

Lean Personalized Medicine?

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Valorisation

This dissertation “*Lean Personalized Medicine? From genetic reductionism towards holistic Personalized Medicine,*” addresses the challenge of broadening the paradigm of PM again and acknowledges the highly interactive systems approach necessary for truly personalization in health care. This chapter on knowledge valorization refers to the translation of scientific knowledge into the practical societal value. The value can have a variety of formats including competitive products, services, processes and new commercial activities. Accordingly, placing scientific activity in an economic, social or environmental context can create more legitimacy and added value of the research activities. Therefore, the aim of this chapter is to describe how the scientific findings reported earlier can yield benefits for different societal stakeholders beyond its value to the scientific community.

Relevance of the Topic

Personalized Medicine (PM) is the response towards the need of a more tailor-made approach in medicine to provide each individual patient with the right treatment, the right dosage at the right time. Current first success stories are mainly reported in the field of oncology. Targeted testing for specific genetic abnormalities has been transforming the classification and treatment. However, development and implementation of Personalized Medicine approaches for other diseases and many aspects of health care delivery are still far from being reality. Genetic effects in isolation are insufficient to identify the risk in the most prevalent disease and it is actually needed to integrate genetic and epigenetic effects with environmental exposure as well as lifestyle components. Genetics are just one of a suite of personalized tools to achieve healthier living, rather than an almighty method to predict future disease. Therefore, this dissertation shed light on additional translational pathways towards holistic personalized medicine.

Target groups

As the results are presented in this dissertation, they might be of interest for multiple stakeholders of the health care system including citizens/ patients, health care professionals and policy makers. In the following I will illustrate how each of the target groups is addressed or assessed in each of the parts of this dissertation. Overall, all projects of the dissertation are directly or indirectly patient centered.

The first target group of this dissertation are citizens as stakeholders in society and in their role of (potential future) *patients*. In Part 1 understanding people's

awareness, attitudes, motivation and concerns about personal genomic testing, accessing genetic data and genetic data sharing is in focus. The assessment provides the chance to integrate the broader public into the debate and ultimately gives insights on how to protect individual rights, like privacy and confidentiality, while avoiding undue paternalism that potentially prohibits (scientific) development. In Part 2 and 5, the proposed solution of HDC put “citizens in the driver’s seat” to take control and ownership over their data. Through increased empowerment of patients due to access to health data and increased health literacy patients have to be acknowledge as partners in the decision making process. There is a need to address the limits of a top-down and expert-based approach. Part 3 and 4 both investigate how to improve patients’ self-management abilities through the integration of lifestyle. All stakeholders will benefit by the increasing awareness of the importance of physical activity among inactive people and the accompanied health benefits. Furthermore, with the mobile health application “MoVit” a direct solution has been proposed to overcome the challenge of behavior change towards a physically active lifestyle.

The second target group is *policy makers*. As described in Part 1, given the overall need for genomic data, the interest that people are showing in accessing their genomic data and even donating them for research, as well as the concerns about the practices of many personal genomics providers an in depth understanding is crucial for developing appropriate and evidence-informed policies and practices in relation to recruitment, informed consent and privacy setting options relevant to personal genomics. As these are new developments, we are only in the beginning of the debate about what measures policy makers need to take at the regulatory level, how to engage the broader public in the debate and ultimately how to protect individual rights while avoiding undue paternalism. Furthermore, as we move to Part 2 the proposed solution of HDCs lead to the need of data sharing regulations on an international level. Therefore, it becomes even more complex to develop global policies responsive to different cultural perceptions about data sharing, different levels of trust to the research enterprise including different health care systems and data protection laws. At the same time, integrating Big Data and Health Data Cooperatives (HDCs) is expected to lead to highly valuable insights that will inform and empower policy making. In sum, on one side, policy makers are challenged by the new regulatory requirements needed for data protection, while on the other side they might strongly increase their effectiveness and impact due to the option of data driven policy making.

Furthermore, *Health Care Professionals* are the third target group of this dissertation. Health care professionals have always wanted to offer their patients the best treatment to suit their specific case. To fulfill this goal, roles of health care professionals might have very different formats. In Part 1 health professionals are reported as a missing piece in a successful interaction of lay people with their

genetic data. DTC-GT companies have frequently been criticized to not provide their customers with professional support after receiving their results. This might lead to an increased health care consumption due to unsettled patients who need support in understanding and wish confirmation of test results. Furthermore, access to genetic and online health data will empower patients and they might challenge the health professionals' treatment decisions or question their authority. Finally, health care professionals will be confronted with (genetic) data they might not be familiar with and unable to integrate this knowledge into their practice. In Part 2 the solution of a HDC will give the health care professional access to a complete set of patient data. The reproduction of previous data points (images, scans, samples etc.) might be obsolete. Furthermore, the integration of new data points (eg. lifestyle data) might lead to new insights and answers to questions that have previously been beyond reach. Part 3 and 4 aim to raise the health care professionals' attention towards the importance of lifestyle as a significant predictor in treatment success. The proposed tool "MoVit" enables and supports the health professional to prescribe organized lifestyle changes and preventive treatment and personal activity reports provide an additional continuous source of information for medical decision making. Finally, Part 5 illustrates how the in depth knowledge on molecular characteristics of patients will lead towards a new paradigm of disease categorization. Soon every patient will be categorized as unique and cannot be treated according to average-based data.

Activities/Products

Building on the previous sections, the results of this dissertation have the potential to be translated and shaped into several concrete products, services or activities:

Findings of Part 1 aim to inform policy makers and can be translated to potential policy recommendations on how to protect people's values and rights while enabling ethically sound research and data sharing activities to support scientific advancement. Furthermore, the potential of citizen science initiated by public institutions has been discussed in detail and would be a great opportunity for further action taking. In Part 2 and Part 5 the solution of HDCs is discussed in detail: HDCs are unified data systems that promote data access and data linkage of heterogeneous data from a multitude of sources from within and outside of the health domain, while still citizen owned. They offer a framework to overcome the technical, political and societal challenges and to empower policy making by the integration and application of Big Data. Part 3 illustrates the potential of lifestyle interventions in chronic complex diseases and Part 4 gives a concrete solution on how to integrate lifestyle by the use of a mobile app solution "MoVit".

Prevention of adverse health outcomes may have an enormous impact on future health care budgets, since these are strongly associated with mortality and long-term morbidity.

Innovation

Overall the dissertation is illustrating translational aspects of the innovative paradigm of PM going beyond genetic reductionism and integrating a holistic approach with the patient at center. The above suggested products and services can be called innovative in respect to the existing range of products, services and activities in various ways:

1. “Citizen science” as a concept that will lead towards an improved dialogue between science and society, as well as the integration of society into the process of co-creating scientific knowledge.
2. Health Data Cooperatives (HDC) and the integration of multiple sources of data on an international level, which will lead to new insights and increased effectiveness in health care and beyond.
3. The innovative model of personalized lifestyle medicine has been introduced: a model enabling lifestyle oriented treatment strategies to improve health outcomes based on individuals health metrics and personal preferences.
4. “MoVit” a physical activity health app which translates scientific evidence of behaviour change into a personalized physical activity coaching program and mobile application to provide health care professionals with a tool to promote an active lifestyle among their patients.
5. Overall the integration of PM will lead towards a new perception on how we define certain disease categories and put the patient at center.

The different valorization proposals as outlined above all have a very different timeline and scope for implementation. While the mobile health application has been followed up and has been pitched and prototyped in different contexts, the concept of integrating citizen science into academic research, the proposed HDCs and the integration of lifestyle medicine need a long-term approach.