

UNESCO Headquarters
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November 1, 2014

Dear UNESCO Guideline Committee:

Thank you for the opportunity to provide input into the UNESCO Revision of the 1974 Recommendation on the Status of Scientific Researchers. Attached are suggested inclusions for the revised text, which focus on the ethical principles that ought to shape the relationship between science, the scientific researcher, and society.

As per the consensus from the 37th General Conference of UNESCO, the Revised Recommendation should pay due attention to the 1999 Declaration on Science and the Use of Scientific Knowledge, as well as the 2005 Universal Declaration on Bioethics and Human Rights. As such, we maintain that the substantive principles of justice and accountability ought to be firmly rooted in the Revised Recommendation. A consideration of these principles raise concerns about: 1) non-discrimination, 2) vulnerable populations, 3) the aim of science and technology, 4) biomaterials, 5) information sharing, and 6) risk management and harm prevention. We believe that attention to these issues will serve as a solid ethical foundation for the status of scientific researchers within a globalized and rapidly changing context.

We welcome opportunities to provide further input.

Sincerely,



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Summary of Recommendations

We advise that **justice** (understood as ‘justice as fairness’) and **accountability** (understood as ownership of actions and outcomes) ought to serve as foundational principles for the status of scientific researchers. These principles yield the following concerns:

I. JUSTICE

1. Non-Discrimination

- a) expand criteria for non-discrimination beyond what is in 1974 Recommendation to include (at minimum) ethnicity, gender, sexual orientation, age, and (dis)ability
- b) address positive discrimination and active recruitment of women and other underrepresented groups in science
- c) address discrimination and stigmatization of research participants and beneficiaries of science

2. Vulnerable Populations

- a) outline criteria for determining vulnerability
- b) outline measures for protecting vulnerable populations

3. The Aim of Science and Technology

- a) science should serve the common good, not the public interest
- b) common good should be defined in terms of international and global values
- c) address sharing of benefits of scientific activity

4. Biomaterials

- a) address whether providers are best viewed as participants, owners, or donors
- b) address transfer of biomaterials
- c) address access to and sharing of biomaterials
- d) address confidentiality of information with respect to biomaterials

II. ACCOUNTABILITY

1. Information Sharing

- a) research and funding structures should be transparent
- b) address privacy of persons and confidentiality of information gathered
- c) promote access to scientific information

2. Risk Management and Harm Prevention

- a) include and define the Precautionary Principle with reference to COMEST (2005) document
- b) discuss the interdisciplinary, interprofessional, international, and global governance of science
- c) address knowledgeable oversight of converging science

RECOMMENDATIONS

I. JUSTICE

Justice refers to a standard of ‘rightness,’ and provides the foundation for thinking about the rights and privileges, and obligations and duties of and towards scientific researchers. Justice concerns scientists, research subjects, and potential beneficiaries of science and technology.

4. Non-Discrimination. The 1974 Recommendation (Section III, 11(a)) makes reference to a commitment to non-discrimination with respect to education, training, and access to employment in scientific research. We think that the scope of discrimination ought to be broadened along three key dimensions.

First, the criteria for discrimination ought to be expanded. While the 1974 Recommendation lists among this criteria, “race, (colour), sex, language, religion, political or other opinion, national or social origin, economic condition.” We believe that the Revised Recommendation ought to also include, at minimum, gender, sexual orientation, age, and (dis)ability. Expanding the criteria for discrimination is consistent with Article 11 of the Declaration on Bioethics and Human Rights, which guards against discrimination on any grounds that violate human dignity, rights and fundamental freedoms. Refinements of this principle of non-discrimination can be made by reference to the 2014 Report of the IBC on the Principle of Non-discrimination and Non-stigmatization.

Second, the Revised Recommendation should address positive discrimination and other ways for nation states and institutions to actively encourage the participation in scientific activities and leadership by women. The Revised Recommendation should also address ways to encourage participation of members of other populations who are under-represented in scientific activities and leadership.

Third, the Revised Recommendation should address discrimination against potential research participants and beneficiaries of research. In addition, it should address the potential stigmatization of research participants. The Report of the IBC on the Principle of Non-discrimination and Non-stigmatization can serve as a useful guide.

2. Vulnerable Populations. The 1974 Recommendation makes no reference to vulnerable populations. First, the Revised Recommendation should, with reference to the 2013 IBC Report on the Principle of Respect for Human Vulnerability and Personal Integrity, outline criteria for determining vulnerability. Second, the Revised Recommendation should outline measures for protecting vulnerable populations affected by scientific activities and, in particular, for guarding against exploitation and providing

just access to the benefits of scientific activity.

3. The Aim of Science and Technology. The 1974 Recommendation makes reference to the “common welfare of mankind” and also to the “public interest.” These concepts are distinct. “Public interest” refers to the interests of the majority of the population. This conception risks marginalizing the interests of some (often, less powerful members of a population) in favour of the interests of the majority (or the more powerful). The “common welfare of mankind” (or, as we suggest it ought to be called, the “common good”) refers to the interests of all, impartially considered. First, we strongly suggest that the Revised Recommendation employ this second conception, namely “the common good” in describing the ultimate aim of science and technology.

Second, the 1974 Recommendation employs the notion of common good primarily in the context of individual nation states. We recommend it be defined in terms of international and global values. Further, the common good ought to also include considerations of the environment, non-human animals, ecosystems, future generations, and the planet as a whole; we maintain that scientific researchers (and the global community) have both positive and negative duties towards each of these. This is in accordance with Article 16 and Article 17 of the Declaration on Bioethics and Human Rights.

Third, in accordance with Article 15 of the Declaration on Bioethics, the benefits of scientific research ought to be shared equitably. The Revised Recommendation should pay due attention to this notion of benefits sharing, such that the results of scientific research and technology can serve to benefit all persons or nation states.

4. Biomaterials. There is no mention of biomaterials in the 1974 Recommendation. The Revised Recommendation should comment on the acquisition, ownership and/ or guardianship of biomaterials used in scientific research. First, it is imperative to address whether providers of biomaterials are best viewed as “research participants” (who can withdraw consent at any point in the process and thus, are effectively “owners” of their biomaterials) or as “donors” (who transfer guardianship or ownership of their biomaterials to the researcher or institution).

Second, it is important to consider what happens to biomaterials when they are transferred between researchers and facilities. Addressing these issues will help to define the rights and obligations of scientific researchers towards these biomaterials and their providers.

Third, the Revised Recommendation should address access to and sharing of biomaterials for scientific research. Finally, the use and transfer of biomaterials also raise concerns about the confidentiality of information gathered from biomaterials. Article 9 of the Universal Declaration on Bioethics and Human Rights (2005) requires the protection of privacy of persons and the confidentiality of their personal information. Respect for the

confidentiality of information is increasingly important given advancements in information technology.

II. ACCOUNTABILITY

The 1974 Recommendation requires that scientific researchers be accountable to the public in instances where the research they conduct is publicly funded. However, given that current scientific funding structures involve both public and private resources, we believe that “public accountability” is insufficient for ensuring that scientific research is conducted responsibly. We believe that “accountability” should be defined broadly to include both individual and collective ownership of actions and associated outcomes. In addition, “accountability” should capture concerns related to both public and private resources. Such accountability can be shared amongst various researchers, institutions, funding agencies, and governing bodies. Special consideration needs to be given to the status of research misconduct, as well as the distribution of moral responsibility for actions and outcomes. Ultimately, research which aims at the public good requires that scientific researchers, institutions, and governing bodies are accountable for scientific research.

1. Information sharing. First, we believe that the accountability of researchers, institutions, and governing bodies requires a degree of transparency, both with respect to the research conducted (including methodology and the disclosure of both positive and negative results) and also with respect to the funding structures that support scientific research. An emphasis on transparency is in accordance with strong advocacy for open information about research by projects, such as *All Trials*. Accountability and transparency are particularly important for promoting public trust in scientific researchers, research, and technologies.

Second, with respect to information sharing, scientific researchers ought to uphold and respect the privacy of persons involved as research subjects and confidentiality of the information gathered from them, in accordance with Article 9 of the Universal Declaration on Bioethics and Human Rights (2005).

Third, the Revised Recommendation should also comment on access to scientific information. In particular, revisions should address specific dissemination strategies of scientific information (discoveries, scientific methods, uses, consequences). Such dissemination practices are significant for a number of purposes: (1) to promote education, especially of young researchers (as per Article 23 of the 2005 Universal Declaration on Bioethics and Human Rights), (2) to permit public debate about the acceptability of scientific activity and its consequences (as per Article 40 of the 1999 Declaration on Science and the Use of Scientific Knowledge), and (3) to permit international cooperation (as per Article 25 of the 2005 Universal Declaration on Bioethics and Human Rights). In line with Articles 16, 24, and 35 of the Declaration on Science and the Use of Scientific

Knowledge (1999), dissemination strategies should be broad and non-discriminatory. As well, access should be open to permit information to flow readily to the public domain. Furthermore, the Recommendation should address and facilitate information sharing of science and technology between all nation states, especially with developing nation states.

2. Risk Management and Harm Prevention. Accountable and responsible research requires a way to manage the risks associated with scientific activities. The 1974 Recommendation makes some reference to risk (Section V, 29(a)), but we recommend that the Revised Recommendation ought to say more to guard against the possibility of harm to persons and their environment resulting from scientific activity, and to hold to account those engaged with scientific research. First, we suggest that reference to the Precautionary Principle be included in the Revised Recommendation. Given the controversial nature of formulating and interpreting the Precautionary Principle, the Revised Recommendation ought to provide a standard formulation of this principle. We believe that the working definition from the 2005 COMEST document on the Precautionary Principle provides a good starting point for a standard definition of the principle: “When human activities may lead to morally unacceptable harm that is scientifically plausible but uncertain, actions shall be taken to avoid or diminish that harm.” We do, however, think (1) that the scope of human activities ought to be narrowed to scientific activity, and (2) that the scope of victims of harm ought to be expanded to encompass both non-human animals and the environment. While the 2005 COMEST document references the need to reflect on the impact that science has on non-human animals and the environment, we believe that considerations of non-human animals and the environment ought to be made explicit in the Revised Recommendation’s formulation of the Precautionary Principle.

Second, given that the Precautionary Principle alone may be insufficient for preventing harms associated with scientific activities, we suggest that the inclusion of diverse perspectives can help to ensure accountability and strengthen support for the global governance of science.

Third, the convergence of technologies, such as Nanotech, Biotech, Information Technology and Cognitive Sciences (NBIC) suggests the need for interdisciplinary, interprofessional, and international oversight. Persons responsible for such oversight should be knowledgeable of both the discrete technologies involved, as well as of the unique interactions between these different technologies. Due attention should be paid to creating oversight in a way that minimizes conflict of interest and promotes objectivity in oversight.

In sum, we have outlined several ethical concerns that are grounded in the principles of justice and accountability. We believe that concerns discussed in this document are important to take into consideration when revising the 1974 Recommendation on the Status of Scientific Researchers.