Chapter 5
Billing Processes in Personalized Medicine

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Abstract Nowadays, intellectual property such as medical research data is strongly associated with the issue of wanting to protect and share such data for the benefit of research, which prevents disclosure of knowledge. For example, pharmaceutical companies avoid publishing certain parts of their drug discovery research to protect themselves from competitors. As of this writing there are only a limited number of billing systems or market places in the rapidly evolving field of personalized medicine available, where intellectual property, e.g. genome sequencing data, can be traded in exchange for a payment. To contribute, I propose a billing system that can be integrated in an exchange platform for medical data that provides the possibility of receiving payments in exchange for sharing data. Additionally, the system offers the possibility to set fees for specific user groups, which in turn allows to define higher charges for competitors, or let collaborators access certain data for free. In my opinion, exchanging data in this way would benefit both trade partners. As the intellectual property was already gathered, the organizations providing data can use it to collect extra funds. Other institutes buying data can profit by having a larger pool of research data available.

5.1 Introduction

In the year 2000, the vast majority of the human genome had been sequenced in the course of the human genome project [115]. Although it took more than ten years to develop the first draft of the human genome, technology has rapidly evolved ever since, and today it is possible to sequence the whole genome of a human being within 30 hours [122].

Another factor, which drastically changed is the cost for sequencing a whole genome. While the cost was as high as 100 million US dollars in 2001, it decreased to less than 10,000 US dollars in 2011 [138]. It is expected that this trend continues,
due to improving technology. Some scientists state that in the year 2020, everyone’s genome might be analyzed [128].

This progress enables further scientific research regarding the human genome. Nowadays, instead of being treated on the basis of symptoms, more and more patients get treated based on the mutations in their genome, if the origin of a disease can be found therein. This idea, to treat each patient according to the individual conditions and the cause of a disease, and not based on how other patients with similar symptoms were treated before, is one basic concept behind personalized medicine [124].

There are many institutes all across the world, which gather genome data, for example, to discover why one treatment for a genetic disease helps one patient, but shows no or less effect on another. As such research is still cost-intensive and everyone wants to protect their intellectual property, some organizations avoid to publish the collected genome data for free.

However, what prevents you from offering access to your intellectual property for a fair price? A price you can set freely and change, whenever you think it is too high or too low. That is why I explored how a billing system for a platform, where you can exchange and trade data relevant for genome research, could be implemented. In my opinion, such a billing system would encourage the exchange of important medical research data, and benefit both sides of such an exchange. On the one hand, the owner of the data can collect extra funds, for data, which was gathered anyway. On the other hand, researchers that need additional data, for example, for a control group, can obtain it via such a system.

To allow protection against competitors, different fees can be set in the billing system for certain user groups, and it is also possible to not offer the data at all for specific groups.

Though it is difficult to set a price for an abstract item, such as genome sequencing data, a suggestion feature, which helps users to find a price for an item, could present minimum, average, and maximum prices of similar items to the user. Moreover, if the proposed billing system is part of a platform that provides genome analysis tools in addition to the possibility of exchanging data, you can use the same billing system to collect small usage fees for the analysis tools provided.

The remainder of the work is structured as follows: In Section 5.2, I explain existing billing models and how usage fees can be calculated. In Sections 5.3 and 5.4, I present the requirements and technology needed for my prototype and how my research prototype is implemented. In Sections 5.5 and 5.6, I show and evaluate the benchmark tests I used to prove that my system can be used for several years and still allows to trade items in less than two seconds, and end with a conclusion in Section 5.7.