Bioethics™
Life, Politics, Economics
edited by Joanna Zylinska

Introduction: Bioethical Mutations in the Age of Capital

Bioethics is a serious business, in every sense of the word. A sub-domain of philosophy which deals with issues concerning life and health, it has to arbitrate not only over practical matters regarding patient care and medical experiments, but also over the very ontology of ‘life’: its manufacturing, patenting and redefinition in and by the biotech industry. Since bioethics functions as a node in the complex nexus of social, political and economic forces, it is perhaps not surprising that technocapitalism does not want to leave it just to philosophers. Instead, it mobilises a whole army of experts: morality salespeople, ethics technicians, value mathematicians, to help us decide on the price of life. Consequently, bioethics increasingly abandons its more
daring ambitions and responsibilities -- such as exploring the metaphysics of life or the politics of everyday survival -- to serve instead as just a ‘technical discourse about values clarification and choice’ (Haraway, 2007: 109). Its methods of working are thus principally procedural, akin to ‘facts and hypothesis testing’ in science (Haraway, 2007: 109). Feminist thinker Donna Haraway points out that medical ethics ‘is now a literal industry, funded directly by the new developments in technoscience. Ethics experts have become an indispensable part of the apparatus of technoscience-production’ (2007: 109). To put it crudely, bioethics’ role is often to get biotech corporations off the hook -- although, of course, it has the potential to be much more than that. Indeed, in its engagement with life in both a metaphysical and material sense, bioethics is conceivably one of the most exciting areas of philosophical interrogation and artistic experimentation today.

Designed as a supplement to my 2009 book, *Bioethics in the Age of New Media* -- which explores and experiments with some alternatives within and for bioethics -- this living book, *Bioethics™: Life, Politics, Economics*, is to act as a warning against the foreclosure of the aforementioned potential by casting light on the increasing marketisation of both life and bioethics under late capitalism. Performed as a form of ‘mutation’, the introduction presented here outlines an academic-artistic method for *reading and writing as genetic recombination*, which can perhaps be seen as a biotech-era take on Roland Barthes’ ‘From Work to Text’. The text below is thus a product of the cross-fertilisation of all the sources that feature in the *Bioethics™* book: between one and four sentences have
been taken from each article and spliced to form a unified whole. The structure of individual sentences has been retained most of the time, and indication has been given whenever sentences have been split. No foreign material has been added to the mix. Phenotypically resembling a standard academic essay, yet referenced in a less conventional way by a series of direct links (although a full page of Attributions is also available here), the text below is an experiment in textual and conceptual hybridisation. Its main function is to foreground the questions of crossing over, intellectual property, political economy and the ethics and politics of academic research that are the topic of this particular living book, and of the Living Books project as a whole -- but it may also of course develop a life of its own...

Today, the pharmaceutical industry has settled comfortably into its place as the most profitable business in America. The media hoopla surrounding the sequencing of Watson’s genome has already had some commentators worrying that genome sequencing could become the next must-have for the rich and privileged.... However, beyond the publicity, it is only a matter of time until genome sequencing will be affordable for most people. Once it becomes commonplace, it will generate an enormous quantity of sequence data from a wide range of humans that could benefit biomedical research and drug development. More importantly, a ‘thousand-dollar genome’ could become an important tool to realize personalized medicine: perfectly tailoring diagnostics and treatments to a patient’s genetic make-up. (T)he emergence of an autonomous health industry establishes a potential structural problem for capitalism: insofar as the growth
of the health industry depends on ‘people becoming more sick,’ its growth seems to be in tension with the growth of other sectors of the economy. The solution to this structural problem is the creation of ‘surplus health,’ or that ‘proportion of health unnecessary for maintaining one’s capacity as a worker’... Preventive medicine is especially well suited for the creation of surplus health, for by enabling the diagnostic identification, and pharmaceutical management, of ‘risk factors’ for diseases, rather than simply the diseases themselves, it becomes possible to expand markets for diagnostics and medication, without at the same time reducing an individual’s capacity for labor.

Over the past half-century, American doctors have begun to use the tools of medicine not merely to make sick people better but to make well people better than well. But does making small normal children bigger also make them better? That is the fundamental and simplistic question underpinning the use of GH (growth hormone) in ‘idiopathic’ short stature. Just when it seemed that eugenics could not return to the forefront of the social arena, it appears once again, although its spectacle has been modified to suit the times. Eugenics, at least on the surface, is only implicitly attached to issues of race improvement or gene pool cleansing. Now it hides under the authority of medical progress and the decoding of nature.

The pharmaceutical industry influences psychiatrists to prescribe psychoactive drugs even for categories of patients in whom the drugs have not been found safe and effective. What should be of greatest concern for Americans is the astonishing rise in the diagnosis and treatment of mental illness in children, sometimes as young as two years old. These children are often treated
with drugs that were never approved by the FDA for use in this age group and have serious side effects.... Ten percent of ten-year-old boys now take daily stimulants for ADHD -- ‘attention deficit/hyperactivity disorder’ -- and 500,000 children take antipsychotic drugs. (I)ndustry uses ghostwriters to insert marketing messages into articles published in medical journals. (O)pen-ended activities such as ‘unrestricted’ research grants, ‘educational’ grants, membership in speakers’ bureaus and advisory panels, consultancies, and stock-holding could be of greater concern, through an insidious blurring of professional boundaries and obligations. There is evidence that these types of ties are common among specialist physicians.

The true purpose of a drug trial is not always obvious. Medical trials are not always conducted to test the drug -- sometimes it’s to seed the market. (R)esearch on humans has become a commercial enterprise. Most clinical trials have moved from academic settings to specialized contract research organizations (CROs), which contract with the pharmaceutical and biotechnology industries. Reports suggest finder’s fees ranging between $2,000 and $5,000 per patient are common, although it is not always easy to distinguish the reward for the recruitment of patients from remuneration for clinical activities that are part of the research. Few would argue that patients in trials should be treated as commodities, but patients have become de facto market products, while ‘market controls’ are neither clear nor sufficiently stringent.

In North America today..., where medical research happily converges with consumer capitalism, even bioethicists believe that the market ultimately works for justice. Ethical issues are a growing concern for
companies, in the wake of a series of corporate governance scandals and the accompanying sharp decline in societal and investor trust in firms. Some companies have responded to these concerns by creating internal ethics programs. (E)thics is an asset that firms can trade upon. Firms are considering ethics as central not only to their research activities and the dissemination of their products to consumers, but also to the reputation and branding of the company itself. (M)anufacturers were reported to demonstrate awareness of existing regulations and engage in strategic behaviors to work around them (e.g., by giving employees lectures about the regulatory environment that were understood to be a smokescreen) or to mask their violations of the law (e.g., by encouraging employees to not enter off-label marketing calls in their logs).

How do we resolve moral and bioethical issues provoked by ‘patenting life’? When do these issues concern the technology itself, such as concerns over stem cell research, and when do they concern the grant or ownership of exclusive patent rights over isolated chemical structures such as nucleotide sequences? (S)ynthetic biology presents a particularly revealing example of a difficulty that the law has frequently faced over the last 30 years -- the assimilation of a new technology into the conceptual limits posed by existing intellectual property rights. Historically, the signal achievement of bioethics was its development of practices, procedures and principles calibrated to specific problems (protection of human subjects in research, issues of justice, the need for bureaucratic norms for health care, etc.). The founders of both American and European bioethics were keenly aware that this calibration of a mode of ethics and problems,
in turn, entailed the construction of specific new venues (e.g. IRBs (Institutional Review Boards, aka independent research committees)), distinct modes of collaboration (e.g. advisory government commissions), and particular types of inquiry (e.g. the rise of bioethics as a discipline). ... it seems not only appropriate -- but scientifically and ethically mandatory -- to consider in what ways these bioethical practices and venues remain adequate to current conditions, and in what way they require augmentation.

Bioethics today has to deal not just with questions of the transformation of life on a biological level -- via genomics, DNA sequencing, cloning, and so forth -- but also with life situated in a broader political context, through questions of the financing of the biotechnological industry, of the database management of the immigration and asylum systems, of the normativity of cosmetic surgery, of national and cellular surveillance, of biocitizenship, etc. (Also, today, the global life expectancy gap is the widest in human history, with a disparity of nearly five decades. The division of the world into organ buyers and sellers is a medical, social, and moral tragedy of immense and not yet fully recognized proportions. Our reluctance to address the issue of whether our body (or parts thereof) is in fact property has resulted in ambiguous organ donation frameworks. Many of the concerns raised ... regarding the directed donation of organs hinge on the question whether transplantable organs should be considered personal property or a societal resource. (M)any proponents of a commercialization of organ procurement state that there is nothing wrong with commodification. Premising Locke’s idea that everyone is the rightful owner of his person and faculties, especially some liberals derive a specific conception of
‘self-ownership’ which entails that ‘each person is free to do with his body whatever he chooses so long as he does not cause or threaten any harm to non-consenting others’. Since most people tend to associate ownership with the right to alienation, this conception also encompasses the freedom to sell parts of one’s body. This line of thought seems to presuppose that the self can act as an autonomous authority disposing over its body like over some kind of property.

(The) preeminence of autonomy as an ethical value within bioethics is deeply related to the increasing commoditization of medicine in developed countries. For the more that medical practices are justified by reference to patient choice, the more that patients will be viewed as ‘clients’ and health care professionals perceived as ‘service providers’. This model of patient as ‘client’, which is prevalent in the United States of America and some parts of the western world, assumes affluence and power: the (literate) patient has to be capable of understanding and rationally weighing his/her options -- possibly even in disagreement with the physician -- and be in a position to pay in exchange for services chosen. The challenge facing bioethics in resource-poor settings is not then to mislead people with unrealistic promises of autonomy that very few people can indeed achieve, but to articulate moral principles and societal values that are oriented around the promotion of equitable access to care and which broaden the goals of medicine and public health.

(C)ritical artists, whose art work has been exhibited in thematic shows about biotech, are ‘fig leaves’. Vested interests require an appearance of actual debate concerning these technologies’ developments. The stage has been prepared for the next phase of the
implementation of such technologies. Is there a continuity between the ways of looking which are fetishized in laboratories, the complacent viewing of art appreciators and the voyeuristic thrill of surveillance TV as low-brow entertainment? Are the subjects of study also the objects of desire? Or, are they subjects of ridicule and objects for control’s sake? ... Is it possible that reflections on being a person trying to retain what it means to be human while under the observation of the whole of society has any redeeming social value or is it just a currently accepted form of pornography?

References


Articles

The Business of Bioethics

Carl Elliott
American Bioscience Meets the American Dream

Jocelyn E. Mackie, Andrew D. Taylor, David L. Finegold, Abdallah S. Daar, Peter A. Singer
Lessons on Ethical Decision Making from the Bioscience Industry

Carlos Novas
What Is the Bioscience Industry Doing to Address the Ethical Issues It Faces?

Ezekiel J Emanuel, Trudo Lemmens, Carl Elliott
Should Society Allow Research Ethics Boards to Be Run As For-Profit Enterprises?

The Commercialization of Medical Research and Patient Care

T Lemmens, PB Miller
Regulating the Market in Human Research Participants

Aaron S. Kesselheim, Michelle M. Mello, David M. Studdert
Strategies and Practices in Off-Label Marketing of Pharmaceuticals: A Retrospective Analysis of Whistleblower Complaints

Adriane J. Fugh-Berman
The Haunting of Medical Journals: How Ghostwriting Sold “HRT”
Ben Goldacre
The True Purpose of a Drug Trial Is Not Always Obvious

Marcia Angell
The Epidemic of Mental Illness: Why? and The Illusions of Psychiatry

David Henry
Doctors and Drug Companies: Still Cozy after All These Years

**Biomanufacturing and Biopatenting**

Antony Taubman
The International Patent System and Biomedical Research: Reconciling Aspiration, Policy and Practice

Arti Rai, James Boyle
Synthetic Biology: Caught between Property Rights, the Public Domain, and the Commons

Paul Rabinow, Gaymon Bennett
Synthetic Biology: Ethical Ramifications 2009

D G Gill
“Anything you can do, I can do bigger?”: The Ethics and Equity of Growth Hormone for Small Normal Children

Joanna Zylinska
Playing God, Playing Adam: The Politics and Ethics of Enhancement

**The Body as Property, Commodity and Gift**

Tarif Bakdash, Nancy Scheper-Hughes
Is It Ethical for Patients with Renal Disease to Purchase Kidneys from the World's Poor?
Mark Schweda, Silke Schicktanz
The "spare parts person"? Conceptions of the Human Body and Their Implications for Public Attitudes towards Organ Donation and Organ Sale

Antonia J Cronin, David Price
Directed Organ Donation: Is the Donor the Owner?

Howard Wolinsky
The Thousand-Dollar Genome. Genetic Brinkmanship or Personalized Medicine?

Global Health Inc.

Robert Mitchell, Catherine Waldby
National Biobanks: Clinical Labor, Risk Production, and the Creation of Biovalue

Kammerle Schneider, Laurie Garrett
The End of the Era of Generosity? Global Health amid Economic Crisis

Jacquineau Azétsop, Stuart Rennie
Principlism, Medical Individualism, and Health Promotion in Resource-poor Countries: Can Autonomy-based Bioethics Promote Social Justice and Population Health?

Stuart Rennie, Bavon Mupenda
Living Apart Together: Reflections on Bioethics, Global Inequality and Social Justice

The Art of Life Between Speculation and Appreciation

Ionat Zurr, Oron Catts
Big Pigs, Small Wings: On Genohype and Artistic Autonomy
Adam Zaretsky
The Workhorse Zoo Art and Bioethics Quiz

Critical Art Ensemble
The Flesh Machine

Joanna Zylinska
If It Reads, It Bleeds; 3' video, 2010
Attributions


Mackie, J. E. et al. (2006) ‘Lessons on Ethical Decision Making from the Bioscience Industry’, PLoS Medicine, 3(5): e129, April 4. http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0030129 Licence: © 2006 Mackie et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Novas, C. (2006) ‘What Is the Bioscience Industry Doing to Address the Ethical Issues It Faces?’, PLoS Medicine, 3(5): e142, April 4. http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0030142 Licence: © 2006 Carlos Novas. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0030309  
Licence: © 2006 Lemmens and Miller. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000431  
Licence: © 2011 Kesselheim et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.


Henry, D. (2010) ‘Doctors and Drug Companies: Still Cozy after All These Years’, PLoS Medicine, 7(11): e1000359, November 2. http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000359 Licence: © 2010 David Henry. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any
medium, provided the original author and source are credited.


http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0030349 Licence: © 2006 Bakdash and Scheper-Hughes. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

http://www.peh-med.com/content/4/1/4 Licence: © 2009 Schweda and Schicktanz; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction
in any medium, provided the original work is properly cited.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2948558/
Licence: Author manuscript. Published in final edited form as: Clin Ethics. 2008 September 1; 3(3): 127–131.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2002559

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2879701

http://www.peh-med.com/content/4/1/1
Licence: © 2009 Schneider and Garrett; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which
permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Licence: © 2010 Azétsop and Rennie; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Licence: © 2008 Rennie and Mupenda; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

http://www.culturemachine.net/index.php/cm/article/view/30/37

Zaretsky, Adam, ‘The Workhorse Zoo Art and Bioethics Quiz’
Link to Adam Zaretsky’s website: http://emutagen.com/wrkhzoo.html

http://www.critical-art.net/books/flesh/
Licence: Autonomedia. This book may be freely pirated and quoted. The authors and publisher, however, would like to be so informed.

Zylinska, J. (2010) *If It Reads, It Bleeds*; 3' video
Licence: © Joanna Zylinska; courtesy of Joanna Zylinska