Session H2

The Change of Health Technologies – Citizens' Engagement in Their Own Health Situation

Chair: Silvia Woll (Institute of Technology Assessment and Systems Analysis)

Health technologies are of great importance for the lives of their users – not only (even though mainly) regarding health issues, but also in terms of societal aspects. Having constantly been enhanced over the last decades, health technologies offer a high potential for users to improve their health condition and quality of life. Recently, more and more people get involved in this field. Laypersons as well as people with a specific background, patients or those who want to use such technologies not for health reasons, but for other purposes, like enhancing their capabilities, get engaged and develop technologies on their own or extend the possibilities of already existing ones (e.g., https://openaps.org/, https://cyborgs.cc/?page_id=9). They believe in their right to apply any health technology to its full potential and to have complete autonomy regarding the way they use it[1]. But manufacturers' strict rules or legal restrictions do not allow this kind of use[2].

Therefore, there is a big gap between the state of the art and the claims of an increasing number of people inside and outside the established network. Also, as health technologies cause significant costs for the health care system, the inclusion of people and ideas of the do-it-yourself (DIY) and open source/open access movements offers a huge potential to connect science and society with the objective to enrich all involved parties[3].

For this panel, we invite contributions in an open call for papers that discuss the following issues:

1) In which ways could the approaches and ideas of cyborgs, hackers, the DIY movement, and any other private person who engages in (further) developing health technologies contribute to enrich the user's lifeworld, support the health care system, and improve the way in which health technologies are applied?
2) What would it mean to responsibly add the perspectives of cyborgs, hackers, and the DIY movement to the established health care system? How could both parties enter into dialogue with each other and enrich each other?
3) What can we learn from analyzing the underlying approaches, ideas, and visions of cyborgs, hackers, and the DIY community including their understanding of responsible innovation and (the application of) ethics? Which social and cultural images of the actors can be constituted that potentially lead to desires for achieving a change in and/or of society? How can the approach of these engaging people be understood as empowerment and as a way to democratize the health care system?
4) How could we draw a line between health and enhancement devices? What constitutes the difference between a patient and a cyborg and what leads to blurred boundaries?
5) Which legal issues come along with the subject and how could an approach of dealing with legal complications look like?

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[1] http://wiki.cyborgs.cc/wiki/Manifest

[2] https://www.bfarm.de/DE/Medizinprodukte/RechtlicherRahmen/inverk/_node.html

[3] Lorenzo, de V., Schmidt, M. (2017). The do-it-yourself movement as a source of innovation in biotechnology – and much more. Microbial Biotechnology, Vol. 10(3), 517-519.

Closing the Loop: Patient Engagement in Artificial Pancreas Systems

Author: Silvia Woll (Institute of Technology Assessment and Systems Analysis)

Type 1 diabetes (T1D) is a severe chronic disease with potentially serious acute and long-term consequences. Achieving the desired blood levels is extremely difficult. Being affected by T1D means lifelong constant self-control that rarely leads to stable glucose levels. Some people with T1D use an insulin pump, which allows more accurate dosing of insulin. A technology that adequately replaces pancreatic function is not yet available.

A community of affected persons and their families and friends expresses their conviction with the Hashtag #WeAreNotWaiting that they can develop better solutions for their specific problems than those offered by the conventional health system. Do-It-Yourself Artificial Pancreas Systems (DIY APS) automatically adjust insulin delivery to keep blood glucose levels in a safe range, by creating a closed loop between a glucose sensor and an insulin pump via a smartphone app. DIY APS are automated and supposed to be “far safer than standard pump” therapy, leading to “remarkable improvements in quality of life due to increased time in range, uninterrupted sleep, and peace of mind” (Lewis et al. 2016). Currently (May 2019), 1303 registered people worldwide use DIY-APS, and the number of users is steadily increasing.

This technology comes with many promises, but also raises questions. DIY APS are not officially tested and approved systems. Since commercial distribution would be just as illegal as free provision of the software, prospective users have to implement the code themselves. Instructions and a supporting community can be found online.

Drawing on empirical findings on DIY APS community in the German healthcare context, this presentation will shed light on the visions that come along with this emerging technology. Why do DIY APS users trust in an unauthorized technology that has massive impact on the therapy of their T1D and requires a lot of engagement? What are the hopes and fears associated with DIY APS? Do DIY APS lead to a significant improvement in metabolic control, and do they affect the users’ quality of life?

References:

- Lewis, D.; Leibrand, S.; #OpenAPS Community. (2016). Real-World Use of Open
- Source Artificial Pancreas Systems. Journal of Diabetes Science and Technology
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Developing a health-related understanding of lifestyle direct-to-consumer genetic testing by users

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Direct-to-consumer genetic testing (DTC-GT) for medical purposes is strictly regulated in Germany and requires medical supervision. Still, commercial companies offer DTC-GT without an explicit medical purpose, for example to improve diet and physical activity. Based on the analysis of single-nucleotide polymorphisms of a DNA sample obtained by a cheek swab, this lifestyle DTC-GT promises insights to an individual metabolism and exercise type.

The typing results in recommendations for diet and exercise, mainly to lose weight. Usually, the DTC-GT is distributed by so-called consultants, e.g. personal trainers, nutritionists or non-medical practitioners. A qualitative study based on narrative interviews with consultants and users showed that they develop forms of understanding of lifestyle DTC-GT which often differ from the interpretation and application of the results offered by the providing companies. Strikingly, the legal and advertised purpose is not adopted by all users. Instead, an own frame of orientation in using the lifestyle DTC-GT is applied. The practice of using a lifestyle DTC-GT, especially the sampling and analyzing in a specialized laboratory relates to medical practice making a differentiation between medical and lifestyle genetic testing for the users (and for the consultants) indistinct. Consequently, the narrow purpose of the DTC-GT is extended to a wider scope including the management and improvement of the own health situation. Not only are the results interpreted in a different manner, new forms of utilization of the results are also applied. These forms range from using the DTC-GT as a basis for living a good and healthy life to using it as a measure of prevention or even as a diagnostic tool in a quasi-medical context.

Evaluation of different stakeholders-values and their weight in AI-based technologies development, constructions and usage-embedment

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It is evident that within their ubiquitous spread in nearly all areas of society, digitalized and AI-based technical applications themselves have to be seen as amplified social entities. Furthermore, they prospectively won't just keep their passive roles as useful tools but will increasingly carry out their active influences on social behavior and organizational structures. Partly because of that, the necessity-ty for approaches on technologies development, construction and (structural) embedment focusing on value-based, -centered or -driven concepts grows steadily. Not at least to secure the responsibility of developers and stakeholders for a conscious shaping on application's usage, an additional importance of those approaches must to be seen in the comprehensive control and management of technologies potentially impacts on future social and organizational structures. To take it to the point: a conscious constructing of technical applications and their structural embedding could be considered as a part of potential construction of future organizational and also social structures.

Based on multiple paradigm shifts in the historical evolution of technology's research and development itself, the obviousness of an associative linking between basic considerations on artificial intelligence (AI) and digitization trends or rather the manifestation of such considerations in these trends is often not given. An example of such an approachable association could e.g. be seen in the domain specific orientation of digitalized applications as an immediate consequence of unsuccessfully paths in AI's development. For various reasons, such as demographic aspects or health economic and health technological factors, especially the medical sector applies a broad range of opportunities for potentially usage of digitalized and AI-based technical application. At the same time, the domain of medical usage implies a high sensitivity towards the construction of technical applications and their usage. Corresponding considerations should there not just address the general debate on theoretical threats but also imply the potential inlying values of different stakeholders.

In this contribution, an approach for value-driven technology should be examined using an example of AI-supported medical diagnostic and the ethical foundation of its usage embedding. The combining of a theoretical analyzing of literary mentioned threats as initial insights into the

normative land-scape with stakeholder-interviews, provides thereby empirical access to normative debates. This opens the possibility of formulating a tentative ethical guideline as a frame for a value-driven technology.

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