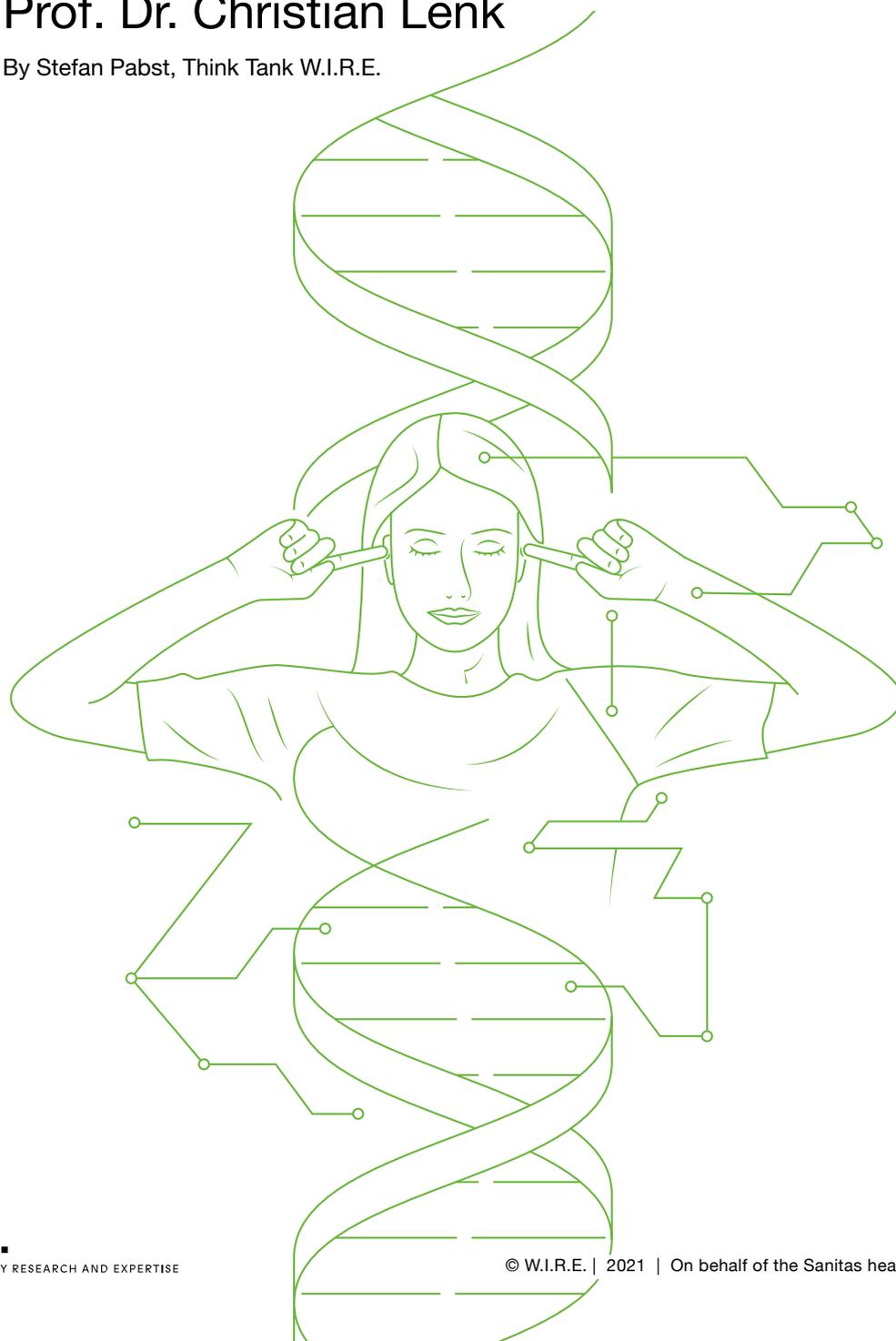


Genetics and big data – the right not to know in the digital age

Interview with **Prof. Dr. Christian Lenk**

By Stefan Pabst, Think Tank W.I.R.E.



The right not to know is laid down by law to ensure that people can refuse information about their genome, for example if they do not want to find out if they have a predisposition to an incurable disease. Professor Christian Lenk from the University of Ulm explains how digitalisation – as driver of the knowledge society – affects the right not to know. In his view, patients will continue to have the right not to know when it comes to genetic testing. He also believes that it provides inspiration for fairer use of digital technologies.

We live in a knowledge society. More and more, knowledge is becoming the basis of social and economic coexistence. What role does this growth in knowledge play in terms of our health?

Knowledge is associated with certain requirements and criteria. It has to be validated, safeguarded and useful. Ultimately, it has to be beneficial to patients. At the same time, we have to consider which person is being confronted with this knowledge. If, for example, young people are given specific information about their genetic predisposition that will affect their lives, this raises questions from the perspective of medical ethics.

What knowledge from genetic testing do you mean and what sort of ethical questions arise?

Take late-onset Huntington's disease, for example, which can be diagnosed using genetic testing. We know that people start displaying symptoms of this untreatable disease between the ages of 60 and 65. Are we doing a 20-year-old a favour if we tell them they are genetically predisposed to suffer from Huntington's? Medical diagnostics also produces forms of knowledge that can make people feel helpless. What good does it do me to know that I have a twenty percent chance of suffering from dementia in 15 years' time? What does this mean for me and others in the healthcare system? We assume that, in some cases, not knowing and having an open mind about the future, is a good thing that every person is entitled to. It allows a certain amount of freedom to make your own plans.

So, knowing more may restrict a person's autonomy?

We have an ideal of the informed citizen in the knowledge society. In order to make an autonomous decision we need a certain amount of knowledge and information at our disposal. But genetic diagnostics put a spotlight on marginal areas, where more knowledge does not make you more informed or better able to make a decision. We know from genetic counselling that this topic really comes into play when people want to start a family, i.e. when a couple wants to know whether they have any predispositions that are likely to be inherited by their offspring. This not only raises questions about the right not to know but also about the obligation to know.

When and why did the debate on the right to know start?

The progress of modern genetics since the 1980s has been a crucial factor in promoting discussion. The notion that people also have a right not to know developed once we had grasped the concept of hereditary predisposition. But initially the question of whether there should be an obligation to know was raised. Whether we should be obliged to know certain things, as we are familiar with in other areas of society. For example, when we open an account, the bank is obliged to inform us of the consequences if we are overdrawn on a regular basis. Why should it be any different in the field of medicine?

Patients must consent to procedures being carried out. Is this consent not a matter of course?

In medical ethics, it is generally assumed that every patient is free to decide whether or not to undergo a diagnostic test, e.g. for hepatitis or HIV. However this means that there is also

a sound claim that patients also have the right not to know. Normally we assume that there is mutual consent between doctor and patient about the nature of tests to be undergone. But in predictive genetic diagnostics, it is also still questionable whether we can assume such consent.

Why is mutual consent not straightforward in genetic diagnostics and how is the right not to know actually put into practice?

Because the aim of medical diagnostics is to establish a clear diagnosis and associated plan for treatment or prevention. An illness that you may suffer from far in the future often does not fulfil these criteria. In practice, patients exercise their right not to know by refusing a test or telling their doctor that they do not want to know the results of a test that has been performed.

What role does solidarity play in the right not to know? Surely the knowledge of a potential hereditary disease must be used in order to lower healthcare costs for everyone?

The question is: how do we classify a single piece of information that we have in the midst of the multitude of pathological predispositions? We have already mentioned neurological diseases, but perhaps I also have an increased risk of heart disease? If we take the whole picture into consideration, how should mankind behave if we are able to document everything? Looking at the bigger picture, I do not believe that the right not to know is ego-tistical; it merely highlights the human condition: the unknown is part of being human. We must try to find ways to deal with this.

You spoke of people's freedom when it comes to decisions affecting their private life, which is also linked to a lack of knowledge. What can you tell us about the right not to know and its relevance in society?

It is linked to our idea of justice. John Rawls' theory of justice, which still has a major impact on our way of thinking today, draws explicitly upon ignorance and not knowing. Under the «veil of ignorance», people should be able to create the right rules for a society without any knowledge of their social status. Not knowing therefore even becomes a prerequisite of the rules of justice.

Discrimination is the opposite of equal or just treatment. The most recent debates on artificial intelligence have always raised the issue of discrimination. How could the right not to know lessen such discrimination?

It has in fact been shown that if you feed self-learning systems with discriminatory information, e.g. gender differences or ethnic origin, they will themselves suggest discriminatory solutions. A recruitment agency is then more likely to recommend a woman for a simple job and a man is more likely to be recommended for a management role. Inequalities are also commonplace with regards to health and medical treatment. We generally believe that patients should receive needs-based treatment and not be treated less favourably, for example, due to their gender or sexual orientation. We must therefore ensure that the algorithms comply with the ethical and legal requirements as envisaged for the respective healthcare system. Here too, the «veil of ignorance» could prove useful in some cases. Specifically, this means that we have to exclude certain information from the systems – with all the chances and limitations for automation that this entails.

In addition to the potential of artificial intelligent algorithms, digitalisation is also synonymous with democratisation and expansion of knowledge. What are the key ethical questions here?

We have a certain idea of what privacy entails: it is part of our culture, governed by law and is meant to protect the individual. The boundaries of privacy are being challenged by some phenomena of digitalisation. These include the collection of and access to information as well as new ways of publication via digital and social media.

Can you put this into a medical context?

Digitalisation is highly relevant in genetics. In the past we weren't able to say anything about individual genetic predisposition. Now we are able to examine the individual genome and genetic data can be stored for future research purposes. Although we still don't know what genes mean for a person in detail, we are trying to find a connection between the occurrence of a disease with the genome by analysing big data. These efforts in medical research might be harbingers of a new situation in which every person, initially those living in industrial nations, will have detailed information about their genetic makeup.

In addition to big data analysis, digitalisation also enables easy documentation of an individual's physical activity. How do you evaluate knowledge gained through self-tracking from a medical ethics perspective?

So-called self-tracking is another challenge, because it is not subject to the conditions that apply in the medical sector. When a patient goes to the doctor with a medical complaint, there are certain medical guidelines on how to determine or diagnose high blood pressure, other risk factors or diseases. However, these often do not correspond with self-tracking methods, which means their medical relevance remains questionable.

Regardless of the quality of the output and recommendations, these tools can have an impact on peoples' lifestyles. To what extent do digital applications have an impact on our freedom to make decisions?

Predictions on our health can really diminish this freedom. Diagnoses and findings from digital tools can make already susceptible people ever bigger hypochondriacs. This can lead to a personal crisis. Many hopes and aspirations are attached to digital applications. People who do not like going to see a doctor, for example, can be motivated by these apps to do something good for their health. This is certainly useful, as we have great health inequalities in our society. People with a poor educational background or low income live, on average, 8–10 years less than people with a good education and higher income.

So the right not to know shouldn't be expanded to include other areas outside of genetic testing?

There are guidelines for medical products in the European Union. Digital tools that offer diagnostic functions are deemed medical products. But this does not apply to lifestyle apps. And if the person is using the application on a voluntary basis, then they can decide not to find something out by not using the app. It only becomes problematic when institutions or companies require their customers to use such tools in order to receive a service.

Digitalisation not only fosters knowledge and information, it can also lead to individuals being completely overloaded by the growing density of information. What can we learn from ethical considerations on the right not to know with regard to how we should cope with the flood of information?

From my point of view, it is correct to say that we live in a knowledge society and that dealing with knowledge is therefore of particular importance. We see this in many areas that

were previously deemed easy to handle and that are becoming increasingly complex. Of course, this development has to be seen in the context of good education and training. People have their own knowledge management and therefore forego information that they find unsettling, incomprehensible or of no use to them. But this knowledge management has a different function to that of the right not to know. It is therefore even more vital that we continue to develop our individual knowledge and information management in the context of digitalisation. This will enable patients to better realise and preserve their own perception of privacy when confronted with the new possibilities of digital medicine.



Professor Christian Lenk is managing director of the Ethics Commission at the University of Ulm. From 2008 to 2011 he was coordinator of the EU project Tiss.EU on genetic research on human cells and tissues, in particular biobanks. From 2002 to 2011 he was a member of the Ethics Commission at the Faculty of Medicine at the University of Göttingen, acting as deputy chairman from 2010 to 2011. In 2016 he was appointed extraordinary professor at the University of Ulm. He is also a guest lecturer in the field of justice in medicine at the University of Mainz. His research interests include topics in medical ethics (enhancement, research ethics, ethics commissions), technology assessment (ethical, legal and social implications) and philosophy (justice, philosophy of science).