"Smart Life Insurances” Offered: Human Biological Data Is Only Useful When Interpreted Correctly

As more and more data is collected about the human genome and lifestyle, it is important that you look after your personal information and are aware of the overall security of your data. Is it reasonable to put this burden on an individual? Should it be transferred to a trusted broker? How does one ensure that this trust is kept, but at the same time, enable others relevant parties to have access to your data? This brings up the question of who collects, interprets and uses this data and do these entities have the competence to do so?

The exponential growth in biological information has an impact on both individuals and communities. It will become possible to predict a person’s entire lifespan with certain genetic premises and lifestyle factors. As this information is increasing, also the possibilities to use this data for purposes other than what it was originally intended for will increase. Do we dare consume unhealthy foods anymore in the future if information is collected about it that may impact our insurance terms, for instance.

Economic and societal impacts will be felt after the next five to ten years when bioinformatics will be applied in preventive health care. For example, if a person has a genetic disposition to fall ill as a result of liver disease, which can be treated by lifestyle changes, revealing the issue to them at an early stage will probably influence the person’s lifestyle choices. Health care professionals can justify their recommendations by presenting well-known examples of life-long treatment histories from the health care system or biobank.

Open questions still remain: How and to what extent is modern biological information interpreted and used in public health care? How will/should the legislation evolve? As the need for better health care for the aging increases, so does the cost, and therefore such issues must be clarified quickly. The legislative aspects is particularly important as many insurance companies and giants of data processing, such as Google, are interested in the opportunities that are opening up.  

Biomedical data is valuable
The American 23 & me provides genetic tests for anyone, which then provides information about hundreds of medical risks re-
lated to one’s own genome. There are already many illnesses that can be analysed at the molecular level so it is therefore possible to diagnose, for example, one’s propensity for cancer, which in turn can radicalise and tailor treatments to reduce side effects related to generic “heavy” treatments. It is envisaged that such new technologies will also be able to predict changes in the state of health of an individual.

Who can, who is allowed to, and who is able to participate in the continuous observation of one’s own health? Who interprets whether a person is drifting towards a serious illness, and can this diagnosis be trusted? Whose rare disease can be cured and should it be done using public resources? Which ethical boundary conditions are used to coordinate access to the latest treatments?

Technology provides increasing opportunities for observing health and lifestyle on an individual level in real time. Different kinds of technological devices for monitoring our own health are becoming cheaper and integrated into devices that we already carry with us – mobile phones, clothes or watches. The Finnish insurance company Lähitapiola is conducting a new experiment where the company provides “Intellectual Life Insurance”. The insurance company cooperates with Polar, who produces biomonitors and collects, for instance, heart rate and lifestyle data for the application that help doctors make predictions about the person’s state of health. It is possible for the client to lower their insurance fees if certain healthy lifestyle options are met in the data given to the insurance company. Individuals would therefore benefit from lower insurance payments that encourage a healthier lifestyle. To return the favor, the insurance company accepts data as a “currency” that it utilises.

This type of data is valuable. Reliable and well organised data sources that are used in interpreting an individual’s health are currency in international commerce. In the UK, the National Health Service NHS has decided to open up the health care history of more than one million Londoners to Google. They are hoping that access to the data would enable Google’s experts to help prevent kidney diseases that are the source of great costs in public health care. It is estimated that as many as every fourth of these cases could be prevented if the risks were detected earlier and the people would change their lifestyle. This would bring about considerable savings in the public sector and improve public health.

Who owns the data and its interpretations?
The data that people accumulate about themselves regarding their lifestyle, e.g. engagement in sports, food and alcohol consumption, currently ends up online in very different services, or is deleted within one year. The aim of the services collecting this data is usually to gain profit by, "encouraging people to be engaged with their technological ecosystem". Connecting this type of accumulated data with third-party data sources is usually not possible. Further, using this type of data to support reliable diagnosis requires access to vast studies, so that an individual’s data retrieved from the sample can be interpreted correctly. This kind of data integration is still in its early phases.

However, the development pace is fast. Examining data collected from dogs, for example, is legally less restrictive than data from humans, and there are many services combining genetics and lifestyle for advancing dogs’ health already available (MyDogDNA). The next great favour by man’s best friend may be showing how genetic biological information should be used in health care.

Health care organisations collect data and samples from people in connection with treatments for research purposes. A medical professional is always responsible for the confidential collection of data and samples. Permission from the collector is requested if these are used for new purposes.

The prevailing practice significantly facilitates conducting studies to improve health. In the Nordic countries, centralised
health care has been in use for decades, which has also been able to organise and provide high-quality data for research purposes. For example, 30 percent of Norwegian citizens have a sample in the biobank. In Finland, more than 150 million medical histories have been collected for archives from 4.3 million citizens.

There are 5.4 million people in Finland, and in 2016 nearly all medicine prescriptions go to the same archive. The Biobank Act that came into force in Finland a few years ago also ensures that responsible research use of the data is allowed without informing every citizen about the issue separately. The collection provides an excellent starting point for interpreting the connections between genetic premises and factors that happen during a person’s life, if safe and sufficiently open access to the data can be created for a large group of international, skilled analysts.

But what can we read in the data now and, above all, in the future? In the UK, Google has been given access to all patient data because it is not possible to know in advance which factors predict and explain the development of a kidney disease. But what if, when trying to predict this, it turns out that the person has an acute risk to have a heart attack? Should the person be informed about this? Nordic biobanks have studied that approximately 60 percent of people want to know about random discoveries. The rest 40 percent do not want to know. Who owns the data and samples collected from people, and who has the right to control it for example for research purposes?

**An open data service as a solution**

Support systems for decision-making related to health care are based on constructed and maintained data sources. In international cooperation, it is possible to build more reliable data sources in light of people’s genetic premises and lifestyle and health care history than any country on its own. For this reason, we should strive for globally accessible data sources also in terms of processing and interpreting biological information related to humans. International access to data increases democracy, because the costs related to the use of the interpretations of the research data collected about people can be shared. At the same time, it is possible to support countries that would not be able to create such data services on their own. It is possible to collect measurement data about people everywhere where the internet is available – the challenge is performing the interpretation of the measurements in a reliable manner. Internationally open and secure data services would be one solution for this.

For example, the human genome has approximately 20,000 genes that guide all functions of the body. Sometimes genetic information becomes corrupted, which can lead to, for example, breast cancer. An international research group has shown in the latest studies that there are exactly 93 genes in the human genome that can change a healthy cell into a breast cancer cell when they mutate. This kind of information is crucial when designing new medication, because the proteins generated by the mutated gene are the targets of the design of the medicine molecules. The person suffering from the illness can also be diagnosed in more detail with this information.

Restricting this type of biodata only to a certain group would be wrong. Therefore there is need for open services for biological information, so that the research results are available to universities, research institutes and the pharmaceutical industry when they are needed. One of these data services is the European Genome-Phenome Archive EGA, which is a part of the European ELIXIR research infrastructure. EGA protects biological information on the old continent. EGA stores vast amounts of biomedical data material about humans and distributes the data based on licensing. Universities, research institutes as well as companies and public administration can save data into this global European service. The service has been much used, for example, in Nordic public health care for publishing long time series and research data regarding the whole population (gene pool).

During the following decades, utilising data collected from humans will be a part of society. Enlightened citizens will know how to demand for new kinds of health services. The private services sector in the field may grow quickly. However, we need international data sources and standards on which the small and medium sectors can build on and that guarantee the quality of the interpretations of the measurement data. The correlations between data sources collecting information about genetic, molecular biological and lifestyle data has only just begun.

Tommi Nyrönen

Tommi Nyrönen is a biochemist and the Director of the Finnish unit of the European infrastructure for biological information ELIXIR. He works at the IT Center for Science CSC.

**FURTHER INFORMATION:**

**CSC - IT Center for Science**

is a non-profit, state-owned company administered by the Ministry of Education and Culture. CSC maintains and develops the state-owned, centralised IT infrastructure.

http://www.csc.fi
https://research.csc.fi/cloud-computing

ELIXIR builds infrastructure in support of the biological sector. It brings together the leading organisations of 21 European countries and the EMBL European Molecular Biology Laboratory to form a common infrastructure for biological information. CSC - IT Center for Science is the Finnish centre within this infrastructure.

http://www.elixir-finland.org
http://www.elixir-europe.org