EXPERT CONSULTATION ON
THE BIOETHICS CORE CURRICULUM PROPOSAL

DIVISION OF ETHICS OF SCIENCE AND TECHNOLOGY (SHS/EST)
UNESCO

Meeting Report

Venue: UNESCO HQs, Bonvin Building
Room XVI
1, rue Miollis, 75015 Paris, France

Date: 4-5 July 2007

Participants:

Members of Advisory Expert Committee:

- Mr Ruben Apressyan, COMEST, Russian Federation
- Mr Amnon Carmi, UNESCO Chair, Israel
- Mr Leonardo de Castro, IBC, Philippines
- Mr Donald Evans, IBC, New Zealand
- Mr Diego Gracia, COMEST, Spain
- Mrs Nouzha Guessous-Idrissi, IBC, Morocco
- Mr John Williams, WMA

Invited Experts:

- Mr Khalid Abdulla Al-Ali, Qatar
- Mr Najib M.H. Al Khaja, UAE
- Mr David Benatar, South Africa
- Mr Moty Benyakar, Argentina
- Mr Gabriele Cornelli, Brazil
- Mr Abdallah Daar, Oman/Canada
- Mr Kwami Christophe Dikenou, Togo
- Mrs Marthelise Eersel, Suriname
- Mr Pierre Effa, Cameroon
- Mr Juan Jorge Farina, Argentina
- Mr Harith Ghassany, Oman
- Mr Zosimo Lee, Philippines
- Mr Iftikhar Ahmad Malik, Pakistan
- Mr Jude Mathooko, Kenya
- Mrs Indira Nath, India
- Mr Soenarto Sastrowijoto, Indonesia
- Mrs Monica Serra, Brazil
- Mr Ruud ter Meulen, United Kingdom

- Mr Evert van Leeuwen, Netherlands
- Mr Charles O.N. Wambebe, Nigeria

Observers:

- Mrs Diana Laurent, Mouvement Mondial des Mêres
- Mrs Ester Polak de Fried, Argentina

Members of the Secretariat:

- Mr Henk ten Have, Director SHS/EST
- Mrs Carrie Marias, SHS Regional Adviser (West Africa), UNESCO Dakar
- Mr Darryl Macer, SHS Regional Adviser (Asia Pacific), UNESCO Bangkok
- Mr Tee Wee Ang, SHS/EST

Apologies:

- Mr D. Balasubramaniam, TWAS
- Mr Koussay Dellagi, Tunisia
- Mr Volnei Garrafa, Brazil
- Mrs Qiheng Hu, China
- Mr Amin Kashmeery, Saudi Arabia
- Mr Manuel de Jesus Limonta Vidal, Cuba

OPENING

Mr Henk ten Have opened the consultation meeting and welcomed all participants. This was followed by introductions of members of the Advisory Expert Committee responsible for drafting the bioethics core curriculum proposal as well as of the meeting's participants. Mr ten Have then briefly outlined the context within which the bioethics core curriculum is being developed, including UNESCO's priority and mandate in bioethics and ethics of science and technology, the Organization's international declarations in bioethics, the Ethics Education Programme and the Global Ethics Observatory (GEObs).

It was emphasized that the core curriculum proposal is designed around principles that Member States of UNESCO have agreed upon within the Universal Declaration on Bioethics and Human Rights; is intended to be a minimum teaching programme in bioethics with the possibility of further innovation, expansion and flexible application in different contexts; is not intended to impose a particular model of teaching but rather as a source of ideas and suggestions on how to approach bioethics teaching; is designed to reach out across various social, cultural and economic backgrounds by using diverse examples and teaching materials; and is intended primarily for medical students at this stage but can be adapted for other disciplines. Participants are invited to provide written and verbal feedback for improving the draft proposal during the consultation meeting.

Once finalized, the bioethics core curriculum proposal will be made freely and publicly available in the six official languages of UNESCO. Efforts are also underway to create the necessary supporting teaching materials for the proposal. Several medical schools have also volunteered to introduce the proposal into their teaching programmes as a pilot to test out its relevance in different settings and to generate further feedback on ways to improve the bioethics core curriculum proposal.

GENERAL FEEDBACK

In general, participants congratulated UNESCO and the Advisory Expert Committee for producing a useful and comprehensive bioethics core curriculum proposal. It was observed that the proposal is relevant for initiating and strengthening bioethics teaching globally, and would provide a very good start for establishing debates in all regions and situations. Participants recognized that the core curriculum proposal tries to address pluralism and diversity, and could be adapted to local and regional needs. It provides a solid ethical grounding for professionals working in the scientific fields and encourages continuous education.

While recognizing that the core curriculum is designed for flexibility so that local and regional adaptations can be included accordingly, concerns were raised that the content needs to be further diversified so as to include more examples and approaches drawn from various cultural, religious and philosophical traditions from all regions. It was also asserted that the curriculum should provide more deliberate discussion of gender issues within bioethics. Although the cases currently included in the proposal are designed to facilitate critical thinking within various cultural, religious, economic, social and gender contexts, this should be strengthened with the establishment of a database to collect and link to more cases from around the world that can be utilized as supporting resources for the core curriculum in the different regions. This would allow people in different regions to develop their own cases and to further expand on the curriculum based on the specific needs and concerns of the region. Moreover, it was recommended that the introduction to the curriculum should provide clarifications and instructions on how the document can be utilized to address these diverse contexts. Participants of the consultation meeting were also invited to propose additional cases and approaches from various regions for inclusion in the core curriculum. Related to this issue, it was pointed out that the curriculum should also take note of the shifting dividing lines created by the convergence of civilizations beyond the traditional dividing lines of cultures and religions.

It was observed that the proposal's top down approach built around ethical principles should be balanced with a bottom up approach emphasizing the experiences and needs of medical students in the day-to-day aspects of the medical practice. The proposal's focus on reasoning and analysis should also be balanced with a focus on changing behaviors and attitudes. The document should be clearly defined as an independent curriculum for self-governing people and self-actualization. It was further suggested that the proposal should provide more discussion of pedagogical methods.

Concerns were raised that the hours allocated for the core curriculum proposal are insufficient. It was asserted that more time should be assigned so that the topics covered by the core can be adequately discussed. However, this needs to be balanced with the competitive demands on time

allocation in different academic disciplines and institutions around the world. The Advisory Expert Committee had deemed the 30 hours allocated for the proposal as an acceptable minimum, but this would be re-examined further. It was emphasized that the document should also suggest at what point a unit could be introduced and the acceptable time gaps between units.

It was highlighted that more discussion and cases on ethics research and ethics in research situations should be included in the core if it was to become relevant for post-graduate programmes. In addition, more topics on genetic medicine, reproductive technologies, global health ethics and public health should also be included. It was also observed that the curriculum should discuss the ethics of health educators since the health care education environment has a tendency to erode the ethical learning of students through ongoing unethical practices.

Since the curriculum is currently intended for university teaching of medical students, it was put forward that the document should explore suggestions on how it could be adapted for other disciplines and faculties. It was further asserted that proposals of a rubric of assessment for the core should also be included in the document.

In terms of introducing the core curriculum proposal within various Member States, it was recommended that UNESCO explore different possibilities to make the document useful by expanding its efforts beyond institutions of higher learning to entities such as medical councils, ministries of health or education, academies of science and other governmental and professional groups.

It was recommended that the core curriculum's 51 learning objectives should be reduced to a manageable list. It was also suggested that learning objective 33 should be rephrased, and objectives 40, 42, 43 and 44 can be compressed into a single objective. It was cautioned that these learning objectives should not stigmatize science and technology as agents of inequality.

Finally, the need for an introduction to the core curriculum proposal was highlighted. The introduction should provide justification for the programme, outline its aims and structure, identify the level of targeted audience, and cover all the issues being raised thus far. The introduction should also clarify that the principles discussed in the core have been accepted by Member States of UNESCO, but does not necessarily cover all aspects of bioethics (perhaps providing supplements or links to resources on topics that are not covered); that implementing schools should decide how and at what level the core should be integrated in their medical curriculum; and that the core is meant to provide teachers a way of getting students to reflect upon the ethical dimensions and human rights considerations of their growing medical practice.

Please also see general written comments of Mrs Indira Nath, Mr Zosimo Lee, Mrs Qiheng Hu and Mrs Monica Serra (attached to report). Please also see the case study provided by Mr Abdallah Daar (attached to report).

DISCUSSION ON INDIVIDUAL UNITS

UNIT 1:

The following issues were identified:

- A suggestion was made to start from the Utilitarian instead of Kantian perspective.
- It was pointed out that the input of philosophical reflection in ethical deliberation should be mentioned.
- It should be specifically mentioned that the intermediate course of action is not the best course of action; and that the right course of action should be emphasized instead of the best course of action.
- It was asserted that the test of publicity does not necessarily indicate nor reveal wrongfulness.
- It was also suggested that the title of section 3-c be modified to include the assessment of consequences.
- Since questions were raised about the case and movie chosen for this unit, participants were invited to submit alternatives that might be appropriate.
- Please see written comments of Mr Donald Evans, Mr Christophe Kwami Dikenou, Mrs Qiheng Hu and Mrs Monica Serra (attached to report).

UNIT 2:

The following issues were identified:

- The assertion that the medical profession was the only profession dealing with life in the past was challenged, and it was observed that other professions have also dealt with life in other ways.
- It was further suggested that the discussion of globalization within bioethics should be expanded beyond universality to include the idea of inter-connectedness and dialogistic concept.
- A suggestion was also made to quote the title of Potter's book in section 1, with a related concern that the discussion provided is a very North American view of the birth of bioethics.
- A further concern was raised about the reasoning for paragraph 2-b as it might be interpreted that values supported by the facts are not uncontested, and a suggestion was made to remove this paragraph from the unit since it might not be necessary (Page 15).
- It was also pointed out that the section on ethics committees should provide discussion on regional and national ethics committees, and that the cases should also illustrate examples of functional or dysfunctional ethics committees (Page 17). A further suggestion was made to modify the title of the section on ethics committees to structure and functions of ethics committees, and to include discussion of how to strengthen bioethics committees in paragraph 4-h.
- It was recommended that the unit should create the link between health, disease and the environment, and how the improvement of the environment could lead to better health.
- It was also recommended that the word "exotic" be removed from Case 1 as this could be discriminatory in certain cultures.
- Please see written comments of Mr Donald Evans, Mr Christophe Kwami Dikenou, Mrs Qiheng Hu and Mrs Monica Serra (attached to report).

UNIT 3:

The following issues were identified:

- It was observed that the unit does not really address the issues raised by Ruth Macklin's article listed for group discussion and that assistance should be provided to the teacher in terms of how to respond to this article.
- It was highlighted that paragraph 3 on comparative cultural views should indirectly emphasize that there are points of convergence from these diverse perspectives. This is especially crucial in light of today's politicization of spirituality and the use of dignity and respect as a justification for violence.
- Please see written comments of Mr Donald Evans and Mrs Monica Serra (attached to report).

UNIT 4:

The following issues were identified:

- The unit should provide discussion on how to quantify and qualify benefit.
- With regards to the case of infertility listed for group discussion, within the first paragraph of background, it was suggested that the term "irrational guilt" should be replaced with "unjustified guilt" since the guilt may be rational given certain beliefs, but the beliefs may be unjustified.
- Please see written comments of Mr Donald Evans, Mr Christophe Kwami Dikenou and Mrs Monica Serra (attached to report).

UNIT 5:

The following issues were identified:

- It was observed that the unit should highlight that most patients feel dependent on physicians and that respect for patients' autonomy by physicians is crucial so that a discretionary space can be created for patients to make their own decisions with respect to their own dignity.
- With regards to paragraph 1-a-i-1, it was cautioned that the state should not only be viewed as an institution curtailing autonomy as it could also function as an enabler of autonomy; and that transnational corporations are often more likely to obstruct autonomy. As such, it was suggested that political philosophy might have to be brought in for the discussion of this point.
- A concern was raised about the assertion that there is no autonomy beyond responsibility in paragraph 1-c. It was argued that autonomy could exist in the absence of responsibility and that responsibility is usually used to curtail the region of autonomy. Further clarification on this paragraph is needed.
- It was suggested that there should be discussion on the various models of decision-making such as the deliberative model, interpretative model, negotiated consent model and shared decision-making model.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath, Mr Christophe Kwami Dikenou and Mrs Monica Serra (attached to report).

UNIT 6:

The following issues were identified:

- In light of the use of placebos in research involving human subjects, it was suggested that a discussion on debriefing volunteers after research be added.
- A suggestion was also made to first establish the specific cultural contexts within which students are expected to practice medicine when discussing consent. It was pointed out that in the Universal Declaration on Bioethics and Human Rights, community consent could never become an alternative to individual consent; and that cultural practices do not carry the same weight as national laws.
- It was emphasized that more elaboration on consent in research and its implications is needed, and cases on research should be added. A further suggestion was made to include examples of consent forms as an annex to the core proposal so that students are exposed to how this is handled in different countries.
- It was pointed out that the unit does not currently include any discussion on the principle of consent as applied in teaching situations as outlined in objective 3. Participants were invited to propose cases of using patients for medical teaching to be included in this unit.
- A further suggestion was made to include cases on gender, husband-wife and father-children situations within the African context.
- It was also suggested that some discussion about deception in research, such as in the case of the Milgram experiment, should be included.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath, Mr Christophe Kwami Dikenou and Mrs Monica Serra (attached to report).

UNIT 7:

The following issues were identified:

- It was suggested that the unit should also include discussion of how persons without capacity to consent are defined within the national legal system of the student.
- With regards to paragraph 2-a-i-3, it was pointed out that in public health cases, it should be clarified that the requirement for consent is overridden by public health interests and not necessarily that the person is unable to consent.
- A suggestion was put forth to make a distinction between capacity and competence. However, it was pointed out that these concepts do not translate well into other cultures and languages and could create more confusion.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath, Mr Christophe Kwami Dikenou and Mrs Monica Serra (attached to report).

UNIT 8:

The following issues were identified:

- An observation was made that vulnerability is a question of perception and a construct, and not necessarily a biological state. However, it was clarified that the principle outlined within the Universal Declaration on Bioethics and Human Rights is addressing biological vulnerability in particular, and that this unit is focused on taking such vulnerability into account in medical practice. In this sense, perhaps the unit could discuss biological vulnerability and special vulnerability as well.

- With regards to paragraph 2-a-ii, it was suggested that "in most countries" be added to the end of the paragraph.
- In paragraph 4-c, it was asserted that human vulnerability does not necessarily lead to a theory of an ethics of care, and this might need to be further refined.
- Please see written comments of Mr Donald Evans and Mrs Monica Serra (attached to report).

UNIT 9:

The following issues were identified:

- It was suggested that privacy and confidentiality should be framed in the context of national laws and guidelines of professional bodies, as well as enshrined sanctions in instances of violation.
- An observation was made that the discussion of privacy in this unit is shifting between two different concepts of keeping things private and autonomy, and the unit should be focusing on the concept of keeping things private since autonomy is already dealt with in another unit.
- It was also emphasized that the common and inadvertent breaches of confidentiality due physicians' indiscretion when handling patients' data or files should be highlighted.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath, Mr Christophe Kwami Dikenou and Mrs Monica Serra (attached to report).

UNIT 10:

The following issues were identified:

- An observation was made that gender issues should be expressed in more explicit terms, especially the gender disparity in health care.
- It was recommended that the role of economic evaluation should be discussed with particular attention on the Utilitarian background guiding such evaluations, the role of wealth and acceptable differences in accessing health care, and rationing and selecting patients in such situations.
- With regards to paragraph 4, it was suggested that discussion on some considerations for and against the different approaches listed should be added.
- It was asserted that more examples should be given about global inequalities.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath and Mrs Monica Serra (attached to report).

UNIT 11:

The following issues were identified:

- It was suggested that discrimination against traditional or alternative medicine by practitioners of modern medicine be included in paragraph 3-a. This issue was recognized as an important issue to be addressed, but perhaps in other units.
- A concern was raised about whether the term "affirmative action" is correctly used in the case listed for group discussion.

- An observation was made that HIV/AIDS cases are missing from the study materials and it would be important to include these as it is the most stigmatized disease of modern times, even amongst health workers.
- It was further suggested that cases of discrimination based on race, ethnicity and sexual orientation should also be included.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath and Mrs Monica Serra (attached to report).

UNIT 12:

The following issues were identified:

- In the context of Africa, it was suggested that traditional and indigenous practices be included in this unit, with a clear understanding of the differences between traditional medicine and witchcraft.
- A suggestion was made to include discussion on the mechanisms with which students could navigate cultural diversity and pluralism to reach possible consensus and consent, as well as establish dialogues and handle the power relationships within such a dialogue.
- It was pointed out that there might be a conceptual problem with the formulation of paragraph 1-b-ii since harmonious interaction is only necessary when cultural diversity exists, while the paragraph currently states that cultural diversity is essential for harmonious interaction.
- It was further suggested that moral diversity be considered for inclusion in the unit.
- Please see written comments of Mr Donald Evans, Mrs Indira Nath and Mr Christophe Kwami Dikenou (attached to report).

UNIT 13:

The following issues were identified:

- It was pointed out that the concept of solidarity as it is now conceived is too Westernized, and should be expanded to include aspects of other realities such as informal care by family groups.
- A concern was raised about paragraph 3-b due to the tendency to share confidential information with family members when informal care by the family is involved. As such, these limits to autonomy should be mentioned.
- Please see written comments of Mr Donald Evans and Mrs Monica Serra (attached to report).

UNIT 15:

The following issues were identified:

- A concern was raised that there are too many learning objectives for this unit as compared to the other units. It was suggested that objectives 2 and 3 could be combined.
- It was also put forth that some discussion be devoted to the negative aspects of existing benefit sharing realities, especially with regards to the patenting of genes and organisms, and the sharing of knowledge.

- It was observed that the cases for this unit are quite lengthy and could be moved into a casebook. It was also pointed out that there are currently no cases on preparedness of pandemic flu and the availability of drugs and vaccines (especially the HPV vaccine).
- Please see written comments of Mr Donald Evans, Mr Christophe Kwami Dikenou, Mrs Qiheng Hu and Mrs Monica Serra (attached to report).

UNIT 16:

The following issues were identified:

- It was emphasized that the need for guidelines for the introduction of GMOs into the environment should be discussed, and that students should be educated on the harms and benefits of such organisms, especially with regards to the environment.
- Please see written comments of Mr Donald Evans, Mrs Qiheng Hu and Mrs Monica Serra (attached to report).

UNIT 17:

The following issues were identified:

- A concern was raised that objective 1 is not currently addressed by the content of the unit. As such, there is an opportunity to highlight linkages between environmental problems and health.
- It was highlighted that there is now an attempt to combine the anthropocentric and non-anthropocentric approaches to environmental ethics through a holistic or humanistic kind of approach. This approach opens up a framework for integrating human rights and environmental/health rights.
- Please see written comments of Mr Donald Evans, Mr Christophe Kwami Dikenou, Mrs Qiheng Hu and Mrs Monica Serra (attached to report).

CONCLUSION

It was indicated that the Advisory Expert Committee would explore the possibility of creating two separate documents, with the introduction and core content in the first document ("universal core") and supporting resources, cases and supplementary materials covering other issues in the second document (illustrating the cultural variety as well as the range of problems and possible solutions). It was also pointed out that the committee is also considering the possibility of creating a multimedia CD-ROM with movie excerpts and other supporting materials as a supplement to the core proposal. In this way, many more examples, cases and topics can be included without overloading the core curriculum. It should be noted that the core proposal should be available in different languages and applicable for various cultural contexts. It was also clarified that instead of referring to materials from specific authors, the proposal tries to identify materials that are easily and freely accessible on the Internet as far as possible. It was further emphasized that materials included with the core proposal should avoid bias towards any particular country, and that there should be a variety of examples from different countries.

Participants were thanked for their comments thus far, and were invited to submit more cases and multimedia materials for consideration and inclusion in the core curriculum, as well as written

comments on specific changes to the content. The Advisory Expert Committee will review all submissions and modify the core proposal as deemed necessary.

APPENDICES

- Written Comments by Mr Donald Evans
- Written Comments by Mrs Indira Nath
- Written Comments by Mr Zosimo Lee
- Written Comments by Mr Christophe Dikenou
- Written Comments by Mrs Qiheng Hu
- Written Comments by Mrs Monica Serra
- Case Study provided by Mr Abdallah Daar

WRITTEN COMMENTS BY MR DONALD EVANS

UNITS 1 & 2

The question of whether we need these 2 units has been raised in the meeting. I think that a possible answer to this question is that we do no need them as they stand. Maybe one joint unit would be a better approach as we need to capture the attention of the students at the outset of the curriculum. This is best done by centering the material on their experiences rather than on theories of ethics.

If we go along with this idea then we will need to reorganize and edit the material of the current units retaining their important features and omitting the remainder.

The important elements are:

i) *An introduction to the nature of moral judgments and their inevitability in human life*. Rather than solely employing the universal notion of duty to do this, it would be better to appeal to the students' experience of making moral judgments which include those which consider an action dutiful. They are adept a praising and condemning behaviors and action. We do not need to teach them to do this as they have been doing it all their lives. We simply need to point this out and then to show that all human relationships, including that between health professionals and patients, are characterized by the concepts they employ in making such judgments.

A teaching suggestion:

An exercise can easily achieve this. Ask the students whether they have been disgusted by any piece of news they have viewed in the past week. Ask them to describe why it was disgusting and they will come up with ideas like "it was dishonest, harmful, conceited, prejudiced, unfair" and so on. Ask them to remember news of some piece of behavior which they admired and they will give reasons for their admiration in the form of "it was generous, brave, beneficial, dutiful, kind" and so on. In three minutes they will have rehearsed all of the values which inform ethical assessments of good clinical practice. It then remains to use some engaging clinical examples to demonstrate this to them. The examples can be presented and they can be asked to respond in the same kind of terms which they used previously.

ii) *An explanation of the nature of moral judgments by comparing them with other kinds of judgments*. The steps outlined in the current paragraph 2, "Facts, Values and Duties", would be a good structure in this though it needs to be worked more carefully as described below. (See Page 7, 2-a)

a) Factual or descriptive judgments are well described. These are assessments of situations made by applying criteria. An example would be "There are 30 chairs in this room". If one disputant agrees with this claim and another disagrees then one must be mistaken – and there is a simple way of finding out, viz. counting the chairs.

b) Expressions using the word "nice" such as "This picture is nice". Someone who makes such a remark is not obliged to be able to give reasons for it any more than someone is obliged to be able to give reasons for saying "Sour milk is nice". They might give reasons but they need not be able to do so. No criteria are required and the remarks are not truth claims about the objects in question but rather they are expressions of the likes of the speaker. They tell us something about the speaker and not something about the objects. They are not therefore judgments, even evaluative judgments.
c) Moral judgments are a subset of evaluative judgments. Aesthetic judgments are also evaluative judgments. They are judgments because they appeal to criteria. Thus "This picture is nice" is not a judgment whereas "Manet's Olympia expresses the truth about the oppression of women" is a judgment. The speaker cannot simply say that that is simply how he feels about the picture, he needs to be able to give reasons for it such as: the architecture of the painting is similar to that of the classical painting of Olympia, but the nude has a real face, the face of a prostitute and is set in a brothel; the skin color of the maid is dark as opposed to the white maid in the classic painting in which the nude has an idealized face; in both paintings the nude looks out of the painting, presenting herself to the male painter; and so on. The statement is an evaluation of the painting employing criteria of judgment.

   Similarly, moral judgments appeal to public criteria of assessment of actions and behaviors. Just as not all art critics would accept the above analysis of Manet's painting, such as Kenneth Clarke who employs opposing criteria, so not all observers of a piece of behavior will be impressed by it in the same way, seeing some oral values as being more important than others. Thus there might be moral disagreements but, nevertheless, they are moral judgments and not simply personal whims of the speakers as they employ public criteria.

   For example, people might disagree about the proposition "The Prime Minister did the right thing when he commuted the prison sentence of his official". One disputant might think that personal loyalty to trusted servants, compassion and generosity are the most important moral values here. Others might think that justice, respect for the privacy of others and avoiding danger to others are the most important factors. Thus each makes a judgment but there is no hierarchy of values to appeal to make them agree with each other. In this way, moral judgments are different from factual judgments.

There is a complex relationship between facts and values in ethical judgment. The facts have moral import because of the social or professional context in which they are perceived. They cannot be identified independently of these values, but different people might see different values predominating – they see different worlds.

Some further specific observations (Units 1 & 2)

1. The section describing the origin of the word bioethics is best left out. It was coined largely in relation to environmental ethical issues. The word has become popular as a shorthand description of medical or healthcare ethics, which is the topic of the curriculum. But these kinds of reflection are much older than the Potter tradition.

2. Page 8, paragraph 1-e: “Do no harm to others” is not a truth claim and therefore not a statement. It is a command which is neither true nor false. It is not a moral judgment either therefore but rather the expression of a moral rule.
3. Page 8, paragraph 2-a: “Nice” is not a predicate or property, as shown above. But neither is “goodness” a perceived property of something. We do no intuit it even. Rather we establish that something is morally good by asking whether it was a generous, honest, dutiful act and so on.
4. Page 9: The value fact relationship in ethics is such that some facts have moral import such as in “X is my father”. This import depends on the institutional context out of which the identity of someone as father arises.
5. Page 11: Intermediate courses of action might be worse than opting for one value over another. For example, treating someone who has refused treatment because it is thought to be in their best interest prizes beneficence over autonomy, and not treating him/her prizes autonomy over beneficence. However, fudging the issue by passing the patient to a colleague without mentioning the patient’s refusal is a despicable compromise for the doctor adding deceit to the mix.
6. Page 11, paragraph 3-d-ii: The publicity test is not about testing the rightness of the choice but is rather about resisting the temptation to do what one knows is wrong for fear of being discovered.
7. Page 14: Whilst it is useful to mention the existence of various kinds of ethics committees (though their functions need to be spelled out), it is misleading to include the matter here. We are trying to teach the emerging doctors to make moral judgments and should not be suggesting that they leave these matters to committees which might absolve them from the responsibility for the decision. Ethics committees should not, in any case, be telling doctors what decisions they should make.
8. Page 19, Examples: We need a wider range of cases than conflict of interest cases. There are countless cases available to illustrate ethical problems in medicine including killing and letting die cases, embryo selection and disability cases, resource allocation cases and so on.

UNIT 3

1. Page 21, Objective 1: Replace “explain” with “employ”. No one has satisfactorily defined dignity but we can all recognize indignities and dignified behavior. It is the same with the concept “chair”; no one can define it but we can all recognize them and use them.
2. Page 22: Delete “agent” in line 1. We do not identify persons in terms of their agency for rationality, deliberation and so on, even though some philosophers like Peter Singer and John Harris think that we do. This is recognized later when people in persistent vegetative states are referred to but we can also think of severely retarded human beings for example.
3. Page 23: “The grapes of Wrath” might be a good film to illustrate lack of respect for human dignity and behaving with dignity at the same time.

UNIT 4

1. Page 28: This case of diabetes is repeated in Unit 6 (Page 37).
2. I recommend that the amputee case and the organ donor case be amplified.

UNIT 5

1. Objective 2: Delete "responsible" as autonomous persons might be risk takers or make silly decisions – they are free to do so.
2. Page 32: Similarly, delete the word "responsible" from the final paragraph.
3. We need some non-psychiatric cases. A case of refusal of treatment for religious or personal reasons like Case 5 in Unit 6 (Page 38-39) would do well.

UNIT 6

1. Page 37: case 2 has occurred in Unit 4 (Page 28).

UNIT 7

1. Page 46: We need more non-psychiatric examples. I recommend the Gillick case regarding children and gaining competence and the Susan Alzheimers case for substituted judgments.

UNIT 8

1. I recommend the insertion of a section on women as a vulnerable group.
2. Cases: Poverty and research incentives (Phase 1 trials and developing countries research). Each illustrate the idea of vulnerability and its correlative exploitation.

UNIT 9

1. Page 53, paragraph 6-c: Consent should be sought here.
2. Page 53, paragraph 6-g: Where there is patient consent, there is no breach of confidentiality.
3. Page 54, paragraph 7-b: What about the issue of epidemiological access to identifiable medical records for purposes of auditing or evaluating health intervention? This is a hot topic in many countries.

UNIT 10

1. Page 59, paragraph 4-c: Replace "equal" with "equitable" as the former is impossible and justice is served by the latter.
2. Resource allocation examples are needed here.

UNIT 11

1. Objective 1: Replace "explain" with "describe".

2. Include some cases where discrimination against groups is to be distinguished from stigmatization as when epileptics are barred from driving public service vehicles. Their defining condition constitutes a demerit for the role.
3. Some further cases are needed, for example, what about the inability to pay for health care as constituting negative discrimination, or psychiatric diagnoses barring people from certain professions.

UNIT 12

1. Page 68, paragraph 1-c-ii: Delete the word "correct" and replace with "important" or "relevant".
2. Page 68, paragraph 3-a-ii: This paragraph is very technical and jargon ridden. It would be challenging for philosophers who cannot agree on the definition of some of these terms.

UNIT 13

1. Cases needed: For example, pharmaceutical company provision of cheap AIDS drugs to South Africa: was this a case of solidarity or self-interest? And does it matter? – OR – Has the move of institutionalized mental patients into the community been a case of solidarity of something else?

UNIT 15

1. Excellent unit. Some rather long but well informed cases, some of which could be used to illustrate vulnerability and exploitation in the previous unit.

UNIT 16

1. Unit ok, but needs some filling out. Further examples might include nanotechnologies and global warming.

UNIT 17

1. This is a good unit but is a bit academic. Will it be client accessible?

WRITTEN COMMENTS BY MRS INDIRA NATH

GENERAL COMMENTS:

Excellent conceptual framework. Congratulations to the drafters. In countries like India, this document would be an excellent base from which a customized curriculum can be drafted to take the needs of the local ethos into account. India, being a pluralistic country, needs such a document. The case studies are very educative though more could be added, such as consent and euthanasia. Some suggestions for improvement:

1. There is a great deal of overlap in objectives and syllabus which may be corrected to make the curriculum crisper. If deliberate overlap was planned, then it needs to be stated.
2. A strong introduction on the aims, objectives and level of the target audience would aid the readers.
3. 51 objectives (page 4) are excessive and unlikely to be retained. Many of the objectives can be grouped under specific topics or combined [Rapporteur's Note: specific comments of groupings not included in view of the decision to remove these objectives from the Course Learning Objectives page]. Objectives 5, 33, 38 and 51 are tall orders in the context of this curriculum.
4. Research should be included as a separate objective/syllabus, covering issues such as reproductive technologies, consent, placebos, genetic information, and susceptibility to disease.
5. The gender issue needs to be brought in at many levels as it is basic to the value system adopted by societies. Females are vulnerable, not informed for consent, etc. in spite of legal support. Ethics falls between legal and moral principles and changes constantly. At present, in many societies females are vulnerable in disease, pregnancy and sometimes even before they are born as in female feticide common in two of the largest growing economies of India and China. Those practicing this are doctors who have sworn on the Hippocratic Oath. Those promoting it may be women such as mother-in-laws or mothers who do not wish to see the "girl" suffer as they did/do. This is not a local problem as Asians live everywhere with this strong bias. It is practiced in spite of good laws. Therefore, bioethics must address this basic concept of "right to life" and dignity when the doctor is still in the early "educative" phase.
6. Pluralism: the center of the universe may not be Europe. Eastern philosophies influence a quarter of the world and more from the rest of the world are joining those philosophies. Though all philosophies are based on "do no harm", there are differences in "when life begins" (affecting ethics of abortion, embryonic stem cell derivatives, etc.). In this globalized world, all thoughts percolate everywhere and therefore this should be included in the curriculum as (i) "comparative religions" are in Theology courses – this curriculum need not include them as religions but as "lifestyle" philosophies/practices; and (ii) it could also be reflected in "euthanasia".
7. Bioethics must be included in "Management Courses" of corporate offices as healthcare, stigmatizing diseases such as HIV, drug trials, advertising tobacco, etc. are being abused.
8. Some suggestions of references from India:
    a. Ethical Philosophies and India: I.C. Sharma, S. Nagin et al. Jullurdhaz 1966.
    b. Indian Council of Medical Research: Ethical guidelines, 2000.

c. Indian Council of Medical Research: Draft Curriculum of MPH on Bioethics.

UNIT 5

1. Paragraph 2-a: Cultural concepts of autonomy, gender bias and village bias could be included.
2. Case 1 and 2: Overlaps with Unit 6.

UNIT 6

1. More philosophies (Eastern) should be discussed, as well as the cultural concept of who has the responsibility for consent.
2. Research components should also be emphasized, such as placebos, incentives, genetic information, susceptibility to disease and reproductive technologies.
3. Outline of Syllabus, point 5-f: Gender bias should be included.
4. Page 37, paragraph 5-d: "Women in some societies" should be included.

UNIT 7

1. Outline of Syllabus, point 2: "Women bound by societal values" should be included.
2. Outline of Syllabus, point 5-d: "potential" should be replaced with "immediate" as potential cannot be predicted in the long term.
3. Outline of Syllabus, point 5: "Consent for placebo" should be included.
4. Teacher Manual, paragraph 1-b-iv: Women in some societies should be discussed.
5. Teacher Manual, paragraph 2-a-i-1: Role of placebo should be discussed.
6. Teacher Manual, paragraph 2-a-ii-1: "some women" should be added in the example.
7. Teacher Manual, paragraph 6-b: "as per national norms" should be added.

UNIT 9

1. Outline of Syllabus, point 1: "in the context of pluralism" should be added.

UNIT 10

1. Female feticide cases should be added.

UNIT 11

1. Introduce HIV, female infertility and disability as potential stigmas.

UNIT 12

1. Female feticide cases should be added.

WRITTEN COMMENTS BY MR ZOSIMO LEE

Community of Inquiry

One dimension that could help elaborate the philosophical deliberation and reflection on ethical issues would be the cultivation of what has been called the community of inquiry by Charles Sanders Peirce. Originally the term meant the community of scientists engaged in scientific inquiry, but later this enlarged to include those kinds of inquiry that were not only scientific. One of the characteristics of the community of inquiry is that there is sufficient openness to pluralism and tolerance of other views, specially the views of the minority. What might be important though, and this is not always easy to achieve, would the kind of facilitation or leadership within the inquiry process that is able to identify what may be the salient or important issues. The professor or the discussion leader could do this but there must be criteria for the eventual sharing with students why certain issues may be considered significant and/or ethical and others not. What was mentioned during the discussion today about the 'singularity' that marks a certain discussion can only really be appreciated after one has been able to go through the discussion or follow the flow of the discussion such that the crucial points or the 'turns' in the discussion are identified, experienced, appreciated and understood. What makes the community of inquiry important I think is that it should be a collective experience, all those involved in this discussion must be together in appreciating what is the value of what is being discussed, or must understand what is at issue more or less in the same way. Such that the turns and flow of the discussion is appreciated in the same way. There can then be a change in awareness, or consciousness of those involved in the discussed because they thought together, or the ideas being propounded by each participant is lived through by each one, and the qualitative achievement of the community is that their thinking evolved in the process of discussion. I think this way of considering the ethical deliberations in Bioethics can enrich the purpose then of the reflections, they improve the capacity to understand the complexity of the issues involved, offer a variety of perspectives, but it also enables the group as a whole to come to an understanding that would not have otherwise been possible without the active encounter with the issue as well as the views of others. The facilitator though has to synthesize the points of the discussion, as much as where the lacunae may be.

The Conception of Human Rights

Generally speaking there are two duties related with the conception of human rights: positive and negative duties. The observance of human rights conceived as positive and negative duties are directed to those who are responsible for responding to particular duties. Negative duties refer to the precepts: do not harm, do not oppress, respect human rights but in a passive sense. Positive duties are more pro-active in the sense that they are responses to the question, what are necessary in order that human rights are fulfilled? These refer to the institutional arrangements (law and legislation, social practices and behavior) that fulfill human rights fully. If I am to respond to my positive duties I must act in such a manner as to institutionalize the social and political arrangements that safeguard and guarantee that human rights are fulfilled.

Human rights should not be conceived only as boundaries, as safeguards against abuse, to serve as protections against violations, but can also be considered as criteria for the evaluation of social

institutions; whether they fulfill these rights. Actions of persons and institutions can also be evaluated whether they are contributory to the fulfillment of these rights. This conception of human rights as institutional criteria may especially be applicable to human rights that have to do with the institutional requirements for basic needs: education, health, water, food, etc.

Evaluation of the Core Curriculum

Following the intervention of Prof. Evans during the discussions that one of the ultimate goals of the Bioethics course is to get students to reflect on their practice, to view patients as central to medical practice, to become sensitive to the ethical dimensions of their cases, and that the core curriculum should provide the students with the experience and intellectual equipment to deal with ethical issues, the core curriculum can then be geared precisely with these criteria for evaluation in mind.

It is possible to have a pre-test and a post-test where students will be exposed to several cases and a five-item multiple choice questionnaire can be developed. The five-item multiple choice questionnaire can be constructed in such a manner that there will be gradations of sensitivity to either reflection or viewing patients as central, and becoming sensitive to the ethical dimensions as well.

One of the graduate students in Bioethics in the University of the Philippines program has developed such a questionnaire although the conceptual framework is based on Lawrence Kohlberg's levels of moral thinking, and could be revised to incorporate more of the attitudinal, rights- and principle-based framework of the core curriculum. The graduate student's questionnaire was aimed at the post-graduate interns, those who had gone through medical school and were in the internship program prior to choosing their specialization or residency. The tentative hypothesis was that there was a tendency for the interns to follow the directions of the senior medical faculty, including the residents, instead of relying on their own assessment and evaluation. As such, the medical practice tended to follow the standard procedures instead of responding to what might be the more sensitive, nuanced and appropriate responses to the case.

The point is that the core curriculum can already have an evaluation component, and the five-item questionnaire can be one such evaluation component.

WRITTEN COMMENTS BY MR CHRISTOPHE KWAMI DIKENOU

Module 1 Qu'est-ce que l'éthique?

P.7 Manuel de l'enseignant

1. Qu'est-ce qui est propre à l'éthique?

Il serait utile que les étudiants puissent situer les concepts éthiques de la Déclaration dans leur contexte historique. Par conséquent, il leur fait connaître l'histoire succincte de l'éthique philosophique.

Module 2 Qu'est-ce que la bioéthique?

3. Principes de bioéthique

P.18 Il serait utile d'aborder le principe 15: Protection de l'environnement de la biosphère et de la biodiversité. Montrer le lien entre environnement et santé humaine. Ce principe donne l'occasion de montrer la complémentarité des approches curative et préventive de la maladie. A voir les différentes pollutions des milieux urbains et ruraux dans les pays en développement, les médecins et professionnels de la santé devraient être les promoteurs de l'hygiène du milieu.

Module 4 Effets bénéfique et effets nocifs

P.27 (forme) Au lieu de : Si l'on examine plus avant la pratique des oins de santé, on s'aperçoit que certains…

Il faut plutôt écrire : L'examen poussé de la pratique des soins de santé révèle que certains…

Module 5 Autonomie et responsabilité individuelle

P.34 Objectifs d'apprentissage du module

(forme) Les étudiants devront être capables au lieu de Les étudiants devraient être capables

P.34 Manuel de l'enseignement

(a) (i) (forme) Les différents acceptations de la nation d'autonomie au lieu de Les différents niveaux (et notions) d'autonomie

P.35 2. La collaboration dans la prise de décisions en médecine

(forme) (b) Le prestataire de soins est un expert en médecine; le patient est libre de ses propres préférences…… au lieu de le patient est un expert pour ce qui est de ses propres préférences

Module 6 Consentement

P.44 Cas 12

(forme) (fin de l'avant dernière phrase)… il serait furieux qu'elle ne lui ai pas demandé son accord préalable au lieu de…. Il serait furieux qu'elle ne lui air pas demandé son accord au préalable

Module 7 Personnes dépourvues de la capacité de donner leur consentement

P.48 (ii) Enfants

(1)(forme)(la dernière phrase est difficile à comprendre)
La règle générale qui veut que … est une importante protection contre le manque de respect de l'autonomie

Module 9 Vie privée et confidentialité

P.59 Cas 5: Le chauffeur de car
(forme, ligne 7) De retour de son congé… en particulier au volant sur les routes de montagnes au lieu de De retour de son congé…. En particulier au volant, en particulier sur les routes de montagne.

Module 12 Respect de la diversité culturelle et du pluralisme

Objectifs d'apprentissage du module

P.71 Les étudiants devront être capables
(forme et fond) 2. d'expliquer le mot pluralisme et les raisons pour lesquelles le respect du principe de pluralisme est important dans le domaine de la bioéthique au lieu de d'expliquer…. lesquelles celui-ci est important dans le domaine de la bioéthique.

P.71 Après Plan du cours il manque Manuel de l'enseignant comme pour tous les autres modules

P.71 Matériels d'étude
1.(a)(i) Déclaration universelle de l'UNESCO sue la diversité culturelle (mettre culturelle en italique)

P.74 cas 3: Traitement inutile
(forme) Une femme âgée de 26 ans….dont elle ne sait pas comment s'en sortir ou se sortir (A vérifier)

Module 15 Partage des bienfaits

Objectifs d'apprentissage du module

P.88 (forme, phrase lourde)
Les étudiants devront être capables
1. de comprendre la nécessité de l'utilisation du savoir scientifique pour l'avènement d'un monde plus équitable, prospère et viable au lieu de comprendre la nécessité de faire en sorte que….

Module 17 Protection de l'environnement

P.109 Plan du cours signale bien (a) La relation entre bioéthique et problèmes environnementaux, mais dans le Manuel de 'l'enseignement ce point (a) n'est pas traité. Ce point est important. C'est là qu'on met en évidence les liens entre bioéthique mondiale, problèmes environnementaux et santé.

P.110 2. Les dimensions éthiques
Il y a une tendance qui fait la synthèse (ou met l'accent sur la complémentarité) de l'éthique de l'environnement anthropocentrique et l'éthique de l'environnement non anthropocentrique d'une part et de l'autre entre le Droit international des Droits de l'Homme et le Droit International de l'environnement, c'est l'holisme humaniste développé, théorisé par le philosophe américain Don E. MARRIETTA Jr.

Par conséquent pour équilibrer les points de vue il faut l'ajouter
a) Ethique de l'environnement anthropocentrique
b) Ethique de l'environnement non anthropocentrique
c) Ethique de l'environnement holistique et humaniste

P.112 4. Respect des savoirs traditionnels
Il faut dire quelques mots sue ce point en se référant aux textes des Nations Unies

WRITTEN COMMENTS BY MRS QIHENG HU

Part 1: Commented by a group of experts headed by Prof. Zhenzhen Li of Chinese Academy of Sciences

Our general opinion is: the Core Curriculum Version 1.0 is comprehensive and rich in its contents and reasonable in its structure.

The content includes eco-ethics, therapeutic ethics, clinical bio-ethics and is consistent to the principles determined in the "World bio-ethics and human-rights declaration". In each unit of the Curriculum discussion is provided together with case studies, so the curriculum is strong in the operability.

The Curriculum is very strong in its logical structure. Profound explanation is given from the basic definition of ethics and its methodology for discursion to the derivation and the basic principles of bioethics, the thorough explanation is given also for various fields of bioethics, so, in general the document owns very good hierarchy.

We would like to propose the following points that we consider worthwhile to be improved:

1. The therapeutic ethics is over dominating the content.

The therapeutic ethics is covered by 12 units of the 17 units of this Curriculum. The bioethics contains multiple fields and is not equals to the therapeutic ethics, although the latter is extremely important field. We consider that the audience of this Curriculum will not be only students of Medicinal Institutes but also from various fields related to bioethics, and we hope that the Curriculum would be a Course not exclusively for students of Medicinal Institutes only. We suggest to adjust its structure, strengthening contents for other branches of the bioethics, in particular, to enhance the case studies and discussion.

2. There is not enough attention paid to issues of the risks and social duties related with high technology.

High-tech risk and the social duty is two different but inter-related issues. The contemporary life-science and technology is one among the fields of the fastest development and the deepest impact to the human society during the past 50 years, and, at the same time, it is bringing serious social risks, this is a fact of common recognition. The Curriculum successfully focused in the 16th unit on issues related with, for example "re-plantation of organs", " food with modified genes" "gene interference for cells", etc., but, in general, it is not satisfactory to just touch upon without enough depth and scope the issues that are involving the advanced frontier of bioethics. The case-studies of this part contain only headers without concrete material. We suggest to:

1. Enrich the case study and the discussion;
2. Add contents on the high-tech risks envisagement and elusion, also the social duty related to the high-tech application.

3. Evident insufficiency in the discussion on the environment justice issue.

Justice is a core issue in the Ethics. The Curriculum contains extensive discussion on the relationship between patients and doctors which is essentially issue of justice and impartiality in all sectors excluding sectors 1, 2, 15, 16 and 17. The Curriculum successfully selected cases on this issue. Nevertheless, problem on justice and impartiality exists not merely in the relations between the doctors and patients, for example the environmental justice. On the issue of environmental justice the curriculum mostly touched only at the level of concept, showing the evident shortage on the case selection and discussion, even lack of any cases (in the 17th Sector). We strongly suggest to enhance the case study and discussion on this important topic.

4. The Europe-Centered tendency

As a Core Curriculum on the Bioethics which will be recommended by the United Nations, the audience should include not only students from developed countries but also that of vast under-developed areas and countries. Although the Curriculum did refer to the issues that developing countries are facing to, in particular, quite sufficient discussion on the issue of "benefit sharing", still behind all the analysis and considerations you can feel clearly the view angle and value judge of the developed countries. Some expression like " " pops out a Europe-centered tendency.

Our suggestion is:

1. In the culture diversity part pay more attention to the case study where the culture diversity may cause conflict,
2. Be more cautious in retouching and revising such kind of expressions like "Jesus".

Part 2: Comments provided by the group of experts headed by Prof. Yali Cong

General remarks:

This Core Curriculum is extremely useful and helpful for the life-science ethics teaching in China. In our country at recent time lectures on this discipline for university students are compiled by each teachers. The advantage of this Curriculum includes: rich in case-study and references, websites, references for teachers, and, more important, audio-video material will be available. Hopefully these materials could be available for us in the future. All these are lack in China at this stage. Additionally, there is very concrete arrangement for teaching hours, so it is operable and is almost ready for use.

Our comments and suggestions:

1. Lack of the discussion on concrete life-science ethical issues like the assistant procreation technology, euthanasia, organ re-plantation, deathwatch, induced abortion, etc.
2. More or less can be observed the theorization tendency.
3. Too many (51 items is listed) teaching goals are listed. Is it possible to focus on less in number but more influential topics, for example the topic of "informed agreement".
4. It is rich in references provided, hopefully the Curriculum could be more inclusive and concrete in content. At least for Chinese teachers it will be more suitable.

WRITTEN COMMENTS BY MRS MONICA SERRA

The initiative of a Bioethics Core Curriculum proposal is very important; there are many countries that do not have any program and could use this proposal as an example, or a guide. The idea of using the Principles of the Universal Declaration on Bioethics and Human Rights – UDBHR as basis for this program is a different, practical and interesting way of constructing the program. It is important to remind that the UDBHR was approved by all Member States; so, its Principles are recognized by them.

Some comments referring the proposal are presented below, listed according to the Program sequence.

I. Course Learning Objectives

There are too many specific objectives. In fact, they are objectives of the Units, and could be presented directly in the respective Units (Unit Learning Objectives). In this item, the specific Objectives should be reduced; the presented objectives could be resumed.

II. Core Curriculum Content

The Unit 1 – What is ethics? and Unit 2 – What is bioethics? are important to introduce the study of ethics and bioethics to the students. These Units present basic knowledge concerning ethics and bioethics, that are essential for the discussion of the other Units, that present the UDBHR Principles, and are more “applied units”.

Unit 1 respects different values. For example, at the Teacher Manual 1.b (page 8) there is a suggestion to “ask the students to provide examples” of different moral values. In the same Unit, the presentation of “an ethical method of reasoning” (page 9) is important. The presented method is very effective, and will be very helpful in the discussion of the cases presented in the other Units.

As this is a Bioethics Program proposal, it is important to present to the students, before discussing specific applied issues, knowledge about Bioethics – its history (the historical context of its appearance), the themes it deals with, etc.

As Unit 2 refers to Bioethics, in general, the cases should contemplate different themes.

As cases and movies are a very important kind of study material, they should be presented in all Units – and there are no examples in Unit 3 – Human Dignity and Human Rights. In this Unit, there is a lack of ethics in research.

Unit 4 – Benefit and harm - stresses clinical issues. Once again, it is necessary to stress also some ethics in research questions.

As Unit 5 - Autonomy and Individual Responsibility – deals with many different situations, the presented cases should illustrate different themes, and not only related to Psychiatry. Ethics in

research is an important issue that should be discussed in this Unit (that discusses mainly healthcare), as well as in Unit 6 – Consent. “The Sea Inside” and “”Million Dollar Baby” are movies that discuss euthanasia, and can illustrate reflections concerning Unit 5. The movie “Miss Evers’ Boys”, suggested in Unit 11, could also be presented in Unit 6. Other suggestions of movies to illustrate and promote a discussion of Units 5, 6 and 7 are: “The Constant Gardener”, “Extreme Measures”, “Control” and “The Island”.

Although the Article 7 UDBHR - Persons without the capacity to consent does expressly refer to research, in Unit 7 there are too few references to research – and there aren’t any cases at all concerning research (the three presented cases are clinical cases).

Concerning Units 5, 6 and 7, the given examples are mainly “western”. It would be interesting to comment other points of view, from other cultures. Research should be stressed in these Units.

Unit 8 – Respect for Human Vulnerability and Personal Integrity – deals with human vulnerability. Three different aspects of vulnerability are presented (item 1.b): biological, social and cultural. However, the vulnerability of populations and nations is not considered. To illustrate this Unit (and also Unit 10 – Equality, Justice and Equity), articles 29 and 30 of the Declaration of Helsinki VI can be discussed. Cases concerning HIV researches carried out in Africa can be presented. The movie “The Constant Gardener” is a suggestion for this Unit (it can also be used in Units 5, 6 and 10).

In Unit 9 – Privacy and Confidentiality – there are six medical cases presented in the study material (three concerning Psychiatry), and none concerning research.

The Unit Learning Objectives of Unit 10 should include research, and not only health care. Article 10 UDBHR does not only refer to health care – it can be applied in other areas. Examples to illustrate the study material were mentioned above.

The movie “Gattaca” is a suggestion for Unit 11 – Non-Discrimination and Non-Stigmatization. Cases of AIDS patients’ discrimination should be included in this Unit, as well as genetic discrimination.

The solidarity among nations, mainly in the relationship North-South, or developed-in development nations, could be discussed in Unit 13 – Solidarity and cooperation, as well as in Unit 15 – Sharing of Benefits. Cases concerning this theme could be presented. The discussion of Article 30 of the Declaration of Helsinki VI could also be presented for the discussion of Unit 15.

Cases 2, 3, 4 and 5 presented in the study material of Unit 16 – Protection of Future Generations are not developed, they only have a title, and no text or story at all.

There are no cases presented in Unit 17 – Protection of the environment, the biosphere and biodiversity. This is an important theme and, following the pattern of other Units, some cases should be presented.

III. Study Material – General Comments

The contents of the Study Material are a proposal for the teachers, and there is no obligation of using all the material. On the other hand, the professors are free to adopt other materials they have, concerning specific issues.

Some Units present more cases than others, and the same occurs with other types of study materials. But, in order to have a pattern, it would be interesting to have more or less the same quantity of Study Materials in the different Units. It is also important to clarify that some materials (as cases and movies), presented in one determined Unit, can be used in another Unit. For example, the movie “Miss Evers’ Boys”, presented in Unit 11- Non discrimination and non-stigmatization, is very useful to discuss issues of Unit 5 – Autonomy and individual responsibility, and Unit 6 – Consent.

The majority of the presented cases refer to clinical issues and dilemmas. Ethical questions in research are also very important, and should be presented.

CASE STUDY PROVIDED BY MR ABDALLAH DAAR

Near Lake Tanganyika

Abdallah S Daar

In a region near Lake Tanganyika lives the isolated Waluba tribe, which has the highest incidence of familial early-onset dementia in the world. For the past 10 years many people over the age of 35 have become affected by this virulent form of pre-senile dementia and have been unable to work.

The Waluba tribe, although isolated, was in the past fairly prosperous but this genetic disease has devastated the population and its economy. Their repeated calls to the government for medical help have produced no results and the medical facilities are totally inadequate to cope with this and the other common medical problems. There is also no clean water in the village and the one primary school building is in dire need of repairs.

A European company that wanted to study their genes had previously approached the tribe to do a study, but the tribe had refused to work with them.

The tribe was also worried that researchers would look for other genes that might affect the tribe negatively. They had heard of a gene that defined who was or was not a native Indian in North America and this had caused many problems for native Indian tribes.

Now a company from another European country, where a very similar condition has been found in several families, wants to study the Waluba to identify a gene mutation that might help the patients in that country and many other patients in other parts of the world. This European company had originally approached the tribe directly and was also rebuffed. Now the company is collaborating with the University of Dar-es-Salaam and they are jointly approaching the tribe through the Ministry of Health.

Questions.

1. Who in the community should the Ministry of Health officials talk to?
2. Does the chief of the Waluba, whose family is not affected by the disease, have the right to give or refuse permission for blood samples to be taken from members of the tribe?
3. Should the tribe specify how the data from the study should be handled? Should it put restrictions on any future use of the DNA not directly related to this study?
4. Should the tribe have the right to review the results of the study and have a say as to whether they should be published on not?
5. Should the tribe have the right to any intellectual property rights to any diagnostic or therapeutic products that might result from the study?