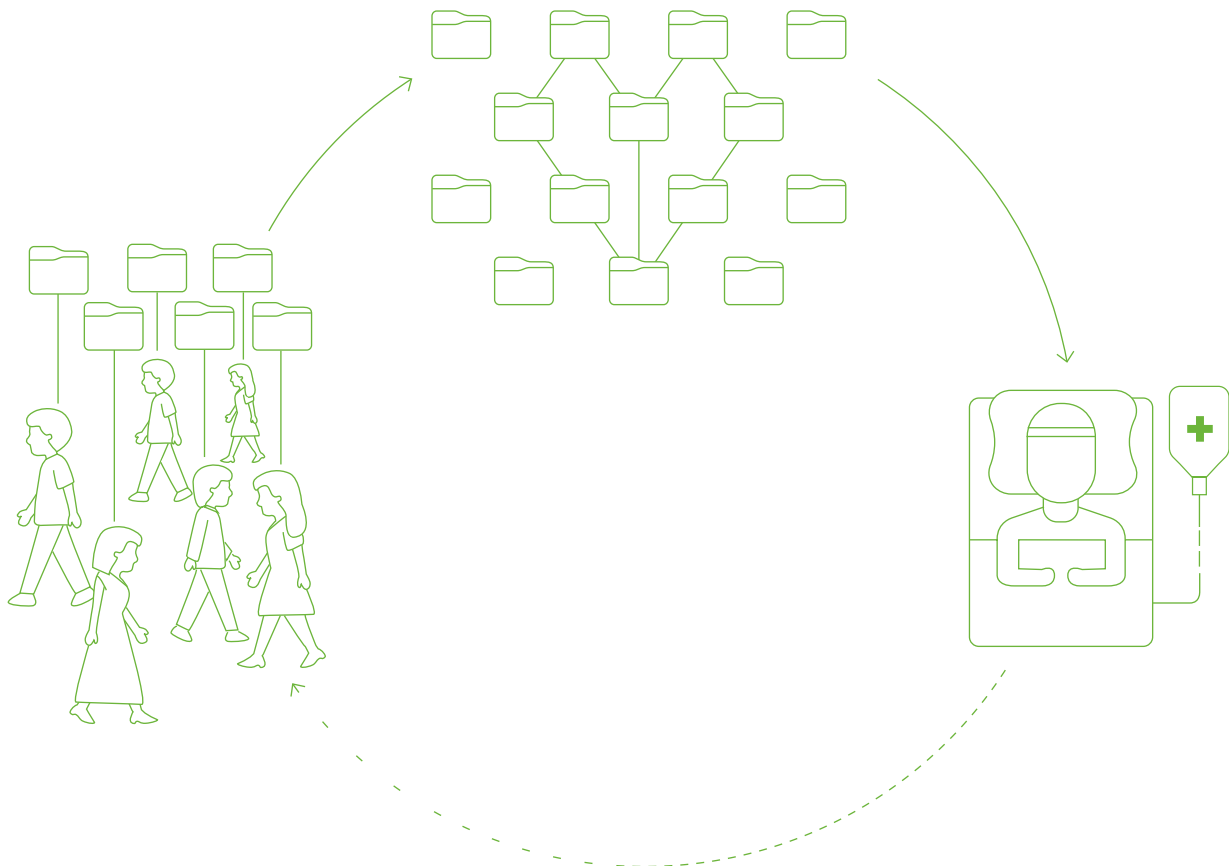


«Solidarity is coming under pressure from the electronic patient record»

Interview with Professor Volker Amelung



In addition to enabling patients and health care professionals to store personal data centrally, the electronic patient record (EPR) also promises to improve efficiency. Professor Volker Amelung explains how this could affect solidarity. On behalf of the Stiftung Münch foundation in Germany, he investigated the differences why the introduction of the patient record is progressing differently throughout Europe. Switzerland is in line with the European average, while the Scandinavian countries are front runners and Slovenia and Ireland are bringing up the rear. Prof. Amelung, the study leader, believes that the difference in progress is due to the different governance structures. He maintains that successful implementation depends, above all, on inspiring leaders – and a little bit of pressure.

Professor Amelung, what are the opportunities and challenges of the electronic patient record (EPR)?

It's fascinating that this question is still being asked. At a time when digitalisation is playing an increasingly important role in the health care sector, a technically feasible application should be a matter of course. Some 10 to 20 years ago, patient data came under the domain of doctors. Today the understanding has changed to the extent that the data must belong to the person they concern: the patient/insured person. However, the data only becomes useful for patients when it improves the treatment itself or the treatment process. The electronic patient record must be more than just a container for data collection, what many wearables in the leisure sector still are today. It must create a link between the professions involved in the treatment process, it must apply algorithms to enable data analysis, and offer considerable added value in terms of time, money and quality for both patients and health professionals.

What are the benefits?

The benefits of the electronic patient record can be simple. For example, when a child is injured at school and you want to find out whether he or she has been vaccinated against tetanus. The EPR can also be useful for people who use it to organise medicines and health care for their elderly parents. However, the data only becomes interesting when it is backed by algorithms.

What does data analysis using algorithms involve?

An algorithm may, for example, identify the extent to which recurrent back pain may have its origin in a mental illness. Or it could detect rare diseases better than a doctor. Some 8,000 rare diseases are known today; in Germany more people are affected by these than patients suffering from cancer and HIV combined. However, because of the sheer number of rare diseases, it is practically impossible for individual, non-specialised doctors to make a correct individual diagnosis within a reasonable period of time. Here, pattern recognition based on algorithms and, in the future, learning systems can provide important assistance.

However, data also poses risks.

It is clear that data can be used to find out much more than patients know themselves. Everyone must decide for themselves how much they want to know and also learn to deal with probabilities in terms of genetic diagnostics. Do I want to know what my chances of getting breast cancer are? Or do I take a more fatalistic approach and decide that I don't want to influence the course of nature.

There's no right or wrong in this case.

Exactly. I always like to quote the American medical ethicist Norman Daniels at this point: "When reasonable people disagree."

How can the EPR help maintain a health care system based on solidarity?

I don't see the EPR as a tool for solidarity, but as one that's used to make existing data available in different places. I would put it another way: The more electronic records I have and the more data analysis is done to determine an individual's insurance risk, the more caution is needed to ensure that solidarity in the health care system doesn't come under pressure.

By using data analysis, we inevitably know more about each individual's state of health. Bad risks can be identified better and in a more targeted manner - and this also increases the risk of discrimination.

Are people aware of this?

I think that many young people aren't aware of the risk they're taking when they receive, for example, an F-diagnosis which indicates a mental disorder. These diagnoses can have serious consequences. For instance, they can make it difficult to be granted civil service status in Germany or stop you from taking out a life or disability insurance. Only in the case of mental disorders is the question asked whether those seeking to be insured have ever had such a diagnosis. With cancer, you're only asked whether you've been affected in the last five years. Some life insurers also want to know whether you've undergone genetic screening. Of course they are entitled to do so. As an insurer I'd also be interested in this issue, but this promotes social differentiation between those who know and those who don't. In an effort to maintain social solidarity, this sort of differentiation must be prevented.

The EPR promises greater efficiency by preventing duplication. Couldn't this increase in efficiency have a positive influence on solidarity?

The problem is that there's not sufficient evidence in support of the electronic patient record. We believe it will increase efficiency, but we cannot be 100% certain.

McKinsey conducted a study¹ to analyse the savings potential of digitalisation in the health care sector. It showed that end-to-end digitalisation would result in a savings volume of 34 billion euros for Germany. End-to-end digitalisation would include the electronic patient record and electronic appointments.

In theory, reducing costs could have a positive impact on solidarity, because aren't people more willing to give when they have to pay less?

Solidarity is an attitude. When serving as Scottish Health Minister, Nicola Sturgeon once said: "We have to take care of each other" - that's a good way of describing solidarity. We need to look out for one another, care for one another: that's solidarity. Healthy people care for the sick, young people for the old, families without children for families with children, and higher income groups for lower income groups. These are the pillars of solidarity in the health care sector. But solidarity also means that many factors should play a role in organ transplants, but money is not one of them. Solidarity means that a cashier in the supermarket has the same chance of getting a new liver as the CEO of a company. Solidarity can be lived on paper or electronically. However, it is also true that, in a health system based on solidarity, everyone should have equal access to a data portal on which their data is stored. The design of the electronic patient record is irrelevant. What's important is that discrimination is prevented. There should be no differences between those who have access to data and those who do not.

1: Digitizing health care – opportunities for Germany: <https://www.mckinsey.com/~/media/McKinsey/Industries/Healthcare%20Systems%20and%20Services/Our%20Insights/Digitizing%20healthcare%20opportunities%20for%20Germany/Digitizing-healthcare-opportunities-for-Germany.ashx>

Thus far, health insurers haven't had access to the data in the electronic patient file. What if this were to change? What impact would that have on solidarity in the health system?

In principle, health insurers should have access to all data as long as they don't discriminate, as long as they are forbidden to discriminate. They would still have to accept all applications; state of health would not be allowed to play a role. But without access to the data of insured persons, health insurers can't develop useful personalized care concepts.

How high is the risk of a data leak? And what would this mean for solidarity?

Of course there is always the risk of a data leak. But I find this fear irrational, because it's clear that data protection standards must be taken into account when implementing the electronic patient file. So, if I were to ask you whether you'd rather have your health record or your bank account hacked, you'd probably opt for your health record. But in the same vein, nobody would prefer to carry out their bank transaction on paper again. We live with a certain risk nowadays. By the way, there's only been one really serious case in which a patient file was stolen: that of Michael Schuhmacher. And that file was paper-based.

To what extent does the EPR increase individual responsibility, and how does this relate to solidarity?

The EPR gives patients many more opportunities to explore how they can take responsibility for their own health developments. And solidarity per se carries the risk of reducing personal responsibility. In other words, the greater the solidarity in a system, the less you're forced to take responsibility for yourself. I personally believe that solidarity involves giving and taking. Purely theoretically, however, an individual in a system of 100% solidarity can let the others pay for him or herself. Solidarity challenges society to think about ways to prevent it from being a one-way street without unduly restricting personal responsibility.

Can't it also work the other way round? Personal responsibility could also help ensure that we don't rest on our laurels and that people show greater solidarity with others, because they realise that the system isn't being exploited.

I believe that the more solidarity there is in a system, the higher the aspirations will be. There's always the risk that the system will be exploited. With digitalisation, the risk is even greater, because people have more access to the system, which increases their expectations. You see this in the differences between cities and the countryside. In cities, people have easier access to health care services, so they tend to use them more. In Switzerland this is reflected in the different regional premiums. Therefore, digitalisation makes a very paternalistic health system model more democratic, because people receive more information, can exchange more information and have greater flexibility.

You've investigated the implementation of the electronic patient record throughout Europe. Why is the implementation not making headway as expected? Does this have anything to do with the different forms of solidarity systems?

Yes, definitely. There is a clear connection: The more centralist the states or their health systems are, the easier it is for them to implement new technologies. The progress of implementation is down to willingness – not due to a lack of money, technologies or data protection. Many centralist states want to achieve something. And they do.

Isn't it a bit simplistic to say that the political structure determines whether the implementation of the EPR is successful or not?²

Of course implementation can also be successful in market economy systems. Kaiser

²: What Ulla Schmidt can learn from the USA (German only): <https://www.welt.de/wirtschaft/article1048804/Was-Ulla-Schmidt-von-den-USA-lernen-kann.html>

Permanente in California – a health organisation that offers end-to-end service: health insurer, hospital operator and pharmacy – is an excellent example. There has to be always someone who wants to make it happen. This can be an organisation or the state.

And how does this relate to the various systems of solidarity?

It's not solidarity that's the key issue here, but governance structures. Switzerland has 26 health laws, which of course makes the implementation more complicated. What's more, Switzerland is a rich country.

What role does wealth play?

Countries with sufficient financial resources tend to be less willing to change their health care systems. A Swiss physician in private practice has little interest in introducing the electronic patient record. For this doctor, maintaining the status quo is the first-best solution. He has little interest in digitalisation unless it comes with immediate benefits. And the EPR poses much more risks for individual physicians, involves more effort and delivers only marginal benefits.

What risks?

Because the EPR enables doctors' diagnoses to be checked more thoroughly. There is greater transparency. And that is not necessarily in everyone's interest. For this reason, the EPR would only prevail in Switzerland if it were mandatory, if the EPR were made a prerequisite for being able to bill certain health insurers. It is naive to believe that doctors will be happy about it unless it leads to noticeable time savings. Ultimately, the EPR promises to provide more information about patients. And knowing more also means more work for doctors, because they can hardly ignore the information when they have to make decisions.

What legislative requirements does the EPR need and what are the obstacles to its introduction?

It needs some enforcement, deadlines and transparency in terms of finances. Above all, however, it needs strong and persuasive leadership. I can tell you what's definitely not missing: money. This applies to Switzerland too. In Germany, the statutory health insurance funds have been making millions in profits for years, the money is available. According to the Federal Ministry of Health, its financial buffer is still around 21 billion euros.

Do we have the technology that would be needed?

Yes, and countries like Germany and Switzerland don't need their own solutions. They could take their lead from countries such as Denmark or Israel or institutions such as Kaiser Permanente who are already using suitable technologies. And a final thought: What's needed is not just a health record, but rather a citizen record that brings together the various areas such as health, taxes, education and fines. It makes no sense to have health data, information on your child's day care centre or tax returns stored half-heartedly in different places. Estonia, for example, is exemplary in this matter. Here you can do everything digitally except divorce or buy a house.

How can solidarity be maintained in such a system?

It's simple. It shouldn't be put up for discussion. Solidarity must remain the basis as it's always been. Solidarity is an issue that simply cannot be tampered with. Full stop.



Volker Amelung is professor for International Health Systems Research at Hannover Medical School. He is also Chairman of the German Managed Care Association (BMC), a pluralistic association aimed at driving innovation in the German health care system to deliver sustainable, quality-assured and patient-oriented care. On behalf of the Stiftung Münch foundation, he and his team conducted a study on the electronic patient record. The results were published in 2018. Born in Appenzell, Professor Amelung did his Abitur (A-levels) in Hamburg before studying Business Administration at the University of St. Gallen.