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## BOOK OF ABSTRACTS

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**Knowing that we don't know: Knowledge and ignorance in relation to health and biomedicine in the digital society**

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### **Decision-making in health care: Will algorithms and artificial intelligence liberate physicians, healthcare workers and patients or re-emphasise paternalistic relationships?**

A range of authors have recently argued that the introduction of advanced artificial intelligence technologies and autonomous computerized systems in the health sector will liberate physicians and health care workers from various time-consuming routine tasks, which would eventually lead to a better and more emphatic and equal relationship between health care professionals and patients (e.g. Aminololama-Shakeri and Lopez, 2019).

In this contribution I will first start with a brief introduction to notions of paternalism, ranging from medical paternalism to technological paternalism. Then I will briefly sketch some recent developments that concern digital technologies, big data, artificial intelligence, machine learning and the health care sector. Following that I am going to use selected examples concerning health and wellbeing predictions created by algorithms, personalized health insurance policies and IT security to discuss various ethical and social problems that also concern the new and emerging relationships between citizens, insurance companies, physicians and health care workers and further stakeholders of society.

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### **Social and structural factors of collective empowerment in online health communities**

Online health communities (OHCs) have become one of the most important e-health services in contemporary society. As Internet-based platforms, OHCs connect various groups of individuals with similar health-related interests; thus, they represent important venues for connecting people with similar health conditions and sometimes access to health professionals. While research on individual empowerment has been for some time one of the central topics in OHC studies, lately studies have also emerged that emphasize the potential of OHCs for development of users' collective empowerment. Collective empowerment in OHC settings refers to users' development of: (1) knowledge of resources and problem-solving skills for identifying and managing personal health-related issues in a health care system; and (2) collective awareness and engagement that unite OHC members in a belief that personal health-related issues can be effectively solved through collaboration with others and by enacting collective influence in wider social structures. Currently it is clear that OHCs are venues of rich intersubjective dynamics, which can result in collective empowerment. However, it is not clear which mechanisms and processes in OHCs contribute to such outcome. The aim of this study is thus to propose a socio-structural explanatory model of collective empowerment in OHCs and empirically test it on a sample of users of the biggest OHC in Slovenia. The model is built on conceptualization of OHC as a socio-technical system, which comprises an interconnection of users and their social practices, technology and emerging structures. The study presents the model, its conceptualization, empirical findings, theoretical and practice implications.

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### **Bodies, data, and data bodies: addressing knowledge and ignorance in a medical technology development process**

Medical practice has been working with bodies and data ever since. Nevertheless, through the rapid increase of digital technologies in the medical field, knowledge practices with bodies and data have re-shaped our understanding of the human condition. Disputes over definitions of life and death, health and illness, ability and disability are nowadays intrinsically interwoven with digital data practices.

This paper addresses such valorization processes based on my current involvement as a social scientist in a medical technology development project funded by the German Federal Ministry of Education and Research. Through an interdisciplinary collaboration between the disciplines of engineering, user design, nursing sciences, and social science, this project seeks to invent a multisensory-system for the prevention of pressure ulcers. The technology under development has the potential of intervening into existing care relations and changing the ways in which society (not) knows and (not) perceives people with immobilized bodies and their respective care needs.

Deploying a material-semiotic approach, I will give examples of the different bodies, data, and data bodies we have been dealing with in the run of the project and discuss how we have been relating them with various forms of knowledge and ignorance from our respective disciplinary backgrounds. Last but not least, this will open up a discussion on the situated practices of knowing and not-knowing as much as on their ethical implications.

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### **Health and body relations through off-line and on-line spheres**

Digital society represents a new situation for humanity, where the societal functions and interactions are extended to the on-line (digital) sphere, and vice versa new digital elements are present in the off-line sphere. The borders between purely virtual on-line sphere and purely real or physical off-line sphere started to be blurred, same entities having simultaneously the virtual on-line and real, physical off-line component and representation. Subsequently, defining the entity only by virtual or only by physical components could be misleading.

The position of humans in the digital society in relation to their virtual and physical components (or representations) appeared as a novel perspective, where the humans cannot be exempted from the virtual-physical duality. In my way the off-line/on-line duality is artificial and the human beings extend freely and continuously without any borders or differences between off-line and on-line spheres. Subsequently, the digital society, if to be established as a novel specific phase of humanity, would represent a seamless continuity between virtual and real.

The controversy on duality between body and mind is in the digital society transformed toward a new relation between virtual and real. The embodiment process of entities belonging to the virtual sphere includes the humans as well, allowing them to be embodied as humans in the virtual sphere. One could speculate that only mind would be “embodied” in the virtual, however due to the fact that digital entities have real counterpart and are attached and communicate with our physical body, the data representation of the physical body (e.g. ECG, pulse data, body temperature, medical images, GPS coordinates, public places video footages) are present in the virtual sphere as well.

Subsequently, if the seamless continuity of human between virtual and real is assumed, the health aspect is to be extended toward the virtual on-line sphere as well. Both mental and somatic health aspects are transferred to the on-line sphere and the digital representation of the health resonates with the physical aspects of the human body. Together with the new possibilities of maintaining health, diagnose and treat illness, the health in the digital society can evolve as a key aspect of the digital human.

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### **Medical decisions under conditions of uncertainty and ignorance – the hard ‘vaccination’ case**

Thomas Schelling, the Nobel-winning economist observed a peculiar phenomenon: people would eagerly donate to save a six-year-old girl with brown hair needing thousands of dollars for an operation that would prolong her life until Christmas, but are happy to complain about the costs of healthcare that usually sustain hospital facilities and effectively prevent the deaths of many such girls. This phenomenon, known as the *identified victim effect*, captures the human tendency to prefer to rescue identified individuals over unidentifiable ones. This tendency leads not only to less than optimal allocation of medical resources, but causes many difficult issues in medical decision-making.

One of the most difficult – and currently most discussed problems – which explores the meaning of this phenomenon, is the issue of child vaccinations. The notoriety of this issue stems from the clash of two perspectives: the private, which irreducibly focuses on the good of the individual (one’s) child, and the public, which sees the matter *sub specie statistica*.

The aim of my paper will be to analyze the colliding normative frameworks for the hard-case decisions under conditions uncertainty and ignorance, through the prism of their underlying cognitive basis. I will juxtapose: 1) private healthcare ethics (bioethics, medical health and clinical health ethics), which in dealing with private agents is inherently more susceptible to cognitive biases, and due to its deontological orientation also legitimately tolerant towards them, with 2) outcome-oriented public health ethics operating under its irreducible veil of ignorance and thus particularly obliged towards the unidentifiable victims. I will also discuss potential ways of soothing the clash of these perspectives in which digitally mediated gap-bridging between conditions of knowledge and ignorance play a crucial role.

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### **Knowledge and its leftovers**

The article provides some preliminary thoughts on the difference between negative and expanded knowledge. It shall focus on its political implications considering the proliferation of information in the digital age which has not lead directly to more knowledgeable and informed society. What the author tries to highlight is similarities between expansion of knowledge and sciences in the classical age as named by Foucault and the proliferation of technologies, information and sciences in the present times. The author uses examples from history (of medicine) and more recent research in the field to show how discovery of new knowledge is tied up with negative knowledge as being part of the given political system and its episteme. This is shown by using standpoint approach.

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### **The progress of human enhancement technologies on the cross-point of digital and biotechnological revolutions: are the new technologies leading to the realization of mind-body dualism?**

Traditional Cartesian mind-body dualism could be interpreted in the times of recent interlinks of nature, technology and human beings also in the sense that the 'human' is only contingently located in the body of homo sapiens. In the recent times of tremendous progress of the human enhancement technologies the four hundred years old Cartesian philosophical vision is increasingly transforming in reality. It seems that what was in the former times only loopy philosophical concept could change in long- (-middle?) range future in real fact. If it will be realized such dualism, there might come to situation that distinguishing features of homo sapiens will nothing to do with existent physical morphology of human beings but exclusively with the character of human being minds. How else to understand Ray Kurzweil's (2005) 'singularity' talk of uploading human consciousness into indefinitely powerful computers, Georg Basalla's (2006) talk about prospect for extraterrestrial life or »exobiology« or - last but not least - Steve Fuller's talk about the humanity 2.0 (Fuller, 2011)? Because the recent progress of the human enhancement technologies proliferate in various directions, e.g. through genetic enhancement, morphological enhancement, pharmacological enhancement (Sorgner, 2016), there are opening practical questions which deserve attention also in the context of discussion about knowledge and ignorance in relation to health and biomedicine in the digital society. Namely, the human enhancement technologies are arising at the cross-point of two technological revolutions: on the one hand, there are growing digital technologies which in prevalence »define« every day life of human beings, on the other hand, there are growing biotechnologies (only about 20 years after the discovery of Human Genome) which involve cyborgisation, xenotransplantation, in vitro cultivation, synthesis and genetic recombination of life forms, etc. In our contribution, the focus will be given to the above stated dilemmas of the tremendous recent and future progress of human enhancement technologies. There will be made attempt to include in the conceptual level of discussion some case based on our empirical analyses.

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### **What knowledge to navigate the caringscapes: why some questions become research questions and other not**

The metaphor of knowledge as a landscape is also applicable to the complex and intricate knowledge of caring professions. Caring practice itself resembles a journey through a demanding and sometimes dangerous territory, hence the expression caringscapes for the field. What luggage do the caring professionals need for their journeys?

Caring work evolved around the basic need of humankind to survive and develop. However, to perform it efficiently, resources for quality care, including knowledge, are needed. The so called helping/caring professions need power to help. It is not possible to provide help if you yourself are helpless. And this is what happens to members of many caring or helping professions whose intentions to care are limited by different barriers, one of the most important being the lack of evidence based knowledge on which to base their interventions. The questions that emerge from their everyday practice seldom, if ever, become research questions, and part of a systematic research process into different caring phenomena.

Caring work has changed from an informal component of the traditional society life-world and has moved to health care institutions during the modernization processes. In the field of health care the long established medical profession took the central place in the health care system, and various assisting occupational groups developed more or less under its control. With time, members of those occupations accumulated experiences, skills and culture which enabled them to claim their separate identity and autonomy. An important step in process of developing of these new professions were social movements in the second half of the 20th century, asserting the ideas of emancipation and empowerment. Knowledge is a core element of both emancipation and empowerment. We will discuss these issues based on the case of Slovenian nursing profession and its trials and tribulations in the last decades.

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### **Women's Post Body: Posthuman and Gender**

What is the posthuman era? Everybody tells about posthuman era. But there are no denition about the posthuman era. Due to the development of science and technology, the human body has become cyborg in a broad sense. This paper discusses the problem of human Enhancement in relation to women 's menstruation. The period during which women are menstruating is: one month per month, about 400 times during their lifetime, and 10 years for menstrual periods throughout their lives. For a long time menstruation was regarded as the essential biological value of women. Women's menstruation has also been discussed in the context of the right to reproduce. These discussions have strengthened menstruation to be considered a natural symptom of the female body. Today, however, women are equipped with contraceptive devices in the womb for the purpose of increasing the quality of life, not the purpose of contraception. Thus, women are considered to be able to control or inhibit

menstruation. Women are questioning whether they have a right to menstruation or a right not to menstruate. In this paper, I will examine the arguments for it and the arguments against it, and discuss what position is more persuasive.

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### **DNA as my heritage? On socio-technical systemic ignorance imbedded in the direct to consumer genetic testing.**

This presentation discusses knowledge distortion and the discontinuity between genetics and genealogy in direct to consumer genetic testing, the complex relation between knowledge and ignorance, and its socio-technological underpinnings.

The interest in genetic information has a persistent history. The Human Genome (HUGO) project made human genetics a scientific and societal modern Holy Grail (Svalastog 2012), and though the Human Genome Diversity project (HGDP) apparently fell apart due to political-scientific controversies, research on genetic-historic homogeneity continued under new research umbrellas (Svalastog 2013). Today genetic testing has moved outside of the established medical and research based institutions to commercial agents, and private companies and individual consumers have become key actors as new agents mapping and interpreting human genetic material. The move is made possible by the present socio-technological systems facilitate and accepted this practice. Tests that overlap with medical practice have been quite vividly discussed in relation to clinical practice, ethics and quality of life, and certain aspects of historic inquiries based on genetic analysis have been discussed, not the least in controversies related to the HGDP-project. Still, the tests have managed to flourish quite undisturbed. In this presentation the focus will be on at-home ancestry tests.

It is more than 26 million customers that have taken an at-home ancestry test (Regaldo 2019). This makes the direct to consumer genetic testing an important societal phenomenon, and a large industry. At-home ancestry tests are promoted by different agents, including globally respected agents like National Geographic (<https://genographic.nationalgeographic.com/>). There is frequent on-line questions and answers discussing which test is the best, and how accurate the tests are, depending on what the chosen DNA-test is analysing. In addition, there are home pages that summarizes the pro et con for the consumer, like the Top10com-home page (<https://www.top.10bestdnatesting.com/best-dna-testing-kits>). The commercial success, and individual curiosity and willingness to pay for these tests represents socio-cultural-economic significance, and carries meaning in and beyond the use of it as a joyful social event and party tricks.

The scientific knowledge about the limitations of genetic genealogy goes back to the early 1980s (MD Edge and G Coope 2019). It implies that when 'genetic ancestors' are highlighted, most of the actual genealogy of the individual is left out, as most of the family we are related to is not leaving genetic traces in a person. This means that in addition to hide social upbringing (who was actually there), and

culture (how was the person brought up), genetics is a poor way of identifying who was actually reproducing with whom - and more than 10 generations behind, it makes no sense at all 1980s (MD Edge and G Coope 2019).

The absent of knowledge on these limitations, in the discussion of genetic heritage, and in the promotion of direct to consumer genetic testing, will in this presentation be approached and discussed as ignorance, not in terms of ignorance as a dichotomy to knowledge, but in terms of ignorance and distortion of knowledge that need to be understood in relation to socio-technological-economic underpinnings and consequences. The key analysis in the presentation starts with four selected home pages that concerns direct to consumer genetic testing. The analysed focuses on the content of the home pages, and their reference to knowledge about, genetics, genealogy, ethnicity and identity. The result of the analysis will be discussed in relation to further techno-social contexts, and how to best understand the present success and celebration of the idea of a biological finite collection of loci for relations and presents. The presentation closes with some tentative conclusions on the relation between ignorance and knowledge in direct to consumer genetic testing and what it may reveal about the meaning and politics of genealogy, ethnicity, history, individuals and groups in society.

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### **Inscription of ideological dichotomy in virtual debates on 5G and health**

New European technologic step in digitalization is based on Chinese wireless network 5G and the global navigation satellite with the generic name GNSS. The structure is to be fully operational by the year 2020 with the EU GNSS – Galileo navigation satellite system. It has been created by the European Union through the EU GNSS Agency - GSA. Currently there are at least 50 projects going on with the aim to do business in the field, which are financially supported by the GNSS Agency GSA. According to the experience of the researcher, who was involved in the ethics appraisal of the 19 project proposals of the last GSA research call, all ethics issues except personal data protection were intended to be ignored (environment, dual use, i.e. probable military use and civil application, safety and security, and – health).

The existing public debates on the various internet platforms (protests of experts, circulating scientific articles, specialized opinions ...) on 5G and health are often reduced to the basic contradiction in lay virtual communities: either they are associated with the development-regardless- of-the cost neoliberal ideology, or they are considered to be kind of retrograde neo-hippies' fantasies.

With the aim to prove the above hypothesis, the FB profile of the known Slovenian eco and health activist is being checked for two months. Analyses of her well argued posts on 5G and health are mostly replied according to the indicated two matrices: development vs. regression.



The segmented collection of the replicas is contextualized by the scientific and expert voicing the health issue in relation to 5G technology. This is the tool to show that the ignorance is on both sides of the contradiction. As with the other major social issues, it is impossible to lead the public debates subverting the extremes and having in mind the continuum of possible positions, and their internal tensions. In the conclusion the conditions of populist thinking in two ideologically biased think-tanks are presented (interest in capital, and other rude power relations, politics based on antagonisms on the one hand, and fake news as the consequence of the wish to contribute to the 'de-growth' socio-economic movement at any price, truth included). The described example of 5G related health issue in the virtual debates is helpful in detecting the concrete forces behind the ideologically ridden think-tanks. The initially mentioned GSA case which is also the case of the EC is an important actor in this regard.