



Rethinking Health Care

– Insights from the Gyllenberg Symposium 2019

*The “Rethinking Health Care: techniques, challenges and ways forward” symposium brought together researchers, medical practitioners and engineers to discuss how digital technologies shape the future of health care. The internationally renowned speakers discussed issues related to artificial intelligence (AI), self-tracking and health data. The symposium was the XXVI in the Gyllenberg symposia series organised by **Signe and Ane Gyllenberg Foundation** this time in collaboration with **Tekniska Föreningens i Finland Foundation**.*

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Medicine and AI: practical applications and ethical questions

The symposium began with a fascinating introduction to the possibilities artificial intelligence offers for doctors, with Professor **Johan Lundin** shedding light on how AI can ease the workload of doctors and pathologists. Lundin, who currently works as a research director at the Institute for Molecular Medicine Finland (FIMM), focused on image-based diagnostics in his presentation. According to Lundin, image analyses conducted by AI can help health care professionals mine and combine data, create virtual assistants and reduce errors and personal biases or in diagnostics.

Professor **Linda Hogle** from the University of Wisconsin-Madison approached the theme from the perspective of data-intensity. She addressed the use of personal information in various contexts, from private companies to public health care. In particular, her presentation revolved around the question of what counts as medical data. Some companies in the United States are currently using self-tracked information and social media updates to build data profiles of people's health and well-being, and then interpreting the data using AI. Naturally, this raises ethical concerns.

These ethical questions came under close scrutiny in **Tamar Sharon's** address. Sharon, an associate professor at Radboud University in the Netherlands, challenged the audience to think about the values we may lose while pursuing better health through technology. She reminded us that we should keep transparency, fairness, democratic control and the common good in mind while thinking about technological development. Sharon discussed some of the challenges AI creates for privacy and security, which Lundin and Hogle explored in their presentations, noting that we should build frameworks that ensure they are protected. For example, people should have the right to be free from surveillance. Sharon's presentation also touched upon some of the other ethical issues that Lundin had introduced. Should AI be explainable and to whom? Who is responsible for the mistakes committed by AI? Although there are no clear answers to these questions, the questions have to be identified and should be engaged with, Sharon emphasised.



JOHAN LUNDIN

Data for health: where can it be used?



NATASHA DOW SCHÜLL

Päivi Metsäniemi, MD, approached the issue from her point of view as a doctor. Metsäniemi works as the chief medical officer at the Finnish Student Health Service (FSHS), and is very enthusiastic about measuring and improving health care outcomes and the working environment of doctors. According to Metsäniemi, the key thing in development is data. She pointed out that there are heaps of data in health care but they are largely underused. In her address, she discussed how health care systems could move forward from simply having scattered data to using it for producing insight and making shared decisions. Everyday health care data, from prescriptions to diagnosis, could be used on all levels of the healthcare system. Metsäniemi gave the audience great examples of this kind of multi-level usage: patients could improve their self-care, professionals could make more informed decisions, providers could improve their services and society could measure the quality of health care.

Anthropologist **Natasha Dow Schüll** introduced digital health technology from the perspective of lifestyle management. Dow Schüll discussed in more detail one of the themes of her upcoming book, *Keeping Track*, which explores the rise of self-tracking technologies and the new modes of introspection and self-governance they engender. She covered technologies such as Fitbit, Spire and HAPIfork, which aim to help their users make healthier choices in their everyday lives. Dow Schüll pointed out how these technologies indicate that self-care is moving towards algorithmic care, in which algorithms suggest healthy choices for individuals. For example, people should take the stairs and not lie on the couch for too long, and these decisions are being outsourced to algorithms. Dow Schüll also reminded the audience that too much self-tracking can make the world appear toxic and make people feel like there are only bad decisions to be made. Consequently, ethical questions should be kept in mind when developing new self-tracking technologies.

Collaborative care: stories about digital health care

In the collaborative care session, the audience heard stories from digital health projects that use collaborative care methods. Associate professor **Stine Lomborg** from the University of Copenhagen and **Gustav From**, MD and gastroenterology consultant, described their experiences with using MyChart. The MyChart online health management tool is in use at the Abdominal Centre in Copenhagen, where From is in charge of quality control and patient safety. MyChart gives patients the opportunity to, for example, reciprocally exchange messages and book appointments. Even though Lomborg and From have had



KRISTIINA PATJA

some great experiences using MyChart, they still referred to the implementation process as a battlefield. The process of transitioning to new technologies takes time, since the operative environment is constantly changing. Lomborg and From also reminded the audience that different patients need different things: some appreciate face-to-face meetings while others prefer receiving written instructions. Health care systems still need to find the right balance between patients' preferences and implementing new platforms.

Kristiina Patja and **Michael Quarshie** from Wellness Foundry told the audience about their projects in Kirkkonummi and Kotka. The company has arranged interventions that focus on improving self-efficacy and lasting behaviour change. Specifically, the interventions focused on nutrition, and the participants tracked their eating habits with an app created by Wellness Foundry, called MealLogger. The project provided intrinsic motivational coaching by using image-based food journaling. The interventions yielded encouraging results and many participants found the experiment valuable. Although the results were promising, Patja and Quarshie also highlighted that there is a significant group of people who are underserved when it comes to digital health. The people who really need to make their lifestyles healthier rarely use technology to monitor their health, and find it hard to start using the existing applications that support behavioural change. Patja's observations on how autonomy, realism and having clear goals help in creating lasting behavioural change were thus extremely valuable.

Patja and Quarshie's presentation was followed by a commentary from **Mikko Lehtovirta**, a postdoctoral researcher from the University of Helsinki's Institute for Molecular Medicine Finland (FiMM)i. Lehtovirta's talk had a holistic point of view and discussed how difficult it is to maintain the relationship between a medical expert and the patient in the digital context.

Self-tracking: the self-tracker's point of view

The symposium's final session offered a practical perspective on self-tracking, with **Thomas Blomseth Christensen** and **Jakob Eg Larsen** sharing their experiences. Christensen is widely recognised as one of the most experienced and influential self-trackers of the global Quantified Self community. He has, for example, monitored his every sneeze for years and has been able to manage his allergies through self-tracking. In his speech Christensen focused on the art of self-tracking, instead of the changes he made to his diet, for instance. Larsen shared Christensen's perspective in his own presentation. He told the audience about how he tracked his headaches and tried to find an explanation for them. Like Christensen, he stated that curiosity is the main driver of his self-tracking.

These real-life experiences were followed by a talk by **Gary Wolf**, the co-founder of Quantified Self. Wolf elaborated on the philosophy behind the movement that has influenced self-trackers in more than 30 countries. Wolf introduced self-tracking processes as "everyday science" that seeks knowledge through personal discovery. Wolf stated that everyone has the right to monitor their life and gather data on it. He explained that even though the movement has been able to collect massive amounts of data, the scientific community has not yet been interested in utilising it. With the aid of the notion of everyday science, new collaborations towards that direction become possible.

In her speech earlier on in the symposium, Natasha Dow Schüll had brought attention to the addictive aspect of self-tracking. However, Wolf, Blomseth and Larsen did not find self-tracking to be addictive. They emphasised that while the regular user normally gets excited about an app or wearable technology for a period of time, they soon get bored with it. As members of Quantified Self, the three had a more nuanced view of self-tracking.



GARY WOLF

Closing words from Minna Ruckenstein:

“We pay a lot of attention to what technology does, but ignore the work humans do for technologies. In the symposium, we focused on that work. We gained an overview of how technology currently shapes health and medicine. The terrain is complex and unstable, but with experts from various fields, we got valuable conceptual guidance for navigating in this changing environment. The huge amount of data offers us possibilities, but as Tamar Sharon pointed out in her presentation, it also poses questions about our values. With the newest developments, we face ethical tensions and dilemmas. In fact, we are only in the beginning of understanding how data and technology can help us in building better healthcare and in steering our society towards the common good.”

Minna Ruckenstein was responsible for the symposium’s scientific programme. Ruckenstein works as an associate professor at the Centre for Consumer Society Research and the Helsinki Center for Digital Humanities at the University of Helsinki.



MINNA RUCKENSTEIN

Greetings and questions from the symposium message wall

- *Great symposium coming up. A warm welcome to everyone! Gyllenberg Foundation and TFIF Foundation teams.*
- *Great to be here!*
- *Excited :)*
- *AI and neural networks become more common and take over a big part of the experts' jobs in the near future. Is there a risk that we actually create a lack of human expertise in these medical fields as we delegate the heavy lifting?*
- *Could an AI put together the best possible social and health care system...? Teach the rules or give all the possible examples and give it a go!*
- *We prioritize care already, so could AI evaluate our choices and guide us to make valuable choices for patients and population? Where are the most valuable investments?*
- *It is a bit of a strange approach to totally turn health into a monetary issue, is it?*
- *Health is very much a money issue in the U.S.! As it appears to be becoming in Finland as well.*
- *Very important to move beyond the hype.*
- *Everything technology enables will be done at some point of time. No legal framework now and in the future will prevent us human beings from being exploited! What are the means of recovery?*
- *Thank you Päivi! It's useful to hear a doctor's point of view.*
- *Interesting to bring in the communication aspect to the discussion.*
- *Inspired by Sara's story!*
- *Thomas: how do you think your path would've been different if you had access to lab tests from the start, for instance?*
- *How does Everyday Science solve correlation vs. causation questions? E.g. do you get eat aspirin due to a headache or get a headache due to eating aspirin (or maybe there is a 3rd unknown variable)?*
- *What is the most prominent self-tracking device, like Fitbit, where the service is offering a self-hosted backend giving you control of the data?*
- *In medieval time disease was an individual curse, then medicine promised a cure, failed. Now back to individuals?*
- *Behavioral medicine has a long history of using self-monitoring to identify trends between variables within persons. Technology gives individuals the tools to do this themselves, but larger buy-in of the healthcare system is needed to better identify WHAT individuals should track in relation to their own health issues.*
- *Thank you for an inspiring day!*
- *The symposium was really interesting and versatile. Thank you!*

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