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Comparing Biobanks: Towards a New Form of Biopolitics?

prepared for the International Comparison of IHTs Workshop, Rome, June 20-21, 2005

Biobanks

Biobanks are collections of human biological material within the health care system and the medical sciences



Iceland's deCODE Genetics

Biobanks

- "traditional": key themes
 - ethics and bioethics
 - biobanks as a rights issue
- my approach: biobanks as sites to study new aspects of the ever closer interrelationship between life and politics
 - how do life and politics interact?
 - how do they transform each other?
- biobanks as heterogeneous, biopolitical strategies that combine "old" and "new" modes of biopolitics in a flexible way

Biopolitics

M. Foucault:

from the primacy of sovereignty, law and coercion or force "to take life" to the development of new forms of power constitutive of life

two strategies:

- disciplining the body and
- regulating populations



"Old" Version of Biopolitics

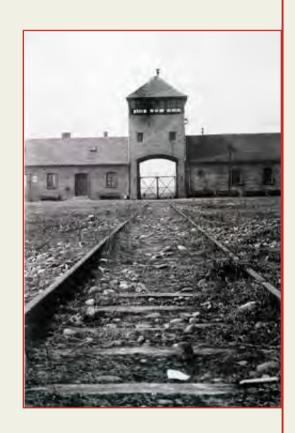
- (1) State-centered: state as central biopolitical actor
- (2) Body-Centered: the locus of intervention was the human body, conceived as a coherent, whole entity
- (3) Discipline-Centered: panopticism as the essence of social control
- (4) Nation and Population centered: bodies were territorialized in the context of the modern nation state
- (5) War-centered

"Old" version of Biopolitics

(6) State of exception & Bare Life

G. Agamben:

- the sovereign decision of excluding people from the realm of the law by stripping them off their rights, remains a constitutive feature of contemporary state power
- "Bare life", the reduction of certain articulations of life as lacking individual and political rights, as the most intimate link to sovereignty





Biobanks & Biopolitics

- Body surveillance in the context of the developments of contemporary life sciences means something distinctly different than in earlier times
 - with respect to surveillance
 - with respect to bodies
 - with respect to the shaping of infrastructure of surveillance and monitoring



Biobanks - what they are

- Biobanks grew out of the history of medicine, but achieve new meanings in contexts of 21st century life science development
- two large types of biobanks are distinguished in the literature
 - biobanks that are based on biological specimens from patients or donors
 - population-based research biobanks that are based on biological samples from (parts of) the general population with or without disease
- the emerging landscape of biobanks is not a phenomenon of local interest; rather the creation of world-wide biobanks networks and cooperation is framed as a crucial step in rebuilding the genomics/postgenomics apparatus

Biobanks & Policy Visions

- new possibilities for
 - health research
 - knowledge production
 - understanding of causes, progression, prognosis and treatment of different diseases (Berg 2001)
- development of preventive, genetic and "personalized" medicine:
 - biobank projects as "implementation" of the idea of "personalized medicine", understood as the development of new, "tailored" drugs



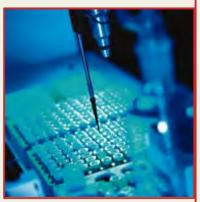


- (1) <u>Decorporalization</u>, <u>Molecularization</u>, <u>Informatization</u>
- biobanks seem to indicate the reinforced tendency of decorporalization in modern biopolitics (Brown & Webster 2004)

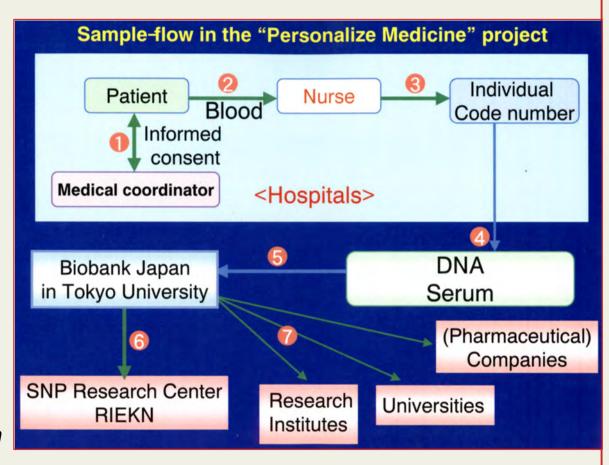
The body of biobanks is a body split into systems and collections of blood, proteins, serums, genes and SNPs

- they obtain value on their own
- they do not represent other bodies, but form their own bodies
- "Politics of Disappearing Bodies"









Biobank Japan

Molecularization & Informatization as precondition of decorporalization

- Molecular biological approaches
- advances in computer and information sciences
- convergence of these two domains has also



led to a fundamental reconceputalization of health and disease in medical discourse



(2) From macro-steering to micro-steering

- Biobanks promise a new and systematic approach towards disease and drug development
 - they promise to predict the likelihood that an individual would develop a disease so that pharmaceutical drugs could be used to prevent its onset rather than resorting to treating the symptoms
 - Lifestyle advice targeted to those "genetically susceptible"
 - biobank policies would constitute a major effort in establishing a preventive and "much more costefficient" approach towards medicine

- <u>"background":</u> fundamental change in current health policy practices and disciplinary transformations in medical research
- shift of the burden of health responsibility from macro-actors such as the state to the individual level
 - health is increasingly discussed in terms of "self-control" and an ethics of health
 - concentration has moved from "society as a whole" to "risky individuals" and to "risk groups" (Rose 2001)



- Rise of new actors
- gradual establishment of a regime of appropriation via patenting
- Today, we observe in health and medical policy a tendency of the state pulling out of financing and decision-making, and new actors, ranging from health-care providers, patient groups, citizen groups, and private companies moving into the center of health and medical policy decision-making.

Island: deCode registered in the US



the Estonian Genome Project is funded by the private company EGeen



the private non-profit sector patient organization,
Association Française contre les Myopathies (AFM) is
identifiable as the major actor in the field of
biobanking





- (3) contemporary biopolitics is always a politics of biovalue
- Catherine Waldby: "the surplus of in vitro vitality produced by the biotechnical reformulation of living processes " (Waldby 2000; 2002)
 - Tissues can be leveraged biotechnically so that they become more prolific or useful
 - surplus in vitro vitality may eventually be transformed into surplus commercial profits, as well as in vivo therapies (Waldby 2005)
- issues of ownership and patenting have become major topics in the discussion on genetic databases



(4) modern biopolitics is dominated by highly decentralized rhizomic assemblages (Deleuze & Guttari)

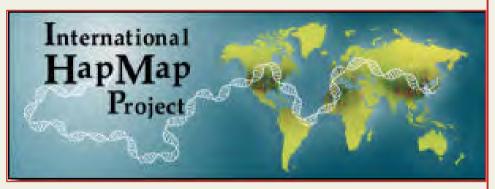
 assemblages of a multiplicity of heterogeneous objects, whose unity comes from the fact that they work together as a functional entity



 the focus is not on disciplining or control of bodies, but on the transformation of the body into information and binary codes in order to so that they can be rendered more mobile and comparable (Haggerty & Ericson 613)

"New" Version of Biopolitics

- (5) Biopolitics as an increasingly globalized phenomenon
- neither the nation state nor populations are its main or exclusive technical-scientific point of reference, but global/transnational networks and assemblages



HapMap Project

Biobanks between "old" & "new" Biopolitics

"New" Biopolitics

(1) decorporalization,
 molecularization & informatization
 (2) micro-steering
 (3) the politics of biovalue
 (4) rhizomic character
 (5) transnational/global orientation



"Old" Biopolitics:

- (1) State-centered
- (2) Body-Centered
- (3) Discipline-Centered
- (4) Nation and Population centered
- (5) War-centered
- (6) State of exception & Bare Life



- State has lost importance
- emergence of "biological citizenship" (Petryna 2002, Rose & Novas 2005)
 - On a collective level, biological citizenship is articulated in new forms of "biosociality" of collectivities defined by categories of corporeal vulnerability, genetic risk and susceptibility (Rose/Novas 2004, 441-442)
 - in bioethical discourse, the issues of informed consent, personal integrity, self-determination, confidentiality and non-discrimination convey the image of individual, citizens taking care of their rights and needs

- current bioethical and legal discourse in the field of biobanking literally conjures images of the human being of modernity while the applied medical-scientific practices and technologies seem to deeply question and undermine this 18th/19th century version of the human subject
 - obsessions with informed consent, confidentiality and privacy as one important reaction
 - Bartha Maria Koppers & Ruth Chadwick (2005): calls "to rethink the paramount position of the individual in ethics"

- tension between the rhizomic nature of biobank information assemblages and the potential guidance character of "personalized medicine"
 - while self-guidance by active citizens and patients surely is one option in such still to be realized medical systems
 - we can also easily imagine more constrained, top-down structured versions of genomics medicine and health care dominated by strict regimes of population politics and guided by information flows from biobank projects

- Is the "state of exception" also an integral element of any biobank constellation?
 - the complicated systems of anonymization used in all current biobank projects and intended to secure the anonymity of donors seem to have built in the potential to be put out of order under special circumstances
 - In Sweden, lawmakers passed a temporary change in the law after the 2004 Tsunami catastrophe giving police the authority to match DNA from bodies in Thailand with blood samples in the biobank, which originally was only intended for medical research

Summary

- contemporary biobank development emerges as a heterogeneous, strategy that combines "old" and "new" modes of biopolitics in a flexible way
 - neither a simple continuation of the well-known biopolitical strategies
 - nor the abdication of sovereign power

Summary

- the "new" biopolitics indicate a politicization of life in which the "state of exception" that potentially questions individual rights is as much a scenario as the diligent upholding of principles of bioethics and the new politics of self-guidance in health matters
- Pending national elections, tsunamis, the modernization of the health care system, economies of hope or international competition might all be aspects of such contexts that give sense to a biopolitical order in which (post)modern normality co-exists with timeless states of exception.