Report on

BCSSS-WS II - EPISTEMOLOGY OF BIG DATA: HEALTH AND HEALTH CARE

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THE "TRUTH" ABOUT HEALTH AND DISEASE BY BIG DATA

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:

1. Big data effects on health, health knowledge and health literacy

Monitoring a whole population regarding health issues by wearables, health apps, health platforms and other pathways of data gathering is supposed to lead to a "real" understanding of health and disease. This results in *Big data* (BD), and this development seems to have a reasonable goal of Public Health in order to increase the health level in the population. However, as everybody knows, the drivers of this approach are economic aspects that also intend to monopolize "health knowledge" for the data, information or knowledge market.

First independent scientific studies show a *lack of quality control* of health information and communication technologies (ICT; SVSR 2016). There is also a high degree of intransparency regarding the *definition of "health"* that is reduced to some measureable aspects of lifestyle. BD inverts the epistemic problem to define "health" by using measureable data and calling them "health". In contrast, health in health sciences and medicine is a subject that is hard to define, and there is no final consensus about it. It is seen as a highly *bio-psych-social functional state of a living system*, but it is more than "wellness" and must be defined in r*elation to disease*.

2. Big data in medical science

In addition, collecting *biochemical data* by Omics-research in *medical science* that analyses the genome, transcriptome, proteome etc. by high-throughput technologies also proposes a "new" understanding of health and disease on the basis of molecular medicine (e.g. "P4 medicine"; Hood 2013) and it promises more effective treatment of cancer and finally all diseases, including mental disorders. This new direction of medical research also changes the understanding of health and disease that currently still is defined by "proper function" in bio-psycho-social dimensions according to WHO and ICF (comp. bio-psycho-social model; Engel 1977).

3. Quality control

Universities have to join industrial big data research as public research money is too sparse. In addition, both Big data-centered developments occur in context of a hyper-diversified medicine

that lacks a field that can be called “theoretical medicine” and that can help to understand the various health research approaches in an integrative framework. Correlations alone cannot explain health and disease. In this context the General System Theory designed by Ludwig von Bertalanffy might be interesting.

4. Citizens health “production”

Finally, there is change in the role of the people and the patients as the trend towards a self-organized health literacy is aimed by heath policies. Wearables, health platforms etc. at some point might change health / disease knowledge in a wrong way: even if motion, non-smoking, alcohol abstinence, low-caloric nutrition are universal health protectors they are neither necessary nor sufficient to become a quite healthy about 90 year old person (Churchill, Schmidt)! It is hard to communicate probabilities to everyday life!

CONTRIBUTIONS AT THE WORKSHOP

The workshop was introduced by Felix Tretter (BCSSS) where he focused on misconceptions and asymmetries in “health knowledge” by big data gathering strategies. He questioned if knowledge by data alone is possible, as it is often said that “data speak for themselves”? In consequence, the notion that “more data enable better understanding” implies a qualitative jump from quantity, an idea that obviously is wrong. He also reminded Plato’s cave metaphor with the basic notion that observations (and data) are possibly not the “reality”: they might only be shadows of the system under study. He also stressed the point that extensive data collecting can have several undesirable side-effects in too simple understanding health and disease. Also the reports of “high rates of correct diagnoses (and predictions)” lack a test theoretical correct characterization of the epistemic power of these technologies.

From correlation to causal inference

In a first section of the workshop we discussed the difficulties to derive causality from correlative data (Alfred UHL, GOEG, Vienna). Dr. Uhl demonstrated the fallacies of statistical reasoning and also of evidence-based medicine as pathways to “truth” by illustrative examples such as parachuting in a RCT to “prove” that parachutes are lifesaving when jumping out of a plane. Also, simple causal inference cannot be based on observations alone because several assumptions have to be made in order to construct a valid causal model. This becomes evident already by gestalt phenomena in visual perception that show mechanisms of unconscious neural interference. In an next step he demonstrated examples from epidemiological statistics that very often are used by health politicians to “prove” that certain policies have “succeeded”: e.g. tax and price elevation of addictive substance like tobacco and alcohol and reduction of sales and number of consumers etc. very often showed pseudo-correlations. A most recent example was the reduction of consumption of alco pops with (Switzerland) and without price elevation (Austria) – there was a decline of the hype of these products in youth culture. Also, other examples of changes in alcohol consumption in the population and life expectancy, involvement in traffic accidents showed the risk of false interpretations of data coincidence.
In conclusion it was evident that hypothesis- and theory-driven research might be a good way to avoid pseudo-knowledge by pure data analysis.

Big data: Understandable by Complexity research?

Regarding the hype of "complexity research" that is closely connected to big data analysis, Guido STRUNK (Complexity-Research e.V., Vienna) contributed under the title: ***Size doesn't matter: "Big" is of no help in complex systems.*** Basically, he highlighted the diversity of meanings of the term „complexity": it is often overseen that only three interacting physical components (earth, sun, moon) can exhibit complex behavior with irregular movements. This was shown already by Henri Poincare with his famous three body problem. This is the most important message regarding the issue ": size of the system and / or the data set does not matter!
Dr. Strunk highlighted the observation that modern world is highly interconnected, for instance by globalization. This structural complexity opens new questions: how to analyze complexity? Protagonists of complexity research claim that no theories are needed anymore, because correlation analysis of extensive data bases (Big data) with times series data can compute causal relations that enable predictions. Thus empiricistic approach ignores theories that usually provide explanations and a solid conceptual basis for predictions. He explained these epistemic issues referring to a scheme that depicts important components of the structure and production of knowledge.

Gerd GIGERENZER (MPI Developmental Psychology, Berlin, Germany) presented his research with the title: ***Health care needs better doctors and better patients, not bigger data"!*** Dr. Gigerenzer focused on Self-defense, innumeracy and conflicts of interest as factors that *reduce the quality of medical performance* made by physicians. First, he highlighted that most doctors don't understand health statistics: they *overestimate a positive findin*g in a screening test regarding the probability that the respective patient has the disease that should be detected by the test. In other terms, doctors cannot calculate the relative probability that the patient is sick by using the appropriate calculation based on Bayes conditional probability. On the other hand, most patients want to know exactly the likelihood to have cancer etc. In most discussions of the value of tests mistakes such as the lead time bias: survival rate difference at age 70 when cancer is diagnosed compared to survival after a test in stages where no symptoms are reported overestimate the test power. Also overdiagnoses occur regarding survival rates if benign and malign diseases are put into one category which results in "improvement" in treatment. In consequence, most medical experts *overestimate the benefits of cancer scre*ening by a factor of 10 or even 100 and more. If for example, Microsoft Big Data Analytics, that has a true *positive rate of 10 %* , is applied for cancer detection in 100.000 persons, where 10 persons have cancer, *only 1* of the 10 sick persons will be identified. Even if the *false positive rate* is 1:10.000, the result will be 10 persons with false diagnosis – taking all positively tested persons! This is not a nice experience for these persons! For this reason, Dr. Gigerenzer proposed a special training for doctors to translate scientific probabilistic information into communicable information for the patients. He also could present data about success of these courses.

Roland SCHOLZ (ETH Zurich, Switzerland; Danube University of Krems, Austria; Institute of Advanced Sustainability Studies [IASS], Potsdam, Germany) talked bout
Unintended side effects of irresponsible use of digital data for health management: Perspectives of and for the "Digital Data as Subject of a Transdisciplinary" (DiDaT) project. He proposed that different aspects of knowledge production – academic rigor and lifeworld wisdom - should be combined in a useful way. If on contrary, quantitative scientific knowledge would substitute qualitative knowledge of physicians and individual illness knowledge of chronic patients, a loss of medical knowledge would occur. Especially the trend towards BD overshadows the problem to extract knowledge about causal structures: *causal inference analysts* are a new profession that should provide competence to discover causal mechanisms in huge data bases. Regarding these issues of big data, the transdisciplinary program DiDaT, headed by him and Ortwin Renn

(Postdam), aims mutual learning between scientists and other stakeholders of digitalization, accepting the otherness of the other. This program will start in summer 2019, covering not only health issues but also farming, mobility etc. By cross-sectional comparisons of *unintended (negative) side effects of digitalization*, evidence for a better use of digitalization in health issues can be expected.

In a second section of the workshop, we discussed question of how to define and to measure "health", what can we find in data, how to measure and quantify hospital processes (QM) ?

The cultural relativity of the concepts of health and disease were highlighted by a talk by Daniel DICK (Philosophical Anthropology, Academy Fine Arts, Vienna) referring to pain as an example. In his contribution ***Symptoms, diagnosis and judgement of pain: reflections on cross-cultural aspects*** he underscored the general issue that the doctor has to find the appropriate treatment for the individual patient by using the general knowledge of the respective medical culture. In case of pain, *subjectivity* and *individuality* are large obstacles to find the appropriate diagnosis and treatment. Pain in context of medicine is defined internationally as an unpleasant sensory and emotional experience that is associated with an actual or potential tissue damage or that is described in terms of such a damage. Pain is a rather unspecific symptom which can be accompanied by several severe diseases. For this reason, a wide spectrum of differential diagnoses must be considered by the doctor. Basically, also the context of patient-physician relations is relevant: can the doctor trust that the patient has pain and that he does not simulate? Can the patient trust that the doctor "believes" him that he suffers from pain? Furthermore, the cultural learning to have pain and to cope with it modulates the phenomenon pain. This *psychosocial dimension* as it was demonstrated by the pain issue is a challenge for digitalization. Daniel Dick also highlighted that similar to western medicine, Chinese medicine contextualizes the symptoms such as pain and aims to balance the whole bio-psycho-social system as it is called in western medicine. He concluded that a polyvalent and polycontextual logic might be a useful extension of a systemic conception of medicine. In this case, digitalization of medicine might be an even larger problem as it is already now.

Dieter KORCZAK (GP-Research Group, Bernau/Berlin) presented a brief overview on wearables for health promotion: ***Monitoring Health - Wearable devices and their implications".*** Dr. Korczak showed that an unforeseeable number of wearables and health-related apps are on the market. He highlighted that Health Monitoring Devices have evolved from simple data collection devices to algorithm-controlled programs of personalized medicine. He listed some types of devices: Smart Mobile Phones, Smart Watch (Apple Watch, AsusZen Watch, Fitbit Surge, Fossil, Samsung Gear, Sony Smart Watch), Whristband (Withings Pulse, Misfit Shine, Jawbone Up24,Fitbit Flex), Smart Glasses (Google Glass), Smart Shoes (Nike+iPod), Smart Clothing. He reported about studies that, for instance showed that about 50 % of the users opt out after some months. Also regarding the precision of measurements, according to a Chinese study, disappointing results must be accepted: High correlation for steps (0.89) and distance (0.84), activity period (0.59), energy consumption (0.59). Low correlation for sleep duration (0.30) and sleep depth (0.27). He also mentioned that insurance companies more and more offer clients who use these devices a lower premia. Finally, he suggested some preliminary criteria for assessment of wearables.

Gerhard KRANNER (Viscovery GmbH, Vienna, Austria) demonstrated some practical examples of ***Big Data Mining*** referring to ***Explorative analysis of mortality data***. First he defined the usual meaning of "big data" as a 3V phenomenon of high amounts of data (volume), with a high variety, that can be processed very fast (velocity): Regarding a volume of about 10 million data the category of Big data seems to be appropriate. For example, if about 100 million telephone calls are recorded each day several Gigabyte have to be processed regarding when, and how long from

where to where a call was made. Then he demonstrated principles of multivariate statistics that are applied for data analysis in big data matrices.
As an example he used complex data sets about mortality that are related to 340 ICD diagnoses. By the method of "self-organizing mapping" several clusters of risk constellations can be identified ……

Klaus PIWERNETZ (Quality Management, Munich, Germany) presented his conception of a reformation of health care. His notion was: ***We don't need only better doctors but we need a better system:*** **Sanitopia.** After the definition of a „good" doctor he displayed a matrix for evaluation of the various aspects of a good medical service that is provided by a doctor. In a next step he showed a top-down oriented qualitative multi-level systems analysis of the health care delivery system. He focused on the potentially dysfunctional interplay between medicine, economy, organization and ethics that seems to be responsible for several insufficiencies of the system and that also contributes to the high ratio of burnout syndromes of health professionals. He presented an alternative conception – Santopia – which starts with the goal setting function of the top level, that should be operationalized at the level of self-regulation and that becomes regionalized and finally organized in order to realize the treatment at the micro-level of interpersonal medical interaction. He thinks that some features are essentially important: Patient oriented health care targets, a self-organizing and self-learning health care system, incentives for good medical outcomes and efficient resource allocation, transparency via public reporting – Targets, outcome, resource consumptions, target achievements and a needs orientation instead of supply orientation. In planning and delivery of health care, besides economy, also epidemiology, socio demography and regional geography must be considered more and in an integrated way.

At the final discussion the focal point was that Big data of wrong, because marginal variables will improve the marginal sides of health (e.g. economy) instead helping to improve health-related functionality of the system. In consequence, the evaluation of the process of "digization" of health care should be related to theories of health and disease and to a multi-level perspective of health care. For assessment of digital hardware and software instruments that are supposed to improve prevention, diagnosis, treatment and care tools and procedures for Digtal Health Technology Assessment (DHTA) should be developed in a transdisciplinary process that includes representatives from insurance companies, physicians, ICT experts, patients etc. One initiative that aims these objectives is DiDaT, organized by Roland Scholz and Ortwin Renn in Potsdam/ Berlin. The next workshop should focus on "assessment".

SOURCES AS BACKGROUND (examples)

Anderson, C. 2008. "The End of Theory: The Data Deluge Makes the Scientific Method Obsolete." WIRED Magazine 16/07. http://www.wired.com/science/discoveries/magazine/16-07/pb_theory

Auffray C, Chen Z, Hood L. Systems medicine: the future of medical genomics and healthcare. Genome Med. 2009;1(1):2. doi:10.1186/gm2

Batschkus MM: Chatbots - Sprechende Roboter in der Medizin (10-2018) Bayerisches Ärzteblatt

Batschkus MM: Wohin steuert die IT - mit uns allen? (11-2017) Bayerisches Ärzteblatt

Chang, H. , Cartwright, N. (2008). 'Measurement' The Routledge Companion to Philosophy of Science, Psillos, S. Curd, M. (eds.), Routledge: London, pp. 367-375

Engel, G.L. 1977. The need for a new medical model: A challenge for biomedicine. Science 196(4286): 129–136.

Floridi, L. (2012): Big Data and Their Epistemological Challenge. Philosophy & Technology 25(4).

Gigerenzer, G. 2015. Simply Rational. Oxford Univ. Press, Oxford

Habermas, J. 1968. Erkenntnis und Interesse. Suhrkamp, Frankfurt

Helbing, D. (2018). Towards Digital Enlightenment: Essays on the Dark and Light Sides of the Digital Revolution. Springer, Berlin

Hofstetter, Y. (2015) Die Macht der Algorithmen: Selbstbestimmung trotz(t) künstlicher Intelligenz, Akademie für Politische Bildung, Bayerischer Landtag, 11. November 2014, München / Tutzing

Hood, L. (2013). Systems Biology and P4 Medicine: Past, Present, and Future. Rambam Maimonides Med J. 2013 Apr; 4(2): e0012. Published online 2013 Apr 30. doi: 10.5041/RMMJ.10112; PMCID; PMC3678833;PMID: 23908862

Leonelli S. 2014. What difference does quantity make? On the epistemology of Big Data in biology. First Published April 1, 2014 Research Article. Big Data & Society, April–June 2014: 1–11. DOI: 10.1177/2053951714534395 , https://doi.org/10.1177/2053951714534395

Leonelli, S. (2014): What difference does quantity make? On the epistemology of Big Data in biology. Big Data & Society 1(1).

Mitchell, S. 2003: *Biological Complexity and Integrative Pluralism*, Cambridge: Cambridge University Press
online 2013 Apr 30. doi: 10.5041/RMMJ.10112; PMCID; PMC3678833;PMID: 23908862

Renn, O, Scholz, R. 2018. DiDaT: The Responsible Use of Digital Data
as the Focus of a New Transdisciplinary Project. IASS, Potsdam, https://www.iass-potsdam.de/sites/default/files/2018-12/IASS_DiDaT.pdf

SVRV, Sachverständigenrat für Verbraucherfragen (Hg) 2016. Digitale Welt und Gesundheit. eHealth und mHealth – Chancen und Risiken der Digitalisierung im Gesundheitsbereich (Gigerenzer, G, Schlegel-Matthies, K., Wagner, G.G.), Berlin, SVRV, http://www.svr-verbraucherfragen.de/wp-content/uploads/Digitale-Welt-und-Gesundheit.pdf

Todd, P.M. Gigerenzer, G. 2012. Ecological Rationality: Intelligence in the World. Oxford UNiv. Press

Tretter, F. (2017) Homo Informaticus: Image of Man in Information Society: Social and Technological Problems. In: Hofkirchner, W., Burgin, M. (eds) The Future Information Society. World Scientific. Singapore, pp.475-505 https://www.worldscientific.com/doi/abs/10.1142/9789813108974_0027

Tretter, F. et al. (Ed)(2010). Systems Biology in Psychiatric Research. Wiley, Weinheim