

# Conference "IV International Conference "Social Sciences & Health Innovations: Multiplicities"

Olga Zvonareva, Olga Ustyuzhantseva, Ekaterina Borozdina, Alexandra Endaltseva, Evgeniya Popova, Klasien Horstman, Jessica Mesman, Susanne E Bauer

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IV International Conference

# Social Sciences & Health Innovations: Multiplicities

MAY 23-25, 2019, TOMSK

### PROGRAMME



#### Chairman (s) of the Organizing Committee

Yu.V. Kistenev, Deputy Vice Rector for Research, Director of the "Institute of Biomedicine", Tomsk State University

#### **Deputy Chairman of the Organizing Committee**

E.V. Popova, Director of the Centre for Policy Analysis and Studies of Technologies, Tomsk State University

#### Members of the organizing committee

O.V. Ustyuzhantseva, Senior Researcher, the Centre for Policy Analysis and Studies of Technologies, Tomsk State University

E.A. Borozdina, Senior Researcher of the the Centre for Policy Analysis and Studies of Technologies, Tomsk State University, Associate Professor of the European University at St. Petersburg

O.I. Zvonareva, Researcher, Department of Health, Ethics of Social Research, School of Public Health and Therapeutic Services, Faculty of Health and Medicine and Natural Sciences, University of Maastricht, Netherlands

O.S.Fedorova, Professor of the Faculty of Pediatrics Department with a course of childhood diseases of the Medical Faculty of the Siberian State Medical University

M.S.Netaeva, Head of the International Cooperation Department, Siberian State Medical University L.A. Torlopova, junior researcher, the Centre for Policy Analysis and Studies of Technologies, Tomsk State University

A.M. Kamenshchikova, PhD Student, Department of Health, Ethics of Social Research, School of Public Health and Therapeutic Services, Faculty of Health and Medicine and Natural Sciences, University of Maastricht, The Netherlands

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O.I. Zvonareva, Researcher, Department of Health, Ethics of Social Research, School of Public Health and Therapeutic Services, Faculty of Health and Medicine and Natural Sciences, University of Maastricht, Netherlands

E.S. Kulikov, Vice-Rector for Research and Postgraduate Training, Siberian State Medical University

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Yu.V. Kistenev, Deputy Vice Rector for Research, Director of the "Institute of Biomedicine" O.V. Ustyuzhantseva, Senior Researcher, the Centre for Policy Analysis and Studies of Technologies E.A. Borozdina, Senior Researcher of the Centre for Policy Analysis and Studies of Technologies, Associate Professor at the European University in St. Petersburg

Klasien Horstman, Professor of Philosophy of Public Health, Faculty of Health Care Medicine and Natural Sciences, School of Public Health Emergency Medical Services, Maastricht University, Netherlands Jessica Mesman, Assistant Professor, Faculty of Arts, Social Research, Maastricht University, the Netherlands

O.S.Fedorova, Professor of the Faculty of Pediatrics Department with a course of childhood diseases of the Medical Faculty of the Siberian State Medical University

### **Organizing Committee:**

**OLGA ZVONAREVA (CHAIR)**, Maastricht University, Tomsk State University, Siberian State Medical University.

**OLGA USTYUZHANTSEVA**, Tomsk State University

**EKATERINA BOROZDINA**, European University at St.Petersburg, Siberian State Medical University

**ALEXANDRA ENDALTSEVA**, École des Hautes Études en Sciences Sociales\ Linköping University

### **Advisory Committee:**

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SUSANNE BAUER, Oslo University

The conference is supported by the Russian Foundation for Basic Research, project 19-013-20078\19













|          |  | 7:1                         |                          |   | 1000  |                         |  | 17-                              |
|----------|--|-----------------------------|--------------------------|---|---|-------------------------|--|----------------------------------|
|          | Ma   | May 25'                     |                          |   | May 24"                                       |                         | May 25                                     |                                  |
| 9:30     | Confer   | Conference Hall             |                          | Ϋ́  | Keynote lecture                               |                         | <b>Making Socialist</b>                    | States and                       |
|          | (room 229,   | (room 229, Main Building)   |                          | Impression                                      | Impressionable Bodies: corporeal              | orporeal                | Drugs: Develop-                            | happenings of                    |
| 10:00    | Participan   | Participant registration    |                          | plasticity and biosociality from ancient        | biosociality fr                               | om ancient              | ing, Testing and                           | health-1                         |
| 10:30    | Conference o   | Conference opening. Welcome | ne                       | medici  | medicine to epigenetics                       | tics                    | Smuggling New                              | Small Conference                 |
|          |  |                             |                          | )W  | (Maurizio Meloni)                             |                         | <b>Pharmaceuticals</b>                     | Hall (Research                   |
|          |  |                             |                          | Conference Hall                                 | Conference Hall (Research Library of TSU, old | of TSU, old             | in Central and                             | Library of 150, old<br>building) |
| 11.00    | tonyo  | Kownote lecture             |                          |   | (Suma)  |                         | Eastern Europe,                            | 1                                |
| <u>.</u> | Patient organizations' nolitics of knowledge           | s' nolitics of              | knowledge                |   | Coffee-break                                  |                         | ca. 1930-1990.                             |                                  |
|          | and the multiple paths of democracy                    | paths of dem                | locracy                  |   |   |                         | search Library of TSU)                     |                                  |
| 11:30    | (Vololona  | (Vololona Rabeharisoa)      | ,                        | Beyond one                                      | Interactions                                  | Knowl-                  | Coffee-break                               | reak                             |
| 12:00    | Keynot   | Keynote lecture             |                          | health. The                                     | and rela-                                     | edges and               | Keynote lecture                            | ecture                           |
| 12:30    | The role of patient community in the Russian           | mmunity in t                | he Russian               | politics of                                     | tionships-1                                   | practic-                | Borders, medical geography and             | geography and                    |
|          | healthca   | healthcare system           |                          | inclusion and                                   | Small Con-                                    | es-2                    | the new epidemiological imagi-             | logical imagi-                   |
|          | (Yan   | (Yan Vlasov)                |                          | multiplicity-1                                  | ference Hall                                  | Room 75A                | nation                                     | Ē                                |
| 13:00    | Discussion: roles for patients and patient             | r patients an               | d patient                | English Reading                                 | (Research                                     | (Research               | (Komatra Chuengsatiansup)                  | igsatiansup)                     |
|          | organ  | organisations               |                          | Room (Research<br>Library of TSLI)              | Library of 150,<br>old building)              | Library of<br>TSU)      | Conference Hall (room 229, Main Building)  | 229, Main Building)              |
| 13:30    | 1  | Lunch                       |                          | (2)   | Lunch   |                         | Lunch                                      | 4                                |
|          |  | 1000                        | 7000000000               |   | 040:40  | Modolo                  | \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \      | Ctato                            |
|          | ine backstage or                                       | International               | Nnowledges               | beyond One                                      | Interactions                                  |                         | Antimicropial re-                          | States and                       |
| 15:00    | patient organiza-                                      | Collaboration               | and practic- Health. The | Health. The                                     | and rela-                                     | ot mental               | sistance. Building                         | happenings of                    |
| _        | tions' work: how                                       | in Innovating               | es-1                     | Politics of                                     | tionships-2                                   | health and              | health and cross-disciplinary              | health-2                         |
| 00:9     |  | for Health:                 | Reading Room             | Inclusion and                                   | Small Con-                                    | illness                 | collaborations                             | Room 75A                         |
|          | come into being Cha                                    | Challenges and              | No/ (Kesearch            | Multiplicity-2                                  | ference Hall                                  | Room 75A                | Small Conference Hall                      | (Research Library                |
|          | Small Conference Hall <b>Opp</b>                       | Opportunities Page 1        | Library of 15U)          | Reading Room                                    | (Research<br>Library of TSU,                  | (Research<br>Librarv of | (Research Library of<br>TSU. old buildina) | of 15U)                          |
|          |  | Library of TSU)             |                          | Library of TSU)                                 | old building)                                 | TSU) 🤇                  |  |                                  |
| 16:30    | Coffe  | Coffee-break                |                          | )   | Coffee-break                                  |                         | Coffee-break                               | reak                             |
| 17:00    | Roun   | Round Table                 |                          |   | Round Table                                   |                         | Round Table                                | able                             |
| 17:30    | Health and society perspectives:                       | iety perspect               | ives:                    | Ι   | Healthy cities                                |                         | Media, wellbeing, and health               | s, and health                    |
| 18:00    | When bridgi  | When bridging goes wrong    | Jg.                      | Small Conference Hall (Research Library of TSU, | Hall (Research Libr                           | ary of TSU,             | Small Conference Hall (Research Library of | esearch Library of               |
| 18:30    | Small Conference Hall (Research Library of TSU, old bu | ch Library of TSU           | I, old building)         | old building)                                   |   |                         | TSU, old building)                         |                                  |
| 19:00    |  |                             |                          |   |   |                         | Banquet                                    | iet                              |
| 20:00    |  |                             |                          |   |   |                         |  |                                  |

# May 23<sup>rd</sup>, 2019

Conference Hall (room 229, Main Building)

10:00 - 10:30 Participant registration

10:30 – 11:00 CONFERENCE OPENING. WELCOME

Conference Hall (room 229, Main Building)

**Chair:** Prof. Klasien Horstman, Maastricht University; Dr. Olga Zvonareva,

Maastricht University

11:00 - 12:00 KEY-NOTE LECTURE: Patient organizations' politics of knowl-

edge and the multiple paths of democracy

Key-note lecture by **Vololona Rabeharisoa**, Professor of Sociology, Center for the Sociology of Innovation, PSL MINES ParisTech, France

Chair: Dr. Evgeniya Popova, Tomsk State University; Prof. Olga Fedorova,

Siberian State Medical University

12:00 – 13:00 KEY-NOTE LECTURE: The role of patient community in the Rus-

sian healthcare system

Keynote lecture by **Yan Vlasov**, Professor of Neurology and Neurosurgery, Samara State Medical University, Russia; Chair of the Patient

Protection Council and Co-chair of the Russian Patients Union

Chair: Dr. Evgeniya Popova, Tomsk State University; Prof. Olga Fedorova,

Siberian State Medical University

13:30 - 14:30 LUNCH BREAK

14:30 - 16:30 PARALLEL SESSIONS

### BP: THE BACKSTAGE OF PATIENT ORGANIZATIONS' WORK: HOW LOCAL PRACTICES COME INTO BEING

Small Conference Hall (Research Library of TSU, old building)

Online practice sharing session: representatives of Russian patient movement share their ways of knowing how to live well with chronic illness across the vast territories.

Chair: Dr. Oleg Lavrov, KM Alliance; ovlavrov@mail.ru; Alexandra Endalt-

seva, École des Hautes Études en Sciences Sociales\ Linköping Univer-

sity; aendalts@gmail.com

**Commentator:** Yan Vlasov, MD, co-chair, Russian Patients Union

- **14:30 15:00** Ipatov, O (Russian Multiple Sclerosis Society): online community and maintaining Internet resources
- **15:00 15:30** Zuev, S. (Moscow Multiple Sclerosis Society): the making of online MS patient school
- **15:30 16:00** Kargalskaya, I. (co-chair, Patient-oriented telemedicine committee, Russian Patients' Union): Onconet and what it means for patient-oriented healthcare
- **16:00 16:30** Churakov, M. (Social Mechanics): sociological research as patient activism

## IC: INTERNATIONAL COLLABORATION IN INNOVATING FOR HEALTH: CHALLENGES AND OPPORTUNITIES

### Room 75A (Research Library of TSU)

This session will focus specifically on collaborative ties between Norway and Russia and engage with the questions: What are the current cooperative activities in the research and innovation sector? How are relevant stakeholders engaged? What kinds of strategic investments are involved in different projects?

- **Chair: Dr. Evgeniya Popova**, Tomsk State University; <u>iam.e.popova@yandex.ru</u>
- **14:30 15:00** Trengereid Radina, Advisor on education, science and technology, Norwegian Embassy in Russian Federation. Research and Business within Health Priorities and Opportunities within the Norwegian-Russian cooperation
- 15:00 15:30 Belyaev Alexander, Director of the Center for development of foreign economic actiity (regional center for export support) of the Tomsk Chamber of Commerce and Industry. Russian-Norwegian business cooperation: lessons from the past
- **15:30 16:00** Bauer Susanne, Professor, Centre for Technology, Innovation and Culture. Common activities on research and education, TIK Centre (Oslo University) and PAST-Centre (Tomsk State University)

### **KP-1: KNOWLEDGES AND PRACTICES-1**

### Reading Room №7 (Research Library of TSU)

This first part of the thematic stream "Knowledges and practices" focuses on relations between different kinds of knowledge that meet, clash, compete, and co-exist in health care and medical research. Authors of the papers to be presented here go beyond the apparent uniformity of the knowledge that is relevant and useful for treating people and developing medical technologies. They also reveal the multiplicity of knowledge-based practices in medical research and care and raise questions about the nature of expertise and ways in which divergent knowledges and knowledge-based practices can be productively bridged.

Chair: Prof. Ana Delgado, Univeristy of Oslo; ana.delgado@tik.uio.no

**14:30 – 15:00** Objectified subjectivity: Multiple modes of knowledge production among epileptic patients. Tereza Sedlackova (Faculty of Social Sciences, Charles University, Czech Republic; <a href="mailto:tereza.sedlackova@fsv.cuni.cz">tereza.sedlackova@fsv.cuni.cz</a>)

15:00 - 15:30 Informal professionalization of healthy participants in phase I clinical trials in Russia. Olga Zvonareva (Maastricht University, Netherlands; o.zvonareva@maastrichtuniversity.nl)

**15.30 – 16:00** Multiple interactions between home midwives and maternity hospitals in Russia. Anna Ozhiganova (Institute of Ethnology and Anthropology Russian Academy of Sciences, Russian Federation; <a href="mailto:anna-ozhiganova@yan-dex.ru">anna-ozhiganova@yan-dex.ru</a>).

**16:00 – 16:30** «The multiplicity of morality»: the case of genetic experiments on embryos. Elena Vvedenskaya (Pirogov Russian National Research Medical University (RNRMU), Russian Federation; <a href="wvedenskaya.elena@gmail.com">wvedenskaya.elena@gmail.com</a>)

16:30 - 17:00 **COFFEE BREAK** 

17:00 – 19:00 ROUND TABLE: Health and society perspectives: When bridging goes wrong. Confession session

Small Conference Hall (Research Library of TSU, old building)

**Chair: Dr. Ekaterina Borozdina**, European University at <u>St.Petersburg</u>; <u>eborozdina@eu.spb.ru</u>; Alexandra Endaltseva, École des Hautes Études en Sciences Sociales\ Linköping University; aendalts@gmail.com

Bridging is a reflection anchor, an ethical guidance and a practical labor for many positioned at the intersection of health and society. It is a part and parcel of STS professional and activist routines. We build connections between different topics and issues; we develop international and interdisciplinary networks; we forge together different methods of study, and we aspire to account to the multitude of perspectives: scientists', practitioners', patients'.

However, bridging is a risky and not so innocent enterprise. As we try to merge different dimensions, different approaches, different life worlds, many things can (and do) go wrong. There is always fragility and uncertainty at the point of stitch between different areas.

With this session we intend to share our experiences of something going wrong in the process of bridging. What are the main challenges that we encounter while bridging health and society in the variety of their manifestations? What are the solutions that we work out for these cases? And what hints should we keep in mind to prevent a slip next time?

We propose an experimental session, where each participant is essential for the happening of knowledge and (why not) healing.

# May 24<sup>th</sup>, 2019

9:30 – 11:00 KEY-NOTE LECTURE: Impressionable Bodies: corporeal plastici-

ty and biosociality from ancient medicine to epigenetics

Conference Hall (Research Library, Old Building)

Keynote lecture by **Maurizio Meloni**, Associate Professor of Sociology, Alfred Deakin Institute for Citizenship and Globalisation, Deakin University, Australia; co-editor of the recent Palgrave Handbook of Biology

and Society and Biosocial Matters.

**Chair**: **Dr. Alexander Yashchuk**, Siberian State Medical University; <u>alexnil@</u>

mail.ru; Prof. Susanne Bauer, University of Oslo; susanne.bauer@

tik.uio.no

11:00 - 11:30 COFFEE BREAK

11:30 - 13:30 **PARALLEL SESSIONS** 

### BH-1:BEYOND ONE HEALTH. THE POLITICS OF INCLUSION AND MULTIPLICITY-1

### English Reading Room (Research Library of TSU, New Building)

One Health, as understood in global health, proposes to integrate animals and plants but also microbial ecologies, which have been neglected previously. However, integration can also produce new exclusions, when it strives to channel the world through new universalizing frameworks.

Chair: Dr. Olga Ustyuzhantseva, PAST Centre; olgavust@gmail.com

- 11:30 12:00 'One health' and the quest for integration: Locating the digital ecologies of more-than-human health. Susanne Bauer (University of Oslo, Norway; <a href="mailto:susanne.bauer@tik.uio.no">susanne.bauer@tik.uio.no</a>)
- **12.00 12:30** Viruses as a Subject of Social Sciences and Humanities. Svetlana Martynova (The Herzen State Pedagogical University of Russia, Russian Federation; <a href="mailto:svetlanus.martinova@yandex.ru">svetlanus.martinova@yandex.ru</a>)
- **12:30 13:00** Bioprospecting for new antibiotic compounds and the promissory nature of infrastructures. Ana Delgado (Univeristy of Oslo, Norway; <a href="mailto:ana.delgado@tik.uio.no">ana.delgado@tik.uio.no</a>)
- **13:00 13:30** Attending to microbes. Anne Lie (Universitetet i Oslo, Norway; <a href="mailto:ahlie@medisin.uio.no">ahlie@medisin.uio.no</a>)

#### IR-1: INTERACTIONS AND RELATIONSHIPS-1

### Small Conference Hall (Research Library of TSU, old building)

What does happen and why when doctors and patients or medical researchers and research participants meet? This long-considered question calls for re-examination nowadays, when mutual expectations change, medical institutions evolve, and new technologies emerge. Authors in this session consider anew how doctors, physician-researchers, and patients view one another, how they understand and manage frictions, and what kinds of options we can consider for enabling more rewarding relations.

- **Chair:** Anna Ozhiganova, Institute of Ethnology and Anthropology Russian Academy of Sciences; <a href="mailto:anna-ozhiganova@yandex.ru">anna-ozhiganova@yandex.ru</a>
- 11:30 12:00 'Moaners' vs. 'deceivers': multiplicities of perspectives situated in the perinatal center. Anastasiia Novkunskaya (European University at Saint-Petersburg, Russian Federation; a.novkunskaya@gmail.com)
- **12:00 12:30** "Uneasy" Patient in Urban Russian Maternity Hospital: Not a Single One. Anna Temkina (European University at St.Petersburg, Russian Federation; <u>atemkina@gmail.com</u>)
- **12:30 13:00** How to Protect the Vulnerable Ones: the Attitude of Future Doctors to Clinical Trials of Pharmaceuticals. Tamara Vladimirovna Mescheryakova, Olga Vladimirovna Gerasimova (Siberian State Medical University, Russian Federation; <a href="mailto:mes-tamara@yandex.ru">mes-tamara@yandex.ru</a>, <a href="mailto:okamastro@mail.ru">okamastro@mail.ru</a>)
- **13:00 13:30** (De)constructing vulnerability in clinical trials. Alena Kamenshchikova (Maastricht University, Netherlands, The; a.kamenshchikova@maastrichtuniversity.nl)

### **KP-2: KNOWLEDGES AND PRACTICES-2**

### Room 75A (Research Library of TSU)

This second part of the thematic stream 'Knowledges and practices' focuses on the contingent ways in which doctors, patients, and medical researchers relate to the ideas and practices of Evidence-Based Medicine (EBM). EBM relies on randomized controlled clinical trials as the key source of reliable evidence regarding safety and efficacy of newtreatments. Authors of the papers to be presented here investigate how doctors make decisions in practice and navigate multiple sources of evidence, while negotiating constraints institutions place on their options; how participation in clinical trials influences subsequent treatment trajectories of the patients; and how debates currently evolve about which trial designs are better for producing evidence for medical practice.

- **Chair: Dr. Olga Zvonareva**, Maastricht University; <u>o.zvonareva@</u> maastrichtuniversity.nl
- 11:30 12:00 Making clinical decisions: between EBM and institutional constrains. Ekaterina Borozdina (European University at St.Petersburg, Russian Federation; Siberian State Medical University; eborozdina@eu.spb.ru)

- 12:00 12:30 Management of decision making in real clinical practice. Denis Tyufilin, Igor Pimenov (Siberian State Medical University, Russian Federation; <a href="mailto:dtufilin@gmail.com">dtufilin@gmail.com</a>)
- 12:30 13:00 The key to improving the quality of treatment: the impact of participation in RCT on patient's compliance and adherence. Sergey Yu. Martsevich, Natalia P. Kutishenko, Yulia V. Lukina, Natalia O. Vasyukova (Federal State Institution «National Medical Research Center for Preventive Medicine» of the Ministry of Healthcare of the Russian Federation, Russian Federation; <a href="mailto:natalia\_vasyukova@bk.ru">natalia\_vasyukova@bk.ru</a>)
- 13:00 13:30 New Approaches to Clinical Trial Designs: Appear of New Bioethical Dilemmas in 20-21 Centuries. Igor Pimenov, Fimushkina Natalia (Siberian State Medical University, Russian Federation; <a href="mailto:igor.d.pimenov@gmail.com">igor.d.pimenov@gmail.com</a>)
- 13:30 14:30 LUNCH BREAK
- 14:30 16:30 PARALLEL SESSIONS

### BH-2: BEYOND ONE HEALTH. THE POLITICS OF INCLUSION AND MULTIPLICITY-2

### Reading Room Nº7 (Research Library of TSU)

One Health, as understood in global health, proposes to integrate animals and plants but also microbial ecologies, which have been neglected previously. However, integration can also produce new exclusions, when it strives to channel the world through new universalizing frameworks.

### **Chair:** Prof. Susanne Bauer, University of Oslo; <a href="mailto:susanne.bauer@tik.uio.no">susanne.bauer@tik.uio.no</a>

- 14:30 15:00 Stool and stories: Studying antimicrobial resistance among longitudinal cohort of mobile international global health students. Alena Kamenshchikova (Maastricht University, Netherlands, The; <a href="mailto:a.kamenshchikova@maastrichtuniversity.nl">a.kamenshchikova@maastrichtuniversity.nl</a>)
- 15:00 15:30 Between 'disease' and 'illness': cases of communicative clashes during genetic counseling. Aleksandra Sergeevna Kurlenkova¹, Shirokov Alexandr² (¹Institute of Ethnology and Anthropology, United States of America; ²National Research University Higher School of Economics; askurlenkova@gmail.com, needeeds@gmail.com)
- **15:30 16:00** Space and time as axes of disability constructing. Lyubov Torlopova (National Research Tomsk State University, Russian Federation; <a href="mailto:lyubovtorlopova@gmail.com">lyubovtorlopova@gmail.com</a>)
- **16:00 16:30** Citizens involvement in innovations: A pilot of MedHack in Tomsk Hospitals. Olga Ustyuzhantseva, Eugenia Popova (PAST Centre, Russian Federation; olgavust@gmail.com, lam.e.popova@yandex.ru)

#### IR-2: INTERACTIONS AND RELATIONSHIPS-2

### Small Conference Hall (Research Library of TSU, old building)

This second part of the thematic stream 'Interactions and relationships' moves forward to consider the complexity of technological and societal change. When such far-reaching alterations as digital technologies enter the scene, what do concerned actors, including decision-makers, developers, healthcare workers, and patients do to direct the use of the technologies and manage their consequences? What are the implications of the new knowledge provided by advances of epigenetics for how we understand our responsibilities towards future generations? How are families changing together with wider social, demographic, and digital shifts? Papers in this session allow close tracing of how interactions and relationships between actors, existing and imagined, are shaped together with ongoing sociotechnical transformations.

- **Chair: Prof. Anna Temkina**, Europeam University at St.Petersburg; <a href="mailto:atemkina@gmail.com">atemkina@gmail.com</a>
- 14:30 15:00 E-Health in Russia: Uniformity versus [Unwanted] Diversity. Anna Trakhtenberg, Elena Dyakova (Institute of Philosophy and Law, Ural Branch of the Russian Academy of Sciences, Russian Federation; <a href="mailto:cskiit@yandex.ru">cskiit@yandex.ru</a>)
- 15:00 15:30 Multiple technoworlds of modern medicine. Elena Grebenshchikova (¹Institute of Scientific Information for Social Sciences of the Russian Academy of Sciences, Russian Federation; ²Pirogov Russian National Research Medical University; aika45@ya.ru)
- **15:30 16:00** Gender-related health trajectories and changing families in Western Europe. Valentina Shipovskaya (Tomsk State University, Alumna / University of Zurich, Alumna; <a href="mailto:valenship@gmail.com">valenship@gmail.com</a>)
- **16:00 16:30** Epigenetics: A new challenge for intergenerational ethics. Alexander Yashchuk (Siberian State Medical University, Russian Federation; <a href="mail@mail.ru">alexnil@mail.ru</a>)

#### **MM: MODELS OF MENTAL HEALTH AND ILLNESS**

### Room 75A (Research Library of TSU)

This session aims to initiate discussion and support interaction in the field of mental health care at various levels: between those who experience mental health problems and those who do not; between members of local communities, including families of those who experience mental health problems; between different classifications, hierarchies and models of health and illness. Such interaction is necessary for improving quality of life and creating of effective technologies of preservation of health of the person and society.

**Chair: Prof. Elena V. Gutkevich**, Mental Health Research Institute, Tomsk NRMC, Tomsk; National Research Tomsk State University, Tomsk;

<u>gutkevichelena@gmail.com</u>; SVETLANA VLADIMIROVA, Mental Health Research Institute, Tomsk National Research Medical Center, Russia; <u>niipzso@gmail.com</u>

- 14:30 14:55 Formation of anti-relapse behavior of persons with mental health problems as a factor of heightening their quality of life and effective social communication. Elena V. Gutkevich<sup>1,2</sup>, Valentina F. Lebedeva<sup>1</sup>, Arkady V. Semke<sup>1</sup> (<sup>1</sup>Mental Health Research Institute, Tomsk NRMC, Tomsk; <sup>2</sup>National Research Tomsk State University, Tomsk, Russian Federation; gutkevichelena@gmail.com)
- 14:55 15:20 Experience of coexistence with the illness and change of behavior for successful interaction in the family and socium. Svetlana Vladimirova, Nikolay Bokhan, Yulia Maltseva (Mental Health Research Institute, Tomsk National Research Medical Center, Russia, Russian Federation; niipzso@gmail.com)
- 15:20 15:45 Clinical-psychological features of patients with relapse of non-psychotic mental disorders. Psychological correction of disadaptive behavioral models. Alla Ivanova<sup>1,2</sup>, Elena Epanchintseva<sup>1</sup>, Mikhail Axenov<sup>1</sup>, Elena Gutkevich<sup>1,3</sup>, Alexey Kostin<sup>1</sup>, Svetlana Vladimirova<sup>1</sup> (<sup>1</sup>Mental Health Research Institute, Tomsk National Research Medical Center, Russian Academy of Science; <sup>2</sup>Siberian State Medical University; <sup>3</sup>National Research Tomsk State University; <u>ivanova\_nezd@mail.ru</u>)
- 15:45 16:10 Psychological multiplicities of voluntary behavior of healthy persons of young age. Darya Ustyugova1, Valeria Golovina¹, Elena Gutkevich¹,² (¹National Research Tomsk State University, Tomsk; ²Mental Health Research Institute, Tomsk National Research Medical Center, Russia; gutkevichelena@gmail.com)
- **16:10 16:30** Multiple-factor model of pro-biotic adaptation of the organism and phenomics of health. Evgeny Gutkevich (FSBI SibFSCC FMBA of Russia, Russian Federation; bifidice@gmail.com)
- 16:30 17:00 COFFEE BREAK
- 17:00 19:00 ROUND TABLE: Healthy cities

Small Conference Hall (Research Library of TSU, old building)

**Chair:** Regina Malykh, Siberian State Medical University; <u>malykh\_regina@hotmail.com</u>

This round table invites participants to discuss how urban environment can promote health. Among round table speakers are representatives of the Tomsk city and regional administration, universities, and state and citizen organizations.

Despite the emergent trend to leave large cities for a life closer to nature, the United Nations estimates that 80% of the world population will be city dwellers by 2030. IBM

reports that every week one million people move to live in cities. Currently, 70% of the Russian population (about 100 million people) live in cities.

Cities struggle to care for the health of their residents under increasing pressure in terms of infrastructure, energy, and security. Health risks abound in cities. Think of the noise, pollution, social isolation, and environments stimulating physical inactivity. Yet, cities can also protect and improve health. Examples of actions to improve city health include healthy city planning, assessing health impacts of policies and projects, ensuring access of vulnerable groups to city spaces and services, and initiatives to address social exclusion and loneliness.

'Healthy cities' round table, inspired by the World Health Organization initiative by the same name, invites to discuss how city can protect and improve health of its residents. Among the round table participants are representatives of the Tomsk city and regional administration, universities and state and citizen organizations. Key questions for the round table include:

- What is 'healthy city'?
- What is the role of methods based on 'informing' and 'providing knowledge' to city population?
- Inclusion in the urban environment: what is done and what is next?
- Tomsk as a healthy city: how can physical and social environment in Tomsk support Tomsk residents' health, taking account of the local cultural, political, and epidemiological conditions? Which processes and structures are necessary for systematic and coordinated action to improve health? How to ensure responsiveness to people's health needs and participation of the city residents in governing health?

### Round table speakers:

1) Regina Malykh, Consultant for WHO European Healthy Cities Network, manager of the project 'Improving Healthcare Outcomes in Chronic Disease – Enhancing the Curriculum at Masters Level' supported by Erasmus+ Programme, vice-dean of the Distance Education Faculty, Siberian State Medical University.

"World Health Organization and its Healthy Cities Network: what are the contemporary urban health problems?"

- 2) Nataliia Gribova, Head of the Social Development Committee, Department of Social Protection of Tomsk region population.
- "Activity in senior age as a component of city health"
- 3) Evgenii Monastirski, Professor of Tomsk Polytechnic University, and Iliya Gumennikov, PhD candidate, School of Entrepreneurship in Engineering, Tomsk Polytechnic University "Population health in Tomsk region according to the Russian index of senior generation wellbeing (comparative analysis)"
- 4) Tatiana Sivolobova, Head of Frugal Technologies Centre and Fellow at the Department of Childhood Diseases, Siberian State Medical University. "Smart-technologies of health protection: example of the project Tomsk Region Health Laboratory"

# May 25<sup>th</sup>, 2019

9:30 - 11:30 PARALLEL SESSIONS

Chair:

SD: MAKING SOCIALIST DRUGS: DEVELOPING, TESTING AND SMUGGLING NEW PHARMACEUTICALS IN CENTRAL AND EASTERN EUROPE, CA. 1930–1990.

### Reading Room №7 (Research Library of TSU)

The panel focuses on the histories of new pharmaceuticals in the Soviet Union and the Polish People's Republic between the 1930s and the 1990s and considers their similarities, differences and entanglements with pharmaceuticals in the West.

Dr. Pavel Andrevevich Vasilvev. Van Leer Jerusalem Institute:

|              | pavelv@vanleer.org.il   |
|--------------|---|
| 9:30 - 10:00 | Urine for the New Soviet Man: Revisiting the Miracle Drug Gravidan. Pavel Andreyevich Vasilyev1,2,3 (1Van Leer Jerusalem Institute, Israel; |
|              | 2Siberian State Medical University, Russia; 3Hebrew University of Je-   |
|              | rusalem, Israel; <u>pavelv@vanleer.org.il</u> )   |

| 10:00 - 10:30 | Making Soviet drugs in the heart of Siberia: Clinical trials of Rhodiola |
|---------------|--|
|               | rosea in Tomsk in the 1960s and 1970s. Alexander Petrenko (Siberian      |
|               | State Medical University, Russian Federation; Alexandr_n@mail.ru)        |

| 10:30 - 11:00 | Designing Clinical Trials in the Second Half of the Twentieth Century: USSR |
|---------------|---|
|               | in the Global Context. Veronika Tayukina, Olga Zvonareva, Pavel Vasilyev    |
|               | (Tomsk State University, Russian Federation; nivero70@gmail.com)            |

11:00 - 11:30 Do the End justifies the means? espionage and biotechnology 1970-1990. Miroslaw Andrzej Sikora (Jagiellonian University, Poland; miroslaw.sikora@yandex.com)

#### SH-1: STATES AND HAPPENINGS OF HEALTH-1

### Small Conference Hall (Research Library of TSU, old building)

This first part of the thematic stream 'States and happenings of health' explores people's health experiences, both their own and of others. What is it like to live with multiple sclerosis or celiac disease? What is it like to use assistive technologies for navigating your environment? What is it like to care for dying patients and their relatives? Papers in this session open up a new space to consider theoretical approaches that can be productive for capturing and making sense of what takes place when people's health states change and/or diverge from those of others.

**Chair:** Anastasiia Novkunskaya, European University at Saint-Petersburg; a.novkunskaya@gmail.com

- 9:30 10:00 FROM THE ORIGINALLY TWADDLE'S TRIAD TO A NEW ESA-MODEL: THE NEW "SONETNESS". Cleto Corposanto (Magna Graecia University, Catanzaro Italy; cleto.corposanto@unicz.it)
- **10:00 10:30** CORPOREALITY, TECHNOLOGIES, AND SPATIALITY AS AXES OF DIS-ABILITY-OBJECT'S EXISTENCE. Lyubov Torlopova (National Research Tomsk State University, Russian Federation; <a href="mailto:lyubovtorlopova@gmail.com">lyubovtorlopova@gmail.com</a>)
- **10:30 11:00** Emotional labor of medical staff in hospice. Anastasiia Ugarova (European University at St.Petersburg, Russian Federation; <u>uas@gorod.org.ru</u>)
- 11:00 11:30 On co-labouring and living with 'a little bit less of oneself': Dialogue with many voices. Endaltseva Alexandra¹, Sonja Jerak-Zuiderent² (¹École des Hautes Études en Sciences Sociales, Linköping University; ²University of Amsterdam, Amsterdam, NL; aendalts@gmail.com, s.jerak-Zuiderent@amc.uva.nl)
- 11:30 12:00 **COFFEE BREAK**
- 12:00 13:30 <u>KEY LECTURE: Borders, medical geography and the new epidemiological imagination</u>

Conference Hall (room 229, Main Building)

Keynote lecture by **Komatra Chuengsatiansup**, medical anthropologist, medical doctor, and the director of the Society and Health Institute, which is part of the Ministry of Public Health, Thailand. His research on antimicrobial resistance follows antibiotics, microbes, and discourses to national and international arenas.

**Chair: Dr. Sergey Fedosenko**, Siberian State Medical University; s-fedosenko@mail.ru

13:30 - 14:30 LUNCH BREAK

14:30 – 16:30 **PARALLEL SESSIONS** 

### AR: ANTIMICROBIAL RESISTANCE. BUILDING CROSS-DISCIPLINARY COLLABO-RATIONS

### Small Conference Hall (Research Library of TSU, old building)

This panel will explore the potential of collaborations between human, animal, and environmental health professionals in addressing the rise of antimicrobial resistance, as well as possible obstacles and difficulties that can be met in cross-disciplinary work. The panel

will be organized around questions of whether it is possible to match interests of medical doctors, veterinarians, patients, animals, and environments, and how? And whether non-humans, such as bacteria, should be included in these collaborations, and why?

- **Chair: Prof. Klasien Horstman**, Maastricht University; k.horstman@maastrichtuniversity.nl; Alena Kamenshchikova, Maastricht University; a.kamenshchikova@maastrichtuniversity.nl
- **14:30 14:55** Antimicrobial resistance in Thailand: complex relations between medical, agricultural and environmental sectors. Komatra Chuengsatiansup (Ministry of Public Health, Thailand; <a href="mailto:loxlix@gmail.com">loxlix@gmail.com</a>)
- **14:55 15:20** International travel and antimicrobial resistance: Exploring narratives of daily life with bacteria. Alena Kamenshchikova (Maastricht University, Netherlands, The; <u>a.kamenshchikova@maastrichtuniversity.nl</u>)
- 15:20 15:45 Antimicrobial resistance in Russia: Complex interrelations between human and animal health sectors. Sergey Vyacheslavovich Fedosenko (Siberian State Medical University, Russian Federation; <a href="mailto:s-fedosenko@mail.ru">s-fedosenko@mail.ru</a>)
- 15:45 16:10 Antibiotic use and antimicrobial resistance perception: survey in medical specialists, pharmacists and patients in Tomsk, Russian Federation. Marina Fedotova (Siberian State Medical Universuty, Russian Federation; <a href="mailto:fedotova.letter@gmail.com">fedotova.letter@gmail.com</a>)
- **16:10 16:30** Antimicrobial resistance in National Action Plans of Russia and China. Veronika Anatolyevna Tayukina (Tomsk State University, Russian Federation; <a href="mailto:nivero70@gmail.com">nivero70@gmail.com</a>)

### **SH-2: STATES AND HAPPENINGS OF HEALTH-2**

### Room 75A (Research Library of TSU)

This second part of the thematic stream 'States and happenings of health' considers how different health conditions become defined and how notions of an appropriate intervention are shaped. Using examples such as vegetovascular dystonia, popularly diagnosed in the Soviet Union, authors in this session explore social and political circumstances that make particular disease definitions possible and promote certain approaches addressing health problems over others. This session builds on in-depth, partly historical narratives, and provides rich material for reflecting on the drivers and implications of change in disease categories and accepted treatment approaches.

- **Chair:** Lyubov Torlopova, National Research Tomsk State University; <a href="mailto:lyubovtorlopova@gmail.com">lyubovtorlopova@gmail.com</a>
- **14:30 15:00** Historical Multiplicity of Vegetovascular Dystonia Illness. Anastasia Beliaeva (Russian National Medical Research University, Russian Federation; Gurenovitz@gmail.com)
- **15:00 15:30** Actors as networks: Internal Family Systems Therapy (IFS) and autoimmunity. Márcio da Cunha Vilar (University of Sussex, United Kingdom; md542@sussex.ac.uk)

- **15:30 16:00** Nutritional Anemia and programmatic approaches in India: Reexamining the global health theories of Anemia. Rahul Rauny (Jawaharlal Nehru University, New Delhi, India; rahulcsmch@gmail.com)
- **16:00 16:30** Children's morbidity and mortality in XIX century in Tomsk, Western Siberia. Valeriya Prokopyeva, Malchuk V.N., Fedorova O.S.(SSMU, Russian Federation; <a href="mailto:valeriya.d.prokopyeva@gmail.com">valeriya.d.prokopyeva@gmail.com</a>)

### 16:30 - 17:00 **COFFEE BREAK**

### 17:00 - 19:00 ROUND TABLE: Media, wellbeing, and health

### Small Conference Hall (Research Library of TSU, old building)

This round table brings together representatives from the media, anthropology, and medicine domains to discuss how media can be helpful in understanding and improving health and wellbeing.

This round table aims to provide a platform for discussing the roles of media in understanding and improving the wellbeing of an individual and society. Representatives of the media, anthropology, and medicine fields will present their views on the topic. As a result, participants of the round table will address the key question of how media can be useful for supporting wellbeing and health.

### Key themes:

- Impacts of health communication in the media on health of individuals;
- Life of communities and the media: studying health and wellbeing of social groups and their members.

#### Questions for discussion:

- What approaches and technologies can media productively use to improve health and wellbeing of communities and individuals? How can we appraise the effectiveness of such kind of work?
- How can decision-makers, scientists, and media experts collaborate in creating media projects with the purpose of addressing the problems of communities and individuals?

### Chair:

**Ilya Myasnikov**, Tomsk State University; <u>bit.magazine@gmail.com</u>; **Valentina Evgenyevna Ershova**, Tomsk State University; <u>ervalen@yandex.ru</u>

### Round table speakers:

Valentina Evgenyevna Ershova (Tomsk State University, Russian Federation; <a href="mailto:ervalen@vandex.ru">ervalen@vandex.ru</a>)

Alexander Chernov (Tomsk Regional Center for Prevention and Treatment of AIDS and other Infectious Diseases, Russian Federation; zvonoks@gmail.com)

Vyacheslav Perminov (The Bureau of Medical and Social Examination in Tomsk Region of Ministry of Labor in the Russian Federation, Russian Federation; <a href="mailto:ervalen@vandex.ru">ervalen@vandex.ru</a>)

Elena Petrova (Children's Charity Foundation named after Alyona Petrova, Russian Federation; <a href="mailto:ervalen@yandex.ru">ervalen@yandex.ru</a>)

Anton Unitsyn (Union of Photographic Artists, Russian Federation; <a href="mailto:ervalen@yandex.ru">ervalen@yandex.ru</a>)

Olga Zakharova, Marina Astakhova (Tyumen State University, Russian Federation; <a href="mailto:ervalen@yandex.ru">ervalen@yandex.ru</a>)

Vasily Aleksandrovitch Vershinin (Tomsk State University, Russian Federation; <a href="mailto:virshinin@gmail.com">virshinin@gmail.com</a>)

19:00 - 21:00 BANQUET

#### **ABSTRACTS**

#### **KEY-NOTE LECTURES**

### PATIENT ORGANIZATIONS' POLITICS OF KNOWLEDGE AND THE MULTIPLE PATHS OF DEMOCRACY

Key-note lecture by **Vololona Rabeharisoa**, Professor of Sociology, Center for the Sociology of Innovation, PSL MINES ParisTech, France

In a number of European countries and in North America, patient organizations are today regarded as stakeholders in the domain of health and medicine. Their political and social recognition signposts a larger phenomenon of extension of democratic imperative to activities and debates that have long been the preserve of experts. This extension does not always run smooth and straightforward though, for it questions the epistemic basis for decision-making. How did all this begin? How do patient organizations strive to establish their epistemic authority in order to transform the shaping and governance of medical and health issues? What does patient activism teach us about the forms of democracy in contemporary liberal societies? Those are the questions that I will be addressing in this communication.

Drawing on past and recent research works that I have conducted with my colleagues, I will first display a few historical landmarks on the emergence of patient organizations in Europe and North America in the 1930s-1940s. I will show that patient organizations have always put patients' experience at the core of their missions, be it mutual help or advocacy.

I will then move on to the 1980s onwards, when certain patient organizations have started to turn their experience into a body of knowledge, and to fight for their "experiential knowledge", as it is called, be considered as a relevant corpus of knowledge for forging evidence on medical and health issues that they deem important and legitimate to tackle at an individual and a collective level. My colleagues and I call this form of patient activism "evidence-based activism." I will provide a few examples of how this experiential knowledge and expertise is produced and targeted to a variety of domains, ranging from the clinical understanding of diseases to the functioning of health systems and the pricing of drugs.

Finally, I will provide a few reflections on the progressive institutionalization of the figure of the "expert patient", a category that is today part and parcel of institutional parlance. I will show that though this institutionalization brings in recognition and legitimacy to patients' participation to health policy-making, it also comes with debates on the multiple paths of democracy in contemporary liberal societies.

#### THE ROLE OF PATIENT COMMUNITY IN THE RUSSIAN HEALTHCARE SYSTEM

Keynote lecture by **Yan Vlasov**, Professor of Neurology and Neurosurgery, Samara State Medical University, Russia.

A patient is an individual who has entered into a legal relationship with the medical professional (or institution) and has received rights and obligations associated with this relationship. In Russia, the protection of patients' rights is shaped by the operation of the national healthcare system. The resources and medical knowledge, for example, are not equally distributed within the national borders. This results in considerable differences in the quality of medical care between the urban and rural areas, the western and the eastern regions, and as well - between the territories with the state and departmental affiliation. These differences lead to the breach of patients' rights in the regions, to the decrease of the quality of life and of the lifespan itself, to the increase of social diseases burden, to migrations and conflicts, and to the increased number of court cases. Finally, they lead to a decrease of trust in the medical knowledge, to the growing number of crimes against medical workers, and to the turn towards healers and psychic practices. The emergence of patient movement, the establishment of public organisations of patients, and the patients' involvement in public control over the quality of care have improved the Russian healthcare system a lot, introducing the idea of patient-centered care. However, it has not solved the main problem: the inequalities in access to quality health care. In this talk, I will discuss the failure of current legislation to ensure the equality of access to medical care and the practices of patient organisations to influence the current situation: evaluation of services, reports to the departments and the state, and sociological analysis of patients' complaints. Finally, I introduce eight recommendations based on real patients' experience for the improvement of the Russian healthcare system.

### IMPRESSIONABLE BODIES: CORPOREAL PLASTICITY AND BIOSOCIALITY FROM ANCIENT MEDICINE TO EPIGENETICS

Keynote lecture by **Maurizio Meloni**, Associate Professor of Sociology, Alfred Deakin Institute for Citizenship and Globalisation, Deakin University, Australia; co-editor of the recent Palgrave Handbook of Biology and Society and Biosocial Matters: Rethinking Biology-Sociology Relationships.

Emerging postgenomic disciplines like epigenetics and microbiomics are contributing today to a rewriting of the human body as profoundly permeable to its surroundings and extensively shaped by environmental factors. These views of biological plasticity represent an important discontinuity with the bounded body of twentieth century biomedicine and genetics. By blurring the boundary between the inner and outer of the body, they contribute to an entangled reading of biological and social factors which goes well beyond twenty century debates about 'interaction'.

Although these views are often presented in terms of biomedical innovation, the phenomenological experience of living with a permeable body and thinking in terms of biosocial factors is far from being new. In my talk, I offer an archaeology of the plastic body that is emerging in contemporary postgenomic disciplines and its knowledge implications in terms of biosociality. I investigate a longer history of the beliefs about the plasticity of human biology, and the inextricability of 'biological' and 'environmental' factors, starting

with ancient and early modern medicine, mostly humoralism. I then analyse the biopolitical techniques required to govern such permeability, by focusing in particular on the way in which notions of corporeal plasticity have been connected with profoundly racialized and gendered discourses in ancient and early modern times. I also highlight how a longer history of plasticity may help problematize contemporary identification of plasticity and biosocial knowledge with openness, unlimited potentialities, and change. Finally, I interpret the complex sociological and ethical implications of emerging notions of plasticity and biosociality in contemporary epigenetics in the light of this past and often forgotten history, and address their implications for notions of vulnerability, risk, intervention and innovation in the biomedical sciences.

### BORDERS, MEDICAL GEOGRAPHY AND THE NEW EPIDEMIOLOGICAL IMAGINATION

Keynote lecture by **Komatra Chuengsatiansup**, medical anthropologist, medical doctor, and the director of the Society and Health Institute, which is part of the Ministry of Public Health, Thailand. His research on antimicrobial resistance follows antibiotics, microbes, and discourses to national and international arenas.

Borders, like any other systems of differentiation and categorization are subjugated and conditional to temporal fluctuation of human motives, shifting values, and cultural diversities. In other words, borders are historically contingent. Epidemiological transition in the world of hyper-diversity and hyper-connectivity has made national border and geographical boundaries increasingly irrelevant in disease prevention and control. Attempts have been made to ensure disease containment and biosecurity across borders. Taking public health in Thailand as an example, in this talk I will examine to extent to which transborder mobility of diseases, microbes, and pharmaceuticals as well as care-seekers, health professional and medical technologies transcend and transgress national boundaries. These "transborder risks" challenge the implicit geographical imagery underpinning current medical practices and public health interventions. Rather than viewing borders as predeterminedly consisted of geographically fixed points, I contend that borders should be construed as indeterminate; their multiple existences were results of various forms of bordering (and ordering) practices. Viewing border as multiple, flexible and topological is crucial for reinventing medical geography and fostering a new epidemiological imagination. For alternate bordering practices to ensure a more inclusive and equitable global health, critical reflections and creative innovations are needed to avoid reproducing bordering practices of fears, hatred and violence prevalent in concurrent political climate of discrimination.

#### **PARALLEL SESSIONS**

# May 23<sup>rd</sup>, 2019

## BP: THE BACKSTAGE OF PATIENT ORGANIZATIONS' WORK: HOW LOCAL PRACTICES COME INTO BEING

Online practice sharing session: representatives of Russian patient movement share their ways of knowing how to live well with chronic illness across the vast territories

### **Participants:**

**Ipatov, O** (Russian Multiple Sclerosis Society): online community and maintaining Internet resources

**Zuev, S.** (Moscow Multiple Sclerosis Society): the making of online MS patient school **Kargalskaya, I.** (co-chair, Patient-oriented telemedicine committee, Russian Patients' Union): Onconet and what it means for patient-oriented healthcare

Churakov, M. (Social Mechanics): sociological research as patient activism

### IC: INTERNATIONAL COLLABORATION IN INNOVATING FOR HEALTH: CHALLENGES AND OPPORTUNITIES

This session will focus specifically on collaborative ties between Norway and Russia and engage with the questions: What are the current cooperative activities in the research and innovation sector? How are relevant stakeholders engaged? What kinds of strategic investments are involved in different projects?

Internationalization and techno-globalization are key concepts in the modern political rhetoric regarding universities and academic activities in general. On one hand, the push for scientists and students to communicate internationally, outside the state borders, is rooted in the ideology of academic freedom and the free circulation of scientific ideas as conceived in medieval universities. Science and education for a long time were thought of as international and free. On the other hand, professionalization of science and protection of its innovative products have led in some cases to the restriction of academic freedom. The national states and corporations attempt to use the potential of universities and scientific groups to strengthen themselves in both domestic and foreign policy. Both trends persist in the contemporary view on the development of universities in Russia. The relative positions of these trends depend on many factors and both, stimulate and limit the possibilities of creating international teams and collaborations, as well as educational initiatives.

This session will focus specifically on collaborative ties between Norway and Russia and engage with the questions:

- What are the current cooperative activities in the research and innovation sector?
- How are relevant stakeholders engaged?
- What kinds of strategic investments are involved in different projects?

**Trengereid Radina**, Advisor on education, science and technology, Norwegian Embassy in Russian Federation. Research and Business within Health - Priorities and Opportunities within the Norwegian-Russian cooperation

**Belyaev Alexander**, Director of the Center for development of foreign economic activity (regional center for export support) of the Tomsk Chamber of Commerce and Industry. Russian-Norwegian business cooperation: lessons from the past

**Bauer Susanne**, Professor, Centre for Technology, Innovation and Culture. Common activities on research and education, TIK Centre (Oslo University) and PAST-Centre (Tomsk State University)

#### **KP-1: KNOWLEDGES AND PRACTICES-1**

# Objectified subjectivity: Multiple modes of knowledge production among epileptic patients

#### Tereza Sedlackova

Faculty of Social Sciences, Charles University, Czech Republic; <a href="mailto:tereza.sedlackova@fsv.cuni.cz">tereza.sedlackova@fsv.cuni.cz</a>
The paper deals with the lived everyday practice of patients with epileptic seizures and the types of knowledge they are working with in relation to seizures. It argues that cooperation between the multiple modes of knowledge production shapes the treatment of patients experiencing epileptic seizures. The specificity of each particular experience with the epileptic seizures creates conditions in which the multiple biomedical knowledge need to significantly work with the patient's embodied knowledge. Therefore, the patients are encouraged by the experts to work with their bodies and develop personal embodied knowledge about the form of their seizures (such as auras, triggers, forms and process of seizures). The paper discusses ways in which the (multiple) biomedical knowledge (lacking other forms of cognition) use the embodiment of patients, how the phenomenological discourse of embodied knowledge enters the biomedical context and how the patients themselves deal with this situation in their daily life practices. This contribution represents case of epileptic seizures' treatment as relatively successful example of bringing patient's knowledge to his/herself health care.

### Informal professionalization of healthy participants in phase I clinical trials in Russia

### Olga Zvonareva

Maastricht University, Netherlands, The; o.zvonareva@maastrichtuniversity.nl

*Background.* Previous social science research has showed how some healthy phase I trial participants identify themselves as workers and rely on trials as a major source of income. The term 'professionalization' has been used to denote this phenomenon.

*Purpose.* We aim to examine a component of healthy trial participants' professionalization that has not yet been systematically studied: how repeat phase I trial participants develop and claim expertise that distinguishes them from others and makes them uniquely positioned to perform high-quality clinical trial labor. We also aim to explicate the significance of these research results for protection of healthy participants in phase I trials.

*Methods*. This qualitative exploratory study was conducted in Russia, in two phase I trial units. It involved semi-structured interviews with 28 healthy trial participants with varying lengths of experience in trials; observations of work done in trial units; and interpretive conversations with investigative staff.

Results. Interviewed healthy individuals who repeatedly participate in phase I trials describe developing knowledge and skills that involve appreciating the meaning of trial procedures, coming up with techniques to efficiently follow them, organizing themselves and others in the course of a trial, and sharing tacit ways of doing trial work well with other less experienced participants. Our results suggest that a prerequisite for such expertise-centered professionalization is the emergence of a positive identity linked to seeing value in trial participation work. A crucial component of professionalization thus understood is the development of work ethic that entail caring about results and being reliable partners for investigators.

### Multiple interactions between home midwives and maternity hospitals in Russia Anna Ozhiganova

Institute of Ethnology and Anthropology Russian Academy of Sciences, Russian Federation; <a href="mailto:anna-ozhiganova@yandex.ru">anna-ozhiganova@yandex.ru</a>

The practice of homebirth is illegal in Russia but home midwives are engaged in their practice through various parental clubs and childbirth training centers. Births outside medical institutions make up just over 1% of the total number of births (statistics of "conscious" home births are not kept).

My study is based on the interviews with home midwives and women who gave birth outside the hospital settings, the interviews with doctors- obstetricians and hospital midwives as well as on the records of classes and conferences at the Moscow maternity hospitals and childbirth training centers.

In my research, I rely on the methodological paradigm of medical anthropology and anthropological studies of biomedicine, medical pluralism, medicalization and social control, in particular, on the studies of resistance to medicalization of pregnancy and childbirth (Lock 2004), "post-biomedical" subjectivity (Klassen 2001) and multiple identities of home "postmodern midwives": educated, independent, combining different approaches to birth, both biomedical and alternative (Devis-Floyd & Johnson 2006).

I will consider how different practices of obstetric care and different types of medical knowledge about childbirth compete with each other and create complex strategies of formal and informal interaction. A whole spectrum of such interactions between home midwives and maternity hospitals has emerged over the past 15 years.

The formalized interaction is being implemented in a number of private medical and childbirth training centers, which offer their clients the hospital birth with a home (or individual) midwife and a hospital doctor. This practice is carried out in accordance with the official contract between the maternity hospital and the center of preparation for childbirth where a home midwife works. The support of a woman during the initial stage of labor and escort her to the maternity hospital by a home midwife is another common option of the official contract.

Some home midwives (by their background and identity) get a job in private or state maternity hospitals, but continue to take home births. The attitude of physicians (doctors and hospital midwifes) to home birth is also changing: some of them are not only interested in this practice, but also begin to take birth at home, despite the fact that it could entail criminal punishment.

So we could see here a kind of medical pluralism. The identity of home midwives is changing: they make a shift from medical dissidence and esoteric contexts to professionalization, commercialization and cooperation with biomedicine. In turn, the obstetrics practice in maternity hospitals is also changing: the emerging of paid services and private hospitals contribute to the development of a client-oriented approach and physicians appear now more interest in natural (non-medicalized) childbirth. However there is still no public discussion on the advantages and risks of home birth.

### Bibliography

Devis-Floyd, R. & Johnson, Ch. B. (eds.) (2006) Mainstreaming Midwives: The Politics of Change, N.Y.: Routledge.

Klassen, P. E. (2001) *Blessed events: Religion and home birth in America*. Princeton: Princeton University Press.

Lock M. (2004) Medicalization and the Naturalization of Social Control, *Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures*, Volume I, C. R. Ember and M. Ember (eds.), N.Y.: Kluwer Academic/Plenum Publishers, p. 116-125.

# "The multiplicity of morality": the case of genetic experiments on embryos. Elena Vvedenskaya

Pirogov Russian National Research Medical University (RNRMU), Russian Federation; vvedenskaya.elena@gmail.com

The report speaks of "multiplicity of morality" as moral pluralism on the example of the morality of research scientists, patients and society. The concept of "multiplicity of morality" was introduced by N. Hartman in his work "Ethics", based on the facts of diversity and variability of regulatory norms, codes, mores, customs, established in different cultures and in different historical periods.

With regard to the moral evaluation of genetic experiments on embryos, we are faced with moral pluralism. Morality is constructed by the interests of a particular social group. Researchers conducting these experiments, the meaning of which is to change the genes

of embryos from the moment of their creation to the 14th day of development, followed by their destruction, have utilitarian morality. The goal - the salvation of mankind from incurable, hereditary diseases, justifies all means. The group of researchers is adjacent to patients with genetic diseases belonging to patient communities supporting these experiments. Scientists are interested in the rapid introduction of new medical biotechnologies into practice, not only for the sake of preserving the health and lives of subsequent generations, but also for their own personal gain.

Humanistic and religious morality of society is based on the ideas of the unconditional value of human life and therefore genetic manipulations with embryos, which will be destroyed, are perceived as representing a threat to human dignity and humane treatment of individuals.

Legislative regulation or prohibition of genetic experiments on embryos in various countries of the world depends on a certain type of morality that dominates society. So in Europe, these experiments are prohibited by the "Convention on Human Rights and Biomedicine." In the USA, for which traditional is pragmatic morality, genetic experiments on embryos are allowed, but within strictly defined limits. The countries that limit the editing of the genome of human gametes and human embryos as much as possible include Germany, Ireland, India, Switzerland, China recently introduced a moratorium on these experiments.

In Russia, from 1 January 2017, the Law on cellular technologies is in force, in Art. 3 of which ("The principles for implementing activities in the sphere of circulation of biomedical cellular products") refers to the inadmissibility of creating a human embryo for the production of biomedical cellular products, as well as the inadmissibility of using for the development, production and use of biomedical cellular products of biological material obtained by interrupting the development process human embryo or fetus or violation of such a process.

# May 24<sup>th</sup>, 2019

### BH-1:BEYOND ONE HEALTH. THE POLITICS OF INCLUSION AND MULTIPLICITY-1

### 'One health' and the quest for integration: Locating the digital ecologies of morethan-human health

#### Susanne Bauer

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This presentation examines the work of digital infrastructures, metrics and algorithms in 'one health' approaches; it addresses the case of salmon aquaculture as a contested site of production and optimization of human-animal relations. Focusing on omega3 optimization and data mining for 'human and salmon health', I will problematize multiple practices of extraction. In doing so, I will examine the relations of the calculative infrastructures at work in epidemiology to the politics of inclusion and integration advocated by the 'one health' approach.

### Viruses as a Subject of Social Sciences and Humanities Svetlana Martynova

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Social Sciences and Humanities for a long time have based on the statement about human exclusivity, it is a common point for Kantian and Darwinian theories. Thinkers supposed, that we should research a Nature via the principle of rationality and stated that a man/woman is an ultimate purpose of the organic development. Kant thought telos of Nature is moral one, Darwin supposed that it is a reason. Several modern researches are opposite to the position of human exclusivity (Baross J.A., Mol A., Schaeffer J.M.). I suppose that modern position can be a basis for researching humanity and society in the reference to viruses.

An organism is a system engendered by a cooperation of its elements. The elements can be redefined, reduced and appeared that leads to the evolution of the system. Viruses are parts of organism as a system, because they cause transformations of it. Scientific researches in biology and medicine pay attention to viruses as a driver for the genetic differences. We should understand what genetic differences do mean for studying of humanity and society.

According to Darwin the genetic differences is a result of mutation. Human or animal adaptation to the living environment bases on inherited mutations. Mutations are not for everything. Who cannot adopt environment with them have to die. Researches of the NASA pay attention to viruses for reviewing of this statement. They state, that viruses can lead to genetic differences even in space, because viruses transfer information. "Lamarckian, robotic, or informational "life" could have arisen spontaneously from inanimate matter». It testimonies that Darwinian theory is not absolute. Viruses produce migratory genetic

elements, and so we should say about horizontal changes, not only vertical. Horizontal changes mean that mutations of organisms can spread to everything.

Explanation of viruses as a subject of Social Sciences and Humanities include two strategies. Firstly, philosophers should to understand the process of globalization in the Nature. What features can a man/woman receive? What features can a man/woman spread out of him/she? Does it mean that viruses lead to conduct integration between human and other organisms? Secondly, thinkers should to understand the integration of social life. As mutations spread to everything social and cultural lives depend on this mutations. Mutations of viruses point to new habitat and make impossible some environments. Social and cultural consequences of viruses' transferring are impossibility to differ community and individuals, myself and others. Collective or individual, others or myself are determined by the evolution of viruses, ability of infected organisms to fight against them and social establishment of "ontological politics" (Mol A).

All abovementioned means that humanity must change views on its limits, how an individual can control himself. Viruses are out of Darwinian theory frames. Mutations of all organisms exist in common natural and social nets, so manwoman cannot save exclusiveness in toward and onward horizontal mutations.

### Bioprospecting for new antibiotic compounds and the promissory nature of infrastructures

### **Ana Delgado**

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This presentation addresses the recent rise of bioprospecting in Norway. As microbes are emerging as promissory actors of the bioeconomy, the Norwegian marine biodiversity appears as holding a renewed value. I explore how the 'extraction' of such public and future oriented value depends on the orchestration of legal and infrastructural practices.

### Attending to microbes

#### **Anne Lie**

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In this paper, I want to discuss a much neglected part of the history of antibiotic resistance – the history of microbes in the postwar period. The introduction of invasive diagnostics and treatment, like aggressive chemotherapies, transplantation medicine, etc with a concomitant change of the hospital population (increasingly old and increasingly immunosuppressed) also implied a change of the constitution of and lives of bacteria in hospitals. From the 1970s this development was accelerated with rapidly expanding use of (disposable) biomaterials in diagnostics and treatment. In this paper, I will look at how the relationship between human, industrial and biological activity with a particular focus on how bacteria and their ecological niches changed. On the one hand, I would like to explore with you how knowledge and theories have developed in response to these changing biological processes (as does, for instance Sangodevi 2014). On the other, I would like, inspired by Hannah Landecker (2016) to discuss how historical events and processes have materialized as biological events, processes and ecologies. In so doing, I will focus on the transformations of bacteria and bacterial ecologies as temporal and spatial events.

#### IR-1: INTERACTIONS AND RELATIONSHIPS-1

### 'Moaners' vs. 'deceivers': multiplicities of perspectives situated in the perinatal center

### Anastasiia Novkunskaya

European University at Saint-Petersburg, Russian Federation; a.novkunskaya@gmail.com This paper addresses the organizational context of a perinatal center in Russia, as particular settings for interactions between different social actors – healthcare practitioners and patients, communicating in the frame of maternity care services. It focuses on the complexity of the mutual expectations, their failures and discontents, emerging in this kind of communications. Some previous researches, like, for example, meta-ethnography of the literature of 2015-2017 years, devoted to the medical complaints (Scott & Grant 2018) demonstrate that healthcare practitioners can classify 'problematic' patients as "moaners," "abusers" or "malcontents". Patients, in turn, percept it as objectivation, which from their perspective causes dehumanization and disrespectful approach. Thus, any interaction in the context of healthcare organization can be analyzed as an encounter, where the different and sometimes conflicting social perspectives shape both, institutional order and interpersonal interactions.

The analysis is based on the qualitative data, collected in the framework of the collective research project 'Medical interactions in the changing childbirth services: women's needs and professionals' opportunities' (2018) headed by Professor Anna Temkina (EUSP). The research materials consist of observations in the Perinatal center (16 sessions), in-depth semi-structured interviews with the center's workers (n=18), in-depth interviews with patients in prenatal and postpartum units (n=8), and the document analysis (official complaints, on-line reports in the Internet, n=35). Preliminary results of the research show that both, healthcare practitioners and patients have the formed set of expectations concerning the proper way of communication within the context of perinatal center. Both groups of social actors in their narratives problematize those cases, in which their expectations were not met and categorize each other in a particular way. In this way, 'moaners' and 'deceivers' appear as designations of the opponents in the studied medical context and are used in the analysis as metaphors of mutual discontent, which could emerge in relations between patients and healthcare practitioners.

### "Uneasy" Patient in Urban Russian Maternity Hospital: Not a Single One Anna Temkina

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Examining St. Petersburg childbirth services this paper focuses on obstetricians' interpretations of different types of "uneasy" patients in maternity hospitals (MH), their own roles and qualities of interactions are challenged by these patients. The idea of this research come from the discussions with professionals in one MH on a very special type of "aggressive" (or even "terrorist") patient who is inadequate, complains a lot, writes to different authorities, from Putin to the Ministry of Health and posts unjust claims on different websites. Then

numerous inspections come to MH to testify the problems, blame and punish, while professionals spend great amount of time and emotional resources to prove the incorrectness of complaints. Professionals consider this as a relatively new proliferated problem.

I trace the obstetricians' and midwives' explanations (18 interviews, 2018, coauthored A.Novkunskaya ) and find that this "uneasy" patient is not a single one "terrorist", but she has at least four faces. Among these faces are "aggressors" (not trusting, cheating, looking for profit), "demanding moaners" (service oriented), "irresponsible/infantile" (ignorant, do not understand the limits of biomedicine and organization) and miserable/vulnerable women (in their fears or grief). Allsop & Mulcahy founded the description of moaners, nasty, abusers and malcontent patients given by professionals, however they did not specify them as related to concrete situations and to the forced extended roles of professionals (Allsop & Mulcahy 1998, 2001; Mold 2010; Scott & Grant 2018). I argue that the faces of professionals are also multiple, and beside their professional clinical role, they identify themselves and practicized as "victims", "providers", "educators"/quasi mothers, and psychologists/priests depending on the patient's face in a concrete situation of grievance and complaints. According to doctors and midwives such situations and interactions deviate from the proper ones when patients are expected to be honest, reasonable, responsible and managed emotions. As a result we can not only understand more about everyday practices and interactions in MH, when professionals act as a jugglers but also about more broad changes in medical institutions under the growth of consumerism, patients' demands and knowledge, and mother's sensitivity in urban Russia.

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A Mold (2010) Patient Groups and the Construction of the Patient-Consumer in Britain: An Historical Overview Jnl Soc. Pol. 39, 4, 505–521

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### How to Protect the Vulnerable Ones: the Attitude of Future Doctors to Clinical Trials of Pharmaceuticals.

### Tamara Mescheryakova, Olga Gerasimova

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The report presents the results of sociological survey aimed to discover how in the beginning of doctors' career (starting from their training in a medical University) their attitude to clinical trials of pharmaceuticals is shaped.

### (De)constructing vulnerability in clinical trials

### Alena Kamenshchikova

Maastricht University, Netherlands, The; <u>a.kamenshchikova@maastrichtuniversity.nl</u> (De)constructing vulnerability in clinical trials

#### **KP-2: KNOWLEDGES AND PRACTICES-2**

### Making clinical decisions: between EBM and institutional constrains Ekaterina Borozdina

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EBM paradigm that relays on the results of clinical trials has become a golden standard in contemporary medicine. However, the way in which EBM influences actual clinical practice is less straightforward than it might seem. Societal context in the form of institutional arrangements, bureaucratic rules, and local professional culture conditions what knowledge actually becomes available to practitioners and is implemented in their everyday work. This paper addresses the issue of these complex entanglements between EBM, organizational rules and professional decisions of doctors in Russian healthcare. Its empirical base consists of semi-structured qualitative interviews with physicians.

### Management of decision making in real clinical practice Denis Tyufilin, Igor Pimenov

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To date, there are no structured data in the Russian Federation that demonstrates the effect of evidence-based medicine on the decision-making of medical professionals in real clinical practice. There are also no studies that determine the level of awareness of Russian doctors about EBM, and data showing the relevance of the use of information sources about evidence-based medicine in the professional activities of a doctor.

# The key to improving the quality of treatment: the impact of participation in RCT on patient's compliance and adherence

### Sergey Yu. Martsevich, Natalia P. Kutishenko, Yulia V. Lukina, Natalia O. Vasyukova

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Medicine, in general, and preventive medicine, in particular, are committed to improving the quality of treatment, which is indeed impossible without enhancing the compliance of each and every patient. Compliance is defined as 'the extent to which the patient follows the health professionals' advice and takes the treatment'. Moreover, this term has been superseded by the term adherence. Patient adherence is defined as '...the extent to which a person's behaviour – taking medicine, following a diet, and/or executing lifestyle changes, correspondences with agreed recommendations from a health-care provider "(WHO 2003). A meta-analysis by Simpson et al (2006) showed that good adherence was associated with reduced mortality. Thus the goal of the entire world medical community is to reduce mortality rates. Are there circumstances in which patients are more conscious and disciplined about their treatment than patients in the General population? The answer

to that question is 'Yes'. It is no secret that in the framework of randomized controlled trials (RCT), patients, in addition to receiving the therapy prescribed to them in the study, receive a set of instructions for the correct administration of both the studied drug and basic drug therapy. Patients are carefully taught, firstly, taking into account the reception of the studied drug, often additional methods of control over its intake are used, as well as individual drug adjustment and control of the basic therapy, corresponding to current guidelines. In search of a recipe to improve patient compliance, we have formulated the presumption that the methods used within RCT (enumeration of consumed drugs, reminder phone calls, educational leaflet, questionnaires, etc.), improve patient compliance even after the end of the study. This presumption is based on the fact that during the RCT participation, the patient is educated to a schedule of regular medications and visits to the doctor; becomes more informed about his disease and current condition, is involved in the process of his treatment, becomes more confiding in attending physician and prescribed therapy. The patient makes it a habit to a proper medicines' intake and regular visits to the doctor, that as a result undoubtedly has a positive effect on the quality of treatment. We have formulated a hypothesis that this phenomenon of "good compliance" is fixed for patients even after the study completion. Thus, factors affecting patients' adherence to treatment will be identified, that will allow us to introduce these methods in effective healthcare. It could be a step towards the achievement of better patient compliance and medical adherence among the whole population.

### New Approaches to Clinical Trial Designs: Appear of New Bioethical Dilemmas in 20-21 Centuries

### Igor Pimenov, Fimushkina Natalia

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Controlled clinical trials are the foundation of evidence-based medicine. Their aim is to ensure that only safe and effective drugs and medical devices access the healthcare market. However there is ongoing debate regarding ethical weaknesses of traditional clinical trials.

We explore appearance of new ethical dilemmas in several clinical trial designs.

### BH-2: BEYOND ONE HEALTH. THE POLITICS OF INCLUSION AND MULTIPLICITY-2

### Stool and stories: Studying antimicrobial resistance among longitudinal cohort of mobile international global health students

#### Alena Kamenshchikova

Maastricht University, Netherlands, The; <u>a.kamenshchikova@maastrichtuniversity.nl</u> Objective

To investigate whether travelling as a risk factor for dissemination of resistant bacteria should be part of the international actions against antimicrobial resistance (AMR).

#### Methods

In March-August 2017 we developed and conducted a "stool and stories" longitudinal cohort study that involved 64 international postgraduate global health students who travelled to India from the Netherlands, Canada, Colombia, and Thailand. The study included multiple-choice questionnaires (n=64); collection of normal stool samples and faecal swabs at four time moments: before travel (T0, n=45), first week in India (T1, n=44), second week in India (T2, n=41), one month after return to the Netherlands (T3, n=18); and semi-structured interviews (n=11).

#### Results

In the microbiological analysis, we focused on the acquisition of extended-spectrum  $\beta$ -lactamase-producing Enterobacteriaceae (ESBL-E).It was found that the prevalence of ESBL bacteria at T0 was 18% (5/28), while at T3 the prevalence increased for up to 47% (8/17). Statistically significant association was found between a number of countries that students visited before travel to India and a presence of resistance genes at T2. In interviews, our participants expressed that the causes of AMR lie either within individual practices of antibiotic use or within hospitalization practices, and did not associate it with travelling in itself.

#### Conclusion

While microbiological data show that travelling contributes to AMR dissemination, we need to account for the lack of awareness on this issue among travellers. Negative as well as positive social outcomes that can be caused by surveillance of travelling populations need to be further analysed.

# Between 'disease' and 'illness': cases of communicative clashes during genetic counseling

#### Aleksandra Kurlenkova<sup>1</sup>, Shirokov Alexandr<sup>2</sup>

<sup>1</sup>Institute of Ethnology and Anthropology, United States of America; <sup>2</sup>National Research University Higher School of Economics; <u>askurlenkova@gmail.com</u>, <u>needeeds@gmail.com</u> Key words: disease, illness, communication, biomedicine, lay beliefs, genetics.

Abstract: In this paper, we are going to focus on several cases of communicative clashes between patients and doctors of various specialties observed during the fieldwork at the Petrovsky National Research Centre of Surgery and one private clinic in Moscow (2018-2019). Using the notions of medical (*disease*) and lay (*illness*) explanatory models, we will show how they are manifested in the practical organization of the clinical encounter.

# Space and time as axes of disability constructing Lyubov Torlopova

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The presentation considers a new vision of disability studies in the form of application of ontology-in-practice to the experience of ethnographic research of the Russian regional

Bureau of Sociomedical expertise (SME) as an institution that defines the civil status "invalid" ("disabled person"). Following the idea of A. Mol of the multiple body, the author makes the statement that disability is an object, which is assemblaged from practices, concepts, and subjects, and exists in reality situationally. Thus, its existence depends on time and spaces.

The research seeks to eliminate the gap in disability studies, which consists, firstly, in the absence of social studies of Sociomedical expertise accessible to a wide range of readers, including directly social researchers (there are only social studies contributing to the practical needs of the SME), despite the fact that constructing of disability by this actor prevails in Russia. Secondly, there is the absence of a language describing disability that can cut across different disciplines. To fill the first gap, the results of ethnographic research at the Bureau of SME (analyzing not the disability discourse, but practices of its constructing) will be presented. As an attempt to solve the second difficulty, a methodology of empirical philosophy, including the interdisciplinary aspect of disability research, will be proposed. In the framework of this philosophy, disability is produced not only through the created knowledge (standards and statistics) but also through the practice of applying the standards to the individual case of a particular person, as well as the material objects enacted in the construction of disability as a hybrid object.

### Citizens involvement in innovations: A pilot of MedHack in Tomsk Hospitals Olga Ustyuzhantseva, Eugenia Popova

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The concept of citizens involvement is quite often associated with the idea of democracy, people's participation and involvement in political decision-making. In other words, public participation provides the involvement of those potentially affected by or interested in a decision. This can be in relation to individuals, governments, institutions, or any other entities that affect public interests. We apply this concept to the health care system and hospitals in particular. For health care as a sphere of public interest, citizens involvement can be a way of increasing its accountability, and also of sharing responsibility among medical personnel and patients. Russian health care system and hospital practices are quite hierarchical and authoritarian by nature and system of decision making in the public policy field are statist and autocratic. An important question is if the participatory approach can be implemented in this type of institutions and what results can follow. We hold MedHacks in two local hospitals to try the idea of participation in real life. Our goal was to explore the possibility of implementing participation practices and observe the results. We present the outcomes of the MedHack and discuss their specificity.

#### IR-2: INTERACTIONS AND RELATIONSHIPS-2

This second part of the thematic stream 'Interactions and relationships' moves forward to consider the complexity of technological and societal change. When such far-reaching

alterations as digital technologies enter the scene, what do concerned actors, including decision-makers, developers, healthcare workers, and patients do to direct the use of the technologies and manage their consequences? What are the implications of the new knowledge provided by advances of epigenetics for how we understand our responsibilities towards future generations? How are families changing together with wider social, demographic, and digital shifts? Papers in this session allow close tracing of how interactions and relationships between actors, existing and imagined, are shaped together with ongoing sociotechnical transformations.

### E-Health in Russia: Uniformity versus [Unwanted] Diversity Anna Trakhtenberg, Elena Dyakova

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The digital transformation of the healthcare system is a complex process with many actors in unequal positions in terms of their ability to influence this process.

The following main groups of actors can be distinguished: health authorities (purchasers), developers of medical systems, medical workers (users) and patients (customers/beneficiaries).

Health authorities as purchasers are guided by the logic of rational bureaucratic control. There is a well-defined e-health model based on the principles of the new public management. The interaction of the doctor and the patient is understood as services providing, and the task of the health authorities is to monitor the quality of these services. It means the integration into a single information system of all information about patients and the formation of a unified system of control over the activities of physicians based on the unification of the treatment process. Treatment should be based on the principles of evidence-based medicine in accordance with approved protocols. It is this model that underlies the activities of the Information Technology and Communications Department of the Ministry of Health of the Russian Federation. At a lower management level, diversity is allowed in the form of taking into account the specifics of a particular medical institution/ Conflicts between links of the control system are possible and permissible.

As for developers, they design information systems in the logic of technological rationality. The diversity in this logic is considered, on the one hand, as a variety of technologies available for implementation (web platforms, video conferencing, digital diagnostic devices etc.), and on the other – as a competition for the best technological solution. This approach periodically generates conflicts between developers and purchasers.

Neither doctors as users, nor patients as beneficiaries have practically no opportunity to influence the process of digital transformation. As a result, Collingridge dilemma begins to operate: a limited circle of decision makers and those who are able to influence them, while ignoring the opinions and interests of end users, gives rise to a predictable effect: the larger the project, the higher the chances that control over its implementation will be lost and it will be ineffective.

That is what is happening in Russia. Despite the very significant costs (more than 32 billion rubles have been spent on the Unified State Health Information System of the Russian

Federation since 2011), the informatization remains "patchwork" in nature. In the professional community of developers united in Association for the Development of Medical Information Technologies (since 2001) there is an active discussion on what is more preferable: reduce the number of existing regional medical systems or ensure their interaction through the bus network. (The Information Technology and Communications Department is leaning towards the first option).

At the same time, the results of implementation are contrary to expectations: the amount of time spent by physicians on entering information into the system increases to the detriment of communication with patients, and when typing using the copy-paste method, numerous errors are reproduced. The system creates significant opportunities for fraud reporting.

It should be noted that Russian problems are not specific: the digital transformation of health care throughout the world is accompanied by conflicts, scandals, and the strongest organizational resistance. At the same time, patient dissatisfaction with the quality of medical care increases.

But despite numerous failures, the model of a unified information medical system is persistently reproduced. Its reproduction suggests that the design of digital transformation is dominated by the position of healthcare authorities. As a result, the control function supersedes all others, which leads to a decrease in the efficiency of the system instead of the expected radical improvement.

## Multiple technoworlds of modern medicine Elena Grebenshchikova<sup>1,2</sup>

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The development of medicine is inseparable from the process of its technological equipment, from the progress of biomedical technologies, which make it possible to penetrate deeper and deeper into organs and tissues, diagnose, monitor, support treatment, and also connect the physician and patient. Technologies not only "envelop a person" and penetrate into body, but represent its projections and even become the "third participant" in the doctor-patient interaction. Medical electronic records, big data technologies, telemedicine, robotics in the diagnosis and treatment of diseases, mHealth devices are changing the space of medical interactions. Medical treatment becomes distanced (telemedicine) and "intimized" (means of medical control penetrate deeper into the human body); it becomes more individualized due to the processing of huge amounts of information and more depersonalized due to the fact that a particular person too often falls out of sight of the doctor and automated systems, being replaced by standard "patient models".

The digitization and datafication of medicine, the development of mHealth and AI technologies form a multitude of medicine technoworlds, in which new models of healing, patient models, prevention models arise. At the same time, social and humanitarian consequences and aspects represent a large problem field in which questions of attitude to the human body, attitude to one's own health and to the attending physician and medicine in general intersect.

The idea that a person is more than the sum of data about him is repeated by bioethics, anthropologists, philosophers of medicine, doctors, and the developers of the new systems themselves. However, the question is not only to combine the multiplicity of data and the emerging medical technology technoworlds with the individuality, interests of the patient, protection of confidentiality and responsibility, but also to comprehend the problem of the hybrids in this context, i.e. excessive self-confidence, ignoring the inevitable simplifications and semantic losses in digitizing various parameters of human existence, the formation of new "digital identities" in which real identity is lost.

The research is supported by the Russian Foundation for Basic Research, project 19-011-00064a.

## Gender-related health trajectories and changing families in Western Europe Valentina Shipovskaya

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The transformation of the traditional family has overlapped with population ageing. Social, demographic and digital challenges have increased the diversity/variability/multiplicity of the life course/family formation/ageing trajectories. Understanding why some persons remain healthy and others do not is a major research challenge.

The characteristics of the family may have important consequences for healthy ageing, because "the family forms a social world that systematically influences individual identity, perceptions, and action. These, in turn, shape the more proximate determinants of health, such as health behaviours, perceived loneliness, and stress or allostatic load" (Hughes, Waite 2004: 182). However, today fewer people live in families as traditionally defined and more live in non-family households. Variation in ageing families may explain individual differences in the severity and timing of health problems.

Family context affects the health-related individual's experiences of family demands (needs) and resources (opportunities). This is a conceptual tool for specifying the mechanisms by which families influence the individual health. Relatively little research has examined the changing relationship between different family structures and health dynamics. This gap is my research question: How diverse family structures impact gender differences in functional health over the second half of life?

The health status is associated with variations of life course capital, and could be measured as functional health. This paper provides some empirical insights into the question of, how gender dimensions in social belonging/intra- and intergenerational ties shape health trajectories. This study uses regression analysis (polynomial and fixed effects model) based on the balanced panel data from the four waves of Survey of Health, Ageing and Retirement in Europe (SHARE-project.org, waves 1, 2, 4, and 5) released between 2004 and 2013.

The data (N person-year = 28,624) and preliminary analysis show the gender-related variations of functional health trajectories in Western Europe. Families and social ties constitute the closest social environment. However, social ties are not equally beneficial for individuals depending on their familial bonds, relationship status, and gender. The

results of this study could be used to identify the social factors that are most important for maintaining physical health under different normative live conditions and social environment (e.g. reciprocity by family obligation norm, sharing life time etc.).

## Epigenetics: A new challenge for intergenerational ethics Alexander Yashchuk

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The current debate in the field of intergenerational ethics focus primarily on the issues of 'justice' or 'equity' in relation to a moral obligation the present-day humanity has to future generations.

Meanwhile, last decade advances in epigenetics has provided a novel understanding of the relationships between living conditions, lifestyle, gene expression and health within the intergenerational dimension. As discussion on the social and ethical implications of the new findings expands, the growing attention receives the idea of 'epigenetic responsibility' inspired by advances in epigenetics. Responsibility-related concerns discussed cover individual and collective responsibilities to prevent detrimental epigenetic programming, monitor health status and 'cure' the epigenome of at-risk individuals. However, we should not overlook in the heat of discussion important moral asymmetry referring to responsibility in temporal relationships between generations. The living (present) generation is responsible for the actual impact on the fates of generation yet unborn (future). The generation yet unborn will be responsible for the actualizing some of the potential meanings of this impact.

Any normative discussion of personal or collective responsibility regarding epigenetic health should address the multiplicity of the biological mechanisms of epigenetic programming and inheritance. This suggests accordingly the multiple levels and types of epigenetic responsibility.

First, defining *epigenetic norm*, which is the prerequisite for planning preventive and therapeutic interventions, remains a challenge.

Then, according to the 'mismatch model', decease development not depend merely on detrimental epigenetic variant, but rather on the mismatch between the inherited variant and the individual's lifestyle or environmental factors.

At last, preventive or therapeutic intervention can be effective only when we identify 'windows of sensitivity', which vary due to multiple factors.

To make things more complicated, biological uncertainties go together with multiplicity of sociocultural factors contributing to programming of epigenetic variants.

Taken together biological and sociocultural uncertainties give rise for complex ethical questions. How can personal and public health ideals be reconciled within the human rights framework? Should physicians prevent deviations from 'normal' epigenetic programming? Can we justify moral obligation of individuals to optimize their offspring's epigenetic programming to meet the social norm?

The answer to such complex questions lies in the nation-wide health policies framing value-attractors for responsible individual decisions.

#### MM: MODELS OF MENTAL HEALTH AND ILLNESS

# Formation of anti-relapse behavior of persons with mental health problems as a factor of heightening their quality of life and effective social communication Elena V. Gutkevich<sup>1,2</sup>, Valentina F. Lebedeva<sup>1</sup>, Arkady V. Semke<sup>1</sup>

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The problem of the phenomenon of relapses of disorders of mental health and repeated hospitalizations, formation of anti-relapse behavior can be connected with participation of both psychobiological (psychopharmacological) factors, and sociocultural and environmental, psychological and family factors in regulation of mental processes and participating in formation of the certain forms of behavior. Establishment of these factors in the region of Siberia of the Russian Federation where now active migratory processes are observed in which various social groups (students, workers, the population of different age) are involved is relevant.

# Experience of coexistence with the illness and change of behavior for successful interaction in the family and socium

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Speaking about prevention of mental health, it is necessary to pay attention to secondary prevention, formation of anti-relapse behavior, support of positive behavior and thought. It is important to prevent onset of a mental illness. However, how to live when you already got sick? How to prevent relapses, how to reduce number of patients and duration of their stay in psychiatric hospitals? The need for lack of relapses should be formed. In order this need to appear, patients should be shown that they can feel well, think clearly, work, participate in life of society on an equal basis with all if they receive the appropriate general medical, psychopharmacological and psychotherapeutic treatment, psychological and psychosocial support. Patients should be trained to observe their state, to estimate it critically and to understand, what changes in their state can be the indication for visit to different specialists. Working in system of specialized mental health services, the authors consider the thesis mentioned in the title from the perspective of a patient. The authors suggest presentation helping to answer the question how to help mentally ill persons to achieve success in life, work and confrontation with the illness and emphasize the right of patients to get every support on an equal basis with healthy persons.

Clinical-psychological features of patients with relapse of non-psychotic mental disorders. Psychological correction of disadaptive behavioral models

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Aim of our research was to study clinical-psychological features of patients with relapse of non-psychotic mental disorders and to develop programs of psychocorrection of disadaptive behavioral models. 89 patients with non-psychotic mental disorders, of organic and neurotic registers (68 women, 21 men aged from 29 to 75 years) were examined. Three groups were distinguished depending on frequency of repeated admissions: group 1 – less than 3 hospitalizations (41 persons), group 2 – from 3 to 5 (36 patients), group 3 – more than 5 hospitalizations (12 persons). Based on clinical-pathogenetic and dynamic study of long-lasting mental diseases it was identified that the first group was represented by patients with neurotic states which according to diagnostic criteria corresponded more often to adjustment disorder; the second group was mostly represented both patients with pathocharacterological reactions and personality disorders; the third group with major number of exogenous-organic disorders.

In the course of pathopsychological investigation in pateints of group 1 in the profile of Method of Multilateral Investigation of Personality the increases predominantly on scales 1 – neurotic overcontrol, 3 – emotional instability, 7 – anxiety, 8 – tenseness were revealed. The leading traits in the individual-typological profile were demonstrative, anxious-hypochondriac and pedantic traits. In group 2 a significant increase on scales 8 - tenseness, 6 - fixedness, 4 - impulsivity was revealed. The leading traits in the individual-typological profile were fixed, excitable and dysthymic traits. In group 3 in the respondents increases on scales 1 - neurotic overcontrol, 3 - emotional instability, 6 - fixedness, 8 - tenseness predominated. The leading traits in the individual-typological profile were emotive, demonstrative, fixed and anxious-hypochondriac traits. In the considerable number of patients at the moment of actual admission a high level of state anxiety was revealed, according to Actual Mental State technique almost in all patients indices on scales of Activity and Productivity were lowered and indices on scales Anxiousness and Tenseness were heightened. In all groups high degree of inner tension is expressed, caused by fixation on their physical health and psychological state that reinforced emotional instability, anxiousness, ease of emergence of fears regarding the state of their health and future. According to revealed groups and clinical-psychological features the psychocorrective programs were developed which efficacy was shown by results of dynamic experimental-psychological examination.

# Psychological multiplicities of voluntary behavior of healthy persons of young age Darya Ustyugova<sup>1</sup>, Valeria Golovina<sup>1</sup>, Elena Gutkevich<sup>1,2</sup>

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In the changed conditions of social being transformation of behavior of the person (high social mobility, involvement into processes of interaction of environment and society, emergence of new forms of the family system) and human mentality (features of health of the individual, family and population) is observed. Also the health paradigm is transformed when health is considered as the personalized characteristic which is based on a set of features, including biological, psychological, social ones, including in youth.

# Multiple-factor model of pro-biotic adaptation of the organism and phenomics of health

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For qualification of health or illness it is necessary to use integrated interdisciplinary approach at various levels of the organization of an organism. Multiple-factor model of the adaptation of the organism determines health or illness at the level of the microbiota.

# May 25<sup>th</sup>, 2019

SD: MAKING SOCIALIST DRUGS: DEVELOPING, TESTING AND SMUGGLING NEW PHARMACEUTICALS IN CENTRAL AND EASTERN EUROPE, CA. 1930-1990.

# Urine for the New Soviet Man: Revisiting the Miracle Drug Gravidan Pavel Vasilyev<sup>1,2,3</sup>

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The rise of modern endocrinology in the twentieth century was inextricably linked to its special status as an integrative medical discipline, concerned with the difficult task of distinguishing human variation from disease and operating over an impressively broad range of areas of human activity – from sports to sexuality to addictive behavior and so on almost *ad infinitum*. Indeed, endocrinology, with its underlying assumptions of human perfectibility and malleability, might have been the ultimate medical specialty of high modernity. To an extent, however, this paradigm has increasingly been in competition with the genetic explanations that assume that most of the human behavior is hard-wired and unchangeable.

As we know from the early Soviet case studies examined by Nikolai Krementsov and Alexander Etkind, experimental endocrinology and its radical promises found particularly fertile ground in revolutionary Russia.[1] One of the most ambitious attempts of this kind was the story of gravidan - an allegedly all-curing hormonal drug from the urine of pregnant women that was developed and actively promoted by a Moscow doctor Aleksei Zamkov (husband of renowned Soviet sculptor Vera Mukhina) from the late 1920s onward. In the mid-1930s, gravidan was industrially produced on a mass scale and used by Soviet physicians to treat an impressive list of conditions ranging from alcoholism and drug addiction to hemorrhoids to the 'progressive exhaustion of the nervous system' (progressiruiushchee istoshchenie nervnoi sistemy).[2] Even though Zamkov's whole idea of 'urogravidanotheraphy' had been largely discredited by the late 1930s and he himself got in serious trouble with the Soviet authorities, some of his disciples managed to pursue a successful career in medicine and continued administration of gravidan until the mid-1960s.[3] In this paper I use the gravidan controversy as a test case to trace the development of Soviet endocrinology and to examine the cultural values that were at the heart of this scientific discipline.

[1] Nikolai Krementsov, "Hormons and the Bolsheviks: from Organotherapy to Experimental Endocrinology, 1918-1929," Isis 99, no. 3 (2008): 486-518; Alexander Etkind, "Beyond Eugenics: The Forgotten Scandal of Hybridizing Humans and Apes," *Studies in History and Philosophy of Biological & Biomedical Sciences* 39, no. 2 (2008): 205–210. For broader perspectives on the history of 20<sup>th</sup> century endocrinology and its unfulfilled promises, see Christer Nordlund, *Hormones of Life: Endocrinology, the Pharmaceutical Industry, and the* 

Dream of a Remedy for Sterility (Sagamore Beach, MA: Science History Publications, 2011) and Michael Pettit, "Becoming Glandular: Endocrinology, Mass Culture, and Experimental Lives in the Interwar Age," American Historical Review 118, no. 4 (2013): 1052-1076.

[2] Iosif V. Strel'chuk and P. P. Obnorskii, "Gravidanoterapiia v bor'be s narkomaniei," [Gravidanotherapy In The Struggle Against Drug Addiction] *Biulleten' instituta gravidanoterapii* 1 (1934): 37-44; Strelchuk, Obnorskii, N. E. Dudko et al., "Gravidan i problema bor'by s prezhdevremennym odriakhleniem pri alkogol'noi i morfiinoi intoksikatsii," [Gravidan and the Problem of Struggle Against Premature Aging by Alcohol and Morphine Addicts] *Biulleten' instituta gravidanoterapii* 2 (1935): 42-50; N. E. Dudko, "Gravidanoterapiia gemorroia u narkomanov," [Gravidanotherapy of Hemorrhoids in Drug Addicts] *Biulleten' instituta gravidanoterapii* 2 (1935): 61-65; Evgenii Zhirnov, "Mocha i kamen'," [Urine and Stone] *Kommersant Vlast'* 49 (2001): 56; Zhirnov, "Progressiruiuschee istoschenie nervnoi sistemy," [Progressive Exhaustion of the Nervous System] *Kommersant Vlast'* 19 (2009): 64.

[3] Strel'chuk, Klinika i lechenie narkomanii [Clinical Picture and Therapy of Drug Addiction], 2nd edn (Moscow: Medgiz, 1949), 64; Strel'chuk, Klinika i lechenie narkomanii [Clinical Picture and Therapy of Drug Addiction], 3rd edn (Moscow: Medgiz, 1956); Viktor Ostroglazov, "Mif o gravidane," Meditsinskaia gazeta no. 60-61 (2008); Alisher Latypov, "The Soviet Doctor and the Treatment of Drug Addiction: 'A Difficult and Most Ungracious Task'," Harm Reduction Journal 8, no. 32 (2011): 16.

# Making Soviet drugs in the heart of Siberia: Clinical trials of Rhodiola rosea in Tomsk in the 1960s and 1970s

#### **Alexander Petrenko**

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Rhodiola rosea is a Siberian medicinal plant possessing qualities of a central nervous system stimulant that has been traditionally used in the folk medicine of the indigenous peoples in Siberia. Between the 1960s and the 1980s, the plant has been intensively studied in the scientific laboratories of Tomsk. The study of chemical qualities of the plant and its effects on humans was initially carried out in the Tomsk Medical Institute (TMI) by a large research group headed by A. S. Saratikov and E. A. Krasnov. Following a series of animal studies in the early 1960s, Saratikov moved to enlist human volunteers from TMI students and stuff and studied the effects of the plant on concentration and auto-suggestion. These trials were later expanded and a number of medical institutions in Tomsk incorporated them into their research programs, seemingly hailing Rhodiola rosea as a potential all-curing miracle drug for the overworked and stressed modern self. (Interestingly enough, there has recently been a renewed interest in the plant in the West that has corroborated a number of Soviet findings). At the same time, research into the history of Rhodiola rosea trials also highlights both numerous ethically problematic issues in the treatment of study participants as well as unexpected divergences from the officially prescribed Soviet clinical trials practices. Using examples from numerous published scientific studies and corroborating them with materials from oral history interviews with researchers and study participants, this talk explores the local idiosyncrasies that shaped Soviet clinical trials on the ground.

## Designing Clinical Trials in the Second Half of the Twentieth Century: USSR in the Global Context

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The issue of balancing knowledge reliability and ethical acceptability in clinical trials is complicated by that the notions of what robust evidence in (bio)medicine is and the ideas about how to ensure its (ethical) quality are not given or simply determined by existing technological possibilities but are also shaped by a plethora of social, political and cultural considerations. For example, before 1990s pharmaceutical drug testing systems differed dramatically and explicitly between the USSR and the U.S. Effectiveness and safety of pharmaceuticals in USSR were established without making use of the four-phase clinical trial model introduced in the U.S. in the 1960s and currently dominant in drug development globally. This model was not supported in the USSR since it was considered wasteful and too remote from clinical realities. The core characteristics of U.S.-based trials such as randomization, double blinding and use of placebo were rejected in the USSR as unethical and exploitative of research participant. Strict separation of research ethics and treatment ethics, introduced to normatively support the U.S. pharmaceutical drug testing system, was also not accepted in the USSR where knowledge of new treatment options was produced in treatment practice as opposed to laboratory-like experimental conditions of randomized controlled double blinded trials. This paper uses both published and unpublished sources from several Russian archives to explore the evolution of Soviet regulatory approaches to clinical trials in the second half of the twentieth century, to place them within a global Cold War framework and to highlight their unexpected relevance in today's world.

## Do the End justifies the means? espionage and biotechnology 1970-1990 Miroslaw Sikora

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When browsing the recent book on the global history of biotechnology and its societal consequences by Hallam Stevens, it is hard to find references to the contribution of the Soviet Union and its allies to R&D, discoveries and engineering in the innovative area of pharmacy or agronomy throughout the second part of the 20thcentury.

That absence of the communist states (or more specific: states equipped with planned economy) reflects the existence of the overall scientific and further technological gap between OECD and CMEA over the time of the Cold War. Nevertheless the technology-transfer between those two "blocks" was being not equally disrupted by various emergences of the geopolitical rivalry. While nuclear energy on the one hand and electronics along with computer science on the other hand were strictly controlled by Embargo restrictions adjusted by Coordinating Committee for the Multilateral Export controls, many chemical disciplines of science and branches of industry did not undergo those constrains. It did not mean however that the access to modern medicines, vaccines, steroids or pesticides being developed and manufactured by the Big Pharma in the West or in Japan was a formality for Eastern Block's countries.

The obvious obstacle to purchase western solutions was their price and/or monopolistic measures applied by companies like Pfizer, Bayer, Sandoz, Monsanto etc. The fact of insufficient funding of biotechnological R&D in the East combined with permanent shortages of foreign currencies earmarked for trade purposes and licensing agreements, forced governments of the Warsaw Pact to take advantage of intelligence assets. Those were successfully tested by USSR in regard to development of mass destruction weapons (thanks to the famous "atomic spies") already during the 40s and again in the 60s in favor of the co called Unified System of Electronic Computers/RIAD of CMEA (by acquisition and implementation of IBM know-how) to mention only two among many examples.

Starting from the 50s KGB was sharing its spy-craft techniques and experience with allies. Looking at the organizational structure of the scientific-technical intelligence service in GDR or Poland, their resemblance to the Soviet pattern is just striking. By the early 70s – when the societal impact of the civilization diseases became clearly visible in the national statistics of Polish People's Republic - Polish intelligence managed to learn the lesson and master clandestine, cheap and rapid targeting, acquisition and implementation of antibiotics and biotech-engineering into the economy.

During the 80s hundreds of tasks have been addressed by Polish R&D via the Ministry of Chemical Industry to the intelligence HQ. In the last 5-years economic plan (1986-1990) the national health care and agricultural programs were overwhelmingly entangled with "black market" and some of their goals were in fact depending on the achievements of espionage activity.

Author uses Poland as case study do discuss the vague dimension of intelligence's cooperation with the pharma and biotech-industry, explaining mechanisms of that involvement and shedding light on the intelligence's quantitative contribution. Furthermore author attempts to find possible answers to question about the boundaries of the institution of the state's mission to take care of the national wealth, improve quality of live and treat the most dangerous diseases as cancer or cardiovascular disorders with advanced medical products. Do the multiplicity of measures applied by the state for the sake of health care include also illegal ones?

Polish government, next to several post-communist countries, decided to declassify documents of pre-1990 security apparatus including foreign intelligence branch. Author investigates into those records and – wherever it is possible – comperes them with documents of other governmental bodies, as well as with the secondary sources.

#### SH-1: STATES AND HAPPENINGS OF HEALTH-1

# From the originally twaddle's triad to a new esa-model: the new "sonetness" Cleto Corposanto

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Theoretical reflections and empirical investigations in medical sociology and anthropology have had a great boost from the famous Triad due to Twaddle. The 3-dimensions model Disease, Illness, Sickness is very useful in many situations in which researchers want to analyse the lack of well-being of all the possible points of view. Using Twaddle's definitions, "Disease

is a health problem that consists of a malfunction that results in an actual or potential reduction in physical capacities and/ or a reduced life expectancy, Illness is a subjectively interpreted undesirable state of health. It consists of subjective feeling states (e.g. pain, weakness), perceptions of the adequacy of their bodily functioning, and/or feeling of competence" (Twaddle 1994: 8); and "whenever a person is defined as having a disease or illness by others, we can talk about sickness, the social level, as 'unwell'. Irrespective of the reality on the basis for the claim, to be defined as sick is to have certain rights and obligations not shared by others" (Twaddle 1978: 18). Nevertheless the Triad seems to be inadequate analysing the global harm of some particular categories of diseases (i.e. alimentary intolerances). Analysing life and illness histories of patients with celiac disease, what emerge in our research is the awareness of a social harm very important (and in many situations much stronger than biological damage), due to the lack of relational and social capital. For this reason we think that, in some research situations, it can be useful the integration of the originally Triad of Twaddle (already reviewed by Maturo (2007) through the P-model that introduces the Sickscape) with a new dimension that lead to a new Esa-model in which we can introduce the new concept of Sonetness (a kind of loss of social networks). Esa-model seems to be suitable for copying from a theoretical point of view the whole range of health problems, including alimentary intolerances that are in great growth all over the world.

# Corporeality, technologies, and spatiality as axes of disability-object's existence Lyubov Torlopova

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Today's perceptions of disability have changed dramatically compared to those of the second half of the twentieth century. The paradigmatic shift from the medical to the social model of disability consists in the localization of disability moving away from the individual human body towards social space. Disability in the social sciences became seen as a social construct (Yarskaya-Smirnova, WHO). From the STS perspective, disability is not only a subject of discourse but is also a material-semiotic phenomenon. In my presentation, disability is considered as a spatial-temporal assemblage, which contains heterogeneous elements of reality (body, assistive technologies, a given person's situation, etc.). Despite the shift in the understanding of disability, the human body remains an important element of the assembly of the disability-object. Cyborgization of the body changes the limits of disability. The technogenic environment changes daily practices, increasing their diversity and creating heterogeneity of social space. The pace of transformations of the human body and support infrastructure is constantly rising. The presentation discusses the interaction of corporeality, technologies, and disability.

## Emotional labor of medical staff in hospice Anastasiia Ugarova

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Nowadays in Russia many oncological diseases are detected at the last stage and are incurable, modern medicine can offer such patients only palliative care. A significant role

for the modern system of palliative care is the quality of End-of-Life care, which means that attention is paid not only to symptoms, but also to the feelings and experiences of patients, including an individual approach to their needs. Such an approach requires meaningful involvement from medical personnel, including emotional involvement. First of all, it means adequate reaction to the patients' emotions, like tears, anger or depression. Such stressful work is dangerous to the health of medical personnel and may threaten professional burnout. To avoid this, medical staff can develop collective or individual emotional work practices.

The research problem of the current study is that health workers find themselves in a situation of a lack of special knowledge about palliative care when it comes to interacting with dying patients. Hospice staff need to find a balance between emotional separation from death and involvement in supporting patients.

The purpose of this study is to describe the specific of the emotional labor of medical personnel in interaction with dying patients and their relatives in hospice.

The theoretical framework of this project is the theory of A.Hochschield that emotions can be controlled by a person, and we should study how emotions are attributed, evaluated, expressed and controlled [Hochschild A. R., 2003, 216-217]. Emotion management can be carried out at two levels - deep and surface acting, deep acting implies work on feelings and meanings [Hochschild A. R., 2003, 35]. Also, based on theory of B. Glaser and A. Strauss [Strauss, A. L., Glaser, B. G., 1965.] I assume that the contexts of death awareness and the awareness of patients, relatives and medical staff will determine the emotional work of medical personnel.

One of my assumptions is that medical personnel who work with dying patients carry out emotional work in three areas: first, they need to carry out emotional work inside the hospice, communicating with patients and their loved ones; secondly, they carry out emotional work in communication with colleagues; thirdly, they either forcedly or out of a desire to protect relatives, hide their experience from family and loved ones.

At the same time, most medical personnel do not have special education in the field of palliative care, due to the recent appearance of similar training programs. Thus, medical personnel come insufficiently prepared for the specifics of the institution and are faced with the need to search for their behavioral model, attitude to the situation of death and ways of interacting with dying patients. In this regard, I suppose that it is possible to discover different patterns of emotional work among medical personnel.

The next assumption is related to the fact that working with dying patients, the staff are doing deep acting [Hochschild A. R., 2003, 40]. However, they can also perform deep acting in different ways, and our question is which models they use in dealing with dying patients, the topic of the death of young patients is particularly significant for the staff.

In conclusion, I note that this study is devoted to the emotional labor of the hospice medical staff and also affects two significant areas of research - the study of the concept of modern palliative care in Russia and the study of women in the medical profession.

# On co-labouring and living with 'a little bit less of oneself': Dialogue with many voices Endaltseva Alexandra<sup>1</sup>, Sonja Jerak-Zuiderent<sup>2</sup>

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This paper explores the collective doings and happenings that do not explicitly appear as a part of a research project yet are key to conducting (in)dependent qualitative research. We attend to practices of living with a chronic illness in Russia and of 'co-labouring' (de la Cadena, 2015) between two researchers (an academic advisor and a doctoral student). Extending on the notion of 'experimental collaboration' (Estalella and Sánchez Criado, 2018), we are particularly interested in the dynamics of such collaborations as contributing to making and maintaining the conditions and practices of knowing 'living with illness'. Our objective is twofold: first - to acknowledge the neglected practices of doing qualitative research on health by attending to 'where we come from', what emerged in our conversations, and how co-labouring, i.e. working together while accepting different understandings of the world, happens during the research. And second - to discuss matters of living with chronic illness (Multiple Sclerosis). The ethnographic journey that serves as a basis for this paper starts with studying the everyday work of the Russian Multiple Sclerosis Society (RuMSs), which official name in Russian translates as All-Russian Public Organization of Disabled People with Multiple Sclerosis. Witnessing the challenges to appreciate the differences that living with MS brings along in every day, makes us equally wonder if and how our scholarly account of what we witness speaks to such challenges of co-labouring. By studying how everyday living with MS happens through the interactions between material settings, the activities of (more than) human participants, and the creativity embedded or cherished by them (including ourselves), we learn to appreciate vulnerabilities as a condition for both living with (a chronic) illness and a life 'with a little bit less of oneself'. Developing sensitivities for life with 'a little bit less of ourselves', this journey leads us to a discussing the co-creation of a photo-story exhibition in Moscow with which we learned the matters of living with illness.

In dialogue unfolding our own vulnerabilities as researchers, we ask, how do vulnerabilities matter for co-labouring between people, across situations, between creativity and givens of living with illness? What material and social elements contribute to co-labouring? What does this teach us about the potential of vulnerabilities and co-labouring as a concept for knowing and living with care?

### AR: ANTIMICROBIAL RESISTANCE. BUILDING CROSS-DISCIPLINARY COLLABO-RATIONS

Antimicrobial resistance in Thailand: complex relations between medical, agricultural and environmental sectors

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Antimicrobials are part of our daily lives – they are embedded in medical practice, farming, and agriculture. These different sectors adapt various use practices of antimicrobials for the means of treatment, prophylactics, and/or growth promotion. As a result, in these different sectors, antimicrobials are surrounded by various discourses that have complex, often conflicting, interrelations between each other. While antimicrobials are considered to be essential for human health, its use in farming and agriculture can often be associated with bad hygiene and inappropriate husbandry practices. Based on the case study from Thailand, in this presentation I will follow the networks organized and travelled by antimicrobials through farms, factories, veterinarian clinics, and human hospitals. These networks will help us to understand the processes of discourse formation regarding antimicrobials in the intersectoral and interspecies arena.

## International travel and antimicrobial resistance: Exploring narratives of daily life with bacteria

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Travelling and human mobility have become an important factor in transmission and dissemination of resistant bacteria globally. Researchers in microbiology such as Arcilla et al (2017) and van Hattem et al (2019) define international travelling as a potential for being colonized with resistant bacteria that may cause an infection if given an opportunity (e.g. among immunocompromised travellers). Although microbiological research highlight that travelling can be seen as a potential for colonization with resistant bacteria, but not a definitive risk factor that will cause a disease, some travelling groups such as refugees have been already put under microbiological screening in the Netherlands and Germany. However, the phenomenon of travelling and its association with antimicrobial resistance (AMR), beyond screening of refugees, have been scarcely discussed outside of microbiology literature. In the presentation, I will address this issue, while raising the question of how AMR and travelling can co-construct each other's narratives, and what are the potential consequences of such narratives. On the one hand, as it has been shown by Nerlich and James (2009) and Brown and Nettleton (2016), AMR is often associated with a coming catastrophe of modern medicine. "Foreign" bacteria are seen as being smuggled to different countries within the bodies of travellers, transforming them into potential risk groups, from which host communities have to protect themselves. On the other hand, the opportunistic nature of acquired bacteria may symbolize shifting narratives about bacteria and human-microbe relations. In her work Wald (2007) elaborates that human interconnections do both make us sick, and constitute us as a community. Therefore, defining travelling as a vector for catastrophic bacteria would mean defining communal life itself as a risk. In conclusion, I would like to explore how a developing knowledge in microbiology can (re)shape the narratives of both AMR and travelling.

# Antimicrobial resistance in Russia: Complex interrelations between human and animal health sectors

#### Sergey Fedosenko

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The importance of antimicrobials as well as a shared concern of antimicrobial resistance for both human and animal health has been widely recognized. However, the interconnection and communication between these two fields are often loaded with contradictions, mis-coordination, and blame allocation – questions of responsibility for antimicrobials misuse, and antimicrobial resistance dissemination. In addition, a coordination of these two sectors can be further complicated by the organizational structures at national levels. For example, human and animal health sectors in Russia are coordinated by different ministries, and therefore standards and regulations produced by these ministries are not always coherent between each other. In the presentation, I will discuss the current state of antimicrobial resistance in human and animal health sectors in Russia, and I will explore the opportunities and complications for the collaboration between these two sectors.

# Antibiotic use and antimicrobial resistance perception: survey in medical specialists, pharmacists and patients in Tomsk, Russian Federation

#### Marina Fedotova

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Nowadays, the development of antibiotic resistance represents one of the most important issues of the global public health. Actually antibiotic misuse mainly contributes to the growing problem of microbial resistance. To understand the current knowledge and practices regarding antibiotic use among Russian community 55 in-depth interviews with medical practitioners, pharmacists and patients were conducted. The in-depth interview method revealed the general perception of the problem in the community from different sides: doctor-antibiotic prescriber, the consumer and the antibiotic seller. Such integrative approach is necessary for the subsequent qualitative survey in medical specialists and patients. It would be necessary to strengthen educational initiatives in the community and to improve antibiotic prescribing in medical specialists.

## Antimicrobial resistance in National Action Plans of Russia and China Veronika Tayukina

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People knew about antimicrobial resistance (AMR) since antibiotics were invented. But nowadays it became a global threat. World Health Organization (WHO) is a leader in fighting against AMR. So, one of the steps to overcome the AMR spreading was Global Action Plan development. Following the example of the Global Action Plan, WHO's member countries agreed to develop their National Action Plans. Many of them got a flurry of criticism because National Action Plans don't represent national contexts.

As far as my research, it is interesting to explore Russian and Chinese National Action Plans fighting against AMR, because they are neighboring countries with long border and long history of cultural exchanges. I'd like to investigate both countries' documents and compare them with each other and Global Action Plan.

I will use document analysis approach in order to understand what kind of discourses are present in these National Plans. Exploring the discourses could help to clarify how Na-

tional Action Plans of Russia and China associate with the Global Action Plan in national context. In my work I will examine in what way discourses formulate according to these documents. So, doing this work I explore the discourses present in National Action Plans of Russia and China, and the way they are interlinked with goals stated in Global Action Plans.

I argue that National Action Plans sometimes could resemble steps and actions from the Global Action Plan, and it could generate inconsistencies between documents and contexts.

#### **SH-2: STATES AND HAPPENINGS OF HEALTH-2**

## Actors as networks: Internal Family Systems Therapy (IFS) and autoimmunity Márcio da Cunha Vilar

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Autoimmune diseases and psychological 'wounds' are often characterized as a battle against oneself: autoimmunity as the reduction of one's immune system's capacity to distinguish between one's own cells and foreign ones (the 'self' from 'non-self'), while in many ways psychological wounds are seen as implying self-sabotage. The 'disease' is normally seen as a part of the person (its immune system and/or a neurosis) and, hence, it is classified as 'chronic' by established biomedicine and psychology. However, in opposition to conventional approaches, emerging immunostimulant therapies, such as Vitamin D3 Therapy and the Complex of Essential Amino Acids (Vilar 2018), and the so-called Internal Family Systems Therapy (IFS) see these parts of the person as the key to tackle their suffering and seek to mobilize them as to improve one's health. That seems to provoke significant resonances in society. In recent years, IFS-associations and training centers have been grounded outside the US, like in Europe. In 2013, a randomized controlled study with 79 patients with rheumatoid arthritis suggested that IFS-based intervention helped patients to diminish pain and depression (Shadick et al 2013). In the face of its apparently increasing acceptance, how does IFS affect conventional treatments? How its therapeutic premise concerning the 'self' as multiple does affect established psychological ideas about person, body and mind? How IFS-practitioners do relate autoimmunity, environment and stress? In my proposed paper, I aim to report on the use and impact of IFS to treat autoimmunity in the UK as a case study, and as part of my broader anthropological study on the development, circulation and regulation of immunostimulant therapies to treat autoimmunity.

My presentation is based on unstructured interviews conducted between Mid-December 2018 and Mid-February 2019 with IFS-practitioners who are members of the British IFS-community. Analytically, I discuss my findings in light of studies that, in recent decades, have pointed out causal relations between emotional stress during childhood, psychological wounds and autoimmunity. Inspired by somatic approaches, many health professionals now tend to perceive autoimmune responses less as predisposed by genetic dysfunctions than as part of intergenerational stories that unfold cyclically. That points to the construction of the person as a process that embodies and reinvents multiple ele-

ments of the entwined healthy and 'toxic' environments through and between which one moves and grows (family, education system, neighborhood etc.). One of the key premises of IFS is that every individual is made up of further sub-personalities. That supports an ongoing reconceptualization of the body-mind dichotomy as multiplicities of the self.

My hypothesis is that stimulating therapies seem to provide means that enable their users to validate and recommit specific parts that co-constitute themselves, instead of suppressing them as conventional therapies do. Through it, IFS-practitioners seek to re-organize the internal script that 'rules' their own lives. Finally, I seek to understand whether and how IFS integrates the so-called 'regenerative medicine' as the set of 'sciences and technologies involved in the collective project meant to coax the body to repair itself' (Hogle 2007, 359).

## Historical Multiplicity of Vegetovascular Dystonia Illness Anastasia Beliaeva

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I am going to consider the multiplicity of historically manifested versions of the same illness. My presentation focuses on the case of vegetovascular dystonia (VVD), one of the most common Soviet diseases, and I am going to demonstrate how the same set of symptoms exists as different illnesses depending on the social and political environment at a particular moment of history.

At first VVD existed as neurasthenia. From the very beginning, neurasthenia is a disease bound with local environment; the construct of the disease is always determined by the social and political situation in a particular place. Before the 1917 revolution, many physicians thought that the main cause of neurasthenia was the oppressive social and political environment, which literally lead people to illness. However, after the victorious revolution that put an end to the Tzarist regime and brought to reality a social order free from the maladies of the past (at least that was proclaimed by official propaganda), such interpretation was no longer politically appropriate and had to be abandoned. After the revolution, Pavlov's theory of neuroses redefined the main causes of neurasthenia to acute or chronic overstrain of the nervous system due to physical exhaustion, overwork, lack of sleep, and also personal predisposition.

After the end of WWII, neurasthenia, already transformed in Pavlov's theory, merged with traumatic war neurosis and essential hypertension, and developed into cardiovascular disease under the name of vegetative dystonia. It was Georgy Lang who first articulated and established the link between essential hypertension and symptoms of neurasthenia. He described the cases of "vegetative neurosis" or "vegetative dystonia" in his book "Hypertension" (1950). The symptoms which earlier were considered as an indication of neurasthenia, according to Lang, represented the initial stage of essential hypertension. Lang established a link between vegetative symptoms, psychological state, and hypertension using Pavlov's principle of nervism. VVD at this stage was a war syndrome. High blood pressure was reinterpreted as an emotional response to mental strain, psychological trauma, and intense emotions, which legitimize those emotional experiences.

From the 50s to late 70s, VVD existed exclusively within cardiology. VVD has confirmed its position as a somatic expression of neurosis, which eventually leads to essential hypertension.

As a separate disorder VVD comes into existence in the 80s. In the 80s there were two competing constructs of the same disorder. The first one under the name of neurocirculatory dystonia which resumed the earlier cardiological version, where cardiovascular symptoms remained the most important. The other construct considers VVD a neurological syndrome and deals with mostly neurological dysfunction. Both of these constructs have much in common: both suggest that the cause of the considered disease, in most cases, is neurosis that literally damages the brain and alters its functioning, provoking all described symptoms. Eventually, the two constructs merged into one disease, which became separate and autonomous.

# Nutritional Anemia and programmatic approaches in India: Reexamining the global health theories of Anemia

### **Rahul Rauny**

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Anemia is the most prevalent nutritional disorder in the world and is one among the most important contributing factors to the global burden of disease. World Health Organisation estimates that more than 40% of the total global population is anemic. Among all countries, India has the highest number of anemic people as well as one of the highest prevalence rates in the world. In poorly performing states of India, the prevalence rate is as high as 80% among women and children.

The initiatives to reduce anemia prevalence have had a minimal impact globally. Clinical interventions such as Iron supplementation and iron fortified food programs are being pushed as magic pills to address the problem of anemia. Only a few countries have shown visible improvement in this regard.

Far from being a problem of iron deficiency that needs to be restored by clinical interventions, it is a condition which exist because of the inability to identify and link multiple etiologies and causal factors and design programmes that respond to its etiologies. Multiple causes have multiple realities often entrenched in different biosocial, technical, historical and evolutionary processes which is not well mapped.

Anemia has a multifactorial etiology of which iron deficiency is generally considered as the prime cause that contribute to half of anemia. However, this assumption has recently been challenged in a finding that demonstrates that the iron deficiency attributable to anemia in south Asian countries is much lower than previously estimated. Iron deficiency seldom occurs in isolation. It coexists with a number of other causes, such as malaria, parasitic infections, nutritional deficiencies such as vitamin A, B12, folate, and haemoglobinopathies.

Plant-based Cereals are the only source of nutrition for the majority of Indians. Research shows that the vegetarian diets even in sufficient amount cannot compensate the iron deficiency. The diversified foods such as pulses, milk, meat, and fat are inaccessible, and

their intake is much lower than recommended. Per capita, food availability has also declined in last decades.

Health services, nutritional welfare programs and safe drinking water are inaccessible to majority. Majority of rural population still practice Open defecation. This complex scenario makes the disadvantaged and underprivileged social groups vulnerable to the recurrent infections. Infections and Anemia are intrinsically linked and mutually exacerbate each other.

Contrary to nutritional deficiency theory, Evolutionary theory explains iron deficiency as a response to the nutritional adaption of the body to protect itself from harmful pathogenic infections. Blatant use of iron-based interventions may increase the risk of higher infections as which demonstrated in Zanzibar, Tanzania study. Therefore, addressing the dichotomy of iron deficiency as nutritional adaption and iron deficiency as a potential health risk remains critical to explain the problem of Anemia.

The high prevalence of Anemia among socially disadvantaged groups is the result of larger maladies rooted in structural causes of health and nutritional crisis in the country as well as because of failure to recount historical and evolutionary aspects rather than mere clinical solutions of iron deficiency.

This study synthesizes the recent research using "critical narrative review" methods to explain the epidemiology of Nutritional Anemia, identify the underlying causes, and critically analyse the epidemiological and public health relevance of the intervention programs to provide future recommendations. The study defines Anemia beyond the limited horizon of clinical perspective and explain the dichotomy of multiple theories around Anemia using clinical, evolutionary and Historical perspectives to fill the major gaps in global health theories of anemia.

# Children's morbidity and mortality in XIX century in Tomsk, Western Siberia Valeriya Prokopyeva, Malchuk V.N., Fedorova O.S.

Federal State Budget Educational Institution of Higher Education, Siberian State Medical University, Ministry of Healthcare of Russian Federation, Department of Faculty Pediatrics, Tomsk, Russian Federation.

Aim: To review the children's morbidity and mortality in the Tomsk, Western Siberia, by the analysis of the official medical records of the outpatient and inpatient departments of Children's Clinic of Tomsk Imperial University from 1893 – 1899 years.

Materials and methods: We reviewed the official books of inpatient department records for the period of 1893–1899, and outpatient department records from year 1897.

We used all collected information from the inpatient and outpatient department's records including demographic (age, sex) and medical data (diagnosis, type of treatment, month of hospitalization, outcome, etc). The database was created using Microsoft Excel. Statistical analysis was performed using Statistica, version 10.0.

Results: We registered 569 patients who admitted to the clinic. The number of patients who admitted per year was  $81.2 \pm 5.9$  cases. Number of patients who applied on outpatient department were 1025. Of the 1122 patients we excluded 53 with unknown diag-

nosis and 44 patients who visited clinic for vaccination. These patients were not taken into account structure. The mean age of patients was 4.02±4.14 (1 month-16 year); the majority of them were children under 3 years of life. The boys/girls ratio was 572/542.

In the structure of the incidence in children's clinic we found that infectious pathology was prevailed – 32.2%; tuberculosis was 18.4%, rickets – 16.9%, respiratory diseases – 10.9%, pathology of the digestive system – 9.8%, diseases of the nervous system – 5.2%, skin diseases were registered in 4.5%, anemia – 4.4%. The results of hospitalization in inpatient department showed that most recovered patient with infection pathology 49.6%, digestive system 15.4%, skin diseases 8.3% and diseases of respiratory system 7.9%. The results of the study indicate fairly high hospital mortality in the analyzed period – 7.5%. In the structure of causes of death were leading infectious diseases (scarlet fever – 24.4%, stenosis of larynx – 7.3%, diphtheria 14.6%, smallpox 7.3%) and diseases of digestive system- hepatitis and cirrhosis 9.8%.

Conclusion: The study provided data on the structure of morbidity and hospital mortality in childhood in the Tomsk region in 1893 - 1899. The leading cause of morbidity and mortality were infectious diseases, pneumonia, which is due to the lack of vaccination preventive programs, antibacterial therapy and the low socioeconomic status of the population.

#### **ROUND TABLE**

#### MEDIA, WELLBEING, AND HEALTH

This round table brings together representatives from the media, anthropology, and medicine domains to discuss how media can be helpful in understanding and improving health and wellbeing.

This round table aims to provide a platform for discussing the roles of media in understanding and improving the wellbeing of an individual and society. Representatives of the media, anthropology, and medicine fields will present their views on the topic. As a result, participants of the round table will address the key question of how media can be useful for supporting wellbeing and health.

#### Key themes:

- Impacts of health communication in the media on health of individuals;
- Life of communities and the media: studying health and wellbeing of social groups and their members.

#### Questions for discussion:

- What approaches and technologies can media productively use to improve health and wellbeing of communities and individuals? How can we appraise the effectiveness of such kind of work?
- How can decision-makers, scientists, and media experts collaborate in creating media projects with the purpose of addressing the problems of communities and individuals?

## Health issues and quality of life in the regional media: methods of risk communication

#### Valentina Ershova

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What is the role of the regional media in covering the quality of people's life and their health? Do journalists recognize their role in emergency situations, for example, epidemic or ecological threats to the population?

We will try to find out to what extent media influences risk communication in the health sphere on the local level.

Practical application of the risk communication phenomenon allows media researchers and practitioners to bring up new issues. Are the media used as a discussion platform and a way of collaboration with the society? Who and how opts for these opportunities, and what positions do experts, journalists, and PR specialists take up in this communication? What new meanings connected with risks, illnesses, health, and quality of life appear in risk communication?

# The role of media environment in preventing diseases and preserving the health and wellbeing of a person: the issues of responsible covering of HIV/AIDS matters in the regional mass media

#### **Alexander Chernov**

Tomsk Regional Center for Prevention and Treatment of AIDS and other Infectious Diseases, Russian Federation; <u>zvonoks@gmail.com</u>

We are going to consider problems of negative coverage of HIV/AIDS topics in the media, sensationalism, journalists' choice of characters and private stories. The report will also cover the problems of stereotypes and stigmatization in the media (for example, "The plague of the XX century").

The purpose is a try to answer the following questions:

- what is the role of mass media in publicity of health and diseases prevention topics?
- how to make the subject more comprehensible for laypeople?
- how to change people's attitude to HIV/AIDS problems in the long term (in particular, what special approaches could be applied to various social groups)?
- how to overcome a gap in communication between medicine representatives, policy makers, journalists, and the public?

# The disability phenomenon in Tomsk mass media coverage: the medical and social examination bureau expert's view of the problem

#### **Vyacheslav Perminov**

The Bureau of Medical and Social Examination in Tomsk Region of Ministry of Labor in the Russian Federation, Russian Federation; ervalen@yandex.ru

The problem of disability phenomenon coverage in the media is actively studied by scientists in humanitarian fields. We will try to look at media contexts of disabled peoples' rep-

resentation from the point of view of the medical and social examination bureau expert. Whether journalists help to inform the population or, on the contrary, disrupt data? What topics are interesting to journalists: stories of real people with disabilities, officials' activities, legislation changes, or some other topics? What narrative connected with the disability phenomenon is created in the local media? What attitudes and values concerning disabled people are formed by the regional media? What should the interaction between journalists and doctors be like from the point of view of the latter? Do they have common goals and grounds?

## Charity media contexts in health and children's cancer spheres Elena Petrova

Children's Charity Foundation named after Alyona Petrova, Russian Federation; <a href="mailto:ervalen@yandex.ru">ervalen@yandex.ru</a>

It is planned to discuss the following questions:

- what contexts and information background are utilized by the local media in covering the topics of charity and children's cancer incidence?
- what mistakes journalists make when covering these topics, and what goals they are trying to achieve?
- what media instruments and genres are used by the media to influence people's attitudes and beliefs in the spheres of charity and children's oncology?
- what problems exist in media communication between charity foundations, journalists, press secretaries, doctors, patients and their parents? How are these problems solved?

# Photography as an instrument in dealing with problems of a community and a person

#### **Anton Unitsyn**

Union of Photographic Artists, Russian Federation; <a href="mailto:ervalen@yandex.ru">ervalen@yandex.ru</a>

The report presents a photo as a finished media project. We will try to answer the question of how a photo artist can influence the community life and the wellbeing and health of a particular person. We will have a close look at the experience of creating real projects.

# The role of media projects in developing wellbeing of indigenous communities Olga Zakharova, Marina Astakhova

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Media environment may create an umbrella concept capable of favorably influencing the development of indigenous cultures and designating their place in the modern society. Media play the forming role, projecting, formulating, and supporting the general sense of activity of certain groups. The report discusses the example of the Tyumen regional public organization of indigenous ethnic groups "KEDR", which actively uses media to position themselves. Thus, media help to form a concept which is implemented in shaping the pub-

lic organization's activity in the sphere of education, popularization, charity, nature protection, volunteering, development of international cooperation, preservation and protection of authenticity, culture, languages, and traditions of peoples of the North.

# "The Selkups: save as...": stages of creating the media project and assessment of its influence on local communities

#### **Vasily Vershinin**

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In 2018 students and lecturers from the Faculty of Journalism of TSU created a big journalistic project devoted to one of the smallest community in the world. Its authors will speak not only about the principles of creating a qualitative multimedia project, but also consider methods that can be used in assessing its influence on the wellbeing of the project heroes and readership.

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