ACADEMIA ENGELBERG

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«THE TRANSPARENT PATIENT»

Participants and Abstracts

PARTICIPANTS AND ABSTRACTS

The Autumn Academy provides a platform for graduate students and post docs from all academic fields to present their paper and discuss various aspects related to the conference topic.

BOUWSMA Jasper
The Netherlands / Zurich, Switzerland

With the invention of the Internet the digital revolution has been unleashed. The original idea of Sir Tim Berners-Lee to share knowledge has been realized to anyone with an internet connection. Besides the abundance of improvements and opportunities, new threats and dangers have emerged. Access and transparency of knowledge is generally good, whereas transparency of individual and private information has been misused. The opportunities for further improving health and wellbeing are within our grasp as more data becomes available as does required search and computing power. On an individual level patients and specialists are able to tap into more and deeper data than was possible only decades ago. Following Hippocrates' writing, patient data transparency could lead to further improvements in health and well-being. As illnesses and child-deaths could be treated more effectively or even prevented, also macro societal and global health can be improved. As indicated, health transparency can also have negative consequences and has proven to be misused. Balancing opportunities and threats of patient transparency and transparent patients must be weighed carefully. The discussions are delicate and lead to complex mono- as well as multidisciplinary discussion between legal and ethics, medical and biology, research and economics, public and private, etc. In the multitude of stakeholders, patients might go under.

GUGLER Stefan
Zurich, Switzerland

Big data and machine learning are key elements of many applications within 21st-century technology such as telecommunication, mobility, banking and also health care. This affects not only private companies but public institutions, too. We investigate how the Swiss health care system is being transformed by the advent of big data and machine learning. In addition, we propose concrete policies on how to shape this process in accordance with the needs of Swiss citizens. In particular, we show how the introduction of the electronic health record (EHR) could have potential benefits for patients i) as new health data sources become more readily available (e.g. smartwatches) and ii) to give them back more power and responsibility over their own data. Another beneficiary of the digital turn in medicine is basic scientific research which profits from new data sources to improve personalized medicine or study rare diseases. The drawbacks of this development must not be ignored, however. The implementation of the EHR requires careful consideration of the challenges: i) clear legislation for data access and patient abuse protection ii) privacy laws, as well as anti-discrimination laws, need to be extended to EHRs and health data in general iii) ongoing education of doctors and health care providers is needed to ensure conscientious handling of sensitive personal data.

KAPPEN Marie
Germany / Zurich, Switzerland

As a psychologist, I see a great potential in a nationwide electronic patient dossier as planned by the Swiss eHealth strategy 2.0. Especially the direct access to discharge reports and neurological test results would facilitate a seamless treatment process without time passing while waiting for important information. In addition, the direct access would prevent unnecessary double testing and the present treatment could be adapted more easily to past treatments. An electronic patient dossier with all that bundled, easily retrievable information would very much simplify the interdisciplinary cooperation and communication between therapist and thus, I would have more time for the treatment of the patient. However, as a patient, the idea of becoming transparent is accompanied by an unpleasant feeling of being naked without having control about who is seeing through me. This makes me feel dependent on the good will of unknown people to not abuse my sensitive data. Also, many questions regarding my privacy come to my mind. What will happen if in a dystopian future my health data is freely available to health insurance companies for the sake of efficiency? Will I be able to get a Zusatzversicherung? Will I be discriminated because of health-deviant behavior? But even if this dystopian future will not come true, will I be overloaded by excessive demands or decisions that have been handled by my physicians before, but must be coordinated by me now? Then, in my last role as a curious researcher, I am excited to explore the potential behind big data and machine learning in the area of mental health. I am enthusiastic to analyze digital phenotypes and define predictors of changes in mental health behavior reflected by the mobile phone usage patterns. In addition, I support the development of blended treatments as they reach a greater range of patients and allow for a continuous interaction with the contents of therapy.

MARCINIAK Marta
Poland / Zurich, Switzerland

Focus on the digitalization of medical services is one of the crucial points in modern medicine development. It not only makes life easier for doctors and helps patients to collect all the data about their health in one place but also provokes discussion about data protection and potential use in business and science. As a psychologist and cognitive scientist, I see the urgent need of developing more mHealth tools to increase mental health. For instance, stress-related mental disorders are now one of the most widespread societal diseases; in an ageing society memory training will become even more relevant. In the same time, around 70% of Western European society has access to a smartphone. Therefore, a growing number of interventions should be delivered via this channel (for instance, via apps) in order to maximize the ecological validity of the treatment. It would allow people to train their stress management skills, learn new emotion regulation strategies or even how to reduce symptoms of mental disorders and significantly increase positive well-being among users with a broad range of psychological problems. Next important issue is relatively easy access to this kind of psychological assistance. People do not have to pay as much as for professional help, do not feel stigmatised by society and can start and finish the treatment whenever they want to. mHealth apps may postpone the necessity of intervention of a qualified psychologist as well as provide a valuable means of support even after therapeutic procedures are complete. It may be really helpful not only for patients and psychologists but also for the economy of countries that would benefit from the development of this kind of assistance.

MARTANI Andrea
Italy / Basel, Switzerland

Although "Personal Responsibility" has always been a crucial legal and ethical component of Healthcare in Europe, the advent of digitalisation in healthcare has the potential to re-design the outreach of this concept. Traditionally, personal responsibility in healthcare has been conceived as the "flipside" of solidarity: whereas solidarity underpins the conviction that healthcare should be mainly funded collectively, personal responsibility entails that single people have the obligation to act in a responsible way as to preserve the sustainability of the healthcare system. In this respect, it has always been a bone of contention to decide to what extent choices of the single person (e.g. smoking) can – or indeed should – be used to take decisions about the rationing of healthcare resources. In other words, if a patient smokes, should he be held accountable for this choice, for example by increasing is basic health insurance premium or limiting the health services his basic insurance (and thus society) would cover? In the paper for the Academia, I present a reflection on the potential impact of digitalisation on the concept of personal responsibility, with a particular focus on the use of this principle in the field of resource allocation. In particular, I first present some practical examples of how digitalisation and personal responsibility are connected. I will then argue that digitalisation fosters an atomistic idea of health, whereby the latter is not conceived as a collective effort of society, but rather as the product of a series of individual choices. In this sense, "quantifying" patients through their data paves the way to demand more responsibility for the decisions taken by the single person. This, in turn, promotes the idea that people should be held accountable for their own health-related choices, which amounts to reinforcing a "moralistic" version of personal responsibility.

WAMUNGA Daniel M. Owino and ODERO Michael
Kenya

The Midan health nutrition and wellness Centre is a proposed modern healthcare system. It is both web-based and it employs use of android application to track disease, malnutrition and any other health abnormality .It is key also in tracking management and outcome of the management of the disease and malnutrition. This should be done by employing three components of the App namely the survey component, Logistical Management Information System (LMIS) and the Wellness Center where right intervention is arrived at after dietary and nutritional assessment online. The survey system has specific questionnaire format where the user enters specific client details, the results are seen by the researcher in a graphic presentation format .This is a way of reducing total cost of printing several questionnaires and at the same time giving real-time authentic data. The LMIS System is a data storage analysis and processing hub. It can be used for FBP, medicine and other commodities e.g. HIV testing kits and first aid kits. This system is also able to use message alert system and QR code to track the final commodity user and final change on the final status of the beneficiary as per the indicator. The Midan Nutrition , Wellness and Oncology Centre therefore seeks to prioritize cancer prevention, treatment and management using the available resources and minimizing travel time to see a doctor .This can be done through working on modern detection system applied in modernized hospital incorporated in the mobile application system.

ROCKENSCHAUB Patrick
London, UK

A person's health status is among the most sensitive personal information imaginable, and unauthorised access to it might have devastating consequences for the individual. How much the public indeed cares about the privacy of this information has been repeatedly shown in different countries. When the United Kingdom moved to introduce a comprehensive patient record called care.data in 2013, public outcry arose and an opposition by patients and doctors successfully prevented its introduction. Just last year, similar plans to open patient records to public research in Austria were met with outrage and the Ministry of Health quickly retracted its proposal. In both instances, citizens were worried about the safety and integrity of their personal data, fearing that the data might be hacked and published or intentionally sold to insurance companies. Public debate was dominated by emotional arguments and constructive discussion nipped in the bud. Any arguments for and proponents of the benefits of comprehensive health records were immediately drowned out by a plethora of valid yet often exaggerated fears. These records can contain a variety of information in structured or unstructured formats, including basic demographic and administrative data, performed investigations and procedures, prescribed drugs and, most alarmingly, medical diagnoses. Records are added by the doctors during a consultation and they aim to convey a complete picture of a patient's medical history and current health status. Knowing about a patient's past is vital for effective healthcare and enables clinicians to avoid adverse events, make the right diagnosis and deliver high-quality care. For this reason, medical professionals have kept records for decades, first on paper and now on computers. Objections only arise once we try to make doctors communicate with each other, for example if a service is proposed that would allow a hospital clinician to access a patient's primary care history (where a large proportion of medically crucial can be found). Patients and doctors, both of whom should be delighted by the medication errors prevented by this measure, decry the risk of losing sensitive information. What if someone might be outed as HIV positive, they ask. What if insurance companies are allowed access to a cancer diagnosis? Instead, many advocate the status quo in which exactly this information is requested via fax or email, which not only wastes valuable time but also repeatedly leads to data breaches due to human error. But here is the catch: despite all the attention given to electronic patient dossiers, they are not the only health data in today's connected world. Browsing behaviour (think webmd.com or NHS choices), location data and online shopping lists all contain information about a person's health status and should thus also be regarded as "health-related data". In the case of poster boy of security risks, HIV, frequent visits to HIV clinics and pharmacies might actually provide more information about the disease status than official medical records, which often contain limited information on HIV status due to anonymous testing sites. Most importantly, however, much of these data items are already collected, and not by our national health services. A recent article in the scientific journal Nature highlights that commercial tech companies already possess (freely given) data that allow them to the infer many of the most feared privacy risks, without any of the public benefits that could be derived from sharing information among health professionals. In a democratic discourse we can set the rules and regulations to use our data for the public good while making sure it's kept as safe as politically and technologically possible. We can make sure that they are used in the best interest of the patient.

SELS Laura
Belgium / Zurich Switzerland

Technological innovations offer considerable possibilities to innovate the mental health domain, such as its integration in psychological treatments. It can not only greatly enhance accessibility to necessary information and services, but also increase the efficacy of treatments, and enhance intervention and prevention. During my PhD time, I used digital technology to examine fundamental processes underlying people's well-being, and I became gradually aware of the value it could have in more applied clinical settings. Therefore, I moved into a postdoc that exactly focuses on the potential contribution of digital technology to the improvement of mental health: by examining the feasibility of the development of a digital protocol in suicidal ideation monitoring and prediction. Suicide is an important cause of deaths, and the numbers continue to rise, making a better prevention one of the top priorities on (inter)national research agendas (e.g., WHO, 2014). One of the greatest challenges to suicide prevention is that suicidal thoughts have to be intervened upon as they unfold and evolve in real life, where they change and fluctuate rapidly, and can escalate quickly. Because people continuously carry their smartphones with them, even in times of crisis, digital technological innovation may offer new opportunities by helping to reach vulnerable individuals in critical moments and providing links to just-in-time, cost-effective interventions. Although there has been a rapid increase in suicide prevention apps, most to date are actually not evidence-based or clinically validated. In our project, we use psychological theory to design digital indices and test their ability to predict suicide ideation and psychiatric hospital readmission in high-risk individuals: psychiatric patients after discharge. This could provide direct pointers for future interventions. In this way, I hope to make a first contribution to the integration of digital technology in mental health settings.

VON ARX Martina
Geneva, Switzerland

Health has always been measured with numbers: body temperature, weight, blood pressure. The quantification allowed, and still allows today, to establish numerical norms of the human body. Medical treatments intervene when health measures deviate from normality. With some exceptions (e.g. weight), health components were mainly measured by a healthcare provider at a particular time. Thanks to smart devices, health-related data can now easily be collected around the clock and in real time. These huge amounts of data open up a new and unique way to cluster human health on an individual and on a societal level. Sharing health-related data online (e.g. PatientsLikeMe) has been shown to benefit especially those with rare diseases and can provide important community support. However, analyzing non-specific data relies on algorithms which are exceptionally good at reading patterns of Big Data. When it comes to software controlled medical treatment we should be careful about the way this program evaluates the patients' health status: It will only rely on the information provided by other individuals and/or the programmer's choices on the characteristics of this health component. Will it still be able to account for the patient's individual needs? If the patient gets more and more transparent, meaning that his whole life gets increasingly quantified, we need as well transparency on who has access to our personal data and for what purpose it is used. Data should not be used without the informed consent of the patient, which is an especially tricky issue when third parties (e.g. health insurances) offer money as an exchange. This leads to a difficult question whose answer will depend on the respondent: What value do personal data have?

WAGNER Sophie
Vienna, Austria

My current research focuses on self-tracking wearable technology in Austria, where a shift in the location of responsibilities is happening in terms of privacy and the public good via government decision-making and broad public debate. I focus on sensor enabled monitoring devices, which not only form an expanding market, but also gain particular value in healthcare, where the gathered data can potentially fill gaps in traditional methods of medical monitoring and create a more comprehensive picture of individuals and their health. Emerging citizen science initiatives further frame individual contribution indispensable and push individuals to contribute their personal data to research. But data sharing is part of a larger social narrative, which entails the belief, that Big Data systems instill objectivity and rationality in irrational human existence. As part of the existing "social imaginary", data sharing becomes imperative in contributing to a better future, with multiple implications for the understandings of privacy, transparency, trust and responsibility. I ask how this "data philanthropy" and the growing value that is added to "mundane" data gathered from sensor enabled devices, impact on individual engagement with self-tracking devices and the according apps. I ask how this process alters perceptions of the body, un/healthiness, and processes of subjectivation by applying Lupton's considerations of "data sense" as an epistemological vantage point. By illuminating how subjective meanings are ascribed to self- monitoring practices, my research adds insight into the interrelationship between self-tracking, flows of data, and modes of subjectivity. In order to better understand the relational existence of technologies and social phenomena, and add to the dynamic understanding of human ontologies, we have to add a specific, human-centerd approach to the discourse about AI and Big Data based systems.

ZIMMERMANN Bettina
Basel, Switzerland

Predictive genetic tests (PGT) give healthy people information about medical risks on diseases they might develop in the future. By law, professional genetic counselling has to accompany such testing in Switzerland. Genetic counselling for PGT is a complex task for several reasons. First, it should be informative but non-directive, meaning it should remain a personal choice whether to do testing or not. Second, there are many medical, psychological and social consequences involved in PGT. These include e.g. the involvement of family members, possible stigmatization and discrimination. Third, counselling is complex because PGT has the potential to create transparency and knowledge, but also uncertainty and fear. The outcome depends highly on what is tested exactly, but also on how the test and its results are portrayed to affected individuals. For all these reasons, genetic counselling has to be provided by specialists. In Swiss university hospitals, a limited number of specialized medical doctors (MDs) provide genetic counselling for PGT. However, the demand for genetic counselling is going to experience a steep increase, because more applications of PGT enter clinical practice thanks to technological breakthroughs that have made genetic testing faster and cheaper. So far, every hospital is dealing with this increasing demand individually. No general measures have been conceived. Other countries, such as the United Kingdom, Sweden or France, implemented the profession of genetic counsellors. These specialists have a Master degree in genetic counselling but no approbation as MD. In the US, peer counselling and online education are used to meet the exploding demand for genetic counselling. Another possible solution would be to educate more MDs in genetic counselling, but the interest among MDs is low and the curriculum is packed. Our paper discusses these possible solutions and assesses which ones are most suitable for the Swiss context.

ACADEMIA ENGELBERG

ORGANISATION
Academia Engelberg
Geschäftsstelle
Sigrid Züst-Strähler
Rütliweid 11
6043 Adligenswil

www.academia-engelberg.ch
admin@academia-engelberg.ch