







Research Centre for Policy Analysis and Studies of Technologies (Tomsk State University, Russian Federation)

Department of Health, Ethics and Society (Maastricht University, The Netherlands)

with the support from The Open Society Foundations

#### The International Conference

**Social Sciences & Medical Innovations:**Doing Things Together

21-24 May 2015, Tomsk State National Research University, (Tomsk, Russia)

#### **PROGRAMME**

#### **Advisory Committee:**

**Klasien Horstman**, Professor of the Philosophy of Public Health, Leader of the Research Programme Health, Ethics and Society, Maastricht University, the Netherlands; **Jessica Mesman**, Associate Professor at the Department of Technology and Society Studies; Maastricht University, The Netherlands;

**Vladimir Demkin**, Vice-Rector of National Research Tomsk State University, Russia; **Evgeniya Popova**, Director of Research Centre for Policy Analysis and Studies of Technologies (PAST-Centre), National Research Tomsk State University, Russia.

#### **Organizing Committee:**

**Olga Melnikova**, Research Fellow, Centre for Policy Analysis and Studies of Technologies, National Research Tomsk State University;

**Olga Zvonareva**, Research Fellow, Department of Health, Ethics and Society, Maastricht University and Centre for Policy Analysis and Studies of Technologies, National Research Tomsk State University.

Conference hall, Main Building, National Research Tomsk State University, Lenina, 36; Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34 a.





**Laboratory for Physical Processes Modeling in Biology and Medicine (NR TSU)** 

## Timetable

	May 21st		May 22 <sup>nd</sup>		May 23 <sup>d</sup>	
	Conference hall	Library	Library	Conference hall	Library	Conference hall
11:00			Keynote lecture 'The Social Study of Collaboration' (Bart Penders) (Conference hall)		3. Co-production of innovations and values. Normativity of togetherness	3. Co-production of
11:30						innovations and
12:00						values. Normativity of
12:30	Participant registration		Coffee Break (café "Minutka")			togetherness
13:00	Conference Opening. Welcome Speeches.		1. Making innovations work? 1.2. Evidence-Based Medicine and Standardization in Health Care	2. Innovations and governance: participatory and inclusive practices? Politics of togetherness	3.1. Innovation via Demedicalisation	3.2. Addressing asymmetries and inequalities (online)
13:30	Keynote lecture 'Politics of Blood' (Boel Berner) (Conference hall)				Lunch (cafe "Minutka")	
14:00					. , , , , , , , , , , , , , , , , , , ,	
14:30					4. Bringing everything	
15:00	Coffee Break				together: cases of visualization and	
15:30	1. Making innovations work? Contextualising togetherness		Lunch (cafe "Minutka")		telemedicine	
13.30					technologies	
16:00					Closing lecture	
	1.1. Entanglements of 'hard' and 'soft' in innovating (Conference hall)		1.3. Innovating in drugs and medical devices	Continued 2. Innovations and governance: participatory and inclusive practices? Politics of togetherness	'Reflections on studying	
16:30					togetherness'	
					(Klasien Horstman)	
17:00						
17:30	Coffee Break					
18:00	Research Seminar	Round Table. 'Linking		_		
18:30	'How to study socio- history with the here		Coffee Break			
	medical innovations	and now: Post-Soviet	Round Table			
19:00	in the wild?'	public health and the	'Trajectories of			
10.20	(Klasien Horstman)	biomedical sciences'	Russian		-	
19:30		(Susanne Bauer)	(bio)pharmaceutical			
20:00			innovations in the			
20:30			world'			

### May 21st, 2015 (Thursday)

(Conference hall, Main Building, National Research Tomsk State University, Lenina, 36).

This conference explores modes of togetherness in innovating in medicine and health. We will talk about collaborations between disciplines and fields, analyse ways in which innovations and settings work or fail to work together, and investigate the intertwinements of technologies and politics. In their explorations, conference participants go beyond the focus on collaboration between humans, stretching the understanding of 'togetherness' to include technologies, contexts, and values. That is 'doing things together' is about innovation processes working in collaboration with governance structures, material environments and cultural landscapes.

12:30-13:00 - Participant registration.

13:00-13:30 - Conference Opening. Welcome Speeches.

13:30-15:00 – Keynote lecture 'Politics of Blood'

**Boel Berner** (Linköping University, Sweden)

**Discussant:** Ivan Tchalakov (PAST-Centre, National Research Tomsk State University, University of Plovdiv, Bulgaria).

15:00-15:30 - Coffee Break.

### 1. Making innovations work? Contextualising togetherness

Innovations in the area of health and medicine are conceived, developed, and implemented by various actors working across diverse institutional and cultural settings. Despite the widespread expectations of universal efficiency, innovations do not function in a similar manner everywhere, may make little sense for their intended beneficiaries, and often bring in unintended consequences. Making innovations work entails embedding them in wider contexts in a process where both the contexts and innovations themselves change. This section explores the challenges and stakes in developing, introducing, and making innovations work in different contexts, and the different engagements that arise or fail to arise along the way.

#### 1.1. Entanglements of 'hard' and 'soft' in innovating

Innovations in health and medicine are of different levels (including institutions, national health systems and global programs) and of different kinds (for example, medical devices and drugs as well as standards and policy initiatives). This subsection explores the interconnections between the 'hard' and 'soft' in innovating, exposing how for innovations to work various elements need to collaborate: technologies have to collaborate with work practices; infrastructures – with regulations, and artefacts - with values.

Subsection leader: Bart Penders (Maastricht University, The Netherlands).

15:30-16:00 – 1.1.1. Andrei Korbut (National Research University Higher School of Economics, Russia) 'Making sense of electronic medical records in everyday clinical practice'.

16:00-16:30 – 1.1.2. Anna Trakhtenberg (Ural Branch of the Russian Academy of Sciences, Yekaterinburg; Department of Philosophy, Russia) **'IT adoption in Russian health care as a clash of values'.** 

16:30-17:00 – 1.1.3. Márcio da C. Vilar (Leipzig University, Germany) **'Biomedical innovation and legal constraints through a case-study in Brazil'**.

17:00-17:30 – 1.1.4. Alexandra Kurlenkova (Institute of Ethnology and Anthropology, Russia) **'Ethical standards of ART use in Russia and UK'**.

17:30-18:00 - Coffee Break.

# 18:00-20:00 – Round Table. 'Linking history with the here and now: Post-Soviet public health and the biomedical sciences'

(Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34a)

**Lecturer and moderator: Susanne Bauer** (Goethe University Frankfurt, Germany).

# Key round table presenter: Mikhail Gribovskiy (National Research Tomsk State University, Russia) 'Medical research in classic university: Russian traditions, practices, and perspectives'

This lecture and round table explore temporal dimensions of togetherness. Current practices and trajectories of medicine and (bio)medical sciences in the post-Soviet territories have absorbed remembered and forgotten narratives, hopes, conflicts and values. To understand the here and now of medical science and practice, we need to depart from ideas of transition and linear progress. Rather we need to study the complex entanglements of the past with current challenges and opportunities opened up by new technologies, reorganizations in governance regimes and the shifts in the role of the public, the state as well as academic and professional communities.

This round table brings together scholars from diverse disciplinary backgrounds to trace and reflect on the half-presences of the various pasts, which continue to co-shape health-related fields in post-Soviet settings. Analysing the entangled histories of technological and organizational change, the round table discussion contributes to a better understanding of how to approach issues faced by medicine and (bio)medical sciences in post-Soviet locations today. This also helps to foster a productive interaction and collaboration between scientists and health professionals in these locations and elsewhere.

# 18:00-19:30 – Research Seminar 'How to study socio-medical innovations in the wild?'

### **Klasien Horstman** (Maastricht University, The Netherlands).

(Conference hall, Main Building, National Research Tomsk State University, Lenina, 36)

This seminar provides an introduction in qualitative research of socio-medical processes and practices in health and medicine 'in the wild' from a constructivist perspective. That implies the idea that practices are considered as being constructed in complex interactions and processes. The meaning of concepts (health, risk, body, human, social, individual, economy, etc.) is not taken as a given but rather as being constructed in these interactions,

and we follow the sociological Thomas theorem: if men define situations as real, they are real in their consequences. The construction of meaning (although these meanings are considered as untrue or non-rational by others) has consequences.

In the seminar we will address subjects like the role of theoretical concepts in a study, how to collect and analyze data, how to account for quality, how to organize responsiveness or participation, how to perform transparency while studying practices "in the wild", and how to deal with ethical issues. We will illustrate these questions by taking examples from different concrete studies: studies of the co-production of genetic testing and everyday family life, the construction of health practices among lower educated social classes, the analysis of the back office of clinical trials, a study of the knowledge culture of organizations on the interface of science and policy, and how to analyze health promotion practices?

Please prepare a short introduction (3 minutes) of your own study and questions that we may deal with in the seminar.

### May 22<sup>nd</sup>, 2015 (Friday)

(Conference hall, Main Building, National Research Tomsk State University, Lenina, 36).

### 11:00-12:30 – Keynote lecture 'The Social Study of Collaboration'.

**Bart Penders** (Maastricht University, The Netherlands)

**Discussant:** Olga Melnikova (PAST-Centre, National Research Tomsk State University, Russia).

12:30-13:00 - Coffee Break.

### 1. Making innovations work? Contextualising togetherness

(Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34 a)

#### 1.2. Evidence-Based Medicine and Standardization in Health Care

This subsection continues the reflections on the interconnectedness of 'hard' and 'soft' in innovating while further focusing on a specific topic that has attracted much attention and debate – evidence-based medicine (EBM) and the standardization in health care. The subsection explores how ideas of EBM and medical practice settings come together and what the consequences are. It further investigates how standards and guidelines are and can be made, by whom, and what they *do* in health care practice.

Subsection leader: Susanne Bauer (Goethe University Frankfurt, Germany).

13:00-13:30 – 1.2.1. Nikita Zorin (Russian Society for Evidence-based Medicine, Russia). 'Why has the introduction of evidence-based medicine in Russia been so difficult?' (online).

13:30-14:00 – 1.2.2. Alina Valieva (Kazan State Medical University; Kazan Federal University, Russia) 'Adaptation strategies of medical organizations: analysis of the introduction of quality management system into the work of clinical hospital'.

14:00-14:30 – 1.2.3. Alena Kamenshchikova (National Research Tomsk State University, Russia) 'Clinical-economic standards and expert knowledge in daily medical practice'.

14:30-15:00 – 1.2.4. Nataliia Shishkina (Federal agency of research organizations, Russia) 'Development of mechanism for using the results of scientific activities in clinical practice for interaction in the medical organizations'.

15:00-15:30 – 1.2.5. Olga Fedorova (Siberian State Medical University, Russia) **'Clinical guidelines and system of medical standards in real clinical practice'**.

15:30-16:30 – Lunch (cafe "Minutka", Main Building TSU)

#### 1.3. Innovating in drugs and medical devices

Drugs and medical devices are 'big hit' technologies commonly perceived as holding promises of economic and social development. These promises have prompted a wide adoption of policies and an influx of state funds aimed at stimulating advances in these technologies in various countries, including Russia. This subsection examines the

collaborations involved in developing innovative drugs and medical devices that could work to improve human health, and attempts to stimulate these.

**Subsection leader**: Evgena Popova (PAST-Centre, National Research Tomsk State University, Russia).

16:30-17:00 – 1.3.1. Evgeniya Popova (PAST-Centre, National Research Tomsk State University, Russia) 'Business strategies of hi-tech companies in the field of medical equipment in Russia'.

17:00-17:30 – 1.3.2. Violetta Khabibulina (Medical-social researcher, St. Petersburg and Kazan, Russia) 'Interaction of pharmaceutical business with science and education with regards to an innovative product'.

17:30-18:00 – 1.3.3. Munir Shakirov (Centre of Corporate Medicine, Russia) 'Industrial Medicine. Modern challenges and technological development in the industry' 18:00-18:30–1.3.4. Olga Zvonareva (Maastricht University, The Netherlands, PAST-Centre, National Research Tomsk State University, Russia) 'Sociotechnical imaginaries: boosting drug development and production in the Russian Federation'.

18:30-19:00 - Coffee Break.

# 2. Innovations and governance: participatory and inclusive practices? Politics of togetherness

(Conference hall, Main Building, National Research Tomsk State University, Lenina, 36).

Multiple and at times conflicting actors, institutions and frameworks are involved in governing innovations for health, simultaneously being a part of wider political governance processes and structures. This section explores the opportunities, challenges and stakes in governing innovations and addressing people's health needs in different settings in the world of changing health risks and the increasing numbers of novel technologies and insights into mechanisms of health and disease.

Subsection leader: Klasien Horstman (Maastricht University, The Netherlands).

**13:00-13:30 – Klasien Horstman** (Maastricht University, The Netherlands) **Section opening**.

13:30-14:00 – 2.1. Tetiana Stepurko (School of Public Health; National University of 'Kyiv-Mohyla Academy', Kiev, Ukraine) 'Governance in Health Care: what does it mean in post-Soviet countries and how to measure it? An example'.

14:00-14:30 – 2.2. Amitabha Sarkar (Jawaharlal Nehru University (JNU), India) 'Prescription of Global Governance: Innovative Medicine for Global South – Universal Health Coverage'.

14:30-15:00 – 2.3. Ruslan Mitrofanov (European University at St. Petersburg, Russia) 'The institutionalization of psychiatry in the Russian Empire: case of Kazan province'.

15:00-15:30 – 2.4. Marina Nurbina, Sergey Taranenko (NRC "Kurchatov Institute", Russia) 'Telemedicine application to solve demographic issues and binary population growth model'.

15:30-16:30 - Lunch (cafe "Minutka", Main Building)

#### Section continues after lunch

16:30-17:00 – 2.5. Maria Kazakova (Medical University-Plovdiv, Bulgaria) and Ivan Tchalakov (PAST-Centre, National Research Tomsk State University, University of Plovdiv, Bulgaria) 'Logics of choice and logics of care: KRAS status testing in Bulgaria'.

17:00-17:30 – 2.6. Andrey Kuznetsov (PAST-Centre, National Research Tomsk State University, Russia) 'Doing things public. Could care be a new order of worth?'.

18:30-19:00 - Coffee Break.

# 19:00-21:00 – Round table 'Trajectories of Russian (bio)pharmaceutical innovations in the world'.

(Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34 a)

Currently in Russia much effort by private companies, scientific organisations and state structures is focused on innovative drugs development. What will these efforts bring? Will Russian citizens become the main users of newly developed drugs or these drugs will also be available in the international market? Participants, whose expertise ranges from fundamental research in biology to such advanced stages of drug development as clinical trials, will discuss the goals of boosting innovative pharmaceuticals R&D in Russia and trajectories of Russian innovations in the world.

#### **Organizers:**

Policy-Analysis and Technologies Studies Center, Tomsk State University



Department of Health, Ethics and Society, Maastricht University

#### **Moderators:**

**Evgenia Popova** (PAST-Centre, National Research Tomsk State University, Russia) **Olga Zvonareva** (Maastricht University, The Netherlands, PAST-Centre, National Research Tomsk State University, Russia).

#### **Key speakers:**

**Evgeny Denisov,** Candidate of Biological Sciences, Senior Researcher, National Research Tomsk State University

**Vladimir Chernov**, Doctor of Medical Sciences, Professor, Vice-Chair of the Radionuclide Diagnostics Department, Tomsk Scientific Research Institute for Oncology

**Viktor Skuridin**, Doctor of Technical Sciences, Professor, Head of the Nuclear Reactor Laboratory 31, Tomsk Polytechnic University

**Olga Vaisova**, Doctor of Medical Sciences, Professor, Siberian State Medical University, Head of the working group for Strategic research programme of the Technology Platform 'Medicine of the Future, Secretary to the Working Group on Federal Target Programme 'Pharma-2020'

**Oleg Melikhov,** Candidate of Medical Sciences, Director of the Institute for Clinical Research, Chair of the Coordination Board of the League for Clinical Research Support

**Veniamin Khazanov**, Doctor of Medical Sciences, Professor, the Director of the drug R&D centre IPHAR (CO., LTD), mentor in the 'Skolkovo' Biomedical cluster.

### **May 23d, 2015 (Saturday)**

### 3. Co-production of innovations and values. Normativity of togetherness

This section explores the processes through which medical innovations become entangled with social norms and power. Questions pertaining to defining health and illness, inequalities in access to health care, as well as modes of applying new medical knowledge in practice have given rise to profound controversies, including disagreements over who is to decide and how. Presentations in this section analyse various examples of innovations embedding and being embedded in normativity and hierarchies.

#### 3.1. Innovation via Demedicalisation

(Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34 a)

Medical Innovations in modern society involve not merely development and use of new technologies but also the demedicalisation processes. The shift to "natural" approaches is supported by various groups of health professionals and patients' movements, who argue for minimization of technological intervention and against overmedicalisation in modern health system.

Especially interesting is the mobilization of physicians and patients for 'naturalness' in the countries with emerging or reforming health systems, shifting regulatory rules and practices, Soviet-type service provision and human rights violation in medicine. In this section we discuss the results of studies of obstetrics care in post-Soviet countries focusing on midwifery clubs, the social movements of patients and the other forms of mobilization to oppose medical standards and support the legislation of homebirth and "soft way" of delivery.

**Subsection leader:** Ekaterina Borozdina (European University at St. Petersburg, Russia).

11:00-11:30 – 3.1.1. Ekaterina Borozdina (European University at St. Petersburg, Russia) "Natural' childbirth in Russian hospitals: between neotraditionalism and modernization'.

11:30-12:00 – 3.1.2. Anna Ozhiganova (Institute of Ethnology and Anthropology Russian Academy of Science, The Group of Medical Anthropology, Russia) 'Delivery stories of the natural childbirth movement participants'.

12:00-12:30 – 3.1.3. Antonina Doroszewska (Medical University of Warsaw, Poland) "Between the past and the future. Midwives' practices in a country after political transformation. The example of Poland".

12:30-13:00 – 3.1.4. Olga Melnikova (PAST-Centre, Tomsk State National Research University, Russia) **"Technologies of Natural" in Russian Maternity Hospitals.** 

13:30-14:30 – Lunch (cafe "Minutka", Main Building).

#### 3.2. Addressing asymmetries and inequalities

(Conference hall, Main Building, National Research Tomsk State University, Lenina, 36).

Inequalities and asymmetries in the quality of life, access to care and health outcomes continue to persist in the modern world. One of the main goals of medical innovations is to address the inequalities in health. This section investigates how various dynamics play out to put some population groups at a disadvantage, how human and nonhuman actors (can) work together to address the unmet health needs of people, and how and which values drive these efforts.

**Subsection leader: Olga Zvonareva** (Maastricht University, The Netherlands, PAST-Centre, Tomsk State National Research University, Russia).

11:00-11:25 – 3.2.1. Lloyd Akrong (Maastricht University, the Netherlands); **'Two worlds behind one gate: Navigating hospital care and clinical research in the same context' (online).** 

11:25-11:50 – 3.2.2. Alexandr Berezkin (Independent social researcher, USA) 'Social innovations in medicine: social support for the intersex people' (online).

11:50-12:15 – 3.2.3. Tatiana Sirotina (Altai State University, Russia; University of Nevada, USA), Tatiana Mazailova (Altai State University, Russia) **'Study of the palliative care development in the Altai region'.** 

12:15-12:40 – 3.2.4. Christine Moon (Brown University, Undergraduate, Canada) 'Bringing Immigrant Communities Into the Conversation for Public Health and Biomedical Interventions and Innovations: A View from Ideals of Life and End-of-Life, for South Korean Elders Living in Toronto, Canada. (online).

12:40-13:05 – 3.2.5. Yana Rocheva (Federal State Organization «St. Petersburg Scientific and Practical Center of Medical and Social Expertise, Russia) et al 'Sociological monitoring of disability rights within the UN convention on the rights of persons with disabilities' (online).

13:05-13:30 – 3.2.6. Maarten Abeel (NGO Handicap International, Republic of South Sudan) 'Challenging inequalities in rehabilitation services – Stroke and landmine survivors' (online).

13:30-14:30 – Lunch (cafe "Minutka", Main Building).

# 4. Bringing everything together: cases of visualization and telemedicine technologies

(Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34 a)

Drawing on the examples of visualization and telemedicine technologies, this section refers back to the main conference question: how can medical innovations work together with governance structures, material environments, and cultural landscapes?

#### **Organizers:**

Policy-Analysis and Technologies Studies Center, Tomsk State University

Department of Health, Ethics and Society, Maastricht University Laboratory for Physical Processes Modeling in Biology and Medicine (NR TSU)



**Section leader: Ivan Tchalakov** (PAST-Centre, National Research Tomsk State University, University of Plovdiv, Bulgaria).

14:30-15:00 – 4.1. Konstantin Brazovskii (Siberian State Medical University, Russia) '3D visualization of complex anatomic structures based on MRI images'.

15:00-15:30–4.2. Denis Sivkov (The Russian Presidential Academy of National Economy and Public Administration, Volgograd, Russia) 'Controversies and coordination in Technologies of immune system's visualization'.

15:30-16:00 – 4.3. Yakov Pekker (Siberian State Medical University, Russia) 'Interdisciplinary collaborations as a basis of medical innovations'.

### 16:00-17:00 – Closing lecture 'Reflections on studying togetherness'.

**Klasien Horstman** (Maastricht University, The Netherlands)

(Small Conference Hall of the Scientific Library, National Research Tomsk State University, Lenina, 34 a)

18:00-20:00 - Banquet (café "Bibliotheca").

### May 24th, 2015 (Sunday)

14:00-17:00 – Discussion 'Formulating the concept of the next conference'.

### **ABSTRACTS**

Maarten Abeel (M.Sc. Rehabilitation Sciences and Physiotherapy for neurological disorders, University of Leuven; M.Sc. Global Health from Maastricht University, including thesis research on the social context of stroke rehabilitation in the Russian Federation in collaboration with PAST-centre; Rehabilitation trainer for the Victim Assistance (VA) project and as member of the Emergency Response Team (ERT), the international NGO Handicap International in Yei, Republic of South Sudan); e-mail: maarten\_abeel@hotmail.com

# Challenging inequalities in rehabilitation services – Stroke and Landmine survivors

Abstract for conference session: Societal challenges: addressing asymmetries, inequalities and exclusion Challenging inequalities in rehabilitation services – Stroke and Landmine survivors Many severe health events can bring drastic and irreversible changes to the lives of people and their relation towards an unpredictable socioeconomic environment. Recovery, rehabilitation and reintegration processes often remain sub-optimal despite the presence of solid scientific evidence and the existence of cheap, cost-effective and simple interventions. Access to these servicees is furthermore highly unequal hereby resulting in a widespread exclusion of people with disabilities from employment, education and leisure activities. This is a problem not only for individual struggles but for society as a whole. The World Bank estimated a yearly economic loss of 1.37 trillion US dollar attributable to lack of inclusion, rehabilitation and reintegration worldwide outweighing the theoretical costs.

It is evident that in order to challenge this exclusion and unequal access to services, the processes of translating and transferring scientific knowledge should be investigated. The interaction and relationship between life choices (agency) and life chances (structure) can be considered crucial as an emphasis on the latter could lead to a fatalistic determinism that minimizes 'choice'. On the other hand, an emphasis on agency would fail to fully understand the causal generative mechanisms and lead to ecological fallacies. From this perspective, structural conditions can be investigated that can potentially affect how people with disabilities and healthcare workers engage in a meaningful therapeutic relationship.

Building on the practical examples of stroke rehabilitation in the Russian Federation and rehabilitation of landmine survivors in the Republic of South Sudan an emphasis can be made on the importance of communication and recognition of differing expectations, claims of legitimacy and health-seeking behaviour in order for the translation of scientific and clinical evidence into effective and applied practice.

**Lloyd Akrong** (Research Fellow, Department of Health, Ethics and Society, Maastricht University, the Netherlands); e-mail: l.akrong@maastrichtuniversity.nl

Two worlds behind one gate: Navigating hospital care and clinical research in the same context

**Susanne Bauer** (Associate Professor of Sociology of Knowledge, Faculty of Social Sciences, Goethe University Frankfurt, Germany); e-mail: bauer@soz.uni-frankfurt.de

**Aleksandr Berezkin** (Independent social researcher, New York, USA); e-mail: aleks.v.berezkin@gmail.com

#### Social innovations in medicine: social support for the intersex people

The main idea of the article – representation of the actual social support for the intersex people for their social adaptation. It is necessary to organize complicated personification type of medical and psycho-social support for intersex people to improve social adaptation and life integration in Russian society.

The problems of the intersex people are significant at present time. The Swiss National Advisory Commission on Biomedical Ethics was in favor of improved social support, particularly in relation to parents of intersex children in 2012 year [1]. But in fact it's not easy for the intersex person to receive even an adequate medical help.

In modern Russia there are 5 federal laws, which define only methods of medical services towards the intersex people. However there are no organizations, which would offer social-medical care of intersex people in Russia, except for special medical services.

Those people who identify as intersex people themselves, they are forced to lead indoor life with minimum social interactions and with sometimes negative feedback to others actions. Most likely this feedback may result in depression.

So social support for the intersex people in ought to include regular medical examination. And providing an individual psychological care in position is very important. The specific of care for these people shows the necessity of individual approach, including individual counseling in order to help with adaptation to society. Timely detection, individual medical support and psychological counseling may reduce number and the duration of depression. It cannot be emphasized enough the necessity of strictly individual approach and care for the intersex people. It is important to ensure coordinated professional help in psychological as well as physiological fields with specialists involved in complex process of medical care.

#### References:

- [1] Summary of Consensus Statement on Intersex Disorders and Their Management, Houk, Hughes, Ahmed, Lee, Writing Committee for the International Intersex Consensus Conference Participants, 2006, in Pediatrics, doi:10.1542.peds.2006-0737. http://pediatrics.aappublications.org/content/118/2/753
- [2] Ellen K. Feder. Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine. Indiana University Pres. 2014.
- [3] Kalinchenko, N., Tyulpakov, A. New classification of diseases. discussion of the international consensus to revise terminology and classification of hermaphroditism. Bulletin of the reproductive health. 2008. #3-4.

**Boel Berner** (Professor emerita at the Department of Thematic Studies – Technology and Social Change, Linköping University, Sweden); e-mail: boel.berner@liu.se

With a background in sociology (Ph.D. at the University of Lund), I am since 1991 Professor at an interdisciplinary department at the University of Linköping oriented towards studies of technology and society. My research is both historical and contemporary, focusing on issues of technical expertise; gender, science and technology; risk; medical technology, and research methodology. My current research concerns the history and politics of blood transfusion, blood donation, and blood research. Recent publications include the books *Technology and Medical Practice* (ed. with Ericka Johnson, 2010); *Blood Flows. Blood Transfusion and Blood Donation in Swedish Society* (in Swedish 2012); *Knowledge and* 

Evidence (ed. with Corinna Kruse, 2013). Home page: http://www.tema.liu.se/tema-t/medarbetare/berner-boel

#### Politics of Blood

My presentation will discuss how blood during the  $20^{th}$  and beginning of the  $21^{st}$  century would circulate, not merely within individual bodies but also within the body politic, nationally and globally. How it entered into political discourses and institutions, into practices to make possible and to designate, to order, exclude and exploit – but also to save lives and advance knowledge.

From the early years of the 20<sup>th</sup> century, blood gained an unprecedented new visibility and importance in medicine, science and society. Blood transfusion was re-introduced during the First World War, and expanded rapidly thereafter, based on a number of social, organizational and technical innovations. In the early 20<sup>th</sup> century, too, a number of new illnesses were identified and defined as being some form of deficiency in the blood. Blood tests could reveal or clarify doubtful paternity and even help solve crimes. And a new language of heredity was inscribed upon a new conceptualization of blood.

We can look upon these and later developments as social, medical, scientific, and technical innovations, brought together by a variety of social actors and artifacts. Their usage and the ideologies behind them can also be seen as forms of *biopolitics*. Three such innovative moments of the biopolitics of blood will be in focus in my talk. They deal with, respectively, the politics of truth, the politics of money, and the politics of risk. In line with the theme of the conference I will also discuss how social sciences have come together with politics and medical practice to understand, advance, and regulate bodies, citizenship and health.

**Ekaterina Borozdina** (Research fellow at the Gender Studies Program of the European University at St. Petersburg, Russia); e-mail: ekaterina.borozdina@gmail.com

# "Natural" childbirth in Russian hospitals: between neotraditionalism and modernization

In both sociological literature and the midwifery practice, the category of "natural" childbirth is used to describe a particular system of ideological beliefs and practices related to preparing mothers for childbirth, assisting delivery and providing postnatal care. This system is considered to be an alternative to the dominant childbirth methods utilized in modern health care systems. The concept of "natural" childbirth was developed in the 1960s in the US and Western Europe, when members of the midwifery movement, the movement for the patients' rights and the second wave of feminism presented criticism of the mechanistic approach to the female body and reproductive experiences employed in the medical profession.

In Russia "natural" childbirth movement (accompanied by midwives' claims for professional authority) constitutes one of the major challenges to obstetrics. First enthusiasts of this approach started their practice in late 1980's. From this early stage they perceived themselves as a dissident community, whose aim was to withdraw women's reproductive experiences from the scope of state control, and to turn birth into private and spiritual event. Contemporary situation in Russian healthcare inherits basic contradiction between "natural" approach and official reproductive medicine: home births (the ideal type of "natural" birth) are legally prohibited in the country; ministry regulations do not allow for midwifery lead births at hospitals and create significant obstacles for realization of "natural" childbirth principles. However, on the contrary with the Soviet period

commercialization and liberalization of healthcare system contributed to (semi-legal) institutionalization of different forms of "natural" childbirth practice.

From sociological perspective "natural" childbirth movement can be considered as a neotraditionalist movement, as it overtly opposes bioscientific innovations and promotes traditional division of gender roles. This conservative orientation is especially true for Russian case (and for some other post-soviet societies), where "natural" childbirth initiative is developing in the context of general neotraditionalist ideological turn.

While acknowledging this fact, in my presentation I would like to highlight inner contradictions of "natural" childbirth practice in Russian hospitals. Deriving my results from the interviews with personnel and clients of several Russian centers for "natural" childbirth (Kazan, St.Petersburg, Volgograd) I argue that medical assistance at "natural" delivery is related to a number of both organizational and technical innovations. Being a neotraditionalist initiative "natural" approach is profoundly linked to modernization of healthcare services. On the organizational level it highly depends on spreading of neoliberal principles in healthcare (both among medical professionals and their patients). On the level of medical practice "natural" approach is justified by references to recent scientific investigations, and is supported by introduction of numerous technical facilities that should (rather paradoxically) help to make hospital births "more natural".

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### 3D visualization of complex anatomic structures based on MRI images

Increase of spatial resolution ability of modern MRI scanners allows to obtain more and more anatomically detailed images. However, alongside the increase in resolution and detail of images, the problem of preservation of details in the 3D reconstructions of anatomically correct models is aggravating. A classic problem arises, necessitating a compromise between the level of detail and exponentially increasing volume of data needed to describe 3D models. This work presents an algorithm of 3D reconstruction of complex anatomical structures based on example of building a model of the inner eat labyrinth. This work has been performed in collaboration by scientists from Maastricht and Tomsk.

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Between the past and the future. Midwives' practices in a country after political transformation. The example of Poland.

25 years ago Poland underwent a political transformation. Since then, there have been a lot of changes not only in its politics and economy, but also in other areas of life. There have been many transformations in perinatal care, concerning both women's and men's attitude to pregnancy, child birth and baby care, and medical care of pregnant women and women in labour. The very profession of midwife has also dramatically changed for the past 25 years. These changes are connected with legal regulations concerning this profession, changes in midwifery education as well as the activities undertaken by midwives in order

to improve their social status and promote their practices. These changes will be discussed in this presentation.

Formally, the scope of midwifery care in Poland is very broad, and it includes care of a healthy woman for her whole life, and especially care of a woman with uncomplicated pregnancy, labour and confinement. Practically, it is rare for midwives to independently perform all the tasks which they are qualified for. This fact can be historically justified – for many years midwives' functions were subsidiary to doctors' roles. In search for autonomy, midwives frequently refer to the past – they postulate demedicalized attitude to pregnancy and child birth (without questioning the progress in medical knowledge and technology). These activities will also be analyzed in this presentation.

Demands that midwives should be given significant independence in caring for women with physiological pregnancy and during normal labour have not been put into practice – the reality is dominated by doctors offering medicalized model of care. This model can be treated as a temporary one, which is characteristic for post-transformation countries. These issues will also be discussed in the presentation, together with the question whether midwives, when building their professional position, tend to use latest developments in medicine or they rather to the past, using natural methods.

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# Clinical guidelines and system of medical standards in real clinical practice

The rapid pace of medical technologies development, the appearance of the results of experimental studies and clinical trials require the creating of regulatory documents for use in medicine. The aim of this report is to discuss main objectives and applications of clinical guidelines and medical standards in healthcare.

Clinical guidelines are presented by document summarizing the criteria of diagnosis, management, treatment and prevention of any disease or a group of diseases. Guidelines are created by professional communities or group of experts and based on the latest scientific data and highest quality evidence. Clinical guidelines can present the algorithms of diagnostic or treatment for practitioners and most important questions and answers for different clinical cases.

In contrast to previous type of document, based on principles of evidence-based medicine, medical standards are oriented to achievement of economic effectiveness of healthcare. This is a formalized description of the healthcare that should be provided to patients in a particular clinical situation. The standards set up the safety, quality, effectiveness of medical care, the rational use of available resources and the strengthening of objectivity in law enforcement.

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Medical research in classic university: Russian traditions, practices, and perspectives

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# Clinical-economic standards and expert knowledge in daily medical practice

Healthcare is often considered to be one of the most fundamental and significant institutions for a modern and prosperous society. Medical doctors are hereby often seen as the main representatives of this institution and are considered to be experts in their field. In the therapeutic doctor-patient interaction, patients don't merely seek a person but mainly seek the expert who is expected to present a cognitive authority.

When clinical-economic standards are put in place, the medical doctor does not abolish his/her expert-status but his/her practice is put within the administrative boundaries of standardized practice. The rationale for the implementation of these standards is often that they protect both patients and doctors from respectively poor treatment and legal complaints. However, these boundaries can also be seen as and are often perceived as a threat for both for patients and doctors. Clinical-Economic Standards cause that Medical Doctors have a reduced level of freedom in diagnosis and treatment. When patients come to a doctor-expert they will receive treatment based on standards which have been designed for standard patients presenting themselves with a standard disease within a standard environment.

In this way, clinical-economical standard provide both protection and create the threat. The question rises on the preservation of expert status of doctors, because as medical practice becomes increasingly standardized, there is a construction of 'standard expert'. Expertise is then subdivided into two levels, a collective and an individual one where one level can potentially dominate the other. Doctors may disregard individual expertise or collective expertise which appears in clinical-economic standard depending on the individual personality and context they reside in.

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### Logics of Choice and Logics of Care: KRAS Status Testing in Bulgaria

The development of personalized medicine based on new knowledge of human genome and the variations of patient's fundamental biology (DNA, RNA, proteins) rises a large spectrum of problems that can be approached from STS point of view.1Studying the

<sup>&</sup>lt;sup>1</sup>Such as *patient privacy and confidentiality, regulatory policy* on science standards, research methods, reference materials, etc., *reimbursement policies* (incorporation of "individual risk factors), *intellectual property rights* (patent protection for diagnostic tools, genes, and biomarkers), etc

introduction and diffusion of new medical innovations such as KRAS status testingprovides an opportunity to analyze how local actors frame and react to the emerging problems, the solutions sought andchanges in the existing practices. The specific aim of the presented study is 1) to summarize currently available predictive and prognostic chemosensitivity tests for metastatic CRC; 2)to identify the emerging actor-network in this specific field of cancer research, diagnostics and treatment in Bulgaria, and to trace the evolution of relationship between actors involved. We believe that such study could provide a good ground for cross-countries comparison of the development of this and other fields of personalized medicine.

Colorectal cancer (CRC) and KRAS status testing

Colorectal cancer (CRC) is one of the most frequent solid tumors in the Western world. Treatment options are dependent on the stage of the disease, the performance status of the patient, and increasingly the molecular makeup of the tumor. KRAS(Kirsten ras oncogene) gene is supposed to be a strong negative predictive biomarker to indicate whether a CRC patient will respond toanti-EGFR (epidermal growth factor receptor)treatment. The validation of predictive and prognostic markers enables the selection of therapeutic administration with optimal efficacy and minimal toxicity for each patient.

The development of new drugs and target drug combinations and the implementation of an interdisciplinary management of CRC resulted in anincrease of survival rate from 6 to more than 30 months. In particular, a KRAS external quality assessment protocol was established in 59 laboratories throughout eight different European countries. KRAS status testing has been recommended by national organizations, including American Society for Clinical Oncology and European Medicines Agency.

In Bulgaria, KRAS status is determined in National Genetic Lab, TOKUDA Hospital, "GENIKA" Lab; and at the Department of Medical Biology in Medical University, Plovdiv. Gene screening is not implemented in routine clinical practice in Bulgaria yet.

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Currently Medical Prevention is her main research topic and a tool of practical implementation (within public sociology paradigm). Her latest research explores: i) dynamics of social-medical aspects of labour migration; ii) interaction of Pharmaceutical industry with a medical university; iii) innovative methods in post-graduate medical education.

# Interaction of Pharmaceutical Business with Science and Education with regards to an innovative product

In post-Soviet development of Russia, on the new modernization turn the attention is increased to the analysis of the interaction of business with public institutions. Fairly is assumed that such interaction between business and science & education is the foundation of sustainable competitiveness of innovative systems.

The research question is how innovation in the biomedical field is positioned and whether the administrative environment at the Russian university supports the university-industry collaboration similar to the Western countries?

I will discuss these topics, important for the development of the country, as a result of participating observation at five biomedical conferences and at three trainings of clinical trials staff; according to talks to health professionals, and according to an analysis of

documents on the released pharmaceutical products. Preliminary findings which were collected from the field had led to the following suggestions, which require conceptual understanding and scientometric clarification:

- An innovative product for Russian health professionals is a medicine, technology or device made in developed countries and implemented in Russian clinical or lab practice;
- Clinical trial ordered by pharmaceutical company at University hospital is becoming one of the most attractive scientific field for academics and clinical scholars, but innovational products out of that system are hardly even articulated as a "near future" for Russia;
- The Russian Federal Program "Pharma 2020" hasn't set up the purpose for pharmaceutical and biomedical clusters to create innovative product(s) that are "newer" than in the Western countries.

So, I have come by now to the conclusion that the process of labelling of a "product" as "innovative" in Russian biomedical practice is questionable on the international scale. The future research based on independent expertise of Russian and of international experts is required, and it should be performed as a Meta-analysis of those expertises.

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Candidate of science in sociology, research fellow and lecturer at the Higher School of Economics (Moscow, Russia). I got an MA in Sociology from the Moscow School of Social and Economic Sciences and defended my candidate dissertation in 2014 at the Higher School of Economics. Now I'm working at the Centre for Fundamental Sociology where I participate in the research project concerning the links between imposed and spontaneous social orders in everyday life. I'm also conducting individual research project concerning the use of electronic medical records in everyday clinical practice. My areas of interest are ethnomethodology, conversation analysis, and ethnography of professions.

### Making Sense of Electronic Medical Records in Everyday Clinical Practice

A great deal of everyday medical work consists of creating, changing and exchanging various sorts of medical documents. Some doctors even say that this is the key clinical activity and that if they knew how much paper work is required in the profession, they would not go to medical school. In this context, those innovators who claim that introducing the electronic document workflow in clinical settings will reduce the load on the doctors, have very good grounds for their proposals. Unfortunately, in most cases these innovators do not know how closely the look and the functions of the paper documents is related to the ordinary medical practice. In fact, what we can find in medical documents and why it is there have very good organizational reasons, intimately connected to the routine tasks that doctors solve every day. In my paper I will discuss one case: the pilot project of introducing the Electronic Medical Records (EMR) system in one of the Moscow outpatient clinic. Moscow have developed its own electronic system for medical documents and clinical workflow, so called UMIAS (United Medical Information and Analytical System). EMR is part of that system and right now it is tested in one clinic where I have an opportunity to observe it. It is planned that later this year all medical outpatient clinics (polyclinics) in Moscow will start to use EMRs. I'm conducting an individual research and collected some data about this pilot project. In my paper I want to present the preliminary findings. Firstly, I will discuss reasons and fears concerning the use of EMRs in general medical practice, expressed by the innovators (Moscow government officials) and experts (from academia). Secondly, I will show how the success and troubles of this particular innovation is determined by the extent to which local innovators (the head of the clinic and official municipal IT specialists that assist doctors there) take the doctors' everyday reasonings and circumstances into account. In this case the result of innovation is conditioned not so much by the innovators's efforts and forethoughts, but by the routine ways of creating and using medical documents in this particular clinic. And it's not the individual doctors that make sense of EMR, but the organized and organizing common ways of doing everyday work in the clinic.

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#### Ethical standards of ART use in Russia and UK

The practice of using ART (assisted reproductive technologies) in Russia is rather novel, although it's getting more and more available, especially for people in big cities. Meanwhile ethical standards of its regulation are still rather underdeveloped and / or sometimes ignored by medical professionals and clinics' administration. In this report I would like to dwell upon Russian legislation and everyday practices of addressing ethical issues emerged in ART use, and compare them with current European ethical standards in the same field (taking as an example UK legislation).

This report is based on the observations that I made during my work at one of Moscow IVF clinics (from October 2011 till June 2012), as well as analysis of social science literature on ART practices (in particular, Sarah Franklin works). Being at the clinic I combined my working responsibilities (correspondence and assistance to foreign patients) and field-work research (participant observation) of some of the ethical and social issues appearing in the clinical course. Based on this experience, I singled out current 'gaps' in ethical regulation as well as implementation of ethical standards of ART practices in Russia that included: adequate informing strategies for patients and oocyte donors; ART use by people "above certain age", by gay couples and by HIV-infected people; monetary compensation and anonymity of oocyte donors; mutual obligations of parties involved; the issues of moral status of the embryo and rights of unborn children, etc.

In Russia the current legal regulation of this area does not consider many economic, medical, social and ethical aspects of ART use. This means that people endowed with power on a local level (first of all, managing staff and doctors in IVF clinics) can/have to resolve many issues at their own discretion. To understand possible models of handling ethical issues of ART use, I decided to look at UK standards of ART regulation called HFEA (Human Fertilisation and Embryology Authority 1990) being one of the first statutory bodies of this kind in the world. By analyzing Russian and UK ethical standards in this area, I try to compare their ways of looking at 'important' ethical values; rights and needs of patients, donors, surrogate mothers, embryos and children; ways to assess 'proper' parents, donors, surrogate mothers before accepting them into the program.

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# Doing things public. Could care be a new order of worth?

My presentation will concern a reading of the book The Logic of Care by Annemarie Mol through the lens of sociology of critique and justification suggested by Luc Boltanski and Laurent Thevenot and sociology of regimes of engagement elaborated by Thevenot. This reading is possible due to the post-critical or rather normative stance Mol takes with respect to her object of study. As an empirical philosopher she not only wants to describe practices of health care but to articulate the logic of care so as to make care a public thing. By trying to make telling personal stories about health care a matter of public coordination (Mol, 2008: 89) Mol takes a position in relation to care that is analogous to Smith's position in relation to market order of worth or Rousseau's position with respect to civic order of worth as described by Boltanski and Thevenot.

Care practices as described by Mol fit well the familiar regime of engagement as suggested by Thevenot. In case of diabetes care practices are aimed at coping with chronic uncertainty of disease thus engaging with the natural and technical environment and gaining highly localized and specific kind of good, i.e. life devoid of suffering. According to Thevenot himself care is governing the regime of familiarity in which as in Mol's description "careful attention to being attuned to one's surroundings does not allow a strict allocation of capacities and responsibilities" (Thevenot, 2001: 78).

However Mol articulates the logic of care in undiluted form so as to strengthening it by devising a language so we could speak about care and communicate it in public realm. By articulating the logic of care and suggesting a language for it Mol seeks to transport it to other sites and situations because "logic of care is not only relevant to health care" (Mol, 2008: 91). In terms of Boltanski and Thevenot Mol wants to generalize a highly personalized and specific good of non-suffering life with disease to the level of common good. By what tools Mol tries to do so? And could care be a new order of worth at all?

To answer this question I will focus in my presentation on several points:

- How care could fit in the model of cité suggested by French sociologists? How an idea of patientism as common human condition make the city of care paradoxical?
- Could we make care public not submitting it to the format of public critique and justification?
- Ontological politics and clinic as a strategic research site where a compromise between different regimes of engagement is possible.
- Research consequences of transition from the metaphor of making to that one of doing within the ontological turn in STS. What is the difference between making things public and doing things public?

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#### Study of the palliative care development in the Altai region

Studying of palliative care became especially urgent in the Russian Federation in connection with acceptance of Federal Law #323 (November, 21st, 2011) «About the Bases of Health Protection of Citizens in the Russian Federation» where the definition of palliative care is first made.

In 2014 the experts of the public health services of the Altai region gave us the interviews. The main goal of the survey was the studying of problems of palliative care development in the region. In the Altai territory death rate because of oncological diseases takes the second place among all reasons of population deaths.

Difficulties of understanding of palliative care concept by experts, complexities of the palliative care development in the region have been revealed as a result of the research.

Experts estimate the need of palliative care in the region as high. In the experts' opinion, this need is so high that the 120 beds hospice which would be set up according to the State Program «Public Health Services Development in the Altay territory till 2020» would not solve a problem and help all being in need. Thus hospice care is considered by experts as the most appropriate form of palliative care as great number of patients being in need of anesthetics. By the moment there is no hospice in the region.

Experts also picked up such form as creation of specialized beds of palliative care on the basis of medical services. However, it demands additional resources the medical services do not have at present. Among the main problems experts allocate: absence of experts of palliative care and space for setting up of specialized beds of palliative care in hospitals.

Also there is a need of exit help service as many patients would like to spend the last days of lives at home.

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### "Technologies of Natural" in Russian Maternity Hospitals

Medical innovations in the field of obstetrics are associated with increase of technology use, medicalization and dehumanization of childbirth. However, in practice one of the approaches to childbirth involves approaching birth "as if natural" with technological intervention. In this presentation I try to show this approach to technologies in obstetrics: it is the way of medicalized delivery minimization.

I concider physicians' understanding of "medical intervention" and "natural childbirth" as a physiological norm, not only achievable by minimizing the use of medications, but in some cases, on the contrary, due to their applications.

Using examples of complex preparations and technologies for physiological childbirth instead of possible surgery, application of technological devices (as infusion pump), and hospital infrastructure, I demonstrate implementation of physician's understanding of proper labor and "natural" delivery.

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# The institutionalization of psychiatry in the Russian Empire: case of Kazan province

Questions regarding the direct effect of government institutions on individuals, as well as its penetration into the individual's psychosis and everyday life, was first raised 60 years ago by philosophers and historians such as M. Foucault, G. Marcuse, A. Negri, and others. This served as practical stimulus for the European movement of the deinstitutionalization of psychiatry. This process, observed most widely in Italy, Germany, France during the late 1960s, advocated closing «solid» state hospitals and creating specialized mobile dispensaries to avoid isolating the patient from society or infringing on his social rights.

In the Russian Empire, and especially in the Soviet Union, where the Institute of Psychiatry often functioned as a "suppressor of dissent," deinstitutionalization of psychiatry did not happen on the national level. The same remains true for Russia today. Many issues related to humanizing psychiatric patients and improving their psychological and physical conditions in hospitals remains unresolved. Therefore, my primary objective is to study the origin and diverse models of institutionalization of psychiatry in Russian Empire with the goal of understanding how it was organized, its unique characteristics, and particular national features in order to argue for the need to deinstitutionalize mental health in contemporary Russia. My research project, "The institutionalization of psychiatry in the Russian Empire: case of Kazan province", seeks to problematize these deep and still relevant issues for contemporary Russian society.

In this sense, Kazan was the first city in the Russian Empire - the birthplace of the institutionalization of psychiatry at the all-Russian context. Founded in 1869, here was established interesting dialogue between the authorities and the emerging expert community - psychiatrists. This research take into account not only history of psychiatry in Kazan province, but the discourse of government in respect of the mentally ill in the Russian Empire. We should try to understand, how the imperial authorities, through the creation psychiatric hospitals and developing specific treatment practices, by training professionals doctors - psychiatrists, formed a vision of the «normal / deviancy» in the society behavior, for preparing new, modern disciplinary legislation and mechanisms of charity «public body».

#### Objective:

To identify the peculiarities of the process of institutionalization of psychiatry in the Russian Empire in the middle of the XIX - early XX century.

We presume that the study of the institutionalization of psychiatry in the Russian Empire cannot be of a monolithic and monosyllabic process emanating from one actor, the state, but as the history of multiple actors - constructing various competing and collaborative institutional projects between the authorities, ministries, professional psychiatrists, «zemstva», church institutions and courts (traditional houses of insanity in the early XIX century, original "Zemsky" hospitals with modern district hospitals and unprecedented religious houses for the insane). Only in this entangled story between different actors and distinctive levels of hierarchy of discourses it is possible to consider the following fundamental questions in empire-wide context: institutionalization, genealogy of the daily practices of treatment of the mentally ill, transnational perspective of the study.

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Bringing Immigrant Communities Into the Conversation for Public Health and Biomedical Interventions and Innovations: A View from Ideals of Life and Endof-Life, for South Korean Elders Living in Toronto, Canada.

This paper examines what constitutes a good end-of-life experience for South Korean immigrant elders living in Toronto, Canada. Elderly individuals of various migration generations and their families, are forced to navigate Canadian social services and supports (including care homes) in the face of changing cultural contexts. Elders and their adult children, furthermore, have increasingly divergent world-views regarding medical and agerelated care for elders, as well as changing ideas of filial piety. Moreover, these cultural and interpersonal exchanges occur in the context of an increasingly biomedical and medicalized societal context.

This study found that elders relied on social services and religious networks for support in a context of 'disappearing' care from their adult children. At the same time, elders must navigate the increased medicalization of their every day lives, and deaths, particularly in the face of western biomedicine, and increasing advances in medical technologies and their usages.

Medicalization of life, death, and dying are increasingly strong forces in medical care and culture for all seniors. Uses and roles of medical technology in society must be further examined, as well as their effects on society, particularly for marginalized groups such as immigrants. Furthermore, the building of culturally competent social services (perhaps even in religious institutions) can help seniors of minority cultural groups navigate the highly biomedical and medicalized social services provided in North America.

As immigrants, South Korean elders are often left out of public conversations about public health and biomedical interventions and innovations. However, they (along with other vulnerable groups, including other immigrant communities) make up much of many public and medical service user base. Public and intellectual dialogue must expand to include these vulnerable populations.

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# Telemedicine application to solve demographic issues and binary population growth model.

Within the framework of proposed 2-component population growth model the difference between "city" and "country" was shown. "Country" is responsible for population growth, since it does not possess a resource limitation that is typical for "cities". Based on this model we discuss the opportunity to implement high-tech medicine (particularly, medical biosensors) in remote and densely populated areas which are characteristic for countryside. Thus, the role of telemedicine (or distant medicine) in such a process is revealed.

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### Delivery stories of the Natural Childbirth Movement participants

The study is based on the material of dozens interviews with women who implemented the idea of "natural childbirth" and several more interviews with obstetrician-gynecologists and lay midwives. All these women protested against medicalization of motherhood and childhood, however, the specific reasons for coming to antimedicalization are different, as well as the degree of their involvement into the movement for "natural parenting".

Despite the fact that the number of people choosing home birth is small, the whole phenomenon - the idea of natural childbirth, spiritual midwifery, "conscious parenting" - seems to be highly significant for contemporary culture. It is a declaration of a new attitude to medicine, health, corporeality.

Nowadays the Natural Childbirth Movement is rather widespread, bringing together enthusiasts of a healthy lifestyle, lay and professional midwives, doctors and alternative medicine practitioners. Formation of the movement is connected with the ideas of G. Dick-Read, F. Lamaze, F. Leboyer, S. Grof. Experiments are going on: the enthusiasts are promoting birth at sea in contact with dolphins, so called "lotus birth" and much more. The idea of soft natural childbirth has become very popular, insofar as prospective parents are inspired bythe possibility of having not only healthy, but even "fully conscious, free from internal conflicts" baby.

Currently, these ideas received further development in the form of utopian projects. In accordance with the conception of French obstetrician-gynecologist M. Odent natural childbirth becomes away to achieve social change and biological evolution of Homo sapiens. In Russia, I. Charkovsky, the creator of original method of natural childbirth, gained international fame in the 1960 s due to numerous publications in the press and films about "children-dolphins"–infants who learn to swim, dive and even eat under the water.

In Russia, home birth movement emerged in the late 1980 s as a protest against the totalitarian system of national health care, as well as a reaction to the horrific living conditions in the most maternity hospitals. Currently, there are dozens training centers for natural childbirth mainly in large cities.

Some women refuse the medical support in labor because of fear and mistrust of medical practice and physicians. This choice also may be a consequence of spiritual search. In this casedeliveryis considered as a special spiritual practice, during which the woman receives a unique spiritual experience.

It is important to note that almost all women, who refused medical childbirth, subsequently began to practice medical nihilism: they share the ideas of natural parenting, do not vaccinate children, are turning to complementary and alternative healing practices, for example, to homeopathy.

On the other hand, the practice of obstetrics has undergone significant changes in recent years. Now it is not exclusively technocratic model, but demonstrates capacity to respond to the needs of women. The presence of husband, family and friends during delivery, free behavior in childbirth, vertical childbirth, swimming pools to give birth in the water – are some of the most remarkable innovations.

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Interdisciplinary collaborations as a basis of medical innovations

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### The Social Study of Collaboration

This keynote will dive into the growth and changing character of collaboration in science. Drawing from developments in the life-, health- and nutritional sciences, it moves away from the view of academia as an isolated group of individuals making knowledge. As the result of many converging developments, first scholars and scientists teamed up with their peers, later with peers from other specialisations and even more recent with other knowledge creators from society. What counts as a 'legitimate' collaborator and as legitimate expertise to contribute to a collaboration steadily changes and expands.

This also creates tensions, for it has become increasingly difficult to decide what relevant, significant or important means - both in terms of produced knowledge or things, as well as with respect to the collaborations themselves.

For these and other reasons, many scholars have taken up the study of collaboration (the work) and collaborations (the structures). For while we thought we knew what is going on in epistemically demarcated communities, we increasingly struggle with what is going on in the hybrid, heterogeneous constellations that now produce knowledge. As collaborations change, so does the study of collaboration.

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# Business strategies of hi-tech companies in the field of medical equipment in Russia

The article focused on what is the hi-tech companies' strategies change in the system for the development and distribution of technological innovations in the Russian healthcare? The data includes interviews with hi-tech companies' directors (2012-2014), the study of web - sites of key informants, government agencies and other web resources describing Russian innovation infrastructure, analysis of relevant policy documents. The analysis identified four types of entrepreneurs according to their business strategies and ways of relations in the health care system: conformists, isolationists, supporters of small steps and revolutionaries.

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# Sociological monitoring of Disability Rights within the UN Convention on the Rights of Persons with Disabilities

The ratification of the UN Convention on the Rights of Persons with Disabilities (the Convention) by the Russian Federation requires an expansion of approaches to the of the researched social group rights. This abstract considers some aspects of the sociological component of the compliance with disability rights monitoring, which aims to identify the changes associated with various aspects of the Convention implementation, negative trends prevention and short-term forecasting of social processes and problems. There is specific attention that paid to the concept of sociological monitoring, the significance of its application, object, subject, purpose, objectives, the definition of empirical indicators peculiarity, the requirements of the respondents selection, as well as questionnaire survey to collect the primary sociological information. The results of the sociological survey allow to characterize the overall consistency rights of persons with disabilities in St. Petersburg The results of the sociological survey allow to characterize the overall consistency rights of persons with disabilities in St. Petersburg. The share of respondents evaluating the rights of the disabled in one way or another positive is from 49 to 75.6% according to various articles of the Convention. In this case, up to a third of the respondents are faced with different situations of non-compliance of the rights and guarantees provided by the Convention. The most problematic issues are about the employment, dignified living standards and education, as well as creating a comfortable and affordable living environment. The findings testify to low awareness of people with disabilities on the ratification of the Convention.

The integration of people with disabilities into society requires additional measures to develop the skills of legal culture, protection of their rights, legal literacy, which ultimately should be targeted to the active social stand of persons with disabilities. Specifics of the relevant disability groups (age, type of Disability, involvement in various public institutions) should be taken into account when organizing outreach activities.

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### Prescription of Global Governance: Innovative Medicine for Global South- Universal Health Coverage

Objective: The emergence of Global Governance for Health has made the structural changes in the governance pattern both at global and national scenario. This new model of governance has acted as stimulator for the pandemic enthusiasm on UHC (Universal Health Coverage). The paper attempts to know the trajectory and the significance of UHC under the context of political economy and political sociology (in developing economies) that guide the global actors to formulate their agendas and shape the instruments.

Research methods: This is a narrative systematic review of secondary documents (including grey literature) to identify, understand and analyse the reasons behind the formation of UHC agenda and the journey so far. The review captures this discourse by tracking and understanding the formation and functional motive of the Global Governance for Health and how it is different from the earlier International Health Governance.

The political economy approach is used as analytical framework to understand the theoretical position of the new global governance that comprises of politics, power, knowledge and interests. M&S (Modeling and Simulation) is conducted as a tool to conduct a conceptually driven theoretical exercise for assessing the competence of global governance led UHC with relevance to the WHO's Building-Blocks HSS (Health System Strengthening) framework in national health system context.

Findings: The innovations of medical sciences are exploited by the existing medical industry complex especially in developing economies. The theoretical perspectives (mooted by the ideology of New Public Management) behind the motive of global governance and the political economy of its agenda to prescribe UHC are discussed in detail.

UHC and global governance for health are two different health system phenomena but embedded into one conceptual structure of equitable access to health. These improvements are reconstructing the power matrix at international level with implications at national level, and situate the non health actors too into the decision making forum.

The paper questions whether the UHC is maneuvered to create an effective demand for the predictive medicine at the cost of ignoring real global health determinants.

Policy implications: The existing pattern of global governance and the aspiration of achieving UHC among developing economies invoke policy perspective dilemma between global needs and national wants.

Conclusions: The knowledge system itself is influenced by the various interests and based on the various ideological positions. This research can address the rational and motive behind the policies taken by global governance actors, and how the national government should respond to such policy level adaptation while in need.

The global governance is a process that already gains attention and now needs much stronger reconstruction to secure the health of the population with humanitarian view. Alma-Ata was not just a conference but rather a deceleration for a healthy world, the voice of unheard for the last 36 years has to be heard at first to establish healthy governance for the globe!

### Munir Shakirov (DM, CEO of CCM Global (Centre of Corporate Medicine), Tomsk, Russia).

#### Industrial Medicine.

### Modern challenges and technological development in the industry

Case study presentation: how company working in a field of corporate medicine considers modern challenges and overcomes it using technologies.

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# Development of mechanism for using the results of scientific activities in clinical practice for interaction in the medical organizations

Good Clinical Practice is the international ethical and scientific standard of planning and making the scientific research, which involves human subject. According to the Russian National Standard, clinical trial is research with the participation of human subjects for identify or verify the clinical or pharmacological effects of the investigational product for identify some negative reactions for assessment safety and efficacy.

Federal national scientific and practical medical centers have become a platform for testing and implementation into clinical practice the innovative medical technologies, which include the latest medicines, medical instruments and equipment, the methods of prevention and treatment. The Russian Ministry of Health need to develop and approve the Standard for doing the research with setting the main goal is testing innovative medical technologies. There are the different level problems. The first of all, the majority of practiced doctors do not possess the principles of new medical technologies, moreover they are frightened the complexity of mastering these skills. The second, scientific-medical practice need to the additional time and effort. It can create the «distraction effect» from the main clinical activity. There are many clinical situations in which doctors feel not enough scientific facts. Finally, many doctors do not have enough motivation to change habits. Of course, it is unrealistic to require finding and critically evaluating the scientific results for solving the everyday clinical situation.

The optimal solution this problem can be in the next points. The professional expert organizations, which activities are based on the principles of evidence-based medicine, involves to prepare an information product for practitioners in the form of clinical practice guidelines, systematic reviews, literary digests the most important problems of medicine. It can be realized in two directions. The first direction is development clinical practice guidelines about the most important health problems. The initiators of the building clinical guidelines are the Federal National scientific and practical medical centers. The composed clinical guidelines provide a huge economic impact. Federal national scientific and practical medical centers have to identify, organize and summarize the results of all ever published controlled trials and scientific research.

As a result of this process in the generalization of scientific information is able to assess usefulness the variety of therapeutic, diagnostic and preventive interventions.

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# Controversies and Coordination in Technologies of Immune System's Visualization

In the end of the 1980-s immunology expanded "from laboratory to society" (B. Latour). Nowadays human health, life and death are defined in terms of immunology (E. Martin). Since the 1980-s the number of immune system's depictions has increased dramatically. Visualization of immune system is linked with technology, aesthetics, media, design, education, imagination, laboratory, clinics, innovation, and routine. The studies of immune system's visualization allow to see displacements between different ontological orders in biomedicine on the one hand, and work of coordination (A. Mol), "ontological choreography" (Ch. Thompson) or aligning of biomedical platforms (P. Keating, A. Cambrosio) on the other.

Ethnographic experiments of Emily Martin and Donna Haraway, which involved people in different places trying to relate depictions and their personal understanding of immune system, have shown how immune systems have been constructed. Besides, these experiments have revealed the dissociation of routine and innovation, body and «self», technology and aesthetics.

Different immunological depictions demonstrate and explain how immune system functions. These could be subdivided into metaphorical drawings, schematic images, and electron micrographs. Metaphorical drawings and one-dimensional pictures correlate with each other and could be grouped into three immunological patterns: self-other distinction (F. Burnet), autopoietic (N. Jerne) and symbiotic (L. Margulis). Electron micrographs, made by electron microscope, are sources for models of different immune system's parts, but the evolution from black and white pictures to models suppose complex work of re-colouring, 3D-modeling, and graphic design. Micrographs as fragments of immune system are not linked with immunological patterns. Schematic images are "golden standard" for electron micrographs.

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# Governance in Health Care: what does it mean in post-Soviet countries and how to measure it? An example

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Governance becomes an all-inclusive and popular concept in the area of public service provision and especially in health care system (Lewis & Pettersson, 2009; Merrien, 1998; Rhodes, 1997). However, intangibility of 'governance' is underlined (Fiszbein et al., 2011). Our study aims at developing and applying a pilot methodology to study health care governance, or public sector management dimensions on the case of Ukraine. We consider 'governance' in this study as the management of 'the ship'-facility and search for the answers on the following questions: what are the powers in charge, what is the incentive system, how decisions are made at the top and then enforced to the bottom, what is the information system. Also, the consistency between rules and practices is explored.

Overall, four important dimensions of governance are identified and used for the research instrument development: (a) human resources, (b) planning, budgeting and financing, (c) flow of medical information and (d) procurement. For each of the dimensions, a list of indicators has been developed, e.g. for human resource governance we measure hiring medical personnel, its promotion, motivation, sanctions as well as availability of appraisal system.

The empirical data were collected in several regions of Ukraine during summer 2012. We conducted face-to-face interviews with physicians, nurses and administrators of both health care facilities (chief doctors, their deputies and heads of departments) and regional health care departments. Both snow ball and convenience sampling provided us with approximately 150 respondents.

The study has discovered a big gap between the rules and practices in Ukraine. It appears that Ukraine does not suffer from absence of rules, whereas the country seems to have too many rules. Meanwhile, this is the practices where the system breaks down with some exceptions. For example, in human resources we have found out that there is no open call for vacancy available as well as when here is more than one candidate for a position, no national rules for competitive selection - on how these multiple candidates should be selected - are established.

Since we have scant evidences on how the system works and example public sector management practices in Ukraine, we present rich and conspicuous results of qualitative study. In details, physicians usually seek employment once in their life (especially in towns rather than in the capital) on the base of medical university or colleges. It appears that medical society is often characterized by krugovaia poruka ('cover up') - principle supposed to sustain the importance of personal connections mechanism in decisionmaking. Indeed, respondents reports 'good' practices of hiring medical staff, e.g. presence of competition, interview, and presenting documents, when asked. However, at the same time they indicate that any information on vacancies is available and only a quarter of employees does not give bribes or use connections for being appointed. Furthermore, administrations of health care facilities indicate that they do not have effective means to stimulate good performance of medical staff. Medical personnel are also expected to contribute their own funds (earned as informal income that is tolerated by administration) in order to maintain the department (light bulbs, disinfectant supplies, renovation of the building etc.). Thus, we conclude that the system is based on very subjective management, however the decisions should be based on merit, on what doctors know and what is their curriculum and background rather than on other factors. Therefore, in the existing system, the role and quality of the chief doctor and the system that person establishes in the hospital can define the quality of health care facility governance that does not ensure transparency and equal access to the resources of the system.

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Acknowledgement: The study is financed by the World Bank. The views expressed in this publication are the sole responsibility of the authors and do not necessarily reflect the views of the World Bank or its services.

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### IT adoption in Russian health care as a clash of values

The project focused on the analysis of information technology adoption in health care system of the Sverdlovsk region (Ural federal district).

Relevance of the project was due to the high social importance of health care sector in conjunction with high level of organizational resistance to the introduction of medical information systems and their low cost-effectiveness. Organizational resistance and low efficiency are typical not only for Russia but also for developed countries such as the USA and Germany.

The process of social adoption of medical information systems (MIS) was analyzed within the dual factor model of technology usage (R.T. Centefetelli). The study was conducted with a grant RHF-Ural 14-13-66016a "E-government implementation as a process of social adoption of technology".

The project used methods of qualitative sociology (interviews and focus group). Two groups of actors were involved: the staff of health facilities and the staff of the Medical Information and Analytical Center of the Sverdlovsk region. They have fundamentally different points of view on the issue of objectives and results of the implementation of MIS.

Research has shown that the objectives of medical computerization are given from the outside, within the concepts of public administration formed in the framework of the "new public management". The main objective is to standardize as much as possible the behavior of physicians and nurses in order to ensure strict control over this behavior and over the expenditure of allocated funds.

This objective comes into conflict with the core values of the medical profession. Doctors make decisions under conditions of high uncertainty and relying on personal experience (as stated in the Hippocratic Oath, «to the utmost of my power and judgment»). As a result, what proponents of medical computerization see as the benefits, physicians and nurses estimate as a threat.

Developers proceed from the principles of technological rationality, based on the maximum simplification of the basic procedures and reduction of these procedures to a set of algorithms. These principles correlate very well with the management objectives and very poorly with the "unpredictability" of the medical profession. Specialists who have no

medical training tend to act as all-knowing experts. They believe that doctors will accept proposed solutions regardless of their wishes.

Thus, the problems faced by the main actors in the process of medical information, are not the result of some technical flaws, but the consequence of a collision of value systems and the inability to fully standardize the doctor – patient interaction. In practice, the implementation of medical information systems leads to a tightening of formal control and significant employees overload without appreciable improvement of patients' treatment.

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### The Adaptation Strategies of Medical Organizations: Analysis of the Introduction of Quality Management System into the Work of Clinical Hospital

Nowadays Russian organizations endeavor to create a common workspace with foreign partners, to integrate new models of organizational activities accepted at the international level. The quality management system based on ISO 9001 represents one of such models. Initially designed for the industrial sphere, these standards are extrapolated to the social sphere as well. Therefore, the transformations of social institutions such as medical organization generated by introduction of this system arouse a high interestas they assume the interaction with patients, rather than production processes. It is expected that the implementation of the management system can change the everyday practices of the staff and patients and improve the quality of medical services because it brings the structural, administrative and cultural changes.

The proposed paper analyzes the specificity of implementation of ISO 9001 in the Russian medical institutions on the example of one of the hospitals in Kazan. Based on the data of survey and interviews with hospital employees, the study demonstrates that the attempt to implement a balanced quality management system based on the new standards causes internal conflicts in the organization because the changes do not only serve to harmonization of the work of medical organization, but also often provide the basis for individual and institutional distortions.

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Márcio Vilar concluded the Course of Social Sciences at the Federal University of Paraíba (UFPB) in 2001 and defended his master monograph at the Graduate Program of Sociology and Anthropology (PPGSA) at the Federal University of Rio de Janeiro (UFRJ) in 2004.

Currently, he is concluding his PhD study at the Institute of Ethnology at the Leipzig University. Parallel to his PhD thesis, he has been working on his postdoctoral research on 'contested legitimacy of regenerative vs. established medicine for autoimmune diseases in Brazil` in cooperation with Scholars of the Centre for Global Health Policy and of the Department of Anthropology at the University of Sussex.

### Biomedical innovation and legal constraints through a case-study in Brazil

University of Leipzig How does the development of a new therapeutic model, the potential emergence of which threatens the hegemony of an already established model, affect and

how is it affected by law, science and society? To anchor this question in a particular context, I propose an anthropological study into how scientific innovation, established medical science and informal health care interface and co-exist in contemporary Brazil, and how their relations are mediated by legal institutions. My primary case-study concerns the development, prohibition and unofficial circulation of the *AB vaccine* (VAB) – an 'immune-stimulating' therapy informally used in the treatment of several 'autoimmune rheumatic diseases' (AIRDs), which are conventionally treated with immunosuppressants.

In this paper I will present preliminary outcomes of ethnographically informed work (which I have been conducting since 2009) related to the circumstances under which the VAB was developed. By exploring and reconstituting key transformations and reappropriation processes through which the VAB has passed from its development up to the present day, I intent to identify the actors engaged in regulating the VAB, to posit them historically, and to trace some of their connections and exchanges (e.g., medical doctors, patients and their relatives; governmental actors; market agents, stakeholders, etc.). As part of it, I intent to map the legal constraints related to the VAB, calling attention to some of its multiple implications, continuities and discontinuities – i. e., who these legal constraints affect, and by whom (or what) are they triggered. The idea is to re-trace and draft basic associations that have constituted the VAB as a travelling biotechnological innovative agent, and simultaneously as an object of judicial dispute and regulation.

As I would like to show, this case study allows us to explore how law, science and society shape their mutual boundaries and co-produce the 'legal' and the 'illegal' and, thus, parallel 'cultures of legality' within modern society. Moreover, I argue that research into the production, circulation and regulation of 'immune-stimulating' therapies for the treatment of AIRDs in Brazil – therapies which pose a potential 'paradigmatic' threat to incommensurable, established 'immune-impairing' therapies – can provide critical insights by which to understand the emergence of so-called 'regenerative medicine' as a transnational process, as well as into the development of *other* pharmaceutical circuits. These processes are interlinked and encompass numerous complex changes and conflicts occurring in the last decades in different places, such as courts of law, scientific environments, and formal and informal economies; moreover, they involve a plurality of agents, among which legal institutions stand between the most influential as well as most affected.

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# Why has the introduction of evidence-based medicine in Russia been so difficult?

This presentation will analyse the history of the unsuccessful implementation of EBM in Russia. It will be analysed, why medical community, healthcare system and medical education have been resisting this process.

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### Sociotechnical imaginaries:

### boosting drug development and production in the Russian Federation

In the year of 2009 the Strategy for the Development of the Pharmaceutical Industry in the Russian Federation till 2020 (Pharma 2020) was adopted by the country's Ministry of Industry and Trade (Минпромторг, 2009). One of the main aims of Pharma 2020 is to boost the development and production of innovative drugs in Russia. The adoption of the strategy was preceded by the wide discussion of a crisis of Russian pharmaceutical industry, signs of which have included the fact that drugs produced by Russian companies make only about 20% in value of the country market, with this share consisting mostly of cheap generic drugs (DSM Group, 2006). This paper explores the sociotechnical imaginaries (Jasanoff & Kim, 2013), that have been mobilized and produced in the making of the Pharma 2020 and related drug innovation initiatives in Russia. Sociotechnical imaginaries are understood as 'collectively imagined forms of social life and social order reflected in the design and fulfillment of nation-specific scientific and/or technological projects' (Jasanoff & Kim, 2009, p.120). Drawing on this concept, I analyse how political culture is working to frame the goals and trajectories of drug innovation simultaneously describing and prescribing (national) futures. I am basing my account on document analysis, media analysis and 30 interviews with academic, business and state actors involved in drug innovation in Russia.

The lack of locally developed and produced drugs in Russia has been predominantly framed as a paramount threat to national security. Country's dependence on foreign companies in delivering medicines and a current failure of local companies to harvest profits from the growing Russian market have been assessed as long-term risk factors. The intensified state efforts to stimulate and support drug innovation, that involve distributing funding, constructing infrastructural objects such as (bio)medical clusters and creating dedicated development institutes, co-produce a vision of an independent and self-sufficient nation. Sociotechnical imaginary of a country with a strong local (bio)pharmaceutical industry and state-of-the-art biomedical research institutes has been consolidated by invoking the possibilities of international isolation. As a medical scientist, participating in a Pharma 2020 working group, said: 'If a situation deteriorates, we will have everything here'. Interestingly, in this vision health needs of the individual citizens have been receding on the background, being overshadowed by images of a potent national industry.

The perception of scientific and technological advances as a driver of economic and social development has been prominent globally. Correspondingly, it prompted a wide adoption of policies and influx of state funds aimed at stimulating these advances (Gibbons et al.,

1994). At the same time, new knowledge and technologies are being produced, promoted and assessed differently in various sociopolitical worlds of nation states (see, for instance Sunder Rajan, 2005). In the era of globalization science and technology policies are still closely intertwined with nationhood (Jasanoff, 2005). Analyzing national innovation projects and sociotechnical imaginaries being co-produced (Jasanoff, 2004) alongside their conception and realization is important for advancing our understanding of global politics and governance of science and technology.

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