

Mintegia / Workshop
*I. Jornada de bioética y
cultura científica*



Timetable

- 9:30-10:00 *Autonomy and bioethics* Antonio Casado (UPV/EHU)
- 10:00-11:00 *Cultura y cambio climático* Thomas Heyd (University of Victoria, Canada)
- 11:00-11:30 *Coffee-break*
- 11:30-12:15 *The social creation of ethical imperatives in collaborative scientific networks* Catherine Heeney & Michael Parker (ETHOX, Oxford Univ.)
- 12:15-13:00 *El papel de la ingeniería de sistemas en el primer banco informático de secuencias de ADN, 1980-93* Miguel García-Sancho (Instituto de Filosofía, CCHS, CSIC)
- 13:00-14:00 *Preguntas y discusión / Galderak eta eztabaida*
- *Keep in mind this is a workshop, an opportunity to discuss on-going research between all participants (questions and comments are always welcome)*

Autonomy and bioethics

Antonio Casado da Rocha

Autonomy in biology

- Etxeberria, A. & Moreno, A. (2007), “La idea de autonomía en biología”, *Logos* 40: 21-37.
- Moreno, A., Etxeberria, A. & Umerez, J. (2008), “The autonomy of biological individuals and artificial models,” *BioSystems* 91(2): 309-319.

Bioethics in a wide sense

- “science of survival”
 - POTTER, V. R. (1970) Bioethics, science of survival. *Perspectives in Biology and Medicine*, 14: 127-53.
 - a bridge between science and the humanities
 - need to link what he came to realize had become mainstream biomedical ethics with environmental ethics
- Environmental ethics
- Health care ethics
- Research ethics

Autonomy and environmental ethics

- Could “recognizing the autonomy of nature” provide a philosophical basis for environmental ethics?
- Analogy argument: recognizing X as autonomous - recognizing X has intrinsic (non instrumental) value
 - Heyd, T., ed. (2005) *Recognizing the autonomy of nature: theory and practice*. New York: Columbia University Press.

Autonomy and health care ethics

- Not only decisional: executive and informative concepts of autonomy are also important
 - Casado, A. 2009. Towards a Comprehensive Concept of Patient Autonomy. *The American Journal of Bioethics* 9(2): 37-38.
- Better to frame *autonomy* and *paternalism* in ways other than a tension of opposing, irreconcilable principles
 - Nys, T., Denier, Y., Vandeveldde, T. (eds.): 2007, *Autonomy and Paternalism. Reflections on the Theory and Practice of Health Care*. Leuven: Peeters

Autonomy and research ethics

- Informed consent
- “In any research on human beings, each potential subject must be adequately informed of the aims, [...] the anticipated benefits and potential risks of the study and the discomfort it may entail.” (*Declaration of Helsinki*, art. 22)
- The IC problem with biobanks

Biobanking in Europe

- Very limited role played by a small number of ‘formal’ regulatory actors related to biobanking in some way
 - They favour cooperative strategies, negotiated bargaining, and implicit reliance upon systemic symbiosis
- Greater role played by many ‘informal’ stakeholders
 - They actively compete for power and dominance, producing guidelines and other recommendation documents (which frequently overlap and are mutually inconsistent), setting standards, commissioning research, educating professionals, etc.
- The same could be said of other European countries!
 - J. Kaye & S. M. C. Gibbons. 2008. Mapping the regulatory space for genetic databases and biobanks in England and Wales. *Medical Law International*, 2008, Vol. 9, pp. 111-130

Scientific culture

- Role of TV in medical education
- Role of metaphors: “genetic information” (García-Sancho) and the like
- Public understanding of science
- “PEALS aims to research, inform and improve policy, professional practice and public participation in the life sciences.”

www.ncl.ac.uk/peals/

- Bioethics for lay people
 - www.dilemata.net

Thomas Heyd

- Catedrático en el Departamento de Filosofía de la Universidad de Victoria (British Columbia, Canada). Sus libros incluyen:
 - *Encountering Nature: Toward an Environmental Culture* (Ashgate Publishing, 2007).
 - *Recognizing the Autonomy of Nature* (Columbia University Press, October 2005).
 - *Environmental Consciousness and Action* (Bonn: Ministry of the Environment, Germany, 1996; Analyse der Bedingungen für die Transformation von Umweltbewusstsein in Umweltschonendes Verhalten; with W. Schluchter, G. Dahm, U. Elger, E. Holzer).
- Artículos en castellano:
 - 'Saber tradicional, ética de la tierra y sustentabilidad', *Isegoría: Revista de Filosofía Moral y Política*, No. 32 (June 2005), 175-83.

Catherine Heeney

- Dctora en sociología e investigadora en ETHOX, un centro especializado en ética de la Universidad de Oxford.
- Su especialidad son los aspectos éticos y sociales de los biobancos, materia en la que ha participado en varios grupos de investigación. Sus publicaciones incluyen:
 - Susan M C Gibbons, Kaye J, Andrew Smart, Catherine Heeney, Michael Parker, 'Governing Genetic Databases: Challenges facing Research Regulation and Practice' *Journal of Law & Society* (2007) 34(2)
 - Perri 6, C Bellamy, C Raab, A Warren and C Heeney, 'Institutional Shaping of Interagency Working: Managing Tensions between Collaborative Working and Client Confidentiality' (2006) 17 *Journal of Public Administration Research and Theory* 405
 - Weigand, H. & Heeney, C. (2003), 'Privacy protection and communicative respect, In Weigand, H. Goldkuhl, G. & Moor, A. de (Ed.), *Proceedings of the 8th International Working Conference on the Language-Action Perspective on Communication Modelling* (LAP 2003). (pp. 71-84). Tilburg: Tilburg University Press.

Miguel Garcia-Sancho

- Doctor en filosofía e investigador en el Centro de Humanidades y CC. Sociales del CSIC en Madrid. Tras su doctorado en el Imperial College's Centre for the History of Science, Technology and Medicine (Londres) ha publicado numerosos trabajos sobre la historia de la genética, entre los que destacan:
 - 'The rise and fall of the ideal of genetic information (1948-2006)'. *Genomics, Society and Policy*, vol. 2 (3), 2007
 - 'Mapping and sequencing information: the social context for the genomics revolution.' *Endeavour*, vol. 31(1), 2007.