“We need a balance between promoting people’s health and freedom of choice.”

Interview with Barbara Prainsack

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The medicine of the future will focus on personalised health with the aim of catering to the predispositions and particularities of individual patients. This will be done on the basis of genetic research, but also the increasingly seamless analysis of digitally recorded daily data. In this interview, Barbara Prainsack, a political scientist specialising in medicine and ethics, explains why this personalisation doesn't have to pose a risk for solidarity with regard to public health. What is uncertain according to Prainsack is whether all patients can really afford human support for this machine-based personalisation.

Professor Prainsack, everyone seems to be talking about personalised medicine. But what's really new about this concept? After all, traditional family doctors have always taken the individual characteristics of their patients into account.
That's true, but the data that feeds into personalisation has changed. In the past, doctors had to speak with their patients to find out which medicines they didn't tolerate. This knowledge was also taken into account in determining the diagnosis and deciding on the treatment. However, unlike today, this personalised knowledge wasn't linked with other data. When the doctor died, the knowledge often disappeared, too. Today, information is highly data-based, which means it can therefore be stored and passed on. Nowadays molecular markers, information from health records, family histories, and lifestyle and environment data are used to personalise diagnoses, treatment and preventive care.

The origins of modern personalised medicine can be found in genetic research. The term "individual medicine" is also often used – how do the terms differ?
The concept of "personalised medicine" became popular in Europe in the wake of the international human genome project, which took place from the 1990s to the early 2000s with the aim of fully describing and analysing the human genome. On conclusion of this project, which was backed by considerable public and private funding, there was major pressure to translate the newly acquired knowledge into specific benefits for patients. Genetic markers of groups of people were to be used to predict drug efficacy, which is also known as pharmacogenetics. So far, this research has mainly been applied to oncology.

What is meant by "groups of people" here?
Groups were formed on the basis of ethnic or racial categories. For example, a heart drug for African Americans was approved in the USA in 2004. Of course, not every individual who is part of this group was tested individually to see which drugs worked on the basis of the markers. Instead, group criteria were used. This medicine was known as "race-based medicine", so it's no wonder that many researchers felt more comfortable with the term "personalised medicine".

In the UK the term "stratified medicine" is more commonly used. Why is that?
This term was originally intended to distinguish it from the hyperbolic concept of "precision medicine", which is widely used in the USA and which many people say arouses false expectations. Those who use the term stratified medicine want to emphasise that, at least in routine medicine, it is not usually about individual solutions. Instead, the aim is to classify people into different groups on the basis of family risk, age, lifestyle or the molecular characteristics of their tumour. These groups then receive a specific type of screening, diagnosis or treatment. Stratified medicine isn't all that new either. Medicine has always been applied differently based on sex and age, for example. Even family doctors have never had a one-size-fits-all approach.

Today, medicine and health are often used synonymously, which leads to the term "personalised health". And that's OK?
It stems from the fact that we tend to focus more on prevention. Prevention not only helps save lives but also cuts healthcare costs. The boundaries between health and illness are becoming increasingly blurred, particularly with regard to more data-intensive surveillance medicine. The term "surveillance medicine" conjures up images of Big Brother, but it actually refers to a branch of medicine that observes a person's lifestyle and exercise regime not only when they have acute health problems, but also when they're healthy. Personalised health is therefore not just about treating existing illnesses, but also about keeping people healthy through preventive care.

What kind of sensors should be used for this preventive observation of healthy people? Fitbit devices that people attach themselves – or widespread cameras and temperature gauges installed in public spaces or offices?
That depends on where people live and what programmes they participate in. In some countries, private health insurance companies give discounts to customers who are willing to have their daily steps counted or their sleep recorded by "smart" phones or watches. However, visionaries of personalised health have also mooted the idea of tiny sensors that can monitor blood values, for example, inside the body.

Does personalised health tend to highlight differences or similarities between patients?
Differences. For example, if two people go to the doctor with abdominal pain, a 20-year-old woman will be treated differently from a 70-year-old man. The woman's symptoms, for example, could be associated with pregnancy. This is an example of stratification, albeit a very general one based on broad-ranging criteria. Stratification has, of course, been fine-tuned over time.

In Western societies, categories such as sex, ancestry and skin colour are supposed to play less and less of a role when it comes to job applications or judicial and administrative procedures. However, these categories are very important when it comes to personalised health. Is this a good idea?
But there's a fundamental difference! The labour market rightly tries to make these categories invisible because they are in no way connected to performance. Muslims, Christians and Jews can deliver the same performance regardless of whether they are men or women and regardless of their religion. By contrast, the categories used in personalised medicine have a proven or at least a suspected functional connection. Discrimination must, of course, also always be objectively justified in medicine.

How do you mean?
No one would say it is unacceptable gender discrimination because only women are invited for breast cancer screening. Of course men can also get breast cancer, but screening is about major risk groups. The same applies to certain family clusters.

Like with the actress Angelina Jolie, whose family passes on a pathogenic gene variant that increases the probability of developing breast and ovarian cancer?
Yes, Angelina Jolie is a classic example. However, it's not only individual families that are affected by specific disease risks, but also entire population groups, provided that certain characteristics are more frequent among the common ancestors. Members of these groups can then undergo more frequent preventive medical check-ups in order to detect possible illnesses at an early stage. Preventive testing for Beta thalassemia on Cyprus (editor's note: a congenital, chronic disease of the red blood pigment that causes anaemia) is one such example, because this disease is particularly common among the islanders.

However, collective attributions like this can also be problematic and marked by prejudice.
Attributions of ethnic characteristics can of course also be racially motivated, but there are many contexts in the field of medicine where this is not the case. Attributions must never be understood in social terms. There is no gene that makes people black, white, Basque or Icelandic. Personalised medicine is actually about genetic proximity. The more common ancestors people share, the greater the likelihood that they will have characteristics that occurred frequently among these ancestors. This may be eye colour or, unfortunately, a risk of illness.

To what extent can such knowledge limit the rights of individuals, such as the right not to know? Do you have to get checked out if you belong to the risk group?
This is a legal and ethical question, which most legal systems – and most ethicists – answer with no. Of course you have the right not to know; you can refuse diagnostic and even predictive tests if you prefer not to know the results. However, there is debate about the right answer to this question when this knowledge can save lives – the life of the person affected or the lives of others.

The next step after a preventive examination is personalised treatment. Will all patients really have access to innovative personalised therapy? That will be expensive.
Yes, that really is a sticking point. Today we are able to diagnose far more illnesses than before, and naturally these tests are expensive. And sometimes they have to be paid for privately. It's the analysis of the test results that's particularly expensive. If we're not careful, we'll be in danger of heading towards a future in which only the wealthiest people will have access to the full range of high tech, high touch and thus personalised care in every phase of life. High touch medicine is areas of medicine that require a lot of time and human contact. Wealthy people can benefit from personalised medical care from birth: their genome profile can be recorded, blood tests done and various analyses carried out on their profile. For this 1% of people, problems can be detected before they have serious consequences.

And the other 99%?
For most people, many processes – with the exception of acute care – will become more digital and automated because it is cheaper. In the USA and China, for example, we're already seeing more and more analyses and diagnoses being carried out with digital tools. Diagnostic recommendations are made online by therapy assistants with the help of algorithms, and merely approved by doctors. These processes could be described as "low touch". This is a vision that I certainly don't share.

In the future, will access to specific health services also be linked to a person's willingness to use certain technologies and share their data? If so, how can we prevent the risk of discrimination?
To a certain extent, this socio-economic discrimination already exists. For example, you may not be able to use specific services because you don't have a smartphone or an email account. This affects older people in particular. This form of discrimination is likely to continue to increase – and we need to take action against it.

What can be done?
Above all, it's important that in future people who have a medical concern can easily get in touch with a person who can help and that they're not fobbed off with a bot or symptom tracker. At the very least, if someone wants access to people, this must be guaranteed. Some people prefer not to have this personal contact and are happy talking to a bot if their

problem isn't acute. It goes without saying that care is expensive, but I want to see communicative medicine being expanded, not eroded. And it should be valued more highly and recompensed accordingly. However, patients don't always need to consult a doctor.

How should personalised healthcare for the general population be funded?
We have to make savings in areas where too much is spent on unnecessary diagnosis, therapy and treatment. There are also savings to be made towards the end of our life. Don't misunderstand me: I'm not recommending age-based euthanasia, which unfortunately crops up as a suggestion from time to time. However, if we consider that many people prefer to die at home but are still spending their final days, weeks and sometimes even months in hospital, then there are probably savings to be made here without harming anyone. At the end of our life, we need better and more personalised care. We need to be free to choose how we want to spend our final weeks or days.

But won't that be expensive – especially in view of demographic developments?
The older people get, the more needs to be spent on healthcare. We've seen what's possible recently during the coronavirus crisis, with money suddenly being found for things that were previously considered unaffordable. Prior to coronavirus, breaking even was almost a moral fetish – anyone who claims today that a good healthcare system will soon be unaffordable is making a political statement, not an economic one.

What impact will personalised medicine have on solidarity in the context of health and insurance?
It certainly won't bring about the end of solidarity. Why should it?

Because different risks and different treatment approaches exist for different population groups? Caucasian women, for example, might be less willing to pay for preventive check-ups that only benefit Asian men?
Applying the same logic, you could say that people who have healthy children are less willing to pay for medicines for children with cancer – and fortunately, that isn't the case.

Or because the risk becomes more calculable?
The fact is: in the public health sector, it's always been common knowledge that people incur different costs. And yet people don't pay into the system according to their risks, but according to their income or, as in Switzerland, with a fixed head premium per premium region. In return, you get the care you need when you need it. In other words: differences in risk are deliberately left aside – in contrast to the private health sector, where people with higher risks are excluded from certain services or pay higher premiums. Personalised medicine does not alter this basic principle.

So you believe that the solidarity community should be responsible for the personalised treatment of patients?
If we still want to have a public health service, then yes. There's no reason why people who have a tumour with specific molecular characteristics should pay more than those with a tumour with other molecular characteristics. People have different risk profiles.

However, a person's health or illness can be better controlled through personalised medicine. Will this control also be compulsory?
It's a good idea for people to live healthily and take responsibility for their health. However, it would do more harm than good if people were frightened every time they ate a piece of chocolate cake or had a glass of wine because this increases their risk of getting overweight or cancer. We need a balance between promoting people's health and freedom of choice. We certainly mustn't force anybody to take preventive measures; that would be against their human rights.

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