as a good and disease as negative, as an evil. Nowadays it is usual to identify health with wellbeing. This is the core idea of the definition of health stated by the World Health Organization (see Unit 4). People think today that they are ill when they feel some lack of wellbeing, even without any biological alteration. Because of this new conception of health values are important in the concepts of health and disease.
3. Principles of bioethics
- a. Physicians and other health care professionals have to make health care decisions. Many of the facts they consider have values built into them, for example that a given condition causes suffering or threatens a patient's life or detracts from their wellbeing in some other way.
  - b. Our duties are always the promotion and implementation of values. The duty of promoting values is the origin of norms. When these norms are wide and general, they are called principles. The UNESCO *Universal Declaration on Bioethics and Human Rights* identifies fifteen bioethical principles, encapsulated in the following titles:
    - i. Human dignity and human rights
    - ii. Benefit and harm
    - iii. Autonomy and individual responsibility
    - iv. Consent
    - v. Persons without the capacity to consent
    - vi. Respect for human vulnerability and personal integrity
    - vii. Privacy and confidentiality
    - viii. Equality, justice and equity
    - ix. Non-discrimination and non-stigmatization
    - x. Respect for cultural diversity and pluralism
    - xi. Solidarity and cooperation
    - xii. Social responsibility and health



- xiii. Sharing of benefits
- xiv. Protecting future generations
- xv. Protection of the environment, the biosphere and biodiversity
- c. Many of these principles have not been respected through history. For instance, physicians have traditionally applied their own values and neglected those of patients in making clinical decisions. Doctors as experts have considered that they know best what is good for their patients as fathers know what is best for their children. This historical approach has been called 'paternalism' and is now seen as inadequate.
- d. Paternalism is a behaviour that might be taken as morally acceptable when societies are homogeneous from the point of view of values. This was the case in the past, and might be thought so today in many parts of the world. People in traditional societies shared the same values. When physicians, therefore, made medical decisions taking into account only their own values, they could suppose they were respecting also the values of their patients. But this situation has changed drastically during the last centuries. One of the reasons for this change has been the continuous mobility of people and the mix of different values, beliefs, and traditions in modern societies. There may yet be some societies where physicians can assume that patients share their values but they would be very few. Doctors must therefore take patients' values into account. This is the origin of the doctrine of "informed consent", which counters the traditional paternalism of the medical profession. The moral principles here involved are the following of the previous list: i, iii, iv, vi, vii, and x.
- e. Professionals must respect the values of patients. But in some cases the values of patients cannot be honoured by physicians, because they are in conflict with other bioethical principles. One very important duty of health care professionals is expressed by the traditional saying: "do no harm". Medical interventions are risky, with important side effects, and many times they hurt people. The balance between benefits and risks is essential in order to determine when medical procedures are harmful or not. A limit to the autonomy of patients is set by the moral principles listed with the numbers ii, ix, and xv.
- f. Another limit to the values of patients is fairness in the access to health care and the distribution of resources. The growing technological development of medicine is increasing the price of health care to such an extent that most individuals are incapable of paying their own bills. This has opened another set of moral problems, all of them related to justice, the right to have health care, and the fair distribution of scarce resources. The moral principles to deal with these problems are the following: viii, ix, x, xi, xii, xiv and xv.
- g. Our moral duty is not only not to harm others, but to help and benefit them. This is especially important for health care professionals since their goal is to do the best for people in need. This has always been the main principle of medical ethics but today what is beneficial for patients and what is not cannot be determined only by health care professionals; it is also, and primarily, determined by patients. Ignoring this situation leads to paternalism. To act in the best possible non-paternalistic way: this is the new interpretation of the moral principles listed with the numbers ii,



v, and xiii.

#### 4. Ethics committees

- a. The situation of present day health care is much more conflict laden than ever before. Traditional medical ethics used to work with the moral principle of beneficence and non-maleficence, understood in a paternalistic way. The only decision maker was the professional, and the only moral principle to be taken into account was beneficence and non-maleficence. Therefore, the possibility of moral conflict was very remote.
- b. On the contrary, there are different moral principles and values to be respected in each specific situation. Often, these principles conflict with each other. There are potential conflicts between all of them.
- c. The number of conflicts is not related to the morality of a society, or of a profession. In fact, conflicts arise when people are entitled to decide and take part in decision-making processes. When only one person has the power to decide and the unique moral duty of all others is obedience, conflicts are quite impossible. Conflicts are part of human life, and they are more frequent as respect for human freedom and moral diversity increases.
- d. The problem is not the existence of conflicts; the problem is the will to respect and resolve them. This is the main goal of bioethics, to train people in the management of moral conflicts, in order to take wise decisions and, in this way, improve the quality of health care.
- e. In order to reach this goal, bioethics uses deliberation as the way of approaching and thinking about moral conflicts. People can work individually with this procedure, especially when problems are not very complex. But when conflicts are difficult, or when they involve many people, deliberation should be done collectively.
- f. There are some areas of concern for which special bioethics bodies have been created to build respect for values into health care provision. This is the origin of so-called "bioethics committees". They are platforms for deliberations in order to take wise decisions and to make policy recommendations. There are different types of ethics committees, as described in the UNESCO Guides *Establishing Bioethics Committees* and *Bioethics Committees at Work: Procedures and Policies*:
  - i. Policy-Making and Advisory Committees (PMAs)
  - ii. Health-Professional Association (HPA) Bioethics Committees
  - iii. Health Care Ethics Committees (HECs)
  - iv. Research Ethics Committees (RECs)
- g. Each of these committees has its own characteristics, as described in the UNESCO documents. For instance, HEC committees do important work in clinical bioethics. They consist of physicians, nurses, social workers, and lay members, both men and women. Different backgrounds, expertise and experiences allow a better understanding of cases, enriching all the individual perspectives and facilitating decision-making.
- h. HEC committees are not judicial bodies with the responsibility of sanctioning



wrong conduct and imposing disciplinary measures. This is one of the biggest differences between ethics committees and legal tribunals. The goal of ethics is not to compete with law, but to promote wise decisions among people and professional excellence. Bioethics does not look for what is legally right but for what is humanly best. The goal of bioethics is to promote the best possible action.

#### 5. Medical professionalism

- a. Professionalism refers to the conduct, aims, or qualities that characterize or mark a profession or a professional person. The project “Medical Professionalism in the New Millennium: A Physician Charter” defines professionalism as the basis of medicine’s contract with society. “It demands placing the interests of patients above those of the physician, setting and maintaining standards of competence and integrity, and providing expert advice to society on matters of health. The principles and responsibilities of medical professionalism must be clearly understood by both the profession and society. Essential to this contract is public trust in physicians, which depends on the integrity of both individual physicians and the whole profession”. ([Annals of Internal Medicine 2002](#)). Professionalism is, therefore, directly related with ethics. Its ethical expression is called Professional Ethics. Some of its formulations are the Codes of Professional Ethics.
- b. Throughout the history of medicine, many changes have occurred in medical ethics. The influence of paternalism has decreased, to the same extent as respect for autonomy has increased. There have also been important changes related to access to health care services and the distribution of scarce resources.
- c. But there is one thing that has remained unchanged in professional ethics throughout its history, which is the moral duty of professionals not only not to do harm but to do the best for their patients. This is a primary goal of professional codes of conduct which each professional is obliged to observe.
- d. Professionals must strive for excellence. They have in their hands the most valued things people have: life and health, and their duty is to do the best for them.

At the beginning of the *Nicomachean Ethics* Aristotle wrote: “There is some end of the things we pursue in our actions which we wish for because of itself, and because of which we wish for the other things; [...] clearly this end will be the good, i.e. the best. Then surely knowledge of this good is also of great importance for the conduct of our lives, and if, like archers, we have a target to aim at, we are more likely to hit the right mark”. (*Nicomachean Ethics* I 1: 1094 a 18-26)



<b>UNIT 3</b>	
<b>Title</b>	<b>Human dignity and human rights (Article 3)</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>1. Students should be able to explain and apply the concepts of human dignity and human rights</li> <li>2. Students should understand the relevance of these concepts in the context of bioethics</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. Concepts of dignity in the history of ideas             <ol style="list-style-type: none"> <li>a. Classical antiquity</li> <li>b. World religions traditions</li> <li>c. Modern philosophy</li> <li>d. Contemporary humanitarian law                 <ol style="list-style-type: none"> <li>i. The <i>Universal Declaration of Human Rights</i></li> <li>ii. The <i>European Convention on Human Rights and Biomedicine</i></li> </ol> </li> </ol> </li> <li>2. Human dignity as an intrinsic value of the person capable (at least potentially or as a member of a natural kind) of reflection, sensitivity, verbal communication, free choice, self-determination in conduct and creativity             <ol style="list-style-type: none"> <li>a. Human dignity is an end in itself</li> <li>b. Equality in dignity of all human beings</li> <li>c. Respect and care</li> <li>d. The interests and welfare of the individual are prior to the sole interest of society</li> <li>e. Human dignity as a foundational concept</li> </ol> </li> <li>3. The diverse understandings of human dignity in different cultural and moral traditions (Buddhist, Confucian, Judeo-Christian, Muslim, communitarian, liberal) and different types of societies</li> <li>4. A person's dignity and rights entail others' obligation to treat a person respectfully</li> <li>5. Ethical aspects of health care provider-patient relations in regard to human dignity and human rights             <ol style="list-style-type: none"> <li>a. The problem of paternalism</li> <li>b. In treatment of children, elderly persons, and mentally handicapped individuals</li> <li>c. In palliative treatment of terminal patients and patients in "vegetative state"</li> <li>d. In treatment of embryos and fetuses</li> </ol> </li> </ol>	
<b>Teacher Manual</b>	
<ol style="list-style-type: none"> <li>1. There are several concepts of dignity in the history of ideas:             <ol style="list-style-type: none"> <li>a. Classical antiquity. Common understanding of dignity as deserving of honour and esteem according to personal merit, inherited or achieved. In ancient Greek philosophy, particularly of Aristotle and the Stoics, dignity was associated with human abilities of deliberation, self-awareness, and free decision-making.</li> <li>b. In many world religions human dignity is considered to be predetermined by the creation of human beings in the image of God; those who are weak in body and soul</li> </ol> </li> </ol>	



- have dignity equal to those who are robust and sturdy.
- c. Modern philosophy proposed secular understanding of human dignity and progressively associated this concept with the idea of human rights. In different teachings human dignity was presented as an aspect of personal freedom (Giovanni Pico della Mirandola) or an embodiment of one's public worth (Thomas Hobbes), or as universal virtue, unconditional and incomparable worth determined by one's autonomy rather than origin, wealth, or social status (Immanuel Kant). One of Kant's basic principles of ethics – to treat any other person always at the same time as an end, never merely as a means (categorical imperative) – has been accepted by moral and political philosophy as the actual basis for the conception of human rights and in this sense it is a foundational concept.
  - d. In contemporary international law, national constitutions, and other normative documents, human dignity is strongly connected with human rights.
    - i. According to Art. 1 of the *Universal Declaration of Human Rights* (1948) “all human beings are born free and equal in dignity and rights”. The Declaration establishes human rights (like freedom from repression, freedom of expression and association) on the inherent dignity of every human being.
    - ii. The *European Convention on Human Rights and Biomedicine* in Art. 1 declares protection of “the dignity and identity of all human beings and guarantees everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine” as its main purpose.
2. The notion of human dignity expresses the intrinsic value of the person capable (at least potentially or as a member of a natural kind) of reflection, sensitivity, verbal communication, free choice, self-determination in conduct, and creativity.
- a. Unlike material values, or financial prices, human dignity has no external equivalent; it is an end in itself. Unlike merit as an embodiment of publicly recognized personal achievements, a person is dignified as a human being as such.
  - b. All human beings are equal in dignity irrespective of gender, age, social status or ethnicity.
  - c. Recognition of a person's dignity presupposes active respect for her human rights, self-esteem and self-determination, as well as care for her privacy, protecting her from illegitimate intrusions and preserving her valid public space.
  - d. A society or a community should respect each of its members as a person or a moral agent on the basis of the notion of human dignity. This notion also requires that the interests and welfare of the individual are considered as prior to the sole interest of society, community, or any particular kind of publicly wholesome activity. The emphasis on “the sole interest of science or society” is important. It implies that because of his/her human dignity, the individual should never be sacrificed for the sake of science (as has happened in medical experiments during the Second World War) or for the sake of society (as has happened in totalitarian regimes). But “sole” also implies that there might be exceptional circumstances in which the interest of others or the community as a whole are so important that infringing upon the interests of individuals is unavoidable in order to save others or the community. An example is the threat of a deadly pandemic.



- e. Human dignity is a foundational concept and under some interpretations it is theoretically and normatively inappropriate to reduce it to functional characteristics of a person's activity, ability to make decisions or autonomy. Respect for dignity means recognition of another's intrinsic worth as a human being.
3. In a comparative view, human dignity has diverse forms in different cultural and ethical traditions (for example, Confucian, Judeo-Christian, Muslim) and is respected in various ways in different types of societies (traditional, modern, totalitarian, democratic). It is less respected in totalitarian societies and more respected in modern and democratic societies. Regardless of cultural, confessional, and political varieties human dignity is universally based on the person's self-awareness and appropriate respectful treatment towards her. As it is emphasized in the [UNESCO Declaration](#), the regard to cultural diversity is "not to be invoked to infringe upon human dignity, human rights and fundamental freedoms" (See Article 12).
  4. From the point of view of ethics, the person's dignity and rights are proved by others' obligation to treat a person respectfully, that is to cause no harm, not to abuse, to be fair, not to impose unwelcome models of personal good and happiness, not to treat her merely as a means, and not to consider the interests and welfare of the individual as subordinate to others' interests and welfare, to "the sole interest of science and society" [[see World Medical Association's Declaration of Helsinki](#)].
  5. Health care provider-patient relations are just one kind of human relationship, presupposing all ethical requirements and human rights.
    - a. However, historically these relations used to be considered as unequal. A physician was associated with an active role of decision-maker, providing medical care, taking responsibility. Hence, he or she was higher in status. A patient was associated with a passive role of recipient, being in need, not responsible for his or her condition and, hence, lower in status. In this paternalistic model of health care provider and patient relationship the patient used to be in a dependent position.
    - b. Actual inequality in the status of the health care provider and the patient may be aggravated in special cases when patients are children, handicapped individuals, elderly persons. Particularly risky are cases of patients who are mentally handicapped.
    - c. Special attention in regard to human dignity and human rights is required in palliative treatment of terminal patients and patients in "vegetative state".
    - d. Though there is no consensus either in public or in the expert community concerning the ethical and legal status of embryos and fetuses, the latter should be treated with respect and care.

The principles manifested in articles 4-15 of the [Universal Declaration on Bioethics and Human Rights](#) give a proper framework to respect for patients' dignity and rights and clarify the specific context of human rights in bioethics.





<b>UNIT 4</b>	
<b>Title</b>	<b>Benefit and harm (Article 4)</b>  This chapter of the UNESCO curriculum explores complexities arising from the notions of providing health benefits and avoiding health harms; from the very meaning of 'health', including problems arising from the WHO definition of health as a state of complete physical mental and social wellbeing; and from the ancient medical norm of 'primum non nocere' or 'first or above all do no harm'.



<b>UNIT 5</b>	
<b>Title</b>	<b>Autonomy and individual responsibility (Article 5)</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>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</li> <li>2. Students should understand the relationship between autonomy and individual responsibility</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. The concepts of autonomy and responsibility               <ol style="list-style-type: none"> <li>a. Autonomy:                   <ol style="list-style-type: none"> <li>i. Different levels and notions of autonomy</li> <li>ii. Different theoretical approaches to autonomy</li> </ol> </li> <li>b. Responsibility: its different aspects and dual nature</li> <li>c. Mutual correlation of autonomy and responsibility in ethics</li> </ol> </li> <li>2. Decision making in medicine               <ol style="list-style-type: none"> <li>a. Autonomy and patient's right to self-determination in treatment                   <ol style="list-style-type: none"> <li>i. Autonomy and paternalism</li> <li>ii. Autonomy as a right and an obligation</li> </ol> </li> <li>b. Patient autonomy should be respected by physicians</li> <li>c. The patient's right to refuse a health care provider's recommendation</li> <li>d. Special measures for protecting the rights and interests of socially and mentally disabled patients</li> </ol> </li> <li>3. Patient autonomy and responsibilities in health care. The range of patient responsibilities</li> <li>4. Evaluation of patients' abilities of self-motivation and self-control</li> </ol>	
<b>Teacher Manual</b>	
<ol style="list-style-type: none"> <li>1. The concepts of autonomy and responsibility               <ol style="list-style-type: none"> <li>a. Autonomy - as individual capacity for self-determination, independent decisions, actions, and evaluations.                   <ol style="list-style-type: none"> <li>i. Different levels and notions of autonomy:                       <ol style="list-style-type: none"> <li>1. freedom from paternalistic interference, all the more so, from authoritarian dictates from any agent, including the state and [especially] transnational corporations; one's capability of self-determination;</li> <li>2. capability to act on the basis of rational principles and rules accepted as adequate to one's understanding of good, personal dignity, and happiness;</li> <li>3. capability to reflect upon these principles and rules, to influence their formation and transformation through public discourse.</li> </ol> </li> <li>ii. In the Kantian approach, autonomy is an ability of deliberated self legislation; in the utilitarian approach, autonomy is associated with one's ability to follow</li> </ol> </li> </ol> </li> </ol>	



one's preferences.

- b. Responsibility is one's awareness of one's obligation to make decisions and to act appropriately on the basis of certain commitments (for example, towards an external authority, oneself, one's status, engagements, or agreements, respected others, accepted principles and rules).
    - i. Different aspects of responsibility:
      1. spontaneously obtained status or commitments (for example, responsibility of parents);
      2. consciously accepted status or commitments (responsibility of an officer, professional, self-committed person);
      3. legal responsibility.
    - ii. Dual nature of responsibility:
      1. responsibility as accountability,
      2. responsibility as personal and universalizable duty.
  - c. In ethics, the notions of autonomy and responsibility are mutually related. Responsibility manifests autonomy; autonomy without responsibility is mere self interest, which means that the person in his/her decisions does not take into consideration the interests of others.
2. Decision making in medicine
- a. In medical practice the principle of autonomy underlies the patient's right to self-determination. As such the principle of autonomy has been recognized in opposition to paternalism, which has been typical of a traditional type of health care provider-patient relationship. As a condition for the patient's final decision, autonomy is not merely a right but also, under some conceptions of autonomy, a responsibility. The patient is autonomous to make responsible decisions.
  - b. Insofar as most patients feel dependent on physicians respect for patients' autonomy by physicians is crucial; so a discretionary space should be secured for patients to make their own decisions in accord with their own dignity.
  - c. A health care provider is an expert in medicine; a patient is an expert in her/his preferences, beliefs, and values. A patient may refuse a health care provider's recommendation, but she/he is not entitled to treatment beyond the present medical standards and the availability of treatment. In other words, patients have a right to refuse treatment but they cannot claim all treatments.
  - d. Special measures are needed for protecting the rights and interests of persons who are not capable of exercising autonomy and making responsible decisions concerning medical care and treatment (see Unit 7).
3. Patient autonomy and responsibilities in health care. Patient responsibility has the following range:
- a. Responsibility for consequences of freely taken decisions. If individuals are really autonomous and if they decide in all freedom, they have to take responsibility for the consequences of these decisions. An example is engagement in risky behaviours.
  - b. Responsibility to avoid infringement of another person's autonomy. A limit to the autonomy of an individual is the autonomy of other individuals. We cannot argue that



as autonomous persons we have the right to limit the autonomy of other persons. If we want our free choices, and thus our values, to be respected, we are obliged to give the same respect to the free choices, and thus values, of others. An example is the debate on smoking; we are free to decide to smoke and endanger our own health, but we cannot endanger the health of others.

4. In cases when a patient's ability to make autonomous and responsible decisions is not clear, special steps should be taken to evaluate her/his abilities to self-motivate and self-control, to keep commitments and loyalties, to make decisions while taking into account the given situation, the goals, and the results, and to choose on the basis of reflective preferences and principles.



<b>UNIT 6</b>	
<b>Title</b>	<b>Consent (Article 6)</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>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”</li> <li>2. Students should be able to explain what the process of informed consent requires</li> <li>3. Students should be able to explain how the principle of consent is applied in different interventions, research, and teaching</li> <li>4. Students should be able to explain how exceptions to the principle can be justified</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. Interconnection of principles             <ol style="list-style-type: none"> <li>a. The principle of consent is based on the principle of human dignity and human rights</li> <li>b. The principle of consent is a practical specification of the principle of autonomy and individual responsibility</li> <li>c. If the principle of consent cannot be applied, the provisions of Article 7 (“Persons without the capacity to consent”) are applicable</li> </ol> </li> <li>2. What is the purpose of the principle of consent?             <ol style="list-style-type: none"> <li>a. The principle of consent principle aims to achieve several objectives:                 <ol style="list-style-type: none"> <li>i. it asserts the patient’s autonomy</li> <li>ii. it protects his/her status as a human being</li> <li>iii. it prevents coercion and deception</li> <li>iv. it encourages the doctor’s self-criticism</li> <li>v. it supports the process of rational decision-making</li> <li>vi. it educates the public at large</li> </ol> </li> <li>b. Consent expresses respect for the dignity and rights of each human being</li> </ol> </li> <li>3. Interrelation between consent and autonomy</li> <li>4. Explanation of the principle             <ol style="list-style-type: none"> <li>a. The requirement for consent applies to all medical interventions where it is possible to obtain consent</li> <li>b. What is prior, free and informed consent?</li> <li>c. Consent requires adequate information</li> <li>d. What is express consent?</li> <li>e. Withdrawal of consent</li> <li>f. The patient’s right to refuse and right not to know</li> <li>g. Consent of subjects of scientific research. Compare the provisions for consent in scientific research with those for medical interventions</li> <li>h. Consent by individual, group and community</li> </ol> </li> <li>5. Exceptional circumstances for the application of the principle of consent             <ol style="list-style-type: none"> <li>a. Emergency situations</li> </ol> </li> </ol>	



- b. Minors
- c. Mental patients
- d. Jehovah's Witnesses
- e. HIV patients

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1. Introduction: explain how the principle of consent is connected to other principles of the UNESCO Declaration
  - a. Article 3: A person's basic rights are established on the recognition of his/her human status, the inviolability of his/her life, and the fact that he/she was born free and will always be free. Because human dignity and human rights are to be respected, the person concerned needs to give consent for medical interventions and for participation in scientific research.
  - b. Article 5: Since the autonomy of every person is accepted as an important value, participation in decisions concerning one's own body or health must be recognised as a right.
  - c. A decision to treat should be determined by co-operation between the person who treats and the person who is treated, both parties being linked together by mutual trust and reciprocity.
  - d. Article 6 of the Declaration states that any medical intervention is only to be carried out with the prior free and informed consent of the person concerned based on adequate information. The Article also applies to scientific research.
  - e. If the provisions of Article 6 cannot be applied (because consent is not possible), Article 7 applies with special provisions for persons not able to consent (see Unit 7).
2. The principle of consent has several objectives
  - a. The purpose of the informed consent principle is to achieve several objectives. It asserts the patient's autonomy; it protects his/her status as a human being; it prevents coercion and deception; it encourages the doctor's self-criticism; it supports the process of rational decision-making; it educates the public at large.
  - b. The principle of consent is also important even if it does not achieve any objective. Article 1 of the *Universal Declaration of Human Rights* 1948 holds that all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood. Consent therefore expresses respect for the dignity and rights of each human being.
3. Explain the relation between autonomy and consent
  - a. Autonomy may be defined as self rule and refers to the right of persons to make authentic choices about what they should do and what shall be done to them (see Unit 5).
  - b. Autonomous persons can only make autonomous decisions and take responsibility for these decisions if they can consent to interventions that affect their lives.
4. The provisions of Article 6 are subsequently explained
  - a. The article applies to all medical interventions. Medical intervention includes diagnosis, treatment, prevention, rehabilitation and palliation.
  - b. Being informed implies cognition, understanding, willingness, intention, and



consideration. Consenting implies freedom (no coercion).

- c. Consent requires adequate information. The requested information content should concern diagnosis, prognosis, treatment, alternative treatment, risks, benefits, according to relevant circumstances. The information process should specify: by whom; when (in advance); how (oral, writing, expressed); and to whom (patients, relatives, guardians, others).
  - d. Consent might be expressed or implied. Express consent exists when a patient agrees in verbal or written forms to undergo a medical procedure. Implied consent maybe concluded or inferred from the surrounding facts and circumstances.
  - e. A patient has the right to withdraw consent to treatment at any stage unless he or she is not capable of making such a decision.
  - f. A patient has the right to refuse treatment unless he or she is not capable of making such a decision. A patient has the right to be treated without being informed if he or she is aware of the implications of such a decision and wishes to exercise that right.
  - g. Consent of subjects of medical research:  
This will require additional attention to:
    - i. The nature of the consent
    - ii. The adequacy of the information provided
    - iii. Withdrawal of consent
    - iv. The role of domestic and international human rights law
  - h. Consent by the individual and by the community in appropriate cases of research carried out on a group of persons or a community also requires additional attention.
5. Exceptional circumstances
- a. There are some circumstances in which the application of the principle is difficult or even impossible.
  - b. For difficult circumstances special care needs to be given to the application of the principle, but it still does apply, even if difficult.
  - c. If consent is impossible for various reasons, the provisions of Article 7 do apply (see Unit 7).
  - d. Examples of possible exceptional circumstances:
    - i. Emergency situations
    - ii. Minors/children
    - iii. Patients who are mentally or emotionally incapable of rational decision making
    - iv. Jehovah's Witnesses
    - v. HIV patients



<b>UNIT 7</b>	
<b>Title</b>	<b>Persons without the capacity to consent (Article 7)</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>1. Students should be able to explain the meaning of “capacity to consent”</li> <li>2. Students should be able to explain the criteria for capacity to consent</li> <li>3. Students should be able to explain how the criteria for consent are applied in different circumstances of treatment and research</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. Criteria for capacity to consent <ol style="list-style-type: none"> <li>a. Definition of incapacity</li> <li>b. Criteria to determine capacity to consent</li> <li>c. Article 7: special protection is to be given to persons who do not have the capacity to consent</li> <li>d. Give examples of persons who cannot satisfy the criteria; distinguish different categories of persons not able to consent</li> </ol> </li> <li>2. Categories of persons without the capacity to consent <ol style="list-style-type: none"> <li>a. Different distinctions can be made</li> <li>b. Examples of persons who cannot satisfy the criteria</li> <li>c. Illustrative case of mentally ill patient</li> </ol> </li> <li>3. Legal provisions concerning consent and capacity to consent <ol style="list-style-type: none"> <li>a. The role of domestic legal provisions</li> <li>b. The role of international human rights law</li> </ol> </li> <li>4. Procedures: <ol style="list-style-type: none"> <li>a. Explain Article 7.a. of the UNESCO Declaration</li> <li>b. How to obtain consent in health care practice?</li> <li>c. Special procedures in ethics to construct consent <ol style="list-style-type: none"> <li>i. Determination of appropriate substitute decision-makers</li> <li>ii. Best interest criterion</li> </ol> </li> </ol> </li> <li>5. The context of research involving human subjects <ol style="list-style-type: none"> <li>a. Explain Article 7.b. of the UNESCO Declaration</li> <li>b. Should research be done with persons not able to consent?</li> <li>c. Research for direct health benefit</li> <li>d. Research without potential direct health benefit</li> </ol> </li> </ol>	





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1. Define incapacity and the criteria for capacity to consent
  - a. Incapacity can be defined as lacking the freedom to make authentic decisions because of an inability to make such decisions even when given the opportunity. Various groups of people have been traditionally labelled in this way. They include people with learning difficulties, the mentally ill, children, confused elderly people and unconscious people. A more systematic distinction between categories will be made later in this unit.
  - b. Define the criteria for capacity to consent
    - i. The ability to understand and retain given information
    - ii. The ability to appreciate the nature of the situation
    - iii. The ability to assess the relevant facts
    - iv. The ability to exercise choice
    - v. The ability to use understood information for realistic and reasonable decisions
    - vi. The ability to appreciate the consequences of giving or refusing consent
  - c. Why is it important to make special arrangements for persons without the capacity to consent, as stated in the first sentence of Article 7 of the UNESCO Declaration?
  - d. Give examples of persons who cannot satisfy the criteria; distinguish different categories of persons not able to consent
2. Categories of persons not able to consent
  - a. Different distinctions
 

Capacity to consent can be compromised due to various circumstances. Distinctions should be made between:

    - i. categories of practices
      1. clinical treatment and research
      2. epidemiological research (e.g. use of previously collected data)
      3. public health (e.g. vaccination)
      4. emergency conditions (e.g. resuscitation)
    - ii. categories of subjects
      1. persons not yet able to make their own decisions (e.g. immature children )
      2. persons no longer able to make their own decisions (e.g. severely demented persons)
      3. persons temporarily unable to make their own decisions (e.g. unconscious persons)
      4. person permanently unable to make their own decisions (e.g. severely intellectually impaired persons)
    - iii. categories of contexts
      1. disadvantaged economical conditions
      2. illiteracy



3. socio-cultural circumstances
4. captive audiences (e.g. prisoners, laboratory assistants)

b. Examples

i. Neonates

Neonates cannot think like adults. It is therefore impossible for them to be able to make decisions, to understand information, to process information rationally or to desire reasonable outcomes. As decisions have to be made about them, the best candidates for this role are the parents, on the assumption that above all people they will have the best interests of their child at heart. However, in some cases parents do not make decisions in the best interests of their children. In those cases it is possible for the state to step in and remove the decision making role from them. This is done by making the child a ward of the court.

ii. Children

It might appear that children cannot think like adults. Whilst this is certainly true of very young children, as children develop they show marked differences from each other. The *United Nations Convention on the Rights of the Child* (UNROC) asserts that children have the right to say what they think should happen when adults make decisions that affect them and to have their opinions taken into account (Article 12), have the right to get and share information (Article 13), have the right to think and believe what they want and practise their religion as long as they do not stop other people enjoying their rights (Article 14), and have the right to privacy (Article 16). Research activities involving children are carried out to learn more about the nature of paediatric development, disease and potential treatments. An important safeguard required to minimize loss of respect for autonomy is the general rule that where the research can be carried out on adults then children should not be used.

iii. Confused elderly patients

Various forms of neurological deterioration including Alzheimer's disease rob people of the powers to make decisions. Relatives or true friends who knew them when well should be asked to help to build a picture of the patient's life, including his or her preferences, values and wishes in which one can locate the decision that should be made. A hypothetical consent is a consent which would likely be in accord with the wishes of the patient when well.

iv. Patients with learning difficulties

It is important not to confuse intellectual impairment with mental illness. Patients with learning difficulties represent a wide range of intellectual ability and no simple standard of capacity can be assumed between them. In each case an assessment according to the criteria outlined above is called for in combination with an awareness of the nature of the decision to be made. Only in extremely serious cases will a person with this problem be unable to make a decision about anything. In those cases where either the impairment is so severe that the decision is too onerous or complex to be grasped by the person, a best interest judgement on their behalf should be made.



- v. Mentally ill patients
 

As with intellectual impairment so with mental illness, one cannot assume that all persons possess equal capacity or otherwise. On the one extreme, severely demented people cannot make coherent choices. On the other hand when not in florid state a person with schizophrenia might be quite clear about how he feels about matters of life and how he would wish to address them.
- vi. Unconscious patients
 

Such documents as Advance Directives or Living Wills might be valuable guides but have inherent weaknesses that should be taken into account. They might be old and out of date, they express hypothetical wishes, and there is always the need to know under what circumstances the documents were produced. The documents should be in accordance with domestic law.
- c. Illustrative case of mentally ill patient: A person who is termed incapable is one whose insanity or mental deficiency deprives him/her of the ability to control his/her own interests.
  - i. Explain in this case how the criteria for capacity apply
  - ii. Discuss what will be good medical practice for such a patient
- 3. Legal provisions concerning consent and capacity to consent
  - a. The role of domestic legal provisions- teachers should relate their national legislation for dealing with incapacity to the ethical considerations described in this unit
  - b. The role of international human rights law. The priority of international human rights law over national legislation.
- 4. Procedures:
  - a. Explain Article 7.a.
  - b. Obtaining consent in health care practice
  - c. Special procedures in ethics to construct consent
    - i. Determination of appropriate substitute decision-makers
    - ii. Best interest criterion
- 5. The context of research with persons
  - a. Explain Article 7.b.
  - b. Should research been done with persons not able to consent?
  - c. Research for direct health benefit
  - d. Research without potential direct health benefit



<b>UNIT 8</b>	
<b>Title</b>	<b>Respect for human vulnerability and personal integrity (Article 8)</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>1. Students should be able to explain the principle of respect for human vulnerability</li> <li>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</li> <li>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</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. The notion of “human vulnerability” <ol style="list-style-type: none"> <li>a. Respect for human vulnerability</li> <li>b. Different aspects of vulnerability <ol style="list-style-type: none"> <li>i. biological</li> <li>ii. social</li> <li>iii. cultural</li> <li>iv. religious</li> </ol> </li> <li>c. Implications of the principle: care</li> </ol> </li> <li>2. The powers of medicine: <ol style="list-style-type: none"> <li>a. The fight against vulnerability</li> <li>b. Successes and failures</li> <li>c. Problems with the basic assumption that vulnerability should be eliminated</li> <li>d. Towards sustainable medicine</li> </ol> </li> <li>3. The dilemmas of vulnerability</li> <li>4. Care ethics <ol style="list-style-type: none"> <li>a. New approaches in bioethics</li> <li>b. Solidarity</li> <li>c. The duty to care</li> </ol> </li> <li>5. The notion of personal integrity: <ol style="list-style-type: none"> <li>a. Relation between vulnerability and personal integrity</li> <li>b. Personal integrity does not refer to a virtue</li> <li>c. Personal integrity refers to respect for the patient’s understanding of his or her own life and illness, but also for his/her interests and free will</li> </ol> </li> </ol>	
<b>Teacher Manual</b>	
<ol style="list-style-type: none"> <li>1. Explain the notion of “vulnerability” <ol style="list-style-type: none"> <li>a. The principle of respect for human vulnerability expresses a concern for the fragility of human beings. As whole and integrated entities their functioning can easily be disturbed and deranged so that their health and even existence can come under</li> </ol> </li> </ol>	



threat. The principle is related to the principle of personal integrity.

- b. Several aspects of vulnerability need to be distinguished:
    - i. biological or corporeal vulnerability; this concerns the fragility of the human organism originating from:
      1. natural threats are coming from our biology: ageing, susceptibility to illness and disease, and death
      2. environmental and other natural and man-made threats: famine, earthquake, hurricanes, pollution and environmental disasters
    - ii. social vulnerability; this concerns the fragility of the human capacity for creating coherence in one's life and for sharing goods and services.
      1. social threats stemming from war and crime, prejudice and discrimination, cruelty and indifference
      2. persons also become vulnerable due to hospitalization and institutionalization
      3. social circumstances and conditions
    - iii. cultural vulnerability; this concerns the fragility of particular traditions and conceptions of values that are typical for a community or local cultures.
  - c. In ethics, the notion of vulnerability is not just a neutral description of the human condition but instead a normative prescription to take care of the vulnerability that is characteristic for human beings. Ethics is more than respecting individual choices and decisions; it aims at care for the other. For example, the human face can show the vulnerability of the human person and at the same time appeal for help and assistance.
2. The powers of medicine
- a. The fight against vulnerability. A common idea is that the vulnerability of the human condition should be eliminated or reduced. Science and technological innovations should be used to overcome the natural threats. Medical research should be focused on eliminating the biological threats to the human body. The basic assumption behind this fight is that many vulnerabilities of the human condition are contingent, not inherent.
  - b. This fight has had some successes and some failures. Life expectancy and health have improved, poverty and starvation reduced, but at the same time many people die from common diseases, life expectancy is decreasing in many countries and poverty is still widespread.
  - c. The basic assumption that vulnerability should be eliminated has in itself created problems:
    - i. if vulnerability is regarded as an evil to be eradicated, it cannot be given any positive meaning; we cannot properly understand human vulnerability and thus human suffering
    - ii. religion, alternative medicine and traditional knowledge present different ways of [knowing] perceiving and valuing; because they are open to different perspectives, they can give meaning to vulnerability, but their views are generally not accepted by mainstream science or bioethics



- iii. economic problems; the success of science and technology has created financial difficulties in almost all countries in achieving decent levels of health care for the population. Because of its continuous fight against vulnerability, medicine often is not “sustainable”
    - iv. medical progress itself has created new forms of vulnerability, i.e. chronic illness. This presents continuing vulnerability for a growing population.
  - d. An unrestrained fight against human vulnerability generates its own problems. It is not the struggle against human vulnerability that is a mistake but the struggle to rid the human condition of all vulnerability. For a sustainable medicine it is necessary to accept some vulnerability as a permanent part of the human condition.
- 3. The dilemmas of vulnerability
  - a. “Taking into account human vulnerability”, as stated in Article 8, requires a balance between eliminating and accepting human vulnerability. This balance is manifest in some dilemmas:
    - i. disability: disability is viewed as abnormal and the disabled therefore are by definition vulnerable; at the same time the disabled should not be stigmatized by being treated as abnormal.
    - ii. death: in medicine the place of death in human life is ambivalent; in palliative care, death is understood as being part of life; in some other sectors of medicine death is still treated as the enemy.
    - iii. depression: Prozac is widely and successfully used as an anti-depressant drug, when there are clear clinical symptoms of depression; however it is sometimes inappropriately regarded as medication for unhappiness and sadness.
  - b. Human suffering and misery express human vulnerability. They also pose a challenge. We must at the same time struggle to keep suffering to a minimum and also accept it as part of life. Human vulnerability cannot be merely regarded as an enemy to be eliminated. Too much emphasis on eradication has led to evils in the name of some supposed good: the eugenics movement, Nazism to eliminate the socially and ethnically unfit and totalitarian regimes to eliminate social injustice.
- 4. Care ethics
  - a. The challenge of human vulnerability is that it can never be entirely eliminated from human life. Instead, it should inspire [new] relevant approaches in bioethics
  - b. The human condition requires solidarity; human beings all share common vulnerabilities
  - c. Human vulnerability also leads to an ethics of care. Because it is a shared characteristic, it is also a source of concern for others as well as awareness that we rely on others. It is the basis for the duty to care for those threatened by biological, social and cultural threats as well as by the power of medicine itself.
- 5. The notion of personal integrity
  - a. The principle of respect for human vulnerability is related to the notion of personal integrity; as stated in Article 8, individuals and groups of special vulnerability should be protected and their personal integrity respected.



b Integrity concerns the wholeness of an individual. In ethical discourse, integrity is often considered as a virtue, related to the honesty of somebody's character for example. But respect for personal integrity in this Article does not refer to somebody's moral character or his/her good behaviour. It refers to fundamental aspects of a human life that should be respected.

c Personal integrity refers here to respect for the patient's understanding of his or her own life and illness, but also for his/her interests and free will. Each person's life has a coherence, a narrative whole based on important events in his/her life and by his/her interpretations and values. What is most valuable to a person is grounded in this narrative whole. It is this personal integrity of human beings that must be protected.



<b>UNIT 9</b>	
<b>Title</b>	<b>Privacy and confidentiality (Article 9)</b>
<b>Unit Learning Objectives</b>	
<ol style="list-style-type: none"> <li>1. Students should be able to explain why patient privacy and confidentiality should be respected</li> <li>2. Students should be able to recognise legitimate exceptions to confidentiality</li> </ol>	
<b>Outline of the Syllabus</b>	
<ol style="list-style-type: none"> <li>1. Definitions of “privacy” and “confidentiality”</li> <li>2. Reasons for respecting privacy and confidentiality</li> <li>3. Duty of health care providers to protect the privacy of patients</li> <li>4. Duty of health care providers to maintain confidentiality (also known as “professional secrecy”)</li> <li>5. Confidentiality extends to all personal health information, including genetic data</li> <li>6. Potentially justified breaches of confidentiality include: <ol style="list-style-type: none"> <li>a. Sharing information and access for patient care</li> <li>b. Using interpreters</li> <li>c. Teaching medical students</li> <li>d. Mandatory reporting</li> <li>e. Serious danger to others</li> <li>f. Genetic information</li> <li>g. Patient or guardian consent</li> <li>h. Ethical aspects of the mapping of human genome.</li> </ol> </li> <li>7. Special circumstances of research</li> </ol>	
<b>Teacher Manual</b>	
<ol style="list-style-type: none"> <li>1. Begin by defining “privacy” (it is the right of an individual or a group to be free from intrusion from others, and includes the right to determine which information about them should be disclosed to others – see Units 5 and 6) and “confidentiality” (an attribute of personal information requiring that it not be disclosed to others without sufficient reason)</li> <li>2. Reasons for respecting privacy and confidentiality: <ol style="list-style-type: none"> <li>a. Individuals “own” their information: it is essential to their personal integrity.</li> <li>b. For many people privacy is an essential aspect of their dignity (see Unit 4); invading their privacy against their will is a violation of their dignity.</li> <li>c. Respect for others requires protecting their privacy and the confidentiality of information about them.</li> <li>d. Patients are less likely to trust health care providers and confide in them if they think that the health care providers will not keep the information confidential. This can have serious consequences for the patients’ health and well-being and sometimes for the health of others (e.g. family members).</li> </ol> </li> <li>3. Health care providers have a duty to protect the privacy of patients to the greatest extent</li> </ol>	





possible in the circumstances. For example, they should ask the patient's permission to examine him or her unclothed and should ensure that an unclothed patient cannot be viewed by passers-by.

4. The duty of maintaining confidentiality (also known as "professional secrecy") has been part of Western medical ethics since Hippocrates and preceded the notion that privacy is a right; .
5. Confidentiality extends to all personal health information, including genetic data (UNESCO *International Declaration on Human Genetic Data*: "...all medical data, including genetic data and proteomic data, regardless of their apparent information content, should be treated with the same high standards of confidentiality").
6. Justified breaches of confidentiality *may* include:
  - a. Sharing information for patient care: in the hospital setting, many individuals need access to the patient's medical record in order to provide care; however, each of these individuals is bound to maintain confidentiality to the greatest extent possible; outside the hospital setting, family members may need patient information in order to provide care and/or to protect themselves; (however this should normally require patients' consent)
  - b. Using interpreters: where the health care provider does not speak the patient's language, an interpreter will be needed who will then have access to information about the patient; interpreters should be bound to observe confidentiality and where possible patients' permission should be obtained for the use of the interpreter ;
  - c. Teaching medical students; observation and discussion of patients is a necessary part of medical education; nonetheless patients' permission should be obtained where possible and students should be informed of their obligation to maintain confidentiality;
  - d. Mandatory reporting; health care providers should be familiar with the laws about mandatory reporting of infectious diseases, suspected child abuse and other conditions in the country where they practise; normally patients should be informed that their information has to be reported to the appropriate authorities;
  - e. Serious danger to others: for example, in exceptional circumstances and generally as a last resort, health care providers may need to inform other persons that the patient has threatened to harm them, whether by violence or by sexual contact when the patient has a transmissible disease such as HIV;
  - f. Genetic information: there is controversy and ethical debate regarding whether other individuals with the same genetic makeup (usually close family members) have a right to a patient's genetic information; physicians should consult their national regulations or guidelines when faced with this situation;
  - g. With patient or guardian consent: this should generally be obtained for all breaches of confidentiality and renders the breach acceptable ethically.
7. Special circumstances of research
  - a. Disclosure of personal health information obtained in the course of a research study requires the prior consent of the research subject;
  - b. There is a great controversy and ethical debate regarding whether anonymized patient information requires consent for disclosure; researchers should consult their national regulations or guidelines if such exist, otherwise international guidelines such



as the *Declaration of Helsinki*;

- c. In research, communities as well as individuals have a right to privacy, and information about them should be kept confidential, especially when its disclosure may be harmful to the community.
- d. Scientific publication should respect confidentiality to the greatest extent possible. Consent is always required when an individual research subject can be identified in a publication.