Biomedicine in Society (BitS)

Research Platform

Biomedicine in Society (BitS) brings together scholars in social sciences of biomedicine at the Department of Social Research. It provides a forum for transdisciplinary discussion on development, application and influence of cutting edge medical technology in Finnish society, a framework for common research projects and events, and interfaces across disciplinary and institutional borders of biomedicine and social sciences.

The purpose of BitS is to carry out high quality research on the development and deployment of advanced biomedicine – genomics, stem cell research and neurosciences – in social, economic and ethical contexts. The studies are focused on

- Requirements and environments for development and implementation of biomedical high-tech in clinical work, public health and health policy
- The image and reception of advanced medical technology among the lay publics
- Political and economic interests and dependencies connected to medical high-tech
- Ethical discussion on development of biomedical technology

Besides research activities, BitS initiates and creates opportunities for discussion on these topics in expert and policy-making forums and in public. A main objective is to stimulate stakeholder involvement in these issues and encourage discussion that would transgress institutional and disciplinary boundaries.

Activities of BitS unite the best expertise in Finnish biomedicine with the best expertise in social studies on biomedicine. For this reason, BitS is capable of focusing research and discussion about the social and political dimensions of advanced biomedicine to themes which are concrete and relevant for medical research, health care and policy and for the general public. BitS projects address the most critical issues in public debate on medical research. At the same time, they are able to address those social and ethical challenges which medical research consider central in pursuing new medical technology. Moreover, BitS focuses on concrete issues and challenges in implementation of high-tech medicine which clinicians and policy-makes consider the most topical.

BitS in practice

Director and convener: Docent Ilpo Helén

See abstracts and publications below

Post genomics

- *Privacy Regimes: Variations and Transformations in an age of post genomics* (PrivateGen)
- *DNA and immigration: Social, political and ethical implications of DNA analysis for family reunification* (IMMIGENE)
- Patients, business and the state – Translating health information into sustainable benefits
- *Constituting Difference Through Genetics - From historical to naturalistic explanations of population variation*

Reproductive and regenerative medicine

- *Unique, plural and potential: Multiplicity of human biological material*
- *Pluripotent science: Use of stem cells in the creation, assistance and prolonging of lives*

Neurosciences and mental health

- *Mood Control*

Bioinformatics

- *Vital Digital*

Post genomics

A. Projects

Privacy Regimes: Variations and Transformations in an age of post genomics (PrivateGen)

Today, large amounts of bioinformation are collected, disseminated and used in collaborative research network for life science. Biobanks are the main institutions for storage of this sensitive data and they are therefore the key insertion points for our study of privacy-related issues in an age of post genomics.

PrivateGen projects investigates the current regimes - which encompass statutory regulation (both national and international), self-regulation, and technology-based privacy instruments - in relation to post genomic research in general and more specifically in relation to the creation of large scale life science infrastructures in Austria, Finland, and Germany. Each national case will be first studied from multiple disciplinary angles by the consortium's four subprojects (juridical, ethical, sociological, and political science) and subsequently integrated into a coherent governance framework.

Furthermore, the privacy related complexity of these endeavours is amplified by scientific collaboration operating in a transnational scale. Case studies of PrivateGen reflect this trend, since the cases under investigation play an important role in an effort to create the pan-European Biobanking and Biomolecular Resources Research Infrastructure (BBMRI). They are therefore excellent locations to study particular dynamics of privacy regimes that occur on a transnational scale.

The Finnish research team is responsible for conducting the sociological substudy of the project. In it, the subject of study are the ways by which the exchange of biobank data with population registers and patient health care records bears upon the attitudes of participants in biobanking initiatives toward these practices. It will look at the ways different groups of people, (research participants, experts, researchers, etc.) relate to different types of bioinformation (e.g., lifestyle, health related data, biomaterials) in three cases in Austria, Germany, and Finland. It will also trace variations in the patterns of attitudes between these different segments toward national and transnational regimes of exchange. The subproject will also explore the possibility of people controlling the way their personal information can be used and exploited in register and biobank research, and the challenges this poses for biobank researchers. It will also draw on the studies of governance and juridical aspects in relation to the possibility of inscribing public attitudes into legislative and governance issues surrounding biobanking. The normative issues investigated in the ethical subproject will also be reflected in the sociological study by asking to what degree public attitudes should guide the development of research infrastructures or whether existing legal and ethical frameworks are adequate.

The director of the consortium is professor *Peter Dabrock* (Friedrich-Alexander University, Erlangen and Nürnberg). The study of biobank governance is directed by professor *Herbert Gottweis* (University of Vienna) and the substudy on legal aspects by professor *Jochen Taupitz* (University of Mannheim).

The sociological substudy in Finland is directed by professor *Ilpo Helén* (University of Helsinki) is in charge, with Dr *Karoliina Snell* as researcher and *Elina Helosvuori* as research assistant.

The project is funded by the Academy of Finland, the German Federal Ministry of Education and Research, the Austrian Research Promotion Agency (FFG) and the GEN-AU initiative.

DNA and immigration: Social, political and ethical implications of DNA analysis for family reunification (IMMIGENE)

Since the early 1990s, many countries have been using more restrictive policies to limit the number of immigrants who cross their borders. This change in immigration policies has affected family reunification. Today, many European and non-European countries are using genetic testing to verify that those applying to be reunited as a family are indeed related.

The project focuses on Austria, Finland and Germany. These countries represent three different ways of adopting genetic testing for immigration purposes: as a political non-issue (Austria), in the form of a current discussion on including this issue in the law on genetic diagnosis (Germany), and as a well-established and regulated legal and political practice (Finland).

The general objective of the IMMIGENE project is to reconstruct the historical process and the institutional logics of DNA testing in a comparative and philosophically informed perspective. It will identify and analyze societal, political, legal and ethical issues raised by the use of genetic technologies in the context of immigration policy and provide recommendations for policies and legal regulations.

The work needed to reach these objectives is divided into three distinct steps. The first stage draws together legal documents, codes of guidance, reports, policy statements, and information from expert interviews relevant to the specific historical and institutional trajectories in using genetic testing for immigration decisions/family reunification. The second step consists of identifying the ethical, societal and political challenges at stake, focusing on interviews with representatives of immigration bureaus, lawyers, and human rights activists as well as family members who have provided genetic material in the course of immigration decisions. On the basis of this analysis, we will in the third part of the project develop policy recommendations for ways in which legal regulations and forms of governance could be put in place to regulate immigration processes and to protect family life and privacy issues.

While the use of genetic technologies for immigration purposes is sometimes a heated topic in political and media debates, it remains a non-issue in the scientific literature. This project will provide the first comprehensive study of this field and it will enable the evaluation and comparison of different policy regimes and their advantages and problems. Hence, the project will contribute to the scientific field by exploring the diverse conditions and consequences of genetic testing in the context of immigration. Furthermore, the results of the project will also inform immigration policies with the goal of promoting a balanced relationship between data protection and privacy concerns and political interests in regulating immigration and preventing fraudulent family reunification.

The Finnish substudy has two arms. The research line related to policy-making, politics and administration focuses on the current role and future prospects of DNA testing discussed above. The question is whether the DNA tests will develop a central device of control or will it remain in its currents use as a technique solving specific problems of Somali refugees’ family reunification. The answers are searched for from two contexts: first, regarding the emerging new directions of the Finnish immigration policy and, second, regarding the establishment and use of genetic databases of population for forensic and other surveillance purposes.

The anthropological arm of the study focuses meaning and influence of genetic information in the context of culture and everyday life. Two issues are of particular interest. The first are the ways biological and social categories family and kinship become contested and disputed in a context of 'immigrant life', defined by diaspora and being a subject to the authority of the Finnish immigration administration. In addition, interpretations of genetic information by the refugees themselves in the context of immigrant life and influences of that information to their lives are crucial topics of this study.

The leader of the project is Professor *Thomas Lemke* (Goethe-University, Frankfurt am Main). The Austrian project is led by Dr *Ursula Neue* (University of Vienna) and the philosophical project by Dr *Martin Weiss* (University of Klagenfurt). In Finland, professor *Ilpo Helén* (University of Helsinki) is in charge, with Dr *Anna-Maria Tapaninen* as researcher and *Elina Helosvuori* as research assitant.

The project is funded by the Academy of Finland, the German Federal Ministry of Education and Research, the Austrian Research Promotion Agency (FFG) and the GEN-AU initiative.

Patients, business and the state – translating health information into sustainable benefits

This research that is headed by Dr. Aaro Tupasela examines governance challenges posed by the utilization and translation of healthcare information, including information derived from biobank research and genetic databases into globally sustainable and socially robust healthcare products and services. The starting point of the study is a 1) comparative analysis of governance and engagement regimes in Finland, England, US, Canada and Iceland, as well as supranational actors, to manage the collections, storage, use and commercialization of healthcare and genetic data, 2) exploring the implications that new patient engagement strategies have for the creation and deployment of intangible assets and value creation within the Finnish innovation system, and 3) identifying and scrutinizing critical elements within the patient-business-state axis that play a role in the sustainability of value creation regimes that can be deployed by companies. The study builds on previous research and expertise on consent practices in biobanking (02-07), and public perceptions of biobanking (07-09).

The research is funded by Tekes (2013 -2014).

Constituting difference through genetics: From historical to naturalistic explanations of population pariation.

Dr *Aaro Tupasela's* postdoctoral research project begins with the simple question: How does one define and characterize the borders and boundaries which constitute a population? What are the characteristics according to which groups of people can be said to belong together or differ from one another? The question of boundaries within human populations has been a central element within sociological, historical and anthropological studies of communities, identities and the classification and categorization of people using different criteria.

Recently this question has been tackled within the natural sciences, namely within population genetics, through the analysis and identification of genetic differences among various human populations. The constitution of difference through genetic markers is playing an increasingly important role in biomedicine as it relates to our understanding of disease, the development of public health policies, as well as personalized medicine. This research explores the ways in which new knowledge of genetic variations in population structure creates – if at all – new social categories and communities, the ways in which such population groupings change our understanding of disease and then enter the practices associated with healthcare in Finland.

The goal is to explore the relationship between naturalistic accounts of population structure and classification from three perspectives.

1. In what ways, if any, are new findings on genetic variation and population structure influencing the way patients and patient organizations understand disease in Finland? Do such technologically informed conceptions of variation and difference have any bearing on already established notions of communities and populations?
2. Proponents of these new technologies warn against a priori assumptions of existing groupings, yet they continually refer to such existing grouping in their own studies due to the lack of other alternatives. What is the interplay and interdependence between historical/geographical conceptions of population borders and new genetic conceptions of population groupings? Is it possible to talk of genetics of populations without its social and historical context?
3. What is the significance of such studies from a health and medical perspective? How does knowledge of difference and variation among populations come to play a part in developing new medications and healthcare policies, and what role does it play in the way disease is understood in populations?

Such perspectives are important in developing a more nuanced understanding of the interplay between historical and naturalistic explanations of difference and variation in Finland. It also contributes to the international theoretical discussion in sociology surrounding the role of genetics in classifying and categorizing populations and disease.

The research is funded by the Academy of Finland.

B. Selected publications

Tupasela, A. and Snell, K. (2013) National interests and international collaboration: Tensions and ambiguity among Finns towards usages of tissue samples. *New Genetics and Society* 31: 4, 424-441.

Gaskell, G., Gottweis, H., Starkbaum, J., Greber, H., Broerse, J., Gottweis, U., Hobbs, A. Helén, I., Pashou, M. Snell, K. & Soulier, A. (2013) Publics and biobanks: Pan-European diversity and the challenge of responsible innovation. *European Journal of Human Genetics* 21:1, 14-20; AOP doi: 10.1038/ejgh.2012.104

Helén, I. & Snell, K. (2012) Private life in bits and pieces. Digital and molecular personhood in the information age. In Margherita Carucci (ed*) Revealing privacy*. Berlin: Peter Lang, pp. 133-150.

Snell, K., Starckbaum, J., Lauss, G., Vermeer, A & Helén, I. (2012) From protection of privacy to control of data streams: A focus group study on biobanks in the information Society. *Public Health Genomics* 15:5, 293-302.

Snell, K. & Tupasela, A. (2012: Mitä mieltä suomalaiset ovat biopankeista? *Duodecim* 128: 16,

1685-1690.

Tupasela, A. (2012) Biopankkilaki ei ratkaise vanhoja ongelmia. *Suomen lääkärilehti* 67:18, 1399-1400.

Tupasela, A. (2012) Governing Hereditary Disease in the Age of Autonomy. In Vermeulen, N., Tamminen, S. and Webster, A., (eds.) *Bio-objects: Life in the 21st Century*. Surrey: Ashgate.

Lauss, G., Snell, K., Bialobrzeski. A., Weigel, J. & Helén, I. (2011) Embracing complexity and uncertainty: An analysis of three orders of ELSA research on biobanks. *Genomics, Society and Policy* 7:1, 47-64.

Tupasela, A. (2011) From gift to waste: Changing policies in biobanking practices. *Science and Public Policy* 38:7, 510-520.

Tupasela, A., Sihvo S., Snell, K., Jallinoja, P., Aro, A.R., and Hemminki, E. (2010) Attitudes towards the biomedical use of tissue sample collections, consent and biobanks among Finns. *Scandinavian Journal of Public Health* 38, 46-52.

Reproductive and regenerative medicine

A. Projects

Pluripotent science: Use of stem cells in the creation, assistance and prolonging of lives

The project studies expectations of stem cell based medical interventions into the first stages and last stages of human life. In Finland and globally, stem cells (cells capable of differentiating into diverse cell types) are increasingly involved in the treatment of three proliferating medical problems: infertility, children’s diabetes and Alzheimer’s disease. Our project focuses on stem cell research on these medical problems. The aim is to generate novel perspectives to the ethical, political, scientific, and personal aspects of medically assisted ‘beginnings’ and ‘ends’ of the human life course.

Stem cell research is rooted in assisted reproduction due to its dependency on ‘spare embryos’, donated by couples receiving infertility treatment. Embryonic stem cells are then used to assist the ‘beginnings’ of lives, via research aiming at creating cell replacement therapy for children’s diabetes, and the ‘ends’ of life via similar therapy for brain degeneration in Alzheimer’s disease.

The innovativeness of this project lies in a joint framework of analyzing infertility (Mianna Meskus, Elina Helosvuori), children’s diabetes (Mianna Meskus) and Alzheimer’s disease (Lotta Hautamäki). We suggest that, due to stem cell science, controversial matters of birth and ageing, of bodily reproduction and degeneration are changing. Sociologically, the interest is to explore ‘what it means to be human’ and how this is transforming through medical assistance.

The empirical objective of this project is to broaden the contemporary understanding about hopes, fears and dilemmas experienced by patients, doctors and researchers encountering infertility, diabetes and Alzheimer's disease. The main research questions are:

- How do stem cell researchers frame and 'translate' the controversial biological materials they work with?
- How do patients experience the donation of their biological materials, or the possibility of receiving transplantations for the treatment of disease?
- What kind of networks of agency, dependency and assistance can we outline, between biological matter, techniques, knowledge, and human actors?

The leader of the project is post doc research fellow Dr *Mianna Meskus*, the research team consists of post doc researcher *Lotta Hautamäki* and doctoral student *Elina Helosvuori*.

The project is funded by the Kone Foundation.

Unique, Plural and Potential: Multiplicity of Human Biological Material

Dr *Mianna Meskus's* postdoctoral researcher project studies social, political and conceptual implications of the scientific and therapeutic use of human biological material (stem cells and embryos). She applies ethnographic and printed data to explore how the use of human cells and tissue is defined and justified a) in infertility treatment, and b) in medical research and its commercialization. The focus of the study is in the practical and material exchange relationships between these two arenas of action. The project aims to produce knowledge on the scope of hopes, fears and dilemmas experienced by patients, doctors, as well as researchers when encountering high tech medicine and new reproductive technologies in particular. In addition, Meskus is interested in analysing how the co-workings of scientific research practices, patient activism and state-of-the-art technologies transform our present day conceptions of reproduction and, through this, our understandings of "biological" and "social" aspects of human life. The theoretical aim of this project is to discuss current challenges in social scientific conceptualization and to develop fresh perspectives to the question of what sociological analysis is about.

The project is funded by the Academy of Finland.

B. Selected publications

Meskus, M. (2012) Personalized ethics: The emergence and ethics in prenatal testing. *BioSocieties* 7:4, 373-392.

Meskus, M. (2009) Governing risk through informed choice: Prenatal testing in welfarist maternity care. In Bauer, S. & Wahlberg, A. (eds) *Contested Categories. Life Sciences in Society*. Farnham & Burlington: Ashgate, pp. 49-68.

Neurosciences and mental health

A.Projects

Mood Control

The subject of the study is transformation of mental health in the late 20th and early 21st century, particularly in Finland. The context in which the transformation is connected in the study are the following: 1) metamorphosis of the management of mental health problems from hospital incarceration and treatment to a rhizome of mental health care throughout society; 2) development of 'global psychiatry and mental health care'; 3) changes in the Finnish and Nordic public provision of health care and social services in the context of 'post welfare' state. All in all, Finland provides a good case a detailed analysis of three main features of today's mental health care in the West: conceiving of mental health problems in a population scale, the triumph of medication in the treatment of mental problems, and a new mode of mental health reasoning, based on epidemiology, neokraepelinian classification of mental disorders and neuropsychiatry.

The study focuses on research, clinical management and mental health policy focused on mood disorders. Ilpo Helén studies policy the development by which *depression* has become a public health problem and the major target of out-patient oriented psychiatric health care from the 1970s to 2010s. Lotta Hautamäki's dissertation focuses on the changes in professional and lay understanding of bipolar disorder in the late 1990s and early 2000s. Two questions are central in the studies: 1) *how have mood disorders become the focus of mental health care? 2) how have professional consensus and management standards for mood disorders evolved?* Primarily, these studies focus on the transformation and multiplication of psychiatric care from the treatment of mental illness to the management of mental health risks and further to an array of practices by which individual persons adjust their feelings, desires and behaviour to the demands of their personal life situation. This development is unfold by analysing emergence depression epidemic and a growing research interest in bipolar disorder within the Finnish mental health care system. Thus the primary subject of this study is the historical formation and future prospects of the assemblage of *mood control.*

The approach of the study is embedded in Ian Hacking's studies of historical ontology and in Annemarie Mol's ethnographic philosophy of science and her view on ontology of health, illness and the body as embedded in mundane medical practices and technologies and therefore as multiple. The analysis is greatly influenced by Nikolas Rose's studies on the formation of the psychological and on growing tendency to reason over psychological phenomena in a neuroscientific framework. The methodological approach is based on Michel Foucault's critical genealogy of the present and on Paul Rabinow's anthropology of the contemporary.

The project is directed by Ilpo Helén and it is a continuation of his Academy Researcher project (Academy of Finland). Lotta Hautamäki's dissertation project has been financed by SOVAKO.

B. Selected publications

Helén, I. (2011) Is depression a brain disorder? Neuroscience in mental health care. In Ira van Keulen & Martyn Pickersgill (eds) *Sociological reflections on neuroscience*. Advances in Medical Sociology 13. Bingley: Emerald, 123-152.

Helén, I. (2011) The depression paradigm and beyond. The practical ontology of mood disorders. *Science Studies* 24:1, 81-112.

Hautamäki, L., Helén.I & Kanula, S. (2011) Mielenterveyden hoidon lääkkeellistyminen Suomessa. In Ilpo Helén (ed) *Reformin pirstaleet. Mielenterveyspolitiikka hyvinvointivaltion jälkeen*. Tampere: Vastapaino, pp. 70-110.

Bioinformatics

A. Projects

Vital Digital

Dr Sakari Tamminen's post doc research project is focused on the manners of convergence of digital life and organic life in the new practices of computer driven bio-informatics and different fields of biomedical innovation in the context of Institute for Molecular Medicine Finland's (FIMM) population database practices and other global initiatives.

The first aim of the study is to compare the imagined uses attached to different kinds of biobanks and to study how these imaginative spaces are constitutive to their material and social design in practice. The project will start by reviewing how the collection and use of bio-information in FIMM is presented and analyzes the idioms through which the different possibilities for its use are presented in practice: for example in the digital representation of the organic ("revealing the secrets of life") through standardised bioinformatic packages, the use of this data in order to engineering of designer drugs or genetic therapies ("translational research"), and finally for systems biology and its claims of virtual modelling/reorganising life ("reprogramming the organic"). How do these genetic imageries (witnessed in terms such as "translational research") relate to the practical material constructions of the national biobank at large – why are they built at all?

Second, biobanks require standardized bio-ontologies conditioned by database structures and particular semantics of programming representations of life. The research looks at the ways in which these databases are put together locally at FIMM, what kinds of digital techniques and tools are developed in, what information of organic samples are turned into digitalized forms of representation and finally, what kind of dissemination technologies (www/local DBs) are provided for the use of the data. The main question is what kind of programming (language) is required locally at FIMM for basic bio-information generation and its representation and how a "recontextualization of biology" is enabled between biological and digital (decoding, representing and recoding of genetic/molecular information) as well as between local and global use contexts. This questioning enables an analysis of how the recontextualization of (Finnish) biology happens at intra- and extra-cellular levels in witnessed biomedical/scientific practices.

Finally, given these developments and instead of seeing the role of biology (and the current biomedical fields) as solving the "mysteries of life" and the functioning of already existing entities, its societal mandate and praxis turn towards crafting new entities, thus producing the 'new' biological and hitherto unknown potentials within it. The urgency to study the shifting boundaries of 'the digital' and the 'organic' forms of life stems from the intertwined developments put forward, on one hand, by the new technologies capable of genetically transgressing what once were thought of as natural boundaries between categories of living, such biological beings and their digital modeling. On the other hand simultaneous theoretical and technological advancements in a wide range of biosciences question boundaries within categories of living, such as the life/death border or what counts as genetic (programmed genetic material) and biological (non-programmable non-redundant vital matter, or 'cell plasma') – new emerging bio-object abound. Thus, the third question meditates the 'what' consequences of these developments especially in terms of the elementary boundary crossings with the advent of new powerful techniques and infrastructures made possible by the digitalization of 'life'. It asks how do these crossings relate to our cultural understandings, for example, of a) 'life', not only as a stable 'code of life', but as vital materiality malleable, designable and globally sharable cellular 'writing' or instances of biomedia and b) the idea of humans as 'social animals' in sharing their own DNA base-pair instructions to others.

The project is funded by the Academy of Finland.

B. Selected publications

Tamminen, S. & Vermeulen, N. (2012) Bio-objects and generative relations. *Croatian Medical Journal* 53, 198–200.

Tamminen, S. (2012) Still life? Frozen Gametes, National Gene Banks and Re-configuration of Animality. In Vermeulen, N., Tamminen, S. & A. Webster (eds) *Bio-Objects. Life in the 21st Century*. Surrey: Ashgate, pp. 203-218

Vermeulen, N., Tamminen, S. & A. Webster, (eds) (2012) *Bio-Objects. Life in the 21st Century.* Surrey: Ashgate

Tamminen, S., Raita, E., Lehtinen, V., Silfverberg, S., Ravaja, N. (2012) Teknologian sosiaalipsykologinen tutkimus. *Psykologia* 47, 410-422.

Tamminen, S. (2012) Tieteentutkimuksesta yhteiskunnan uudenlaiseen kokoonpanoon : Latourilainen kosmopolitiikka ja yhdessä elämisen vaikeus. *tiede & edistys* 37:2, 117-141.

Tamminen, S. & Brown, N. (2011) Nativitas : Capitalising Genetic Nationhood. *New Genetics and Society* 30, 73-99.

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