Report on

BCSSS-WS III - EVALUATING HEALTH-RELATED ICT (hICT)

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EVALUATING HEALTH-RELATED ICT (hICT)

The aim of the workshop was to find out the limits of truth production by big data regarding health issues. The workshop continues the work that was initiated at a basic workshop in October 2018 which was designed to discover general epistemological issues of big data. Several topics were discussed:

The basic goal of the series of BCSSS workshops on (human) digitization is to make cyber-systemic perspectives of living systems explicit (http://www.bcsss.org/2018/big-data-epistemological-requests-of-systems-science, 2018). Health and the health care system are therefore also important issues. The aim of the previous workshops (WS I-II) was to examine the epistemic value of individual features of the digitization of our society, especially with regard to Big data as processing technology, but also with regard to sensor and tracking technologies and analysis technologies (e.g. AI) and, in the future, also for robotics as effector technology with an increasing focus on health issues. It is therefore a question of an analytical evaluation of everything that is communicated for digitalization. For the following, it should be noted that the more concrete but general term "Health Information and Communications Technology (Assessment)" (HICTA), which we prefer, has the same meaning as the more common term "Digital Health Technology (Assessment)" (DHT or DHTA).

The first two workshops of the BCSSS, devoted to the epistemological dimension of digitalization, namely relating to the field of Big data, showed the loss of reality concepts as it was prepared already by constructivistic and deconstructivistic debates in context of philosophy: Everything could be a simulation, results of big data, based on analytical learning algorithms can be a fiction without the option of traditional reality control. Scientific realism or constructive realism might be epistemological positions or positions of philosophy of science that could show the limits of unbounded simulation.

Regarding the „reality of health“ as it is changed by new health-related technologies (e.g. wearables and Omics-research) and digitalized Big data analytics opens a wild landscape of fiction. It is hard to evaluate the cores of truth in the propaganda for HICT that mainly seems to be motivated by claims for ownership of Big data sets that also can be sold in other contexts.

In order to find a rational framework of evaluation of new health technologies, a transdisciplinarily based assessment for these tools should be established. First steps into that direction should be discussed using conventional strategies of quality control that must be adapted to these new technologies. It should be mentioned also in advance that "feature lists" for the assessment are understood as "rating scales" or "checklists" as a list of items or subscales or dimensions or simply questions, and the semantic background is regarded here as a "conceptual framework" and not as a "model" as is often found in the literature. The term "model" is used here in a more differentiated way, meaning (theoretical) "system models" for the structure and function of the real (empirical)

system to be represented (Tretter 2005). However, even these distinctions or equations would be worth a detailed examination.

As an introduction to this workshop Felix Tretter (BCSSS) essentially presented a kind of a multidimensional checklist that covers 9 dimensions.

CONTRIBUTIONS AT THE WORKSHOP

Marc BATSCHKUS (Munich), as a physician and specialist in medical informatics reported on his impressions from a trip to Silicon Valley shortly before the workshop. The title of his talk was: "*Is it too late for Healthcare to survive?"*

He highlighted the pressure of economy on the health care system and that HICT promises an enhancement of economic efficacy. With other markets being slowly saturated, Healthcare remains the big economic opportunity. Many investors in ICT shift now to the health issue. They expect high revenues. Tech giants want to disrupt the market. This means that Healthcare as we know it might soon change dramatically.

In spite of this high economic expectation he experienced ICT experts, for instance in Apple comp., to aim real improvements in health by the use of HICT. From within healthcare there are also forces that aim to align it with economic values i.e. profitability. The human being and patient is reduced to biological values and financial value.

As example he analyzed the conditions and effects of the implementation of the electronic health card: it is technology-driven, it monopolizes risk assessment and risk management, it represents also unspecific data, it offers only low options for control by the patients, it is not possible for the patient to obtain a local copy of the data, it implicates a stigmatization of the patient in case of very undesirable diseases. Finally, he raised the question: What can we as group and HTA contribute? Is there a chance to counter or circumvent the strategies of powerful market players?

Klaus MIESENBERGER (University of Linz, Institute Integriert Studieren, Austria), was not able to attend but he sent an elaborated contribution with the title: ***Evaluating h-ICT in context of the lifeworld of people with disabilities - Assistive Technologies and eAccessibility.*** ICT and big data for people with disabilities focusses on inclusion, the goal of self-controlled and independent participation in the lifeworld. Disability is not subject to "healing and curing" [1] but to adapting the interaction and communication with and in the lifeworld environment. The focus is not on the shortcoming but on available skills and competences to implement alternative interaction, communication and participation. This demands for

- **Assistive Technologies (ATs)** providing augmenting, inserting or alternative approaches for personalized communication and interaction with the environment, based on sensor technology for measuring, tracking, reasoning, representing and using individual skills of a person in terms of controlled activities (e.g. with muscle, eye movements, head movement, movements of any part of the body or the body as a whole, electromyography – EMG, electroencephalography – EEG, towards brain Computer Interfaces - BCI) for better employing a diverse set of individual skills for interaction and communication (Miesenberger, 2013),

[1]) This is considerably different to "preventing, healing and curing" in medical and hICT contexts. People with disabilities are not ill. The personal physical and mental condition is of course important, but not in terms what a person can't do (medical deficit) but what a person is able to do. The "medical model" with its focus on deficits is seen as inadequate, stigmatizing and as one of the core reasons for segregation and exclusion. For a critical discussion: Retief 2018, Goering 2015, Makelprang 2016.

- **Accessibility** and **Design for All** of mainstream physical and social environments to allow people with disabilities independent participation based on their way of communication and interaction, what in many aspects relates to the standardized Human-Computer Interface (HCI) (Mueller-Prove 2002), via which all digitized processes and systems provide an adaptable, flexible, multi-modal and multi-media interface supporting also accessibility (e.g. W3C 2019, Miesenberger 2009).

Digitization plays a key role in this enabling and empowering process to better overcome exclusion and stigmatization, what is best expressed by the UN-Convention on the Rights of People with Disabilities (United Nations 2019) referring to ICT/AT/Accessibility in almost all paragraphs. This fundamental change of focus in the disability domain has been facilitated and supported by ICT/AT/Accessibility. The more digital, the more access points for supporting inclusion become available. Thereby, is not only and no longer primarily the physical and mental condition of the individual, which is subject to "healing", but much more the physical, social and cultural environment, which is to become more open for the diversity of approaches and models of communication, interaction as well as own and shared life planning/design. It is the design of the environment, which is disabling or enabling, segregating or including.

This provoked and facilitated a fundamental systemic change in care and service provision for people with disabilities. (Miesenberger 2015) The history and evolution (Krahn 2015) of WHO's International Classification of Functioning, Disability and Health (ICF) (WHO 2019) reflects this development from focusing on disabling medical conditions towards measuring health and disability on base of alternative skills of individuals with personal needs, wishes and plans in diverse physical and social environments. Therefore technical systems are never to be seen as solutions per se but as part of services. AT an Accessibility are defined more as a service rather than as pure tools. (Miesenberger 2017) AT and Accessibility services are defined as an ongoing matching process of people and AT/HCI/ICT/Systems in their physical, social, economic and cultural environment. including ongoing (both user and environment) As changes, learning and training are ongoing, cyclic monitoring, evaluation and adaptation is indispensable (e.g. Scherer 2002, Federici 2017).

This made the ICF the reference framework for the disruptive power of ICT/AT and Accessibility over the last decades and proposes a reflected, user-driven and user centered integration of new developments as big data, nanobots, IoT/WoT, cyber-physical systems, cyborgs, etc. (Sundmaeker 2010, Wilson 2005) and also hICT to allow using the potential and at the same time domesticating and cultivating risks in its holistic setting. ICT/AT/Accessibility services make a strong reference to ethics, security, privacy and exploitability of particular vulnerable groups. (e.g. Howard 2014, Jones 2014) Examples as AsTeRICS, a framework for personalized AT R&D and use (www.asterics.eu, Veigl 2017), EasyReading, a framework for supporting cognitive disabilities (www.easyreading.eu, Miesenberger 2018, Heumader 2019) and the IPAR-UCD, an inclusive participatory R&D method (Miesenberger 2019) will be presented as examples of user-centered and responsible R&D.

Alexander DEGELSEGGER-MARQUEZ (GOEG, Vienna) focused on the problem of quality assurance with a talk with the title ***The quality perspective on health service delivery.*** In this contribution, he discussed HICT on the basis of a quality perspective on health service provision. This relates to the workshop questions of digitalization and the "reality of health". A series of trends (digitalization, individualization, etc) and new digital artefacts (EHRs, real-world data from wearables, omics data, etc) in medicine result in an increased number (and availability) of health-related data and in these data unfolding agency.

HE stated that for the quality assessment and evaluation of health service provision, this sounds like good news: quantification of evidence, more data points and evidence to trace outcomes etc. However, at the same time there is the question of what the data represent, what they "measure".
More concretely speaking, a quality perspective on digitally mediated health service has to be interested in the "digital mirror of the self" that we are continuously constructing (e.g. through the sum of our health data).

- How adequately is an individual represented by these data, and how good does the digital level correspond to the analogue/material level of a person?
- Are there any control loops to adjust or reconcile the digital and the analogue, and how is this process organized (self assessment, expert assessment etc.)?
- Which categories are present and used to provide order in the data base? What are the dynamics of inclusion and exclusion of knowledge / information components that we are dealing with? This also relates to the question of algorithm ethics and quality.

Building on this discussion, we introduce another observation: the blurring of boundaries that have been constitutive for modernity, like those between man and machine, nature and culture
We do not deal with humans, data and machines separately, but with sociotechnical systems and human-machine-assemblies (e.g. the patient and her/his smartphone, the individual and his/her omics data and a specific diagnosis, etc.)
A quality perspective on health ICT, thus, does not only have to take into account the digital technologies involved, but the interfaces. Relevant sociotechnical systems are continuously reconfigured into human-machine-data-complexes.
Again, this leads us to questions of inclusion and exclusion, data ownership, etc.
Against the background of these questions and observations, we can take a look at the state-of-the-art of digital health-related quality guidelines and standardization as group efforts.

Lisa ROSENBERGER (Psychology, Univ. Utrecht, NL) reported on objectives, procedures, results and perspectives of DiDaT regarding the health issues. DiDaT aims within a transdisciplinary procedure to integrate experiential wisdom with academic rigor exploring unintended side effects and “unseens” of digitalization in various domains of the society.
Main goal is the identification of unintended and unwanted side effects of societal digitalization. At the end of the day, a white book providing socially robust orientations should be published. As a next point of her talk she highlighted the conceptual issues of „health“ and „disease“ as spectral concepts that are basically negotiated between the patient and the doctor. She demonstrated several important psychosocial mechanisms that underlie this diagnostic and therapeutic issues. In a next step this basic model was applied to the case when a patient comes with data of his wearable device to the doctor. In this situation the doctor needs additional scientific knowledge and even digital literacy, otherwise the patient would probably not trust the doctor anymore regarding the contemporary nature of his medical competence. Finally she stressed the point that “health”-related digital devices should be evaluated regarding the provider’s concept of health compared to the professional understanding of health:

(1) The main goal of the healthcare system is to secure health
(2) Disease is understood in the context of the bio-psycho-social model
(3) Health and disease of an individual is understood as a continuum.

Horst KUNHARDT (TU Deggendorf) reported on ***DeinHaus4.0 - Lower Bavaria.*** He was been approved in a project by the Bavarian Ministry of Health: DeinHaus4.0 - Lower Bavaria, which is about living longer at home with technical support. Beside model dwellings his group furnishes also genuine houses and dwellings with sensor technology, which are to improve the residential environments. This also includes setting up a protected cloud that uses machine learning to

examine these mass sensor data and, if necessary, triggers alarms automatically. The aim is to create a protective home environment that also allows the treatment chain to be extended. In other words, an extension of the inpatient environment and the rehabilitation environment is provided .

Rania WAZIR (data scientist of the Data Science Group Vienna), gave a brief lecture on the problems of misleading terminology in context of the discussion of digitalization. For instance the term "artificial intelligence" should be understood as "assisted" or "augmented" intelligence" as – in contrast to marketing experts - no ICT expert would claim that machine-based pattern recognition and -detection can be compared with human intelligence. She also explained principles of machine learning and finally suggested to be skeptical about publicly communicated "News" form the ICT world.

Maria RONACHER (data4good, Vienna) introduced into a project where an optimum of matching needs of people with special health needs and support with digitalized care was intended. A special issue was the methodological challenge to digitalize *spoken language* by text mining aiming to identify moments of frustration in the client's mood as early as possible.

Gerd SUMAH (sniccs), as a representative of Viennese start-ups presented an app for nutritional control (sniccs): food can be photographed by the smartphone and these pictures are processed in real time in the company referring to a complex data set on usual meals. In consequence, the user gets information about the caloric value and also about the nutritional composition of the respective meal. In the whole program, the user also should visit a dietologist to explore the nutritional behavior and the kind of problem that are related with her nutrition. He was interested in evaluations regarding the ratings of the clients, their commendations, criticism and adherence. Regarding data security a local server is used.

In the final discussion an 8-dimensional medicine-based assessment scale was discussed regarding the weights of the different dimensions and subdimensions. These issues will be the central theme in a next workshop in July.

SOURCES AS BACKGROUND (examples)

Sources:

1. Deutscher Ethikrat, 2018. Big data und Gesundheit. Deutscher Ethikrat, Berlin
2. NHS, Health Education England (2019). The Topol Review. Health Education England, London. February 2019

References for Dr. Miesenberger

3. Federici, S., Scherer, M. (2017): Assistive technology assessment handbook. CRC Press.
4. Goering, S. (2015): Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine*, 2015, 8. Jg., Nr. 2, S. 134-138.
5. Howard, P. & Jones, S. (Ed.) (2004). Society online. The Internet in Context. Thousand Oaks: Sage Publishing.
6. Jones, S., Augusto, J., and Hara, S.(2014): eFRIEND: an ethical framework for intelligent environment development. In: The 7th ACM International Conference on Pervasive Technologies Related to Assistive Environments: PETRA 2014, 27-30 May 2014, Rhodes, Greece.
7. Krahn, G.; Walker Klein, D; Correa-de-Araujo, R. (2015): Persons with disabilities as an unrecognized health disparity population. *American journal of public health*, 105. Jg., Nr. S2, S. 198-206.
8. Mackelprang, R.; Salsgiver, R.O.; Salsgiver, R. (2016): *Disability: A diversity model approach in human service practice*. Oxford University Press.
9. Miesenberger, K. (2009). Design for All Principles. In Sik Lányi, C.(Ed.). Principles and practice in Europe for e-Accessibility. EDeAN Publication 2009, Veszprém: Panonia University Press.

10. Miesenberger, K.; Nussbaum, G.; Ossmann, R. (2013): AsTeRICS: A Framework for Including Sensor Technology into AT Solutions for People with Motor Disabilities, in: Kouroupetroglou, G.: Assistive Technologies and Computer Access for Motor Disabilities, IGI Global.
11. Miesenberger, K. (2015): Neue Technologien: Inklusion von Menschen mit Behinderungen – eine Herausforderung, in: Dyk-Plos, I.; Kepplinger, B.: hilfe. LenesRisiken Lebenschancen; Soziale Sicherung in Österreich, Trauner Verlag, Linz, Österreich.
12. Miesenberger, K.: Technology and digital revolution, in: Hoogerwerf, E.-J.: Entelis Digital Inclusion, a White Paper, p. 17 ff, Entelis 2017 available online March 2017: http://www.entelis.net/en/node/351.
13. Heumader, P.; Miesenberger, K.; Koutny, R.: The EasyReading Framework – Keep the User at the Digital Original, in: Santiago, J. (Eds): Journal on Technology and Persons with Disabilities, CSUN Assistive Technology Conference, California State University, Northridge, USA, 2018 p.32ff.
14. Miesenberger, K.; Edler, C.; Heumader, P.; Petz, A. (2019): Tools and Applications for Cognitive Accessibility, in: Yesilda, Y.; Harper, S.: Web Accessibility A Foundation for Research, Springer Human–Computer Interaction Series, Heidelberg/New York 2019. (accepted for publication).
15. Müller-Prove, M. (2002). Vision and Reality of Hypertext and Graphical User Interfaces. Dissertation. Universität Hamburg.
16. Retief, M. & Letšosa, R. (2018). Models of disability: A brief overview', HTS Teologiese Studies/Theological Studies 74(1), a4738. https://doi.org/ 10.4102/hts.v74i1.4738
17. Scherer, M. (2002): Assistive technology: Matching device and consumer for successful rehabilitation. American Psychological Association.
18. Sundmaeker, H., Guillemin, P., Friess, P. & Woelfflé, S. (Ed.) (2010): Vision and Challenges for Realising the Internet of Things, CERP – IoT, Cluster of European Research Projects on the Internet of Things. European Commission. Retrieved October 1, 2012, from http://www.internet-of-things-research.eu/pdf/IoT_Clusterbook_March_2010.pdf
19. United Nations (2019): Convention on the Rights of People with Disabilities, online May 2019: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
20. Veigl, C.; Deinhofer, M.; Aigner, B.; Miesenberger, K. (2017): Personalized Access for People with Severe Motor Disabilities - AsTeRICS, FlipMouse and the 2-Level Personalization Software Engineering Method, in: HCI Internationl, Vancouver, Canada, July 9-14 2017, Springer LNAI, Heidelberg.
21. W3C (2019): Web Content Accessibility Guidelines, online May 2019: https://www.w3.org/TR/WCAG21
22. WHO: International Classification of Functioning, Disability and Health (ICF), online May 2019: https://www.who.int/classifications/icf/en
23. Wilson, J. (Ed.) (2005). Sensor Technology Handbook. Burlington: Elsevir.