



EuropaBio Core Ethical Values (CEV)

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**Dr. Erik Tambuyzer, Genzyme
Chair, Ethics Working Group
Past Chair and Member of the Board**



EuropaBio Core Ethical Values 2009 Background

- First set of CEV worked out and published in 1998!
- Review and update of 1998 CEV by EuropaBio Ethics Working Group as part of the Bioethics project was a substantial job:
 - 10 two hour teleconferences and 3 face-to face meetings
- Consensus text reviewed by external experts from academia, patient groups, law ...
- Comments discussed and where appropriate, taken into account by the EuropaBio Ethics Working Group for final consensus document
 - 11 drafts to Board presentation



EuropaBio Core Ethical Values 2009

General principles (1)

1. We are committed to the socially responsible use of biotechnology including genetic engineering, to improve the quality of life, to prevent, diagnose, treat and cure diseases, to improve the quality and quantity of food and feedstuffs, to produce chemicals and to clean up hazardous wastes.
2. We are committed to high ethical standards in the development and use of safe and effective products.
3. We develop and use biotechnology with respect for human dignity and human rights. We take steps to avoid misuse of our technologies.



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General principles (2)

4. We are committed to increasing understanding of biotechnology among all stakeholders including the public.
5. We are committed to an open, informed dialogue with all interested groups (stakeholders) about the ethical, social, environmental and economic aspects of biotechnology and its applications.
6. We communicate and share timely and appropriate information about biotechnology and its derived products and services in an accurate and balanced manner and within the legislative framework.



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General principles (3)

- We strive to innovate and to achieve sustainable solutions for society.** We give priority to health, safety and environmental protection when undertaking the research, development, manufacturing as well as in the distribution of our products and services.
- We support transparent product information** that enables informed consumer choice.
- We are committed to reduce, refine and replace (3R's) animal testing** as well as to develop and promote alternatives. We commit to the highest standards of well-being and to minimize pain and distress for the animals we use, and to use animals in our research only when scientifically necessary.



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General principles (4)

10. **We support the Biological Weapons Convention** banning development and use of biological weapons and will not undertake any research or other activities intended for use in developing, testing or producing such weapons.
11. **We support the principles embodied in the United Nations Convention on Biological Diversity (CBD)** to protect biological diversity including adherence to the principles of access and benefit sharing.
12. **We support the development of bio-preparedness** [to prepare for natural threats and biological warfare] including detection, prevention and bioremediation to support public health and security.
13. **We support cleaner industrial and municipal processes** through biotechnology.



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Healthcare (1)

14. We respect **codes of ethics of the healthcare professionals** who diagnose and treat disease and prescribe, dispense, and use our products or make use of our services whether in research, development or patient care.
15. We support the **principles of openness and transparency** in our relations with patients and patient groups, to respect and safeguard their independence. (See also: <http://www.europabio.org/patients.htm>)



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Healthcare (2)

16. We respect individual privacy and support the protection of the confidentiality of medical information, which includes genetic information.
17. We oppose the use or disclosure of individually identifiable medical information, without informed consent, unless required by law or by regulation to monitor the safety of our products.
18. We oppose any use or disclosure of medical information which could lead to intolerance or stigmatization.
19. We ensure within our responsibilities that the informed consent of all individuals participating in our clinical research programmes is adequately obtained. When individuals are unable to give their consent, it should be sought from their legally authorized representative.



EuropaBio Core Ethical Values (CEV) Healthcare (3)

20. We recognise and support the position that **severe, rare, as well as neglected diseases are public health priorities** and we take our shared responsibility in these areas seriously.
21. We **oppose the use of cloning technologies** to reproduce human beings.
22. We are **committed to ethical research on different types of stem cells**. We support carefully considered embryonic or hybrid stem cell research in order to advance knowledge in biomedicine and its applications in healthcare within the legislative framework of each country.



EuropaBio Core Ethical Values 2009 Healthcare (4)

23. We support the compensation of human tissue donors only for their expenses and inconvenience, when appropriate.
24. We support the identification and relevant disclosure of information relating to (perceived or real) conflicts of interest including financial ones. Conflicts of interest should be avoided, wherever and to the extent possible. When they cannot be avoided these conflicts should be managed so that they neither compromise the safety or well being of patients and consumers nor data integrity.



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Healthcare (5)

25. We **support the timely posting of clinical trials** and making the results of such clinical research publicly available in a timely fashion regardless of its outcome also in order to prevent unnecessary repetition of clinical trials.
26. We **support the current bans on human germ line gene therapy.**
27. We **support the provision of applicable information and/or counseling to patients** prior to and after genetic testing.
28. We **condemn the abuse of medicinal products to enhance athletic performance.**



EuropaBio Core Ethical Values (CEV) Healthcare (6)

29. We support the principles contained in **relevant international declarations** such as those listed hereunder, but not limited hereto:

- **The Declaration of Helsinki** - Ethical Principles for Medical Research Involving Human Subjects (World Medical Association)
- **The Universal Declaration on Bioethics and Human Rights** and its additional protocols (UNESCO)
- **Convention for the protection of Human Rights and dignity of the human being** with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine and its Additional Protocols: (Council of Europe)
- **The Universal Declaration on the Human Genome and Human Rights** (UNESCO)



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Agriculture, food, feed, industrial biotechnology & the environment

30. We **support improvements in the quality and accessibility of agricultural products**, in order to enhance the world's food, feedstuff and industrial raw materials and renewable energy supplies.

31. We **promote efficient and sustainable agriculture and support new biotechnological developments**, which offer additional opportunities for plant breeders and farmers to grow, protect and improve their crops and to use natural resources more effectively.

32. We **support the sustainable use of plant material** for production of bio-based products and of biomass.



EuropaBio Core Ethical Values Next Steps?

“These values should be integrated into every biotech company’s daily work” leading biotech company CEO

- *Making sure these are distributed and read by company member employees*
- *Use these CEV as a beacon and reference*
- *Repeating what we said in 1998: Bioethics = Long term marketing*



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Willy De Greef
Secretary General, EuropaBio



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Special thanks !

**Expert reviewers & the EuropaBio Bioethics
working group members**



EuropaBio Core Ethical Values (CEV) Expert Reviewers

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More information:

http://www.europabio.org/ethics_and_dialogue.htm

Thank you for your attention!

