Session T3

Non/Acceptance of Human Enhancement –Societal and Ethical Considerations for "Good" Decisions

Chairs: Gabriel Bianchi, Miroslav Popper and Tomáš Michalek (Slovak Academy of Sciences)

The term "enhancement" contains the moral ambivalence which reaches from "improvement" to "the subversion of humanity". The basic methods of human enhancement are nano-bio—info-cogno technology based. Their aim is to increase three basic characteristics: healtspan, cognition and emotion, or physical, intellectual and psychological capacity.

As for extent, enhancement is a very broad phenomenon; its extent reaches from "improving" on a genomic level, through pharmaceutical "improvement" of emotions and physical possibilities of the human organ- ism and the physical appearance, all the way to the cognitive functions and memory (Gerlai 2003, Glannon 2006) and connecting the human brain to a computer, surpassing the limits of human intelligence with artificial intelligence and reaching a state of singularity (Kurzweil 2005).

The term "enhancement" also describes a number of various procedures on a genomic, cellular, pharmacological, or physical level, in the area of communication and information technologies (implanted chips, brain-computer interface), in the area of physical appearance and performance, intellectual abilities, psychological perception, and social behavior. Just the categorization of enhancement itself illustrates the differences in approach. Genomic enhancement is from today's point of view the most futuristic version of enhancement.

Attitudes to progressive gene therapies in Slovakia in the light of the ethical dimensions of human enhancement

Author: Gabriel Bianchi (Slovak Academy of Sciences)

The paper attempts to bring more understanding into the diversity and dynamics of attitudes to progressive therapies within the broader ethical context of human enhancement. Results from an empirical study in Slovakia are discussed within the frameworks of diverse ethical dimensions of human enhancement (F. Allhoff), ethno-epistemic assemblages as well as of scientific citizenship (A. Irwin, M. Michael). The study (a qualitative exploration in twelve focus group discussions) was comparing attitudes to three different levels of gene therapy (gene scan, somatic gene therapy and germline gene therapy) in general public and in patients with experience of implants and other progressive therapies. The results confirm previous findings of a decreasing support with the increasing technical and ethical requirements of the particular level of gene therapy. A surprising effect was, however, found: personal/bodily experience with progressive therapy may facilitate more positive attitudes and acceptance of the higher-level therapies, while making people more cautious towards the lover levels of gene therapy. The paper points to a need for transcendence of negativism and affirmative approach to human enhancement challenges (R. Braidotti).

Governing genome editing – dealing with »wicked« problems

Authors: Alexander Lang and Erich Griessler (Institute for Advanced Studies)

In recent years genome editing and especially CRISPR/Cas9 had a major impact on medical research and related public debates. While the development of non-hereditary somatic gene therapy for genetic or other diseases (e.g. HIV) was discussed without much agitation and the focused primarily on efficacy, safety, and cost, the prospect and first cases of genome editing of the human germline initiated heated ethical debates in the scientific community and the wider public. The discussion on genome editing in plants and animals as well as in the wider environment by gene drives have been critically discussed as well, especially considering their appropriate regulation, potential risks and ethical implications.

The study »Genome Editing: Interdisciplinary Technology Assessment«* (2018–2019) investigated chances and risks, the ethical, social, and legal implications of genome editing applications in medicine (germline and somatic gene therapy, xenotransplantation), agriculture (plants and animals), and the environment (gene drive). Based on extensive literature and document reviews and analysis, expert interviews, stakeholder workshops, and a survey of businesses it gave insights into a plethora of technical aspects as well as the societal and legal embedding of genome editing and related applications.

The presentation first focuses on human germline editing that oscillates between therapeutic and human enhancement purposes, but then goes beyond this medical application of genome editing. The paper will draw on empirical insights from medicine and other fields of application to highlight how genome editing (re-)produces »wicked« problems for policy and regulation. The study shows how the technical development is often volatile with unexpected events affecting the societal debate, as e.g. the case of germline editing in human twins in China illustrates. Furthermore, diverging views about technical issues as well as conflicts about the normative assessment of various applications of genome editing exist. In germline editing as well as in other areas of application, many social, ethical, and legal issues are not new but have been debated for decades. Genome editing reinitiated these debates by providing new tools for the biotechnological conduct of experiments and developments. However, while genome editing has enabled new avenues of research and innovation, it is incapable of addressing and solving the underlying societal and ethical controversies. Repeated calls for citizen involvement and informed public debates about genome editing applications can be interpreted as strategies to overcome this challenge, but at the same time add to the complexity of the situation by bringing up new challenges considering their successful facilitation and implementation.

Finally, the paper discusses the potentials and challenges of TA to provide relevant knowledge, recommendations, or policy advice for »wicked« problems related to technologies such as genome editing.

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Quality assurance in 24h-caregiving at home by means of digital support

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The concept of caring is a central element in the care of the elderly. Care and nursing is always a mirror of the organisational and social context (Gallagher, 2015). If little or no care can be provided in nursing practice, the reasons might reside in the society and its organisations that care little for the needs of dependent people.

Due to its cost efficiency and the need for long-term continuous care, 24-hour care is a cornerstone of home care for older people and, with over 30,000 users in Austria, an important alternative to family care and mobile care. The persons to be cared for range from older persons, who only need support for housekeeping activities, up to persons with a high need for round-the-clock care. Burdening working conditions arise primarily due to language problems, the isolation of carers who live together with chronically ill people as well as little or no relevant specific training and a lack of quality control.

The aim of the multidisciplinary research project (2019-2021) “24h-QuAALity” - founded by the Austrian Research Promotion Agency (FFG) - is the development and evaluation of a distributed software solution for the support and quality assurance of 24-hour care. This includes an information- and education portal (eLearning) provided in the languages German, Slovakian, Hungarian and Romanian, an electronic support documentation, an integrated emergency management, as well as links to further tools such as translation pages and networking possibilities.

The project follows a co-design approach (Sanders, 2008) to consider the needs of the target groups not only during the needs assessment and evaluation phase, but during the whole development process. Representatives of the target groups (24-hour carers, recruitment agencies, home nursing) are not only just interviewed but are an essential part of the project team, attend all meetings accordingly and are entitled to make decisions.

As a first step a user survey was conducted using qualitative interviews (Hopf, 2015), cultural probes (Gaver et al, 2004) and mock up studies (Schulz, 2012) with a total of 40 24-hour caregivers, supervised persons, relatives, recruitment agencies and professional health and nursing staff.

The complete results of the user survey will be available on May 2019. Preliminary results show that personal carers primarily need information on their clients' illnesses. Due to the uncertainty caused by emergencies, a high level of interest in professional emergency management is shown. The mediation organisations and caregivers particularly welcome the electronic care documentation for traceability of undertaken activities and measures taken. The interviewees were able to use parts of the software solution to be developed on a tablet and retrieve relevant information.

In order to ensure the quality of care, compulsory quality criteria have to be developed and electronic quality assurance systems have to be provided to the target groups. This is of particular benefit to the persons cared for, but also to their relatives and recruiting agencies, who are supported in achieving a successful care arrangement.

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Co-Creation of Co-design

Author: Patrick Deniz Hos (University of Stuttgart)

In my research, I investigate the potential, preconditions, challenges and possible limitations of Socio-Technical Integration Research (STIR) for what I call the co-creation of co-design. Co-creation, here, means the undertaking of deliberate and collaborative efforts of shaping scientific and technological development in a meaningful, responsible way that takes social considerations, public values, potential unintended side-effects, and normative assumptions into account. If co-production means the mutual shaping of technoscience and society, co-creation means a critical, considerate way of shaping the processes of co-production.

Co-design denotes a new approach to architecture and construction currently developed by the Cluster of Excellence “Integrative Computational Design and Construction for Architecture” (IntCDC) at the University of Stuttgart. My research is integrated into this Cluster. Co-design, in this context, is shorthand for the computer-based integration of design and construction which are supposed to happen simultaneously instead of sequentially, as is presently the case, just like many different steps of the construction process. Co-design can be understood as an essentially holistic approach and as such it requires a considerably increased degree of collaboration between scientists, planners, and engineers of different disciplines.

Co-creation is incorporated in some sense into the Cluster`s research design since the ultimate purpose of co-design is to increase energy efficiency, reduce waste production and contribute to a new liveable and sustainable building culture. Thus, the Cluster has committed itself to certain normative goals and values. Moreover, social sciences, architectural history and sustainability perspectives are deliberately integrated into IntCDC. Hence, one could say that there is a conscious commitment to co-creation.

Whether and to which extent the co-design approach will deliver on these promises is an open question. The challenge here is how to translate the normative commitment into concrete socio-technical arrangements, including informational platforms, robots and other machines, materials, organisational patterns, collaboration forms and more.

In my PhD thesis, I will investigate what contribution STIR can make to achieve the co-creation of co-design. STIR is a method to unpack social and ethical dimensions of science and technology development in a real-time, hands-on, collaborative manner. The idea behind STIR is to expand the range of options for taking social considerations into account. Through accompanying scientists and engaging them in conversations about their ongoing work, I strive to register the values and value-laden assumptions that inform their decisions during the ongoing planning and construction process.

A particular focus will be on notions of fairness, social quality and sustainability. As a participant in technology development, I will introduce social science expertise to expand the value-driven considerations used for decision making and thereby provide alternative options for the development process.

The Cluster specific challenge for STIR will be to account for the holistic dimension of the science and technology under study. Co-design is more than just an additive combination of different technologies. Their tight integration into one socio-technical system requires considerations about possible implications and side-effect emerging out of co-design. At stake is also the interaction between this socio-technical system and larger social, cultural, economic, technological and environmental contexts.

Expectations and concerns of the 'Care Robot for Senior'

Author: Jiyoung Suh (Science & Policy Institute)

Korean government intends to develop a robot that can replace caring personnel and put it into care service. However, there are many unforeseen difficulties in developing a care robot. The elderly and the family of the elderly have a lack of understanding of robots, and companies that produce robots are reluctant to produce due to the difficulty of opening up the early market. Recently lauched Korean government a "care robot translational research program" and is looking for ways to satisfy user demand and market demand.

In this presentation, a translational research project of "Carebidet (excretion robot)" will be introduced. Stakeholder expectations and concerns about caring robots are raised in a variety of ways, including economic, aesthetic and ethical aspects. In the process of technology development, the issues of improvement of the system of technology, such as technology safety and standards, as well as issues of improvement of the social service system such as purchasing support and qualification of service personnel are raised.

Technology and me: Evolved or regressive attitude?

Authors: Wendy Rowan, Stephen McCarthy and Ciara Fitzgerald (University College Cork)

The use of technology is intimately linked to our social and psychological being. One the one hand, the rapid adoption of advanced technologies seems to suggest that we are progressing towards a new post-humanist era, where the lines between technology and the human race are becoming increasingly blurred. Yet, news streams continuously report on cases where our interaction with technology is having a negative impact on our personal relationships, wider society and the sustainability of the world we live in. A key question occurs - are we in need of new approaches for educating how to use technology for more ethical and beneficial purposes?

With the development of Artificial Intelligence (AI), Machine Learning (ML), and connected 'smart' devices there is great potential to realise major improvements in all walks of life from the use of decision tools for complex processes to the creation of assisted living robots for people with chronic health conditions. The adoption of technology could be simply classified as humans selecting relevancies, rejecting the misaligned or disengaging where there is an assessment of little worth. Our engagement with this medium can impact and be impacted by our attitudes and behaviour, at times finding ourselves using technology inappropriately, which can lead to unintended negative

consequences e.g. using mobile phones whilst driving, increasing the level of risk taken, which is reinforced by a lack of self-regulation and a failure to comply with laws prohibiting such practice (Nelson, Atchley & Little, 2009).[1]

Learning to swim does not come instinctively, in general we undertake lessons to master this skill. The same applies to our use of technology: we must learn how our engagement with technology increasingly shapes the reality we experience – for better, or for worse. Yet, to date, questions around the use of technology for beneficial purposes has often been sidestepped in lieu of our fetish for innovation, and instead such questions are left to the individual's own ethical decision-making process on how to regulate their use of technology in the wider world.

Is it time to call for a change? Do we as a society want citizens to learn how to engage with technology in a more soulful, and informed manner? In this contribution, we discuss how change can begin at the individual level, move through groups and then lead to a societal level of acceptance. In particular, we suggest that there is potential for change through harnessing the power of groups – those with questionable practices could become the new pioneers of evolved and ethical technology use - the gurus of the future. Presented here are some questions that are open for debate. Can we clearly answer this; "what do we want our technology interaction legacy to look like?" This is not a trivial question to be relegated to the domain of 'armchair experts', but a global issue demanding engagement from all members of society.

[1] Nelson, E. Atchley, P. & Little, T.D. The effects of perception of risk and importance of answering and initiating a cellular phone call while driving. Accident, Analysis & Prevention, V. 41 N. 3, 2009, PP. 438-444.