Platform for Predicting ALS Disease Using Genomic and Primary Care Patient Data

06.10.2019

In this study Rashad Ismayilzada from Aalto University School of Science has tried to map out the healthcare scene in Finland and find out how one could potentially build a digital ALS prediction tool. This prediction tool would utilize two different sets of data: genomic and primary care patient data. He has found two potential systems that could facilitate the development of such platform – Findata’s sandbox and Apotti’s Healthy Planet.

Amyotrophic lateral sclerosis (ALS) is a progressive and fatal motor neuron disease. There is no effective treatment and the median survival is 4 years from symptom-onset, usually from respiratory failure. About 200 new cases are diagnosed each year in Finland, the highest incidence rate in the industrialized world.

Two major mutations responsible for ALS disease have been identified. They are located on SOD1 and C9ORF72 genes. These mutations are quite informative, but not informative enough for a decisive prediction. Our hypothesis has been to couple patients’ genomic data with their primary care data to arrive at conclusive result. Even though there is no cure for the disease at the moment, earlier diagnosis of the disease would allow an early engagement of patients in clinical trials and improve their QALY (Quality-Adjusted Life Year) at the least.

In the process of finding such platforms we have mapped out the healthcare scene in Finland. We have described data holders and major players in the ecosystem. During the process we have discovered that one can potentially build the aforementioned platform either nationally, on Findata’s online sandbox or regionally, on Apotti’s Healthy Planet system.

Findata will be capable of providing unified health data for secondary use, so the data acquisition and analysis can take place in its sandbox. One will only need to plug in the genomic data to the system. Alternatively, one can implement such a platform regionally (Uusimaa) on Apotti’s Healthy Planet system. This will require approval from Apotti’s decision makers to add ALS into Healthy Planet’s existing monitored disease list. The system will contain the primary care data and will only require addition of the genomic data.

Contact Information:

Rashad Ismayilzada
rashad.ismayilzada@aalto.fi
Two-sentence summary for social media:

This study has tried to find out how one could potentially build a digital ALS prediction tool using genomic and primary care patient data. Two potential systems were found that could facilitate the development of such platform – Findata’s sandbox and Apoti’s Healthy Planet.