

# ARE SMARTWATCHES ERODING SOLIDARITY?

Scenarios for a data-driven healthcare system

*by Jakub Samochowiec & Andreas Müller*



## Imprint

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# Preface

The achievements of digitalisation have become part of all of our lives. Measuring and comparing health and lifestyle is easy and has become more and more common. This sometimes has an impact not only on the attitudes of individuals. Particularly with regard to healthcare, the debate on fundamental issues such as solidarity has intensified in society. The Sanitas Health Insurance Foundation promotes discussion about the effects of digitalisation on cohesion in society and in solidary insurance communities.

New technologies promise highly specialised, tailored medicine and novel possibilities in prevention. Is it self-evident that the costs of such opportunities are borne by the general public? And is it up to the individual to use insights from their own and shared health data for healthy, low-risk behaviour, or is there something like a moral obligation towards society to work on one's own health? Our current experience with the COVID-19 pandemic also shows the explosive nature of such questions.

With the aim of providing food for thought on what a future healthcare system in a modern datafied society might look like and how important solidarity is in this context, the Sanitas Health Insurance Foundation has commissioned the Gottlieb Duttweiler Institute to develop future scenarios addressing these issues. The present study "Are smartwatches eroding solidarity? Scenarios for a data-driven healthcare system?" aims to stimulate reflection on what a future healthcare system could look like and which aspects from the individual scenarios would be desirable, which ones will be unavoidable and which ones will be necessary.

We look forward to broad discussion, because all stakeholders are called upon to help shape an innovative, sustainable healthcare system that takes into account socially balanced concepts of solidarity.

Prof. Dr. med. Felix Gutzwiller  
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*Sanitas Health Insurance Foundation*

# Summary

## Scenarios

Gene sequencing, pedometers, smart blood pressure monitors – our health is increasingly translated into numbers. This datafication not only promises better prognoses of health trajectories, it also enables more control of behaviour. But how does this new transparency affect the solidarity principle of healthcare, i.e. the principle according to which the contribution payments of individuals are not made dependent on their state of health or behaviour? This is not a question of technology alone, but also of social decisions. What conditions does a society impose on individuals to be allowed to benefit from this solidarity? If these conditions are strict, the new health data are likely to be used for control: Are people behaving properly? If, on the other hand, solidarity conditions are designed to be tolerant, health data are more likely to be used to enable individuals to lead lives that are as healthy as possible. The study outlines four extreme scenarios along two axes: the “conditions of solidarity” (strict or tolerant) and the “role of government” (minor or major).

The Big Government scenario describes a strong government with strict conditions for solidary support. People have to share their health data and are urged to adopt healthy behaviours. In the Big Self scenario, the aim is to empower individuals without patronising them. Although government also plays an important role, it limits itself to regulating the use of data and facilitating healthy behaviour. In the Big Business scenario, on the other hand, people with similar health profiles join together in risk pools. These risk pools require the disclosure of data in order to exclude unfavourable risks. The disclosure of data is also central in the fourth scenario, the Big Community scenario. Here, this is done out of voluntary solidarity, however: Individuals share their data without demanding “healthy” behaviour from others. Rather, the diversity of the data is seen here as a strength that enriches the data model, making it more robust.

Although the four scenarios are set in the future, the underlying logic can be illustrated by how the COVID-19 pandemic is handled. For example, governmental control as in the Big Government scenario manifests itself in mask and certificate mandates. In contrast, the demand that unvaccinated people should pay for their own hospital treatment reflects the logic of the Big Business scenario. Measures that correspond to the Big Self scenario are informational campaigns or contact tracing apps that do not store data centrally. The Big Community scenario, in turn, finds its counterpart in the demand to release patients for COVID vaccines.

## Control and solidarity

The current Swiss healthcare system is close to the Big Self scenario, in which the government wants to support and empower the individual. However, datafication acts as a catalyst and can cause shifts in the balance between much and little governmental influence as well as between strict and tolerant conditions for solidarity. For example, the mere existence of the digital control possibilities could tempt people to formulate stricter conditions.

It is true that simple rules can facilitate collective behaviour and thus strengthen solidarity. Even so, if the rules are unnecessary in the first place and/or too complex, they will lead to disenfranchising

micro-management. Tolerant conditions for solidarity and less control in turn have an empowering effect. They give people the resources to take care of their health and act in solidarity with each other. There is a danger, however, that conditions for solidarity that are too tolerant will lead to misuse, ultimately resulting in a collapse of the solidary system.

Rules that are too strict can disempower people, while rules that are too lax can result in misuse or even chaos. So what is the right degree of conditions for solidarity? On the one hand, there are examples of people overestimating the need for control: Contrary to the cliché, aid money is not “boozed away” in most cases. Healthcare organisations can function efficiently and to everyone’s satisfaction without having to meticulously record every step of their work.

On the other hand, the right degree of control is not a fixed value that one only needs to find. The right degree of control is somewhat malleable. Individuals can be empowered to handle health data. Instead of external control, individuals can control themselves. They use data to check whether they are getting closer to their health goals. In addition, institutions can be established that promote trust and consequently also facilitate the sharing of data. This requires that the government and organisations themselves are willing to share data openly.

Technologies do not dictate how they should be used. This is why society needs to discuss the direction in which the datafied healthcare system should develop. This study and the scenarios described in it are intended to help lead this discussion, throw light on implicit assumptions and put trends and demands in a larger context.



# The datafication of health

Sending saliva samples for genome analysis. Predicting fertility cycles using an app. And maybe soon having a smart toilet<sup>1</sup> examine your intestinal flora? We are recording more and more aspects of our health and the relevant influencing variables digitally and in real time. The promise: more data, and especially its confluence, will create comprehensive and detailed digital models of health and uncover previously unknown correlations. This would allow for more efficiency and effectiveness in therapy and prevention with personalised medicine and precise public health interventions. It would be possible to compile dietary plans based on genetic make-up, individually and situationally adapt the selection and dosage of medications, and target vulnerable groups more specifically with preventive interventions.

For this study, it is not decisive which specific medical applications will be possible, when exactly, by means of which data. Rather, two fundamental aspects of a datafied healthcare system are relevant below:

1. the ability to *predict* health trajectories and provide early warning of disease.
2. the ability to record the behaviour of individuals, healthcare providers, the government or other actors in the healthcare system more accurately and in real time, and therefore to better *control* it.

## Prediction

Certain gene mutations (called BRCA1 and BRCA2) increase the risk of developing breast cancer, while noise exposure increases the risk of cardiovascular disease and an unhealthy diet can lead to diabetes. However, a certain gene or certain environmental influences do not have the same health effects in all people. More comprehensive data models promise to identify more complex relationships between genetics, physiology, behaviour and the environment and thus predict health trajectories more accurately. In the short term, this can be used, for example, to predict the effect of medication. Or in the long term, for example, to warn people that the combination of their predisposition, their environment and their lifestyle can lead to cancer.

## Control

The ability to make predictions is complemented by the ability to control. With the help of “wearables”, i.e. portable sensors (fitness trackers, smartwatches, smart socks), it is possible, for example, to measure how much people sleep, move, what their pulse is, etc. In the future, the number of sensors on and in the body will increase – more and more aspects of our health will be converted into numbers in real time.

Already today, some health insurance companies offer their customers reduced premiums on supplementary insurance options if they walk a

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<sup>1</sup> <https://bit.ly/soli-klo> (source: med.stanford.edu; retrieved: 27 October 2021)

specified minimum number of steps every day. People with chronic diseases (e.g. type 2 diabetes) can get life insurance thanks to a healthy lifestyle, which would not be available to them otherwise.<sup>2</sup> The prerequisite is that the healthy behaviours are digitally recorded and the data is shared with the insurance companies.

More sensors also allow more environmental variables relevant to health to be recorded in real time. For example, residents of Barcelona have used networked noise sensors to precisely record the noise pollution in some parts of the city.<sup>3</sup> Such data can be used in interaction with authorities and can be combined with specific verifiable demands.

The key question we want to explore in this study is how this fine-resolution, real-time picture and the accompanying possibilities for prediction and control are changing our healthcare system that is based on solidarity. We will lay out four extreme scenarios for this and derive implications for solidarity from them. These scenarios are based on literature research, interviews with experts and workshops. The text features the quotations from the interviews conducted, which can serve to underline an argument or also to introduce a contrary position. Before we turn to the scenarios, let us first take a closer look at the concept of solidarity.

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<sup>2</sup> <https://bit.ly/soli-blue> (source: bluezoneinsurance.co.uk; retrieved: 27 October 2021)

<sup>3</sup> <https://bit.ly/soli-maps> (source: actionproject.eu; retrieved: 27 October 2021)



# Solidarity

The Swiss healthcare system is designed as a social insurance system based on solidarity – the principle of solidarity is enshrined in law (see e.g. Art. 41 (2) BV [Swiss Federal Constitution] or Art. 1a KVG [Swiss Federal Health Insurance Act]). This means that health insurance premiums or access to medical care do not depend on health status or behaviour. Everyone should be treated as equally as possible and should be supported by society when they fall ill.

The abstract concept of solidarity has played an important role in the context of the COVID-19 pandemic and the discussion about masks, vaccinations and intensive care beds. Nevertheless, defining the concept is not easy. In the field of bioethics, the definition by Prainsack and Buyx is particularly influential:<sup>4</sup>

*Solidarity is an enacted commitment to carry 'costs' (financial, social, emotional or otherwise) to assist others with whom a person or persons recognise similarity in a relevant respect.*

It is important to note that, in this definition, solidarity is not simply a feeling, but manifests itself in the provision of assistance, which may entail costs. The definition also addresses the aspect of similarity. This can refer to a shared illness, to a shared nationality or also to a shared humanity and therefore does not necessarily have to exclude anyone.

In healthcare, we distinguish between four different types of solidarity for the purposes of this study:

- > *Financial solidarity*: the willingness to share the costs of illness incurred by others, for example through health insurance premiums that are not dependent on one's health.
- > *Behavioural solidarity*: organ and blood donations, vaccinations, foregoing expensive but non-urgent examinations or the hasty use of antibiotics, etc. Healthy behaviour can also be seen as an act of solidarity towards society, which would otherwise need to bear the healthcare costs.
- > *Data solidarity*: sharing data for research, public health interventions or within patient groups.

*Monitoring solidarity*: examination of one's own health data in order to address one's own health and health risks in an informed and responsible manner (among other things as these are borne by the general public).

Solidarity can manifest itself on three levels.<sup>3</sup> On the *individual* level, someone voluntarily assumes costs (financial, time-related, emotional or other) to support others, for example by donating blood. On the *group level*, certain acts of solidarity constitute a group standard, for example when people with a certain medical condition share their health data with each other. On the *legal* level, solidarity is institutionalised,

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<sup>4</sup> Prainsack, B., & Buyx, A. (2017). Solidarity in biomedicine and beyond (Vol. 33). Cambridge University Press.

for example in the case of the Swiss basic health insurance. In this system, solidarity in the form of premium payments is mandatory and is penalised in case of non-compliance.<sup>5</sup> On the group and legal levels, individuals are subjects and objects of solidarity at the same time. You can have a say in who should be helped and when, and at the same time receive solidary help yourself.

*We would lose a lot if we were to link solidarity to voluntary action only.*

Luca Chiapperino, Lecturer in Science and Technology Studies,  
University of Lausanne

In particular on a legally institutionalised level, where solidarity is mandatory to a certain extent, the question arises as to who should bear costs for whom. Should A act in solidarity with B and pay their medical expenses? Or should B act in solidarity with A and make an effort not to incur medical expenses?

The different types of solidarity can therefore be in competition with each other. With more behavioural or data solidarity, less financial solidarity may be needed and vice versa. The different demands on solidarity and the benefits and costs of the individual types of solidarity must be weighed against each other, which is done in different ways in the scenarios following later.

*You should not expect behavioural solidarity for public health services. Those who do not want to share their data should also not be placed at a disadvantage. Especially not as far as primary care is concerned.*

Prof. Barbara Prainsack, political scientist,  
University of Vienna

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<sup>5</sup> The authors Prainsack and Buyx argue that even legally prescribed solidarity can be called solidarity if group standards that already existed before are put into law. Moreover, in liberal democracies you can also have a say in what rules we impose on ourselves, which makes them voluntary on a societal level.

# Datafication and solidarity

How do you rate the following statement? People who keep fit and eat healthily should pay less health insurance premiums than others.

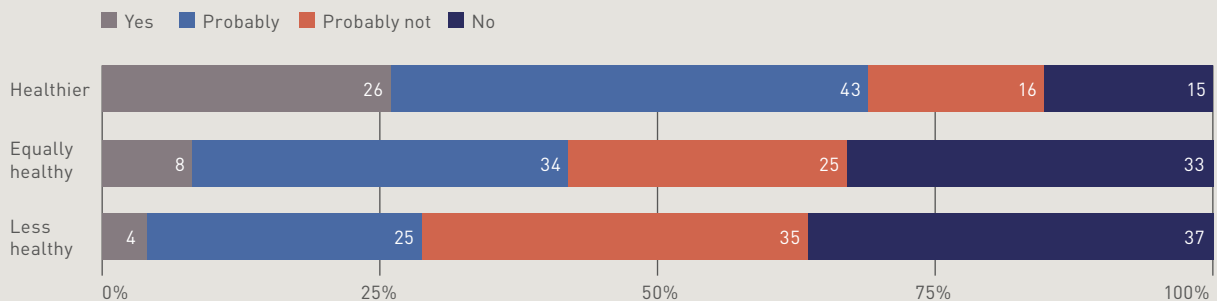


Figure 1: Support for behaviour-based health insurance premiums depending on the assessment of one's own health.  
Source: "Monitor Datengesellschaft und Solidarität 2021" Sotomo

What does the datafication of health with its possibilities of prediction and control mean for the solidarity on which many healthcare systems are based? We want to present three different assertions to clarify this. Each assertion predicts a form of erosion of solidarity, which we will then set against counter-arguments.

## Arguments for and against the erosion of solidarity

### The veil of ignorance

In his thought experiment of the "veil of ignorance", philosopher John Rawls<sup>6</sup> argues that a just world can only be created if its designers do not yet know what role they will play in it. Are they born into a rich or a poor family? As a man or a woman? In good health or struggling with health problems throughout life? Once you hold a position in society, personal interest

gets in the way of the intention to create a world that is as fair as possible for all. Applied to the topic of health, this would mean: The more predictable health gets, the less people will be interested in creating an equitable healthcare system. This fits in with the fact that, in the survey "Datengesellschaft und Solidarität" [Data Society and Solidarity] commissioned by the Sanitas Foundation<sup>7</sup>, those who describe themselves as rather healthy are more in favour of making health insurance premiums dependent on lifestyle (see Figure 1).

<sup>6</sup> Rawls, J. (1978). A theory of justice. University Press.

<sup>7</sup> <https://bit.ly/soli-umfragen> (source: sanitas.com; retrieved: 27 October 2021)

Those who use the “veil of ignorance” to argue that better predictions necessarily undermine solidarity are implying that solidarity cannot be free of self-interest.

As long as you do not know the future, solidarity-based rules are also potentially self-serving. They could be applied to one’s own person. However, if you know, on the basis of better predictions, that certain rules will never be relevant for yourself, solidarity and self-interest are in conflict. Solidarity is at least limited by self-interest.

This is certainly often the case, but it does not have to be. In the healthcare sector, it is already possible today to make certain predictions regarding costs. For example, women incur more costs than men. Nevertheless, this does not manifest itself in different premiums for basic insurance. Unvaccinated people get the same access to healthcare. This list could be expanded infinitely. At least in the case of basic insurance, the people of Switzerland have democratically agreed (in the referendum on the Health Insurance Act 1994) not to take these factors into account precisely because it would jeopardise the principle of solidarity. Such political decisions in the interest of solidarity can also be made when forecasts become even more accurate.

### Culpability

The better it will be possible to predict the trajectory of a person’s health, the less illness will be seen as strokes of fate. Rather, they will become incidents that could have been prevented. It would then be possible to blame people for illnesses that have been predicted. The same would apply to parents who may have accepted a genetic predisposition for a disease. Since hardly any disease is due to genetic predisposition only, however, it is always possible to blame the ill persons themselves. They could have dealt with their health prognosis and may even have been explicitly warned.

It can be controlled whether someone heeds a warning about health risks or not. For example, are everyday habits changed and does the pedometer now register more steps? If this is not the case, assigning blame is even easier. It is someone’s own fault if they were warned about an illness and even then demonstrably did nothing about it. Since these persons seem to be deliberately imposing costs on the general public, unhealthy behaviour could also be described as lacking solidarity. Some might ask why they should still act in solidarity with such persons. Accordingly, those respondents to the survey “Datengesellschaft und Solidarität”<sup>7</sup> who perceive unhealthy behaviour as lacking solidarity are also more likely to support behaviour-based premiums (see Figure 2).

There are two counter-arguments to the argument of culpability. One of them is that already stated in the context of the “veil of ignorance”: Smokers, overweight people or anti-vaxxers could likewise be blamed for resulting diseases. Despite this, we as a society have decided not to treat these groups differently with regard to basic insurance or not to exclude them

A person eats an unhealthy diet and exercises too little. This puts them at increased risk for cardiovascular risk of cardiovascular disease. Is this person acting in a lack of solidarity because he or she is risking high health costs for the general public?

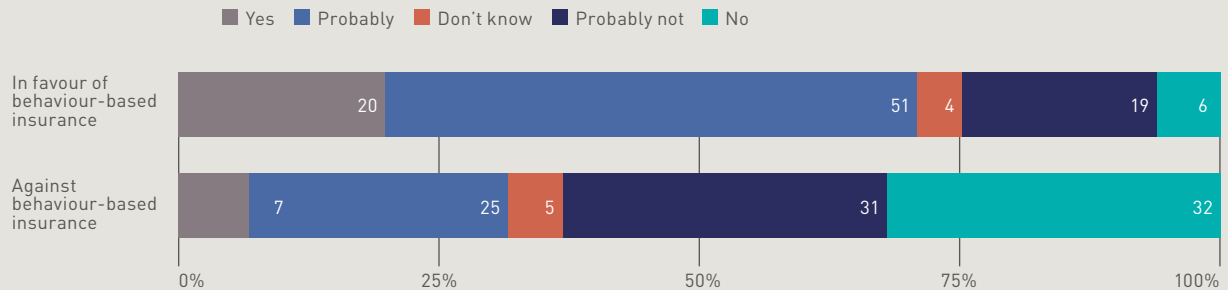


Figure 2: Assessment of unhealthy behaviour as lacking solidarity depending on the approval of behaviour-based premiums.  
Source: "Monitor Datengesellschaft und Solidarität" Sotomo

as recipients of organ donations. Social solidarity thus seems to endure any (apparent) personal culpability.

*The assertion that datafication causes culpability is not an inevitable future, but a dangerous political agenda.*

Prof. Barbara Prainsack, political scientist, University of Vienna

On the other hand, predictions also call personal culpability into question. This is because culpability requires behaviour that arises out of free will. But is will free if it can be predicted? In particular when predictions are based on factors such as place of residence, the relationship with one's parents, blood glucose levels, sleep quality, social inclusion, head injuries, socioeconomic status, dopamine D4 receptor gene variants, stress and glucocorticoid levels, MAO-A gene variants, individualistic or collectivistic culture, toxoplasma in the brain, traces of lead in drinking water, etc.,<sup>8</sup> i.e. things over which individuals only have a very limited degree of control. If behaviour is influenced by all of these factors and can be partially predicted by them, this calls personal culpability into question.

Precise datafication can show that even NCDs (non-communicable diseases) are socially transmitted. Individuals living in an environment where obesity is prevalent are also more likely to become overweight themselves.<sup>9</sup> Unhealthy lifestyles can thus be seen as just as contagious as the flu, losing the stigma of culpability.

*By not focussing on personal responsibility alone, health policy programmes could aim at changing social structures rather than retribution for individual behaviour.*

Luca Chiapperino, Lecturer in Science and Technology Studies, University of Lausanne

The more precisely a behaviour can be explained, the less room there is for personal culpability. In former times, for lack of a better understanding, even epileptic seizures were once interpreted as an expression of evil and possession by demons.<sup>10</sup> With a more accurate

<sup>8</sup> Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin.

<sup>9</sup> Christakis, N. A., & Fowler, J. H. (2007). The spread of obesity in a large social network over 32 years. *New England journal of medicine*, 357(4), 370-379.

understanding as a disease also came increased solidarity with those affected by it. A similar development has happened with regard to addictions, which are now considered diseases thanks to a more precise understanding, weakening the moralising component of culpability. Advances in statistics and probability theory in the 19th and 20th centuries made it possible to identify regularities in certain diseases. This has resulted in a situation where responsibility was no longer sought only in the individual and social insurance schemes were created in many European countries.<sup>11</sup> Here, quantification has led to the establishment of solidary institutions rather than to their erosion.

### Social cohesion

According to the definition (see page x), a perception of (relevant) similarity is a prerequisite for solidarity. In his book “Die granulare Gesellschaft” [The Granular Society], Christoph Kucklick<sup>12</sup> describes how digitalisation is affecting bodies, social relationships, nature, politics, the economy, etc. in finer detail, with higher resolution and more pervasively than ever before. This new resolution then brings out previously hidden differences between people and leads to a crisis of equality. This would mean that digitalisation not only undermines solidarity in the healthcare sector, but also the cohesion of society as a whole.

In contrast to this, sociologist Emile Durkheim already describes how organic solidarity in modern societies does not arise from equality, but from specialisation and division of labour and the resulting interdependencies.<sup>13</sup> In European countries, it can also be observed that the degree of individualism positively correlates with support for the welfare state, trust in strangers and actual assistance to strangers.<sup>14,15</sup>

What is more detrimental to social cohesion is polarisation. Rich vs. poor, urban vs. rural, vaccinated vs. unvaccinated, etc. It has a dividing effect when several such trenches increasingly overlap, as is the case in the United States, for example. Most members of ethnic minorities, a majority of the urban population, most non-Christians associate with the Democrats. The opposite is true of the Republicans. This polarisation leads to all issues being aligned with this dividing line in the culture war, including attitudes towards COVID-19 vaccination.<sup>16</sup>

In Switzerland, cohesion definitely exists, despite or precisely because of a great deal of heterogeneity.<sup>17</sup> According to political geographer Michael Hermann, the reason for this is that the different opposites do not run along the same lines.<sup>18</sup> The line of separation between languages is not the same as the line between Protestants and Catholics or between urban and rural areas.

<sup>10</sup> Pierce, J. M. S. (2002). A disease once sacred. A history of the medical understanding of epilepsy. *Brain*, 125(2), 441-442.

<sup>11</sup> Ewald, F. (1993). *Der Vorsorgestaat*: Edition Suhrkamp.

<sup>12</sup> Kucklick, C. (2014). *Die granulare Gesellschaft: wie das Digitale unsere Wirklichkeit auflöst*. Ullstein Ebooks.

<sup>13</sup> Durkheim, E. (1911). *De la division du travail social*. F. Alcan.

<sup>14</sup> Samochowiec, J., Thalmann, L., & Müller, A. (2018). *Die neuen Freiwilligen: die Zukunft zivilgesellschaftlicher Partizipation*. GDI Gottlieb Duttweiler Institute.

<sup>15</sup> Rhoads, S. A., Gunter, D., Ryan, R. M., & Marsh, A. A. (2021). Global variation in subjective well-being predicts seven forms of altruism. *Psychological Science*, 31(8).

<sup>16</sup> Klein, E. (2020). *Why we're polarized*. Simon and Schuster.

<sup>17</sup> Hermann, M. (2016). *Was die Schweiz zusammenhält: vier Essays zu Politik und Gesellschaft eines eigentümlichen Landes*. Schwabe AG.

<sup>18</sup> Ibid.



Increasing differentiation does not lead to a dichotomy or division into a few segments only, but rather to granularisation, i.e. division into an infinite number of camps. And if everyone is different from each other, there is also more potential for common ground. This requires community-building narratives that are not based on equality. This seems to be the case in the more individualistic countries mentioned earlier. It is also rather the case in Switzerland, where diversity, different languages, cultures and dialects are a source of pride.

In the area of health data, the division of labour mentioned by Durkheim can take on a new dimension. We all contribute different data. The more diverse the data, the more robust the resulting data model and thus our understanding of health. As a consequence, people who behave in an extremely unhealthy way may even of particular value to the data model. In the end, we are all each other's control group and therefore valuable for each other.

## Social determinants of technology use

The counter-arguments against the erosion of solidarity discussed above are in no way meant to imply that concerns about an erosion of solidarity caused by technology are entirely unfounded. Neither the arguments for nor against erosion of solidarity are compelling, however. The juxtaposition of arguments for and against is intended to show that there are alternatives to an erosion of solidarity. While the datafication of health can undermine solidarity, it does not have to.

*Actors in the field of data believe in the neutrality of technology. These are technology-driven forms of politics, however.*

Prof. Stefan Selke, Chair of "Social Change" and  
"Transformative & Public Science",  
Furtwangen University of Applied Sciences

It is not technology itself that defines how we deal with it. Rather technological tools should be seen just as the tools they are, whose use is determined by non-technological factors. In the following, we will take a closer look at two factors that have emerged in the arguments for and against.

### Preconditions for solidarity

Individuals, groups or societies decide who deserves solidary support. They define conditions that must be fulfilled (e.g. resident, in need, no culpability). Similarity is one such condition. Already in the definition, solidarity is limited to those "with whom a person or persons recognise similarity in a relevant respect". The argument of granularisation (see page X) predicts an erosion of solidarity. It likewise assumes similarity as a condition and sees this similarity dwindle. The argument of culpability, in turn, assumes that personal innocence of one's own situation is a condition for solidary support.



Sociologist Wim van Oorschot<sup>19</sup> distinguishes between five possible conditions for solidarity: control, need, identity, attitude and reciprocity (see box for a more detailed description of the conditions).

- > **Control:** Do or did people in need have control over their situation? Are they to blame themselves? Those who are to blame themselves for being unwell or who are accused of not trying hard enough to change their situation (e.g. people suffering from depression being told to “just pull themselves together”) do not deserve support.
- > **Need:** Is someone actually in need? Can the need be proven? This contrasts with state support independent of need, such as public sector care contributions, which all people in care facilities receive regardless of their individual wealth.
- > **Identity:** Is there a commonality between the givers and the recipients of solidarity? The Swiss healthcare system, for example, is based on solidarity with all people living in Switzerland, but not with those living abroad.
- > **Attitude:** Are recipients frugal and grateful for the support, or are they ungrateful and demanding?
- > **Reciprocity:** What are the recipients willing to do in return? For example, would people who incur a lot of healthcare costs be willing to disclose their health data in return?

According to van Oorschot, opinions among the general population differ widely as to what conditions should be placed on solidarity. Some people are more generous with regard to this. An example for this are supporters of an unconditional basic income. Others, however, want to attach strict conditions to solidary support because they believe that many receive aid unjust-

ly, or because they see aid as disenfranchisement that makes people passive and dependent.

These differing opinions on what conditions solidary support should depend on manifest themselves in different social ideas of solidarity and consequently in different group standards or also in different political systems. The Scandinavian countries, for example, are known for having a welfare state that places fewer conditions on receiving welfare state benefits than, say, the United States.

If a society has tolerant conditions for solidarity, health data is more likely to be used to help people achieve their health goals. If the conditions for solidary support are strict, it is obvious that the data will also be used to check whether potential recipients of solidarity really fulfil the required conditions. For example, by checking if recipients are really in need or by requiring them to digitally register their behaviour in order to prove their willingness to cooperate.

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<sup>19</sup> Oorschot, W. van (2000). Who should get what, and why? On deservingness criteria and the conditionality of solidarity among the public. *Policy & Politics*, 28(1), 33-48.

### The role of government

Whether and how digital tools are used in the healthcare sector depends heavily on government regulation. Solidarity can be established on the legal, institutional level. As mentioned in several examples above, it would already be possible today to exclude certain groups, such as smokers, from general solidarity. This is not done, however. Legislators decide who may use which health data and for what purpose. In many European countries, for example, the inclusion of genetic information by insurance companies or employers is strictly regulated.<sup>20</sup> Data protection can also be interpreted in a way that prohibits asking for certain data as a condition for participating in solidary systems such as health insurance.

*The use of data must be regulated by law. As more and more data becomes available, it must be clearly regulated which data cannot be used against individuals, but also which data individuals must provide to their insurance company, for example.*

Dr. Alessandro Blasimme, bioethicist, ETH Zurich

Governments themselves can also use data to promote health. The COVID certificate is an example of this, as it aims to prevent infection and encourage people to get vaccinated. In some countries, health data is collected as standard and stored centrally and can then be accessed by scientists and politicians, for example, to target prevention projects precisely. One example of this is Findata. Through this Finnish data permit authority, it is possible to apply for a permit to use health data that is collected in the primary care of all Finns who do not explicitly opt out. Statistical level data can be delivered to the client, but individual level data have to be analysed in specific environments.

Findata also offers a secure remote access system with statistical analysis tools to look for patterns in the data.

*We don't give out data, but rather grant permits to use it, collect and combine it and provide a secure platform for data analysis.*

Antti Piirainen, Findata

These two aspects, the strictness of solidarity conditions and the role of government, are degrees of freedom that can develop differently over the course of datafication of the healthcare system. They are relevant to the way health data will be handled in the future and how solidarity in the healthcare system will be shaped. As a consequence of openness, we will present four extreme scenarios below. These scenarios result from the quadrants of the intersection of the two dimensions “conditions of solidarity” (tolerant/strict) and “role of government” (minor/major) (see Table 1). The scenarios should not be understood as forecasts with 25 percent probability of occurrence, but rather as corner points of a space of possibilities.

<sup>20</sup> Joly, Y., Braker, M., & Le Huynh, M. (2010). Genetic discrimination in private insurance: global perspectives. *New genetics and society*, 29(4), 351-368.



Four scenarios for the future handling of health data

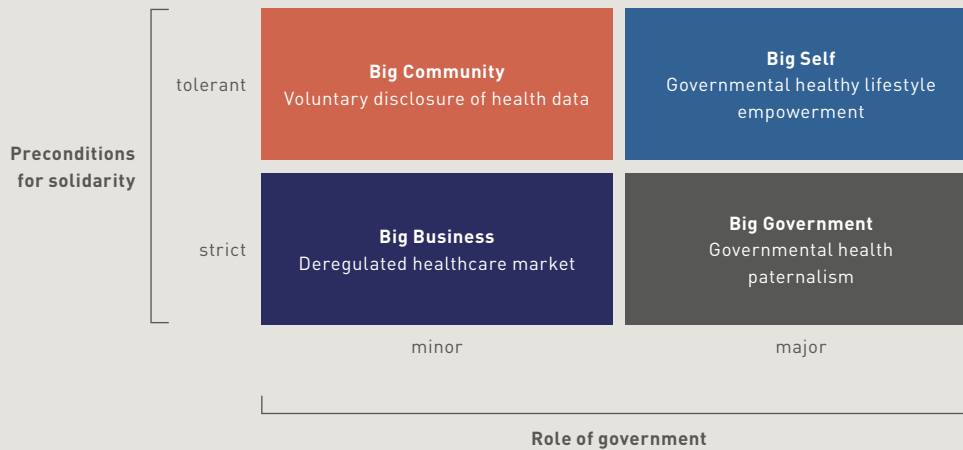


Table 1. Source: GDI 2021

The **Big Government** scenario describes a strong government with strict conditions for solidarity. Individuals are closely monitored and have to comply with governmental guidelines for behaviour. In the **Big Self** scenario, government also plays an important role. However, it limits itself to regulating the use of data and facilitating healthy behaviour. In the **Big Business** scenario, governments have no significance at all. Individuals with similar health profiles join together in risk pools to jointly bear any medical costs. They have to fulfil numerous conditions and share large amounts of data in order to be able to count on support in their pool. In the **Big Community** scenario, finally, governments are also unimportant, but voluntary solidarity is well developed: Individuals share their data without expecting “healthy” behaviour from others. Rather, diversity is seen here as a strength that enriches the data model, making it better.

The four scenarios are exaggerated depictions of a future healthcare system. They should not be seen as monolithic, mutually exclusive possibilities, but rather as corner points. They also do not claim to depict every detail accurately, but rather to convey an impression of this world,

and therefore focus primarily on those aspects that stand out the most in the scenario.

Presumably, the future will comprise aspects of all four scenarios. It is the aim of this study to stimulate reflection on what a future healthcare system could look like and which aspects from the individual scenarios would be desirable, which ones will be unavoidable and which ones will be necessary. What views of humanity do the respective scenarios represent and to what extent are they realistic? Especially under the assumption that technology does not deterministically predefine its use, an examination of such possibilities is important in order to actively shape the future and not simply let it happen to us.

## SCENARIOS

## Big Government governmental health paternalism

The government collects all health data centrally and is responsible for managing public health. All residents must share their data with the government.

Through a comprehensive and long-term view of the government, prevention is a central component of healthcare.

Those who lead unhealthy lives or have poor prognoses receive instructions on healthier behaviour and are guided by means of incentives and sanctions.

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### Description

The Big Government scenario describes a world in which the government pursues the goal of maximising general health in an efficient and evidence-based manner. Other goals, such as increasing wealth, are always a means to the end of improving the physical and mental health of the population.

Maximum health is achieved with the guiding hand of the government. This guidance is legitimised by the assumption that most people are too lazy, too uninformed and too irrational to lead healthy lives on their own. Only a strong government makes it possible for residents to achieve their best possible health.

In order to strengthen public health in an evidence-based manner, the government must have access to a database that is as comprehensive as possible. Citizens therefore have

the duty to collect health data and make it available to the government, which then compiles it in a central data pool. This includes genome sequencing at birth, the digitisation of all laboratory values during routine examinations and wearing so-called “wearables” that continuously measure physiological values such as body temperature, blood pressure or blood glucose levels. This disclosure and collection of data is seen by the government as an act of institutionalised solidarity which, in contrast to financial solidarity, i.e. sharing the health costs of third parties, does not put anyone at a disadvantage. Because everyone provides health data. In turn, everyone can benefit from the data collected, be it in the form of prevention, therapies or research. A state-affiliated pharmaceutical industry, for example, can use the large amounts of data for research and development. The aggregated health data puts the government in a good po-





## A DISCUTER

Do people who do not want to share their data lack solidarity?

sition when negotiating contracts with foreign pharmaceutical companies or other manufacturers of medical products, for example when procuring vaccines.

However, health data alone is not sufficient in order to obtain a comprehensive picture of health, and especially of its influencing factors. It is enriched with social, economic and ecological factors, which are also recorded on a large scale. In addition to conventional census data on income and wealth, this also includes data on environmental pollution or physical activity. Since currency has been completely digitised, the government can also track all financial transactions - and thus can see who is spending their money on alcohol or fast food, for example.

*Data is often difficult to process in large, centralised records, without further context. Therefore, we prefer smaller data pools which allow us to get in touch with people.*

Dr. Bastian Greshake Tzovaras, Director of Research,  
Open Humans

To improve the health of the population, the government relies on two pillars. It provides incentives for its people and puts demands on them. On the one hand, framework conditions are created so that it is as easy as possible for citizens to lead a healthy life. On the other hand, a system of rewards and penalties demands healthy behaviour.

### Healthcare

A key point in creating framework conditions is that everyone has equal access to quality healthcare. There is a uniform tax-financed health insurance and no supplementary insurance. This is due to the assumption that support for such a

distinctive public health system is more likely if everyone in the health system is treated as equally as possible.

*In recent decades, “community medicine” has been severely underfunded in favour of high expectations of an individualistic version of personalised medicine. This can be seen as a continuation of the neo-liberalisation of healthcare, in which governments abdicate their responsibility to provide opportunities for healthy behaviour.*

Luca Chiapperino, Lecturer in Science and  
Technology Studies, University of Lausanne

In the Big Government scenario, datafication and personal contact are not seen as opposites, but as complementary. Every neighbourhood, even in rural areas, therefore features at least one small joint practice or outpatient clinic with doctors, psychologists and health coaches (to design exercise or nutrition plans, for example). Consultations are free of charge, which is why there is a regular exchange with the population. People often know each other by their first names. The idea behind this is: Regular, also informal personal exchange guarantees much more comprehensive and sustainable healthcare than short, symptom-specific consultations. During these exchanges, healthcare workers review the health data of patients, help them understand it and address any conspicuousities. Simple medicines can be prepared or compounded individually based on access to precise physiological and genetic data of the patients. What cannot be produced on site is delivered by drone from a pharmacy warehouse as individual medication (with regard to active substance, dose and number of portions).

Those who live in a remote location or are no longer mobile are visited by mobile healthcare workers. Individuals can also get telemedical advice at any time. Effectiveness and efficiency of the treatment provided by the medical infrastructure can also be accurately measured and adapted due to the high level of datafication.

While certain services of cutting-edge medicine are only provided to a reduced extent for cost reasons, much more emphasis is placed on preventive medicine and incremental treatments,<sup>21</sup> i.e. longer-term treatment in small steps. In a free market, such treatments are often less in demand than acute treatments because their effect is not immediate. In terms of increasing life expectancy and long-term quality of life, however, these approaches are cheaper and more effective, which is why the government particularly promotes them. The focus on prevention means that the occupation rate of hospitals, which are also state-run, is much lower. Except for emergencies, patients are referred to hospitals by the outpatient clinics, with each referral lowering the rating of the clinic – a referral to a hospital referral is seen as a failure of the clinic.

*In Switzerland, we have legally regulated solidarity in the curative field. The same does not apply to prevention and early detection.*

Stefan Wild, board member, pharmaSuisse

### **A health-promoting environment**

In addition to easy access to healthcare, enabling people to live healthy lives is another important component of the prevention-oriented healthcare strategy. For example, the government provides a safe and comprehensive network of cycle paths or ensures that green spaces such as parks or forests are within walking distance for all residents. Fitness centres and swimming pools are free of charge. Unhealthy food is subject to high taxes, while healthy food is subsidised to make it as cheap and widely available as possible. Particularly unhealthy consumer goods such as cigarettes are simply banned.

For prevention and early detection, datafication of health is of particular importance. For example, anyone who has unusually high or low blood pressure over a certain period will automatically be assigned a doctor's appointment. With enough precise and comprehensive real-time data, it is possible to precisely elicit the impact of environmental variables such as noise or particulate pollution on health and to adjust them where they have a negative impact. This minimises the outsourcing of costs, so that the economic success of some does not happen at the expense of the health of others. A reduction in working hours, for example, could ostensibly reduce welfare, but on balance save more in terms of health.<sup>22</sup> Of course, such things cannot always be predicted exactly, but even imperfect models are seen as the better points of reference

<sup>21</sup> <https://bit.ly/soli-care> (source: newyorker.com; retrieved: 27 October 2021)

<sup>22</sup> Berniell, M. I., & Bietenbeck, J. (2020). The effect of working hours on health. *Economics & Human Biology*. 39.



than the particular interests of individual lobbying groups. If predictions turn out to be completely wrong, it is concluded that more data will be needed in the future to develop more accurate models.

A holistic view of data that brings together different factors makes it possible, for example, to not only track illnesses such as a flu epidemic very precisely, but also to predict their course and thus to carry out preventive interventions in a very targeted manner.<sup>23</sup> Similar to a weather forecast advising people to take an umbrella with them, people are warned via messages that they should wear a mask or wash their hands especially thoroughly when taking public transport today. These prognoses based on big data are always supplemented with random clinical laboratory tests to check the validity of the forecast and improve the model.

### Rewards and penalties

In addition to creating ideal framework conditions, the government encourages the population to adopt healthy behaviour by means of an incentive system. Those whose physiological values fall outside a reference range, for example cholesterol levels that are too high, are encouraged to do something about it and are rewarded or penalised accordingly. This also applies to people who are still healthy but whose predicted further trajectory is unfavourable. This may concern people who work too much and/or have a predisposition to cardiovascular disease.

Of course, not everyone has the same chances of being healthy. This may be due to genetic predispositions or unfavourable framework conditions (despite government efforts to improve them). The possibility of predicting different health trajectories indicates that not everyone

has the same opportunities and therefore not everyone can be expected to do the same.

The extent of penalties and rewards therefore does not depend on absolute values such as the cholesterol level or a predicted diabetes. Rather, people who have unhealthy indicators are encouraged to formulate measurable health goals with a medical professional or health coach.<sup>24</sup> For example: covering ten lengths in the swimming pool every day, not working more than ten hours a day or taking the prescribed medication. All this is measured precisely. Rewards and penalties depend on keeping to the agreements. People who disagree with the goals prescribed by the healthcare professionals can seek a second opinion and/or report to a complaints office.

Incentives can work through a reputation system, among other things. For example, if the agreed goal is not reached, friends and acquaintances are made aware of this and asked to motivate and support the person concerned. In case of gross disregard of the agreed goal, every person to whom one transfers money or from whom one receives money will be informed about the failure to meet one's goals. This information is publicly available. During application procedures, companies can check whether applicants neglect their health goals and consequently would not be reliable enough as employees. For government employees (of which there are very many), meeting health goals is a basic requirement.

<sup>23</sup> Dolley, S. (2018). Big data's role in precision public health. *Frontiers in public health*, 6, 68.

<sup>24</sup> <http://clalitresearch.org> (retrieved: 27 October 2021)

## A DISCUTER

Has your opinion on the role of government changed since the start of the COVID-19 pandemic? If so, how?

Financial incentives take the form of discounts for purchases at certain stores<sup>25</sup> or government subsidies for rent deposits or loans. A stronger incentive is to block financial transactions. At some point, it will no longer be possible to buy alcohol or unhealthy food. As a last resort, people who are ruining their health may be admitted to a healthcare institution.

In addition to the agreement of individual goals, there are general rules of conduct. Those who have a fever, for example, are not allowed to enter public buildings or means of transport. The doors then simply will not open because the door can measure the current body temperature of the people entering. Vaccinations against certain diseases are mandatory. Those who refuse not only risk exclusion from buildings and means of transport, but also prison sentences.

## RELEVANT TRENDS

**Social Credit Score**

The scenario is based on the Chinese Social Credit Score. The purpose of this system is to reward socially desirable behaviour and penalise undesirable behaviour. Admittedly, it has not been implemented nationwide yet, so it remains to be seen how much will actually be implemented. It is under discussion to link the use of services to behavioural points. This means, for example, that negative scores could make it difficult or impossible to buy tickets for railway or air travel or to apply for loans. Callers are automatically informed, prior to the call, that the person they have called has abused the trust of others.<sup>26</sup> On the other hand, positive scores could be rewarded with simplified access to the healthcare system or the elimination of deposits when renting accommodation.<sup>27</sup> The assessment includes things such as “frivolous spending”, paying bills on time or a criminal record.<sup>28</sup>

**Measures for surveillance of marginalised groups**

Upon introduction, new technologies are usually very expensive, which is why they are often adopted by privileged groups first. Doctors, diplomats and businessmen were the first to have mobile phones in their cars before they became a mass consumer product. With surveil-

<sup>25</sup> <https://bit.ly/soli-carrot> (source: wikipedia.org; retrieved: 27 October 2021)

<sup>26</sup> <https://bit.ly/soli-social> (source: channelnewsasia.com; retrieved: 27 October 2021)

<sup>27</sup> <https://bit.ly/soli-credit> (source: scmp.com; retrieved: 27 October 2021)

<sup>28</sup> <https://bit.ly/soli-rank> (source: vox.com; retrieved: 27 October 2021)

## A DISCUTER

Are our concepts of privacy still in keeping with our times?  
If not, how would they have to change?

lance technologies, the situation is different: they first make their way into the least privileged groups and then into the middle classes. For example, surveillance cameras were first used in prisons before being increasingly introduced to monitor public spaces. In the so-called “War on Terror”, in which surveillance mechanisms were applied to potential terrorists, the group of people considered terrorists was increasingly expanded so that, for example, the surveillance of environmental activists is now also justified as an anti-terrorism effort.<sup>29</sup>

In November 2018, the Swiss electorate voted in favour of monitoring disability insurance recipients by private investigators in cases of suspected abuse. It is quite conceivable that such surveillance will be extended to other groups of people, especially if the accusation of fraud is also extended to people with an unhealthy lifestyle and technological aids make surveillance easier and cheaper compared to private investigators. For example, apps like those currently used to monitor convicts on parole could be used for this purpose.<sup>30</sup>

### Big data in public health

The current pandemic in particular has shown how valuable data is for tracing contact chains – even if this data is not stored centrally, as is the case with most contact-tracing apps.<sup>31</sup> In Liechtenstein, for example, 5% of the population participated in a study that showed that many cases of infection can be detected using a wearable wristband even before any symptoms appear.<sup>32</sup> A project in the United States goes one step further: The Human Project<sup>33</sup> intends to collect data from 10,000 New Yorkers taken from credit card statements, paychecks, IQ tests, their genome, gut bacteria, social contacts, etc. to get a more accurate impression of

their health and the influencing factors relevant to them.

### Vaccine mandates and COVID-19 restrictions

In many countries, vaccinations or testing has been made mandatory for certain groups of people. In Austria and Italy, for example, employees must provide proof of vaccination, testing or recovery if they cannot exclude contact with other people during work.<sup>34</sup>

The body temperature of travellers and patients is taken at airports and many hospitals; only those who do not have an elevated temperature are granted access. One Chinese food delivery service is even said to offer the option of checking the delivery person’s current body temperature using the ordering app.<sup>35</sup> People are filming themselves during saliva tests for COVID at home to prove that they have used their own saliva.<sup>36</sup>

<sup>29</sup> <https://bit.ly/soli-counter> (source: hrw.org; retrieved: 27 October 2021)

<sup>30</sup> <https://bit.ly/soli-parole> (source: theguardian.com; retrieved: 27 October 2021)

<sup>31</sup> <https://bit.ly/soli-tracing> (source: bbc.com; retrieved: 27 October 2021)

<sup>32</sup> <https://bit.ly/soli-band> (source: netzwoche.ch; retrieved: 27 October 2021)

<sup>33</sup> <https://bit.ly/soli-human> (source: thehumanproject.org; retrieved: 27 October 2021)

<sup>34</sup> <https://bit.ly/soli-3g> (source: srf.ch; retrieved: 27 October 2021)

<sup>35</sup> <https://bit.ly/soli-twitter> (source: twitter.com; retrieved: 27 October 2021)

<sup>36</sup> <https://bit.ly/soli-test> (source: aargauerzeitung.ch; retrieved: 27 October 2021)



**Incentives for healthy behaviour**

In Mexico, the country with the highest obesity rate among children worldwide, the government is trying to motivate citizens to exercise more by offering financial incentives. Anyone who does ten squats gets a free bus ticket.<sup>37</sup> The exercise is recorded by a sensor that displays the number of squats on a screen. Similar experiments are also taking place in Russia and Romania, where the number of overweight people is also above the international average.

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<sup>37</sup> <https://bit.ly/soli-mexiko> (source: theguardian.com; retrieved: 27 October 2021)



# Big Business

## deregulated healthcare market

Healthcare is organised by the free market. Solidarity does not exist at the national level.

People with similar risk profiles obtain insurance from risk pools, but exclude people with unfavourable risks. To assess each other's risk, they have access to each other's health data.

Big tech companies offer data ecosystems that make it easy to manage shared risk pools.

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### Description

In the “Big Business” scenario, health is seen as a private matter. Everyone is responsible for their own health and consequently also their own illnesses. Being unhealthy therefore carries the stigma of personal failure. Governmental aid is minimal. This policy is justified by the assumption that people will make an effort to stay healthy especially if they have to pay for it themselves. The assumption is that, if people know they are in the care of the state, they are more likely to let themselves go, lose their decision-making capacity and become dependent.

Healthcare is almost entirely organised by the free market. There is hardly any government regulation, which also means that there is no legally mandated protection of health data. On the other hand, due to deregulation and competition, there is the possibility of obtain-

ing care and treatment at low cost. Those with little money can have diagnostics done using apps, telemedicine with call centre doctors in India and standard operations performed by robots. You do not have to be a physician to offer treatments. Good online ratings are sufficient. This is why many nurses take over routine outpatient jobs from doctors and offer them at low prices via online platforms. Inpatient care is also outsourced in an AirBnB-like system (CareBnB) to private individuals who have a spare room and are experienced caregivers (often retired nursing professionals). For complex operations, many people travel to Eastern Europe, where they are much cheaper. Discount hospitals also fly physicians from low-wage countries to Switzerland to perform operations and treatments as seasonal workers.

Those who have money, on the other hand, can enjoy first-class personal medical care. In some

## A DISCUTER

Should the cost any behaviour, no matter how unhealthy, be borne by the general public? If not, where do you draw the line?

cases, covering therapy costs is also offered by employers to retain valuable employees. In first-class medicine, medicines are adapted to personal intestinal flora and genetics, tumours are bombarded with particle accelerators, replacement organs are regrown using the patient's own stem cells and arthritis-plagued joints are replaced with artificial joints or robotic prosthetic limbs.

*One scenario that seems quite likely to me involves 99% receiving increasingly automated medical care, while the richest 1% will enjoy high-tech, high-touch medicine.*

Prof. Barbara Prainsack, political scientist, University of Vienna

Healthcare accessible to all is only available in the form of minimal emergency treatment, i.e. under the condition of acute need. Otherwise, solidarity almost only exists where it is also accompanied by self-interested risk hedging due to a residual uncertainty. If the health trajectory could be perfectly predicted, there would no longer be a need for cooperative risk hedging, as everyone would pay exactly what they incur in costs. However, since predictions are never perfect despite progress and never will be, people join together in peer-to-peer (P2P) risk pools. A typical pool is described below, although not all pools have to be the same.

### P2P risk pools

P2P risk pools or P2P insurance schemes are groups of people who pay money into a shared fund, which is then used to finance the health of all members. Any money left over at the end of the year is paid out to the members. In case the costs exceed the amount in the pool, many of these P2P insurance schemes take out P2P reinsurances. These consist of funds from savers and investors who invest in the reinsurances.

The financialisation of health insurance led to trading and ultimately also to speculation in P2P insurance bonds. For example, people bet on certain risk pools exceeding their budget, i.e. That the health of a group of people will deteriorate beyond expectation, so that they can then sell short at a profit.

In contrast to traditional health insurance, no administrative overhead and no marketing need to be financed. There are hardly any health insurance companies with employees and office buildings left. They have met a similar fate as taxi companies before them. They have been replaced by software. This software coordinates money flows from the individual members into the pool and from the pool to service providers such as physicians, hospitals or pharmacies. In addition, the pool software checks the extent to which payments for services are justified by looking at the health records of the members. For example, it checks whether a service provider is on the list of trusted providers negotiated by the P2P community or at least has a sufficient rating.

In many P2P insurance schemes, all health records and benefit payments can be viewed by all members. In this way, members can also check each other – whether someone is committing insurance fraud, whether service providers are legitimate and whether costs or the health prognoses of individual members are still within the reference parameters. Service providers and caregivers must also digitally register all of their actions in minute detail for the purpose of control and traceability. Only this ensures that members of the risk pool can control the legitimacy and efficiency of care.



A condition for membership in such P2P pools is often that one does not pose a significantly greater health cost risk than the average member. This is why everyone must disclose their health data. Members are often required to wear wearables or even sensors in their bodies to prove that they are vaccinated, exercise enough or that their physiological values are within the reference range. Some data can be collected without explicit consent. For example, the voice of a person contains indications of cardiovascular diseases,<sup>38</sup> while a person's gait displays initial signs of Parkinson's disease.<sup>39</sup>

*Already today, health insurance companies could buy data from Zalando to see what the size of the clothes people are buying is.*

Prof. Ernst Hafen, ETH Zurich

In most cases, the disclosure of genetic data is also required. Sometimes even financial transactions have to be disclosed to prove that you are not spending any money on alcohol or cigarettes. Privacy, i.e. not being dependent on a risk pool, is therefore something only few can afford.

Those who show excessive costs over a longer period, do not behave according to the specifications of the respective P2P insurance scheme (e.g. Have too many purchases of spirits and cigarettes on their credit card bill) and/or have bad prognoses are forced to look for another pool with higher premiums. This means that people with similar risk profiles band together in different pools. Healthy people join pools with other healthy people, while ill people join those with other ill people.

There are pools in which aspects of identity, rather than projected health costs, are a condition for membership. For example, Jehovah's

Witnesses are in a health pool together, as are members of larger housing cooperatives or trade unions, where shared risk pools are sometimes a participation requirement. On the one hand, these communities offer a relatively high degree of internal solidarity, if one disregards the direct, informal control that is often exerted in such communities. On the other hand, access to some of these communities is difficult. Those who want to be accepted into the risk pool of Jehovah's Witnesses, for example, must first prove themselves worthy and be present in the community regularly and over a longer period. Cooperatives are also often very homogeneous and exclusive<sup>40</sup>, with the health aspect offering yet another barrier to entry. For overweight people, it is more difficult for overweight people to be admitted.

<sup>38</sup> Maor, E., Perry, D., Mevorach, D., Taiblum, N., Luz, Y., Mazin, I., ... & Shalev, V. (2020). Vocal biomarker is associated with hospitalization and mortality among heart failure patients. *Journal of the American Heart Association*, 9(7), e013359.

<sup>39</sup> Kondragunta, J., Wiede, C., & Hirtz, G. (2019). Gait analysis for early Parkinson's disease detection based on deep learning. *Current Directions in Biomedical Engineering*, 5(1), 9-12.

<sup>40</sup> <https://bit.ly/soli-wohnung> (source: bajour.ch; retrieved: 27 October 2021)

### **Tech companies as administrators**

It is possible to organise P2P insurance schemes in a completely decentralised structure, for example in a blockchain. However, most P2P insurance schemes as well as health records are hosted on health platforms of tech companies such as Amazon or Google for reasons of convenience. This is because these are not only very good at referring people to the P2P insurance scheme that suits them. They also provide easy all-round care with health records, P2P insurance software and some wearables that are available for free or at a significantly reduced price. All this is part of a proprietary data ecosystem and thus very easy to connect, whereas it is often difficult, if not impossible, to legally synchronise the data from a wearable of provider A with health records from provider B. The reason for this is that the companies offering entire health data ecosystems do not want the data collected with their devices to benefit others.

For tech companies, health data is worth its weight in gold. Thanks to this data, on the one hand, they have become pharmaceutical companies themselves, delivering customised medicines directly to the homes of patients by drone. On the other hand, they also sell the data to other pharmaceutical companies interested in the effects of their medicines, or to companies that place targeted advertisements for nutritional supplements, law firms or wellness holidays.

*How do we ensure that some of the profits that companies make with our data come back to us?*

Prof. Barbara Prainsack, political scientist,  
University of Vienna

Merging health data with shopping behaviour, search engine queries, movement data, interaction with smart assistants, social media posts, email content, etc. allows a very comprehensive picture of health and its association with behaviour to be created. This means that health trajectories can be predicted much better, people can be better informed about their risks and therapies and preventive behaviour can be better adapted to physical differences as well as individual preferences and habits.

### **But what about the others?**

But what happens to those people who have unfavourable risks or prognoses but cannot afford risk hedging or treatment? Apart from the emergency treatment earlier, they have no right to medical care. Donor-funded charities and religious communities are stepping into the breach to support people in need. Others collect donations or micro-loans for medical interventions via crowdfunding platforms. Finally, there are medical students who provide care to those in need as part of their training or in their spare time, and also new healthcare providers who do not yet have online ratings and establish them by providing care to those without any money.



## A DISCUTER

## Are people responsible for unhealthy behaviour?

## RELEVANT TRENDS

**Big tech in the healthcare sector**

Big tech companies such as Apple, Amazon or Google have become increasingly active in the healthcare sector in recent years. The latest Apple Watch can measure the oxygen level in the blood, create an electrocardiogram or record mobility metrics such as walking speed or gait asymmetries. This is complemented by a number of in-house apps: a sleep monitor, a digital mindfulness coach and a work-out app that also suggests training regimens.<sup>41</sup>

Google has acquired the activity tracker company Fitbit. In addition, the search engine giant has founded companies such as Verily that are researching various health projects, ranging from glucose sensors to surgical robots to shoes that prevent falls.<sup>42</sup> Within the “Project Baseline”, Google is working to create as comprehensive a picture of human health as possible based on the health data of 10,000 volunteers, striving to offer something like “Google Maps for Health”.<sup>43</sup>

With Amazon Care<sup>44</sup>, it is the goal of Amazon to offer a comprehensive healthcare platform and initially offer this to all of the company’s employees. The platform includes telemedicine services, allowing the online booking of doctor’s appointments, arranging home visits or downloading prescriptions. Amazon HealthLake offers electronic health records.<sup>45</sup>

**Peer-to-peer insurance**

The P2P insurance concept described in the scenario has existed since around 2010 and has since been implemented in various insurance sectors.<sup>46</sup> The goal is, on the one hand, to reduce (and perhaps ultimately eliminate) the corporate overhead of insurance companies, saving

costs in the process. On the other hand, P2P insurance is supposed to solve the dilemma that insurance companies have a financial incentive not to honour insurance claims. In a P2P insurance scheme, the money left over at the end of the year is distributed back to the members.

**Pay-as-you-live insurance**

Since 2018, American insurance company John Hancock has offered life insurance policies only on the condition that customers are willing to collect sensitive health data. This means that they pass on data from fitness wristbands as well as lifestyle and dietary habits to the insurer and are offered cheaper rates in return.<sup>47</sup> Since 2019, life insurance companies have been allowed to use publicly accessible social media content, such as Instagram posts, when calculating the policy.<sup>48</sup> Also in Switzerland, there are health insurance companies offering discounts for supplementary insurance if, for example, people use a pedometer to measure a certain number of steps walked. Advertising for

<sup>41</sup> <https://bit.ly/soli-kit> (source: myhealthyapple.com; retrieved: 27 October 2021)

<sup>42</sup> <https://bit.ly/soli-verily> (source: wikipedia.org; retrieved: 27 October 2021)

<sup>43</sup> <https://bit.ly/soli-base> (source: projectbaseline.com; retrieved: 27 October 2021)

<sup>44</sup> <https://bit.ly/soli-amazon> (source: amazon.care; retrieved: 27 October 2021)

<sup>45</sup> <https://bit.ly/soli-lake> (source: aws.amazon.com; retrieved: 27 October 2021)

<sup>46</sup> <https://bit.ly/soli-peer> (source: wikipedia.org; retrieved: 27 October 2021)

<sup>47</sup> <https://bit.ly/soli-bote> (source: versicherungsbote.de; retrieved: 27 October 2021)

<sup>48</sup> <https://bit.ly/soli-insurance> (source: theverge.com; retrieved: 27 October 2021)

## A DISCUTER

How would you feel about electronic health records being managed by Amazon?

CSS's myStep says that you benefit every day you take 7,500 steps.<sup>49</sup> If sharing data and demonstrable goal attainment means that services become cheaper, this also means, conversely, that withholding data results in those services becoming more expensive.

### **Economisation of the healthcare sector**

More and more private clinics, pharmacies and retirement homes are taken over by national and international for-profit companies. The largest group of private hospitals in Switzerland, for example, is owned by the South African Medi-Clinic group. Physicians are increasingly training to become specialists in a specific field<sup>50</sup> because this brings better earning opportunities, among other things.

According to the Schweizer Ärztezeitung, “physicians face increasing pressure to view patient care from an economic perspective”, resulting in overuse and misuse of care.<sup>51</sup> According to the report, this results in more and more paperwork and increased cost pressure.

<sup>49</sup> <https://bit.ly/soli-step> (source: css.ch; retrieved: 27 October 2021)

<sup>50</sup> <https://bit.ly/soli-statistik> (source: fmh.ch; retrieved: 27 October 2021)

<sup>51</sup> <https://bit.ly/soli-ökonomie> (source: saez.ch; retrieved: 27 October 2021)

# Big Self

## governmental support of healthy living

The government promotes healthy behaviour by removing obstacles.

There is no obligation to behave in a healthy way. However, people are expected to take their health data into consideration in order to make informed choices.

The government enables healthy behaviour by providing the necessary structures and promoting education.

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### Description

In the Big Self scenario, government plays an important role. It pursues the goal of enabling its citizens to make the most informed health decisions and behaviours possible. This is based on the assumption that most people want to live healthily and are basically able to do so. This means they do not need anyone to tell them how to get there and control them, but they may need someone to make it easier for them to reach their goal. This role is assumed by the government.

*In our performance-oriented society, one's health is becoming increasingly important. Social media are also creating more and more pressure.*

Cornelia Diethelm, Center for Digital Responsibility

The minority that does not want to be healthy must also be tolerated and can perhaps contrib-

ute to society in other ways (e.g. through art). In this world, relatively few conditions are therefore placed on recipients of solidarity. One condition for solidarity that remains is that of identity. In this scenario, solidarity is limited to the people residing in a country.

*People should have the opportunity also to live a bohemian lifestyle. Health is not an absolute value. Alternative ways of life are equally valuable and worth the support of the rest of society.*

Luca Chiapperino, Lecturer in Science and Technology Studies,  
University of Lausanne

Those who require solidary support do not have to prove themselves first. Rather, public support makes healthy behaviour possible in the first place. The government removes obstacles. This assumption of good faith is not only granted to individual citizens. For example, caregivers do





not have to register and bill separately for every service if they only provide a hot water bottle, for example. Instead, they organise themselves in a non-hierarchical way and charge by the hour without a set time budget.

Different health insurance companies offer a uniform product that is heavily regulated by the government. Supplementary insurance, on the other hand, is less strictly regulated. Basic health insurance is compulsory, which means that financial solidarity is required by law. However, these premiums are dependent on income, as financial worries make people ill. Placing a financial burden on poor people through high premiums only causes their healthcare costs to rise as well. And that is neither in the interest of the insured person nor of the insurance company.

### **No right to ignorance**

There is no obligation and no expectation to behave in a healthy way. What is expected, on the other hand, is that people collect important health data. The purpose is not to make this data available to the general public in the sense of data solidarity or to control people. Rather, it is about individuals being aware of their own health and potential risks. This means that there is no right to ignorance. At least not with regard to those risks that can be averted or mitigated. This also applies to the health prognoses of unborn children. Responsible and informed decisions are considered more important than the potential stress that might be caused by this knowledge.

*With health data, there is not only a risk of discrimination by the government or health insurance companies. Compulsory personal optimisation, as preached by Silicon Valley companies, can also be a stress factor.*

Isabel Knobel, Co-Head Europe Program, Foraus

This monitoring solidarity is required because it is assumed that informed decisions can only be made on the basis of sufficient information and most people are not very good at assessing their own risks without a basis of data. For example, many people claim that they drink alcohol “on special occasions” only. If the frequency of drinking is recorded, they will find that their lives are full of such “special occasions” – and that their alcohol consumption is much higher than assumed. Confronting people with their own behaviour is a simple “nudge” that has the advantage of not prescribing any specific behaviour, but rather results in people being more likely to follow their ideals.<sup>52</sup> This is like holding up a mirror to them.

### **Fragmented data**

This monitoring can be implemented because the world is full of sensors. Smart toilets that analyse excreta are standard. The same is true for wearables such as smartwatches, which serve as an interface to the Internet, but also analyse blood pressure, pulse and gait or warn of atrial fibrillation. Digital assistants such as Siri

<sup>52</sup> Silvia, P. J., & Duval, T. S. (2001). Objective self-awareness theory: Recent progress and enduring problems. *Personality and social psychology review*, 5(3), 230-241.

## A DISCUTER

## Are data donations the new blood donations?

or Alexa recognise signs of illness in a person's voice,<sup>53</sup> e.g. the flu or COVID by type of cough.<sup>54</sup>

All this data is merged with X-ray images, prescriptions, information on blood group or allergies, etc. in digital health records on government-certified servers. Maintaining such health records is mandatory. However, they are encrypted and can initially only be viewed by the patients themselves, their insurance company and healthcare providers.

*Only individuals can bring all their data together. That is why I, as an individual, have a new power. By offering access to this data, I can buy new services.*

Prof. Ernst Hafen, ETH Zurich

Data extracts can also be made available to third parties, such as fitness centres or nutritionists, so that they can put together a customised exercise or nutrition programme. Such data extracts can likewise be made available to pharmacies, so that they can prepare individual medication if this has not already been done by a physician. Using the data for other purposes is in turn prohibited. For example, employers are not allowed to ask for health information in job applications (except if such information is essential to determining suitability for a profession, such as epilepsy in the case of pilots).

*We keep asking ourselves whether there are more cases of discrimination in countries that are much more advanced than Switzerland in terms of digitalization in the healthcare sector and data use. I am not aware of any examples of this. But when algorithms make a pre-selection, for example for a job interview, systematic discrimination cannot be ruled out, which is of course very problematic.*

Dr. Katrin Cramer, Director Personalized Health Informatics and Director SPHN Data Coordination Center, Swiss Institute for Bioinformatics

Because the data landscape is very fragmented, health data can be used less effectively than in a system where health data is brought together centrally and linked to other data. This means that research is constrained. Another consequence: Implementation and evaluation of public health measures are less effective than in the "Big Government" scenario, for example.

### Data donations

For this reason, the government encourages data donations, so-called data altruism. The protection of privacy is guaranteed by means of technical tools. In addition to encryption, apps are engineered according to a "privacy by design" principle (which takes privacy into account already at the design stage), such as contact tracing apps for highly contagious diseases. Data is only stored locally. Alternatively, privacy can also be achieved through data

<sup>53</sup> Fagherazzi, G., Fischer, A., Ismael, M., & Despotovic, V. (2021). Voice for Health: The Use of Vocal Biomarkers from Research to Clinical Practice. *Digital biomarkers*, 5(1), 78-88.

<sup>54</sup> Laguarda, J., Hueto, F., & Subirana, B. (2020). COVID-19 artificial intelligence diagnosis using only cough recordings. *IEEE Open Journal of Engineering in Medicine and Biology*, 1, 275-281.



masking,<sup>55</sup> i.e. altering data in such a way that it is difficult to make statements about individuals, but a recognisable pattern nevertheless remains. Other data is analysed at the level of healthcare providers such as hospitals. Governments or research institutions do not receive original data, but can have their algorithms trained in several separate data pools from different hospitals (so-called federated learning).<sup>56</sup>

*The survey we conducted together with the Risk Dialogue Foundation shows that relatively many people are willing to share their data. The precondition is that the institution is state-owned.*

André Gollietz, Founding Partner of Zetamind AG und President of Swiss Data Alliance

The willingness to donate data depends on the trust people place in their government, as most are unable to understand or verify claims regarding data masking or federated learning. This trust is reinforced by the fact that the government offers compensation for data misuse if someone can prove that they experienced discrimination because of donated data.

*We need so-called “harm mitigation bodies”, i.e. institutions that reduce the harm to people when data is misused.*

Prof. Barbara Prainsack, political scientist, University of Vienna

Despite this, data donations are often not widespread enough to allow representative statements about the general state of health and its determining factors. This is because, most of the time, people only share data on the health aspects that concern them personally at any given time. Persons who are being treated for renal insufficiency, for example, will agree (while still in hospital) to make precisely this

data available to research. However, this does neither ensure comparison with people who do not suffer from renal insufficiency nor contextualisation with other health data.

*Depending on the effort put into informing patients, up to 85 % of respondents in hospital are willing to sign the general consent and make their data available for research purposes. A recent Swiss study shows that the willingness of patients asked at home is about 60 %.*

Dr. Katrin Crameri, Director Personalized Health Informatics and Director SPHN Data Coordination Center, Swiss Institute for Bioinformatics

As is the case with organ donations, more comprehensive data donations often take place only after death. But privacy is still important after a person's death, because genetic data, for example, is not only related to an individual person, but also says something about relatives who might not have consented to sharing this data.

<sup>55</sup> <https://bit.ly/soli-masking> (source: wikipedia.org; retrieved: 27 October 2021)

<sup>56</sup> <https://bit.ly/soli-learning> (source: wikipedia.org; retrieved: 27 October 2021)

*In Finland, there has been a long history of high level of trust in government institutions, probably due to the tradition of transparent governance. Perhaps this is why utilization of data faces less resistance than elsewhere.*

*Antti Piirainen, Findata*

The government is relatively successful in collecting data on general well-being. Most citizens seem willing to disclose how they are doing at the moment. They give their digital assistants (such as Siri) permission to share this information with the government. Although this data does not allow for a precise understanding of health and hardly enables prevention measures to be planned with pinpoint accuracy, this data provides a first indication when something is wrong. It can be a reason to take a closer look. General well-being is also a valuable indicator that can be used to assess government action in general, so that it is not solely oriented towards the growth of the growth of the gross domestic product.

### **Information and networking**

In order to make informed decisions, people need to engage with and understand their health data. For this purpose, a digital assistant prepares the health data in the health records in a comprehensible way and according to the patient's level of knowledge. Physicians and health insurance companies encourage people to engage with their data regularly. But most people are interested of their own accord and do not have to be asked to do so.

*Technological progress has made medicine more expensive in most cases. If we use personalised medicine to better inform individuals, prices could come down. If medicine simply becomes more sophisticated, it also becomes more expensive.*

*Dr. Alessandro Blasimme,  
bioethicist, ETH Zurich*

The assistant provides information if there are signs of diseases in the data and suggests possible appointments with the corresponding specialist. These are matched with the patient's own agenda as well as the doctor's office.

*What are we actually doing to teach health literacy at school? I have never seen blood pressure being used as an example for a calculation.*

*Stefan Wild, board member, pharmaSuisse*

For a better understanding of health information, the topic of health is discussed in detail at school. An understanding of risks and probabilities is also promoted. Therefore, people not only understand their health data better, but also information about nutritional values on food or risks of interventions or medications. The digital platform on which the data is stored also contributes to a better understanding. For example, all data is linked to explanatory information, as well as forums where patients can exchange information with each other and with experts. The digital assistant also patiently answers all health-related questions and thus provides low-threshold access to health information.

## A DISCUTER

Should you face up to potential disease risks when this information is available? Or do you have a right to be ignorant in any case?

*Improving data literacy in the population is of central importance for a datafied health-care system.*

Isabel Knobel, Co-Head Europe Program, Foraus

### Empowerment to achieve goals

Making informed decisions is not enough. People also need to be able to turn these decisions into consistent habits in the long term. This requires skills and opportunities.

On the one hand, the government promotes self-regulation skills, i.e. the ability to follow the path towards a goal with determination and not immediately give up jogging or healthy eating habits again. This can include very different measures, such as urban planning interventions that strengthen social integration. The background to this: those who are better socially integrated exercise more self-control.<sup>57</sup> Sessions with psychologists and mindfulness courses are covered by basic insurance. Citizens receive free telephone access to health coaches who help them set health goals. The government also provides financial assistance to those affected by poverty, as financial security is necessary to be able to deal with health issues in the first place.<sup>58</sup> Since low socio-economic status is a risk factor for many health problems, the government considers strong social policies as more effective than the latest, most groundbreaking medicines.<sup>59</sup> The savings on health costs are used to finance this social policy.

*It must be ensured that nobody is exploited to be able to afford health insurance. Maybe this is where a discussion of basic income is appropriate.*

Prof. Barbara Prainsack, political scientist,  
University of Vienna

On the other hand, opportunities for healthy behaviour are offered. Similar to the “Big Government” scenario, the goal here is to create an environment that allows healthy living. Digital assistants are used as kitchen helpers, suggesting healthy recipes and ingredients. Food manufacturers and restaurants are required to include nutritional information with their food and restaurant menus. Cycle paths, sports clubs, jogging trails and green spaces are subsidised by the government. Creating an environment conducive to health also includes the fight against climate change, which is also essential from a health perspective.<sup>60</sup> For example in order to prevent heat waves that have a negative impact on health and can even be deadly.

### RELEVANT TRENDS

#### Nudging

The term “nudging” is used collectively to describe methods to influence decisions by adapting the environment without coercion or financial incentives.<sup>61</sup> An example would be placing healthy food at eye level on supermarket shelves. Especially those who do not have a distinct opinion on a certain topic can be influenced in this way (vegans will not buy a steak

<sup>57</sup> Samochowiec, J., Kwiatkowski, M., & Gürtler, D. (2021). Prävention im Umbruch. Stabile Routinen in instabilen Zeiten. GDI Gottlieb Duttweiler Institute.

<sup>58</sup> Ibid.

<sup>59</sup> Prasad, V. (2020). Our best weapons against cancer are not magic bullets. *Nature*, 577(7791), 451-452.

<sup>60</sup> Atwoli, L., Baqui, A. H., Benfield, T., Bosurgi, R., Godlee, F., Hancocks, S., ... & Vázquez, D. (2021). Call for emergency action to limit global temperature increases, restore biodiversity, and protect health. *The Lancet*, 398(10304), 939-941.

<sup>61</sup> Thaler, R. H., & Sunstein, C. R. (2008). *Nudge: Improving decisions about health, wealth, and happiness*. Yale University Press

## A DISCUTER

Who would you share your health data with?

And who would you not share it with? And why?

just because it is at eye level). This is also called “liberal paternalism”. People are given every freedom, but the environment, which has an impact on decisions anyway, is shaped in such a way that the impact is at least in line with certain ideas. A “Behavioural Insights Team” has been established in the United Kingdom. This government institution, also called the Nudge Unit, aims to encourage people to adopt “sustainable” behaviour.

### EU privacy law

With its General Data Protection Regulation, the EU has developed a comprehensive set of rules regarding the handling of personal data. The EU sees itself as offering a third way between China’s state monopoly on data and the approach to data in the United States, which is dominated by large tech companies and puts the informed individual front and centre.

### Informed customers

Customers increasingly want to know more about their products and also receive this information. Be it through the EU’s legally required nutrition labelling on food, the simplified, colour-coded Nutri-Score, or digital tools such as the Codecheck app, which allows you to scan barcodes and then receive information on the sustainability and health value of products.

### COVID data donations

In Germany, the Robert Koch Institute (RKI) has launched a COVID app data donation drive, which allows citizens to make health and activity data from their smartwatches or fitness trackers available to science. This data – including sleep patterns, heart rate and body temperature – is then analysed by an algorithm for symptoms associated with a COVID infection. 500,000 citizens participated in the project.<sup>62</sup>

### Buurtzorg

The Dutch care organisation Buurtzorg shows that outpatient care (i.e. care at home) can be much less complicated than it is today. It is based on the assumption that caregivers are mature enough to make decisions for themselves and do not need to be controlled or involved in a hierarchical command structure. Care needs are charged as timed flat rates and not according to services provided or tariff groups. Buurtzorg is the most popular home-care organisation in the Netherlands among both caregivers and patients and is also more economical than care that is based on fixed time or benefit budgets.<sup>63</sup>

### Voice assistants as advisors

The Amazon Alexa voice assistant can encourage healthier eating.<sup>64</sup> Since Alexa is synchronised with numerous other devices (such as kitchen appliances) and is increasingly used as a kitchen assistant, it could observe cooking behaviour, suggest healthier ingredients in recipes or control a diet plan.

<sup>62</sup> <https://bit.ly/soli-app> (source: rki.de; retrieved: 27 October 2021)

<sup>63</sup> Madörin, M. (2014). Ökonomisierung des Gesundheitswesens-Erkundungen aus der Sicht der Pflege. ZHAW Zurich University of Applied Sciences, Department of Health, Institute of Nursing.

<sup>64</sup> <https://bit.ly/soli-echo> (source: cnet.com; retrieved: 27 October 2021)

# Big Community

## voluntary disclosure of health data

Solidarity is not grounded in institutions. Sharing health data has become the standard in society.

Diversity reinforces a data model. People with unhealthy lifestyles enrich this and are therefore not discriminated against.

Open sharing of data leads to open source pharma and powerful artificial intelligence everyone can benefit from.

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### Description

This scenario outlines a world in which conditions for solidarity are very tolerant while the government plays only a minor role. This solidarity manifests itself particularly in the sharing of data. Many people willingly share their health data, which ultimately benefits everyone. Sharing data is standard in society and not a mandate imposed by the government. Solidarity is created from the bottom up, on the initiative of individuals. People can be in solidarity with each other without governmental guidelines and pressure, with certain people falling off the grid.

This data solidarity has few preconditions apart from access to technology. Health data, at least in aggregate form, become almost like Wikipedia entries. This is because data is understood as a non-exclusive, public good. It is not used up by a single individual and is therefore not

understood as a raw material, as with the tech companies in the “Big Business” scenario, but rather as an infrastructure that everyone can use – just like roads or bridges, for example.

*The data commons is a way to re-energise civil society.*

Prof. Ernst Hafen, ETH Zurich

### Common data standards

Common data standards are essential for such an exchange of data. They allow everyone to speak the same data language and are a prerequisite for any exchange. This is at odds with the intention of tech companies who would prefer to keep their data to themselves. However, due to regulations such as the GDPR, manufacturers of wearables and other sensors are required to make data accessible. But customers are also simply not interested in devices from which no data can be read in order to use it for other pur-





## A DISCUTER

Would pay health insurance premiums if you did not have to?

poses. Comparable to the agreements on HTML codes, an international consortium has agreed on uniform data standards for health data, which have finally become accepted worldwide.

Everyone has electronic health records which contain the data according to the international standard. They contain genetic data, MRI images, current physiological data measured with a variety of sensors around and inside the body and many other health-related parameters. These health records are hosted partly on servers of cloud providers and partly on servers of data cooperatives.

The health records allow data to be viewed and access rights to be determined or managed. Theoretically, each data request could be assessed individually and then either accepted or rejected. But quite a few users allow all queries. Some have a digital assistant that organises data allocation and follows basic values once specified. Many hand over their data to a data cooperative, which establishes common rules for data use and also elects a committee for this purpose.

*The cooperative approach is intended to help people share their data in a self-determined manner.*

Ernst Hafen, ETH Zurich

Some data cooperatives restrict access rights in that they only allow the analysis of data on their local server and do not release data, or only do so in aggregated form. The rules for sharing data are rather generous in the vast majority of cases. In contrast, some people do not agree to share their data with for-profit companies or projects. This has the side effect that medical research is almost only published in open-access

journals, and not in journals of profit-oriented publishers, as it used to be.

### Sharing for fun

In the beginning, it was mainly people with specific symptoms, especially those that received too little attention from science, who exchanged health data with each other. This sharing of data has now become common across all age and income groups. Tech-savvy seniors collaborate to study how different medications and dietary supplements affect the length of their telomeres (chromosome caps that limit lifespan). Young people show each other their physiological responses to fitness workouts or the cinnamon challenge (trying to eat a spoonful of cinnamon powder). Data sharing originates less from a sense of suffering than from an exploratory joy in technology, in experimentation and in sharing itself. This is also valued more and more in science, which is why publishing raw data is increasingly as important as publishing articles.



## A DISCUTER

What would happen if all your health data was publicly accessible? What if everyone's health data was?

*The ageing society can be an opportunity for a more open exchange of health data. The risk of being discriminated against when looking for a job, a reason why people may not want to share their data, is of no importance to retired people.*

Cornelia Diethelm, Center for Digital Responsibility

The availability of one's own as well as other people's data in the same format in combination with smart assistants that help with statistical analysis leads to many people taking an interest in their own quantified health and becoming citizen scientists. How much belly fat do I have compared to the aggregated average of people my age? How does the cholesterol level change if half of the people in our chat group eats an egg every day for a week?

### Success through diversity

Because many people are involved with health data, it has become clear to a wider population how valuable it is to share it. And above all, how valuable it is when many and very different people do it.

*Health data is more likely to be shared than disease data. This can cause us to have a distorted image of others.*

Cornelia Diethelm, Center for Digital Responsibility

Initially, it was mainly the very healthy or very ill who shared their data, which distorted results. Demographic groups who were not digitally mapped thus received poorer health support. The broader the data base, the more representative the data model, which is why any data is valuable. Obese persons, people with alcohol issues or "couch potatoes" are not seen as a burden on the health system, but rather as an enrichment of the data base that makes a data

model more complete and robust. The feared discrimination due to unfavourable health data did not occur.

*The more data we have, the clearer it becomes how different people are, and the more difficult it becomes to give them guidelines.*

Stefan Wild, board member, pharmaSuisse

Rather, datafication makes it clear that people, no matter how different, need each other as a data context. And everyone has something to contribute. Individual health data only makes sense when contextualised with other data. This is comparable to an experimental group being worthless without a control group in an experiment. In this world, everyone is each other's control group. And the more diverse it is, the more meaningful the data. Those who do not share their data are also tolerated. They can still benefit from the general data trove, but do not gain any advantage by withholding their own data.

*What do you want to get out of health data?*

*Who will stand up and show use cases?*

André Gollietz, Founding Partner of Zetamind AG und President of Swiss Data Alliance

People are motivated to share data when they find out what has been done with it. For example, individuals or cooperatives regularly receive news about successes made possible with their with their data – be it individuals who have improved their health, activists who have been able to prove a health hazard caused by a factory and force it to take action, or even medicines developed through the use of citizen science that are now available to all patent-free as open-source medication. It is precisely the widespread and free availability of medicines

that people can print out themselves at home using a 3D printer that has greatly reduced healthcare costs. The production of medicines at home makes it possible to react immediately to acute physiological conditions and to administer the right dose of the right active substance at the right moment. A global sensorium for diseases by people who openly share their data also makes it possible to print out vaccines and self-vaccinate with mRNA vaccines at home against the latest influenza or COVID variants. This means that risk groups can be vaccinated in the right place, at the right time – epidemics are suppressed instantly.

### Medical care

Medical care is provided at several levels. First of all, a digital assistant can answer initial questions, as it can access the data from the wearables and sensors of the respective person as well as a comparison group and recognise anomalies. The assistant can also refer to scientific literature, as it is freely accessible. Thanks to access to an enormous amount of data, the artificial intelligence used by the assistant is extremely powerful. In addition, people with similar experiences or symptoms can exchange their knowledge in online discussions to which they are actively invited based on their data. Medical professionals often have their say in an advisory capacity in these forums. Researchers in particular see this as a quid pro quo for the donated data.

*Participation is a prerequisite for sharing data. Not everyone has to be a health expert. But being offered the opportunity to have a say is important. Why should I participate in a system that does not take me seriously? An example is doctors rolling their eyes when patients have googled something.*

Dr. Bastian Greshake Tzovaras, Director of Research,  
Open Humans

Care is often provided by relatives and neighbours, as many older people who are already retired like to volunteer and civil society is very strong. Since many care tasks are also taken over by machines, the volunteers are mainly there to keep people company. People are more willing to visit the elderly because they do not have to worry that the heavy work will fall on them. And it is also nice for the elderly people because their exchange with the volunteers takes place on an equal footing and is not characterised by a relationship of dependency.

Surgery is almost exclusively performed by robots. Operating by hand seems as dangerous as steering a car weighing several tonnes by hand in city traffic. Due to open access to data, surgical robots have also become very much better, because with every surgery somewhere on the globe, all robots worldwide become “smarter”. Healthcare costs have dropped significantly due to robots and off-patent medicines. The costs that remain are paid from a health fund, which is financed by voluntary contributions and charitable donations. In particular, people who have undergone treatment in the past or their relatives donate money to this fund.

## A DISCUTER

Do people act in solidarity without any pressure, without incentives, without laws?

## RELEVANT TRENDS

**Open-source pharma**

Especially for diseases that are rampant in developing countries, profit-driven development of medicines has proven to be unhelpful. This is because most people suffering from malaria or tuberculosis have few financial resources. Only 10% of global research funding is dedicated to diseases that account for 90% of all preventable deaths. India's "Open Source Drug Discovery Project"<sup>65</sup> and the "open source pharma"<sup>66</sup> movement were founded for this reason. Community participation and the open sharing of data are intended for the development of an alternative model for the production of medicines.

**Citizen science / quantified self**

Counting birds, identifying plants, exploring ways of folding proteins online – citizen Science has been in vogue for years. The idea: you do not need a PhD to collect valuable data for science. Internet-based platforms and interfaces make it easy to collect and share data and crowd-source scientific processes. Anyone who discovers a bird in their garden can simply enter this in an app, allowing a body of knowledge to know like a grassroots movement. Citizen scientists, however, cannot only participate in the progress of knowledge by collecting their own data on nature or even on their own bodies, but also by conducting their own analyses. For example, about 100,000 volunteers identified cancer cells in breast tissue data as part of the "Cell Slider" project in the UK.<sup>67</sup> The analyses by the volunteers were as accurate as those of trained pathologists.<sup>68</sup>

**3D printing medicine**

In 2015, the US Food and Drug Administration (FDA) approved a drug produced by 3D print-

ing for the first time.<sup>69</sup> The tablet called Spritam contains the active substance levetiracetam, which is used to treat epilepsy. The active substance is applied layer by layer. Although there are no efficiency gains associated with this compared to the conventional production of tablets with presses, the dosage, which is adjusted to white adult males in the case of conventionally produced pharmaceuticals, can be individually adapted.<sup>70</sup>

The company CureVac considered the idea of manufacturing mobile mRNA printers that could produce COVID-19 vaccines anywhere in the world.<sup>71</sup> Theoretically, it would be conceivable that in future any gene sequence could be downloaded as data in order to produce the corresponding proteins on site.

<sup>65</sup> <http://www.osdd.net> (retrieved: 27 October 2021)

<sup>66</sup> <https://www.opensourcepharma.net> (retrieved: 27 October 2021)

<sup>67</sup> <https://bit.ly/soli-crowd> (source: sciencedirect.com; retrieved: 27 October 2021)

<sup>68</sup> <https://bit.ly/soli-citizen> (source: news.cancerresearchuk.org; retrieved: 27 October 2021)

<sup>69</sup> <https://bit.ly/soli-drucker> (source: sueddeutsche.de; retrieved: 27 October 2021)

<sup>70</sup> <https://bit.ly/soli-drug> (source: computerworld.com; retrieved: 27 October 2021)

<sup>71</sup> <https://bit.ly/soli-tesla> (source: reuters.com; retrieved: 27 October 2021)



Quelles sont les philosophies qui se cachent derrière les scénarios ? Quel est le rôle des données ? Comment les exemples de cas déterminants pour la santé sont-ils traités ? Le tableau ci-dessous confronte les quatre scénarios.

	Big Government	Big Business	Big Self	Big Community
<b>Philosophy</b>	Those who do not lead healthy lives must be forced to live healthily.	Those who do not lead healthy lives do not receive solidary support.	Those who do not lead healthy lives need more information and help in overcoming obstacles.	Those who do not live healthy lives are an asset to the data model.
<b>Role of data</b>	Control instruments	Raw material	Self-reflection tools and expression of personal autonomy	Infrastructure
<b>Funding of healthcare</b>	Funded by taxes	Financed by P2P insurance or self-paid	Income-dependent premiums for state-regulated health insurance schemes	<ul style="list-style-type: none"> <li>&gt; Many benefits are free of charge</li> <li>&gt; Voluntary health fund</li> </ul>
<b>Prevention</b>	<ul style="list-style-type: none"> <li>&gt; Prevention by means of specific behavioural guidelines</li> <li>&gt; Thanks to a comprehensive data model, a very comprehensive, long-term and structural view of health and prevention is possible</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Prevention is the task of individuals (not structural)</li> <li>&gt; Short-term, easy-to-measure prevention measures are required as a condition of participation in the risk pool</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Prevention through structural offers to enable healthy behaviour</li> <li>&gt; Prevention by empowering individuals through information and education</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Prevention thanks to accurate recording and quantification of environmental impact on health</li> </ul>
<b>Organisation of care</b>	<ul style="list-style-type: none"> <li>&gt; At public hospitals, if necessary</li> <li>&gt; Home care with regular visits from mobile caregivers</li> <li>&gt; Behaviour (of patients and caregivers) is precisely prescribed and digitally registered</li> </ul>	<ul style="list-style-type: none"> <li>&gt; CareBnB, provided by private individuals</li> <li>&gt; Risk pool members look for past behaviour to limit coverage</li> <li>&gt; Exact digital recording and accounting of each care step with strict efficiency specifications</li> </ul>	<ul style="list-style-type: none"> <li>&gt; At semi-private hospitals</li> <li>&gt; Home care organised jointly by patients and caregivers</li> <li>&gt; No detailed bureaucratic review of individual care services, but flat-rate reimbursements</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Patients involved in citizen science project investigating the impact of psychedelics on chronic pain</li> <li>&gt; Download of medication</li> <li>&gt; Care provided by robots, relatives and neighbours</li> <li>&gt; Professional care only if really necessary</li> </ul>
<b>Risk indication in prenatal diagnostics</b>	The government covers all costs.	Unfavourable health risks cannot be insured, so ill children is something only few can afford.	Parents should be informed about possible risks and make conscious decisions.	<ul style="list-style-type: none"> <li>&gt; Exchange in forums with other parents and experts about the meaning of the results and possible consequences</li> <li>&gt; Home test kit for child genetics and possibility of genetics and possibility of genetic manipulation</li> </ul>
<b>Approach to smokers</b>	<ul style="list-style-type: none"> <li>&gt; Smoking bans</li> <li>&gt; Cigarette ban</li> <li>&gt; Mandatory government target for reduction</li> </ul>	Participation in risk pools more difficult or complete exclusion, resulting in personal assumption of any treatment costs	<ul style="list-style-type: none"> <li>&gt; Non-smoking campaigns</li> <li>&gt; Social media challenges</li> <li>&gt; Monitoring of one's own smoking behaviour</li> </ul>	Citizen science commitment of smokers to determine the negative impact of different smoking products and brands
<b>Treatment of a cruciate ligament torn playing football</b>	Paid for and operated by the government	<ul style="list-style-type: none"> <li>&gt; Personal assumption of costs, as the risk pool considers football as a hobby too dangerous to be insured</li> <li>&gt; When funds are tight B surgery performed abroad or by a seasonal doctor at a discount hospital</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Digital assistant provides information about warm-up exercises before training sessions</li> <li>&gt; Surgery is paid for by the health insurance fund</li> </ul>	Surgery is performed by robots that, thanks to large amounts of available data, can do this much better than a human would.

Table 2: Comparison of the scenarios

# COVID-19 measures as an example

The scenarios outlined above are future scenarios. However, the logics of the scenarios can also be applied to today's examples in the healthcare sector. In the following, we will illustrate this with different approaches to coping with the COVID crisis.

## Big Government

**Lockdowns**

**Mask mandates**

**Vaccine mandates**

**Mandatory certificates**  
(proof of vaccination, recovery, testing)

**Reward systems**

Big government has steered the health of its citizens with various authoritative measures during the COVID pandemic. Schools were closed, people were ordered to work from home, in Italy and Spain people were not allowed to leave home unless absolutely necessary. Mask mandates were introduced on public transport. France, for example, has made vaccination for nursing staff mandatory, while Austria and Italy require proof of vaccination, recovery or testing in the workplace. Across Europe, proof of vaccination, recovery and sometimes testing is required to eat at a restaurant. The premise: Because the risk of infection with the virus for individuals and others is not a personal but a collective one, the decision-making power must be transferred from the individual to the government.

Many countries are discussing rewards as a positive incentive. In Germany, free sausages were offered in some places to entice people to

get vaccinated, Switzerland discussed a 50-franc reward for people who persuade others to get vaccinated, and in California people received a lottery ticket after vaccination with the chance to win 1.5 million dollars ("Vax for the Win").<sup>72</sup>

## Big Business

**Unvaccinated persons to cover their own hospital costs**

In the "Big Business" scenario, people are excluded from solidarity if they do not fulfil certain conditions or do not comply with certain rules. In the case of the pandemic, this manifests itself in demands that the unvaccinated should pay for their own hospital treatment.<sup>73</sup> In the United States, the costs of treating the unvaccinated in the summer months of 2021 is estimated at almost six billion dollars.<sup>74</sup>

## Big Self

**Awareness campaigns**

**Low-threshold accessibility to vaccination**

**Privacy-by-design contact tracing apps**

In the "Big Self" scenario, solidarity is not attached to any conditions. Rather, the government sees its task as enabling people to make informed decisions. The focus is on information and education, for which the Swiss Federal Of-

<sup>72</sup> <https://bit.ly/soli-cali> (source: handelsblatt.com; retrieved: 27 October 2021)

<sup>73</sup> <https://bit.ly/soli-kasse> (source: aargauerzeitung.ch; retrieved: 27 October 2021)

<sup>74</sup> <https://edition.cnn.com/2021/09/14/health/unvaccinated-covid-patients-treatment-cost/index.html>



fice of Public Health invested almost 20 million francs in the first year of the pandemic.<sup>75</sup>

On the other hand, the goal is to make healthy behaviour as easy as possible, which is why mobile vaccination teams went to retirement homes, churches and mosques, or vaccination trams ran in some cities.

Contact tracing apps storing data in a decentralised manner are also created following the “Big Self” logic. They only inform individuals about a possible infection and no one else. Individuals must then take action themselves and are not obliged to do anything.

## Big Community

### Relaxing of patents for COVID vaccines

The “Big Community” scenario, in which the conditions for solidarity are tolerant and data is shared, also has its counterpart in the COVID crisis. An example for this is the demand to relax patent protection of COVID vaccines for developing countries. Even in the United States, the front of those who insist on strict protection of intellectual property is crumbling because otherwise incentives for the development of expensive vaccines would be lost. For example, President Joe Biden wants to relax patent protection, at least temporarily, in order to promote the production of vaccines in poorer countries.<sup>76</sup> Ultimately, the rapid development of the COVID-19 vaccines is owed to the fact that Chinese researchers made the genetic material of the virus available to the research community as early as January 2020.

Many Swiss readers, as well as participants in

<sup>75</sup> <https://bit.ly/soli-kosten> (source: persoenlich.com; retrieved: 27 October 2021)

<sup>76</sup> <https://bit.ly/soli-biden> (source: faz.net; retrieved: 27 October 2021)



# Control and solidarity in the Swiss healthcare system of tomorrow

the workshops for this study, feel most familiar with the “Big Self” scenario. Government is considered to play an important role in the Swiss healthcare system, and the “conditions for solidarity” are rather tolerant. It does not primarily rely on the regulation of behaviour, controls or financial incentive systems, but expects people to behave healthily of their own accord.

## Change over time

The parameters determining how strict the conditions for solidarity are and how pronounced the role of the government is change over time. In the nineties and noughties, there was a paradigm shift away from a “caring” to an “activating welfare” (promoted by Schröder, Blair, etc.) in the vein of “third way” politics, which expected increased individual effort as a condition for government support (to support and challenge at the same time). This also entailed demands for market-based liberalisation, closing loss-making hospitals and cost reductions.

In the wake of the COVID crisis, a change of course has taken place. For a while, no one talked about closing hospitals anymore. The new goal is to increase the number of intensive care beds for COVID-patients as quickly as possible. Government, which some had already declared dead in the context of globalisation, has returned with a vengeance: It imposes curfews, prescribes social distancing and closes schools. One could indeed say that “Big Government is back”.

## Datafication as a catalyst

It is plausible to assume that there will also be shifts in the extent of government influence and between strict and tolerant conditions for solidarity in the future. In particular because data-

fication will profoundly change the healthcare system. It makes an established structure more malleable, facilitating shifts towards other scenarios. Datafication acts as a catalyst.

The Swiss healthcare system is currently still rather non-digital. For example, at the beginning of the pandemic, infections were still reported to the Federal Office of Public Health (BAG) by fax. However, the pandemic has already accelerated digitisation and electronic health records will probably become established also in Switzerland sooner or later. But even without the BAG, the datafication of healthcare is in full swing. According to the survey “Datengesellschaft und Solidarität”<sup>77</sup> commissioned by the Sanitas Foundation, more than half of Swiss women aged between 18 and 35 years use digital aids to register their menstrual cycle. 41% of respondents actively record the number of steps walked using mobile phones or fitness bracelets. For comparison: in 2018, this figure was only 26%. With new sensors and more sophisticated algorithms, the volume and variety of health data will continue to increase in the future.

What is particularly relevant in this context is the control aspect of datafication mentioned at the very beginning. This makes it possible to better check conditions for solidarity. We therefore expect a greater influence of datafication on the dimension of “conditions for solidarity” and want to take a closer look at it. What are

<sup>77</sup> <https://bit.ly/soli-umfragen> (source: sanitas.com; retrieved: 27 October 2021)



arguments in favour of a datafied healthcare system in Switzerland moving towards stricter conditions for solidarity and consequently also stricter control of this (i.e. in the direction of the “Big Government” or “Big Business” scenarios)? What would be the reasons for a development towards more tolerant conditions for solidarity, i.e. the “Big Self” and “Big Community” scenarios? And what influence would the severity of the solidarity conditions have on solidarity itself?

### Development towards stricter conditions for solidarity

Those who do not believe that others generally act in solidarity will attach strict conditions to solidarity, the compliance with which must be proven – among other things with health data, which is then also used for control purposes. Did Steve really try hard enough to avoid becoming ill? Should Sylvia, who takes painkillers all the time and is unable to work, scale down her leisure activities? Those who do not fulfil solidarity conditions are either forced by the government to adopt healthy behaviours (“Big Government” scenario) or are excluded from solidary support (“Big Business” scenario).

The datafication of the human body simplifies the control of behaviour (physical activity, eating, sleeping) and consequently also the verification of solidarity conditions. This simplicity alone could already lead to stricter conditions and pave the way for a development towards the “Big Business” or “Big Government” scenarios. In the private sector, strict control has already been established in part thanks to technical possibilities. An extreme example is Amazon, where a machine in the warehouse checks the pace of work and automatically fires workers if

they do not meet the target.<sup>78</sup> The tech giant has patented a wristband that is intended to track the exact arm movements of employees and thus enables even more close control.<sup>79</sup>

There is also an interest in control in the healthcare sector, in particular because cost pressure is increasing. Do patients take their medication as instructed by their physician? Do the right people receive support? Are resources used efficiently? Treatments and care must be registered in detail in tariff systems such as Tarmed. According to healthcare workers, the administrative burden is constantly increasing.<sup>80</sup> Detailed digital tracking by video, smart voice assistants or even Amazon’s wristbands could also be seen as a solution in treatment and care to simplify administrative work (see the “Big Business” scenario).

With the step counters mentioned several times, healthy behaviour is already monitored today and promoted with financial incentives. Other dimensions, perhaps those of a sleep tracker, could be added. Although this only affects supplementary insurance, a creeping erosion of solidarity could ensue if the benefits catalogue of basic insurance is thinned out at the same time and supplementary insurance consequently becomes more important. The cancellation of basic insurance benefits and the expansion of

<sup>78</sup> <https://bit.ly/soli-bot> (source: bloomberg; retrieved: 27 October 2021)

<sup>79</sup> <https://bit.ly/soli-wrist> (source: theguardian.com; retrieved: 27 October 2021)

<sup>80</sup> <https://bit.ly/soli-befragung> (source: saez.ch; retrieved: 27 October 2021)

How do you rate the following statement? People who keep fit and eat healthily should pay less health insurance premiums than others.

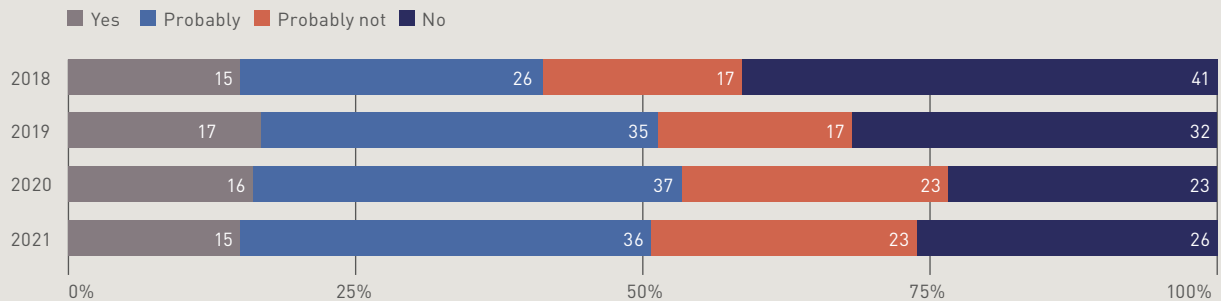


Figure 3: Approval of health insurance premiums depending on behaviour from 2018 to 2021.  
Source: "Monitor Datengesellschaft und Solidarität" Sotomo

individual cost sharing are regularly discussed by politicians. There is also a willingness among the general population for individual cost sharing. In the survey by the Sanitas Foundation already mentioned above (see page x), about half of the respondents in 2021 are also in favour of people who lead healthy lives paying less in health insurance premiums. This value was only 41% in 2018 (see Figure 3).

A shift towards more governmental control, i.e. towards the "Big Government" scenario, is also plausible. In a referendum, the Swiss population voted in favour of monitoring recipients of disability insurance in cases of suspected fraud. Digital tools could also simplify control here, for example by checking where recipients of disability insurance are staying. Especially during the pandemic, government influence in the healthcare sector is also enforced by digital means (think of vaccination certificates). Due to the uncertain epidemiological situation alone, it is unclear how long this will continue and to what extent governmental control will be established as a new standard.

### The impact of strict conditions and a high level of control on solidarity

Stricter conditions for solidarity do not necessarily mean less solidarity. It would be conceivable, in theory, that the strict solidarity conditions and their digital control are necessary because only through them people make an effort to live in solidarity and lead healthy lives, and so they ensure that solidary support is not misused. The realisation would spread that society functions better thanks to digital control. Attitudes towards regulated behaviour would adapt and the rules would be internalised,<sup>81</sup> just as the initially unpopular smoking ban in restaurants is hardly perceived as a ban anymore. Maybe wearing a mask when you have a cold will also become a matter of course. Strict solidarity conditions would in this case result in more solidary behaviour and could perhaps even be reduced after a while without the changes in behaviour being lost.

<sup>81</sup> <https://bit.ly/soli-credits> (source: socialcapitalresearch.com; retrieved: 27 October 2021)

*Control is necessary when there was previously no trust in the system.*

Prof. Markus Freitag, political scientist, University of Bern

However, strict controls could also disempower people and undermine responsibility and solidarity. This would be the case in particular when it comes to micro-management of behaviour (see the “Big Government” and “Big Business” scenarios), although this micro-management would not even be necessary as people would behave in a responsible manner anyway.

Instead of leading healthy lives or showing solidarity, it is then only a matter of maximising one’s characteristic values. What is not recorded by the system the system then does not exist and is not done. This would mean that a new sport that is attractive per se might not catch on if it cannot be easily documented digitally. On the other hand, a black market for unhealthy products could emerge that manages to escape digital control.

*Any attempt to quantify processes ultimately results in unmanageable complexity. Ultimately, it is almost impossible to map qualitative processes metrically in order to completely capture them.*

Prof. Stefan Selke, Chair of “Social Change” and “Transformative & Public Science”, Furtwangen University of Applied Sciences

## Development towards more tolerant conditions for solidarity

Digital control of personal health or behavioural data would probably meet with resistance in Switzerland. On the one hand, there is a mistrust of government interventions of a centralistic character. Compared to neighbouring countries, the COVID measures imposed in Switzerland were the most liberal. On the other hand, people also do not want to give private companies too much power over data. For example, in a trend analysis prior to the e-ID referendum, which was rejected in March 2020, 82% of Swiss respondents expressed the opinion that an electronic ID should not be entrusted to private parties.<sup>82</sup> The mistrust of giving private companies too much power over data could also be reflected in the healthcare sector. So far, despite known differences in health costs between groups (e.g. people with diabetes costing more than they pay in), a solidarity principle has been maintained in basic insurance. Any attempts to water this down would be described as opening the floodgates and would probably be difficult to implement.

However, the datafication of health also allows a development towards more tolerant conditions for solidarity, more solidarity overall and less need for (external) control. Better predictions of health trajectories enable better individual decisions and prevent diseases. The opportunity to receive feedback on one’s own behaviour can also promote healthy behaviour. Experiments have shown, for example, that people eat more when the leftovers are put away while they are still eating – in other words, when they cannot see how much they have already eaten.<sup>83</sup> This purely personal feedback can also take place in

the digital sphere and can result in healthier behaviour. This means that external control of behaviour becomes less necessary.

Since data is not a scarce commodity - it can be copied an infinite number of times and does not get worn out through use - sharing data entails relatively few costs, but on the other hand provides great benefits ("Big Community" scenario). This means it opens up new fields of how to act in solidarity, and it enables a much more accurate understanding of health of health and the factors that affect it. This better understanding could lead to illnesses being less associated with personal culpability (see page X). Instead of imposing conditions on solidarity, public health interventions would preventively address the determinants of health on a non-individual level and enable healthier lives for many.

### **The impact of tolerant conditions and a low level of control on solidarity**

Unconditional solidarity can empower people to be responsible and act with solidarity themselves. If, for example, homeless people suffering from alcohol addiction are provided with accommodation, they are more likely to overcome their alcohol addiction and find a job than if the accommodation is conditional on abstinence.<sup>84</sup> When people do not have to fear that the disclosure of their data will lead to them being controlled and disadvantaged, they are much more willing to show data solidarity and help other people be healthy in citizen science projects.

*Patient groups deciding collectively on the use of their data demonstrate how a community is created that goes beyond individual benefits.*

Dr. Bastian Greshake Tzovaras, Director of Research,  
Open Humans

But maybe control is also necessary because people need clear boundaries and sanctions for misconduct in order to show solidarity and be responsible. Too much tolerance and too little control would then tend to lead to misuse and dependencies. If the number of those taking advantage of the system were too large, a society would no longer be willing to support such a solidarity system. Few conditions for solidarity would ultimately cause the solidarity system to collapse.

<sup>82</sup> <https://bit.ly/soli-trend> (source: cockpit.gfsbern.ch; retrieved: 27 October 2021)

<sup>83</sup> Wansink, B., & Payne, C. R. (2007). Counting bones: environmental cues that decrease food intake. *Perceptual and Motor Skills*, 104(1), 273-276.

<sup>84</sup> Kirst, M., Zerger, S., Misir, V., Hwang, S., & Stergiopoulos, V. (2015). The impact of a Housing First randomized controlled trial on substance use problems among homeless individuals with mental illness. *Drug and alcohol dependence*, 146, 24-29.

## Conclusion

In the previous chapter, we outlined how the Swiss healthcare system may develop in the future. Is it heading in a direction where there are strict conditions for participation in the solidarity system and compliance is checked with digital tools? Or will solidarity conditions become even more tolerant because it is assumed that people are capable of healthy behaviour themselves and technology should enable them to do so, but not control them? The impact of strict or tolerant conditions for solidarity was also discussed. If solidarity conditions are too strict and if there is more control than necessary (i.e. when people would act responsibly and in solidarity even without them), individual responsibility is undermined. This would lead to a focus on the optimisation of characteristic values instead of doing what is considered sensible. If, on the other hand, solidarity conditions are too tolerant and there is little control, this can lead to misuse and the collapse of the solidarity system (see Table 3).

But what does “too strict” or “too tolerant” mean? How strict should conditions be, how much control is actually necessary? What is the right level of conditions and control? It depends on the individual view of humanity how you personally assess this. According to a 2019 study by the Ergo insurance group, for example, one in five Germans would approve of the introduction of a social credit score based on the Chinese model.<sup>85</sup> These people have a different view of humanity, than advocates of an unconditional basic income, for example.

It is interesting that many see themselves as solidary and trustworthy, but do not see their fellow human beings in the same positive light. Concerning the unconditional basic income, for example, most believe like to think that

they themselves would continue to work anyway, while assuming of most others that they would not make much of an effort any longer if the received money without any conditions attached.<sup>86</sup> Similar attitudes can be found regarding the healthcare sector. Most participants in the German “Vermächtnisstudie” [Legacy Study] rate themselves as more health-conscious than most others.<sup>87</sup> The Swiss survey “Datengesellschaft und Solidarität” already referred to several times above comes to a similar result. Only 15% of respondents think they pay less attention to a healthy lifestyle than others their age. Do people overestimate themselves or do they underestimate their fellow human beings?

Underestimating other people can destroy potential, because views of humanity are often self-fulfilling prophecies. If people’s own responsibility is diminished by strict controls, the control in turn seems appropriate in view of the low level of responsibility (caused by control). This is true in particular if you trust people too little and control them a lot, because you then never realise that more trust and less control would be possible.

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<sup>85</sup> ERGO Group AG (2019): ERGO Risiko-Report 2019. Über die Risikokompetenz und Eigenverantwortung der Deutschen, München. <https://www.ergo.com/de/Microsites/RisikoReport/Start/Digitalisierung>

<sup>86</sup> <https://bit.ly/soli-einkommen> (source: mein-grundeinkommen.de; retrieved: 27 October 2021)

<sup>87</sup> Allmendinger, J., & Wetzel, J. (2020). Die Vertrauensfrage. Für eine neue Politik des Zusammenhalts, Berlin: Duden.



Impact of low and high levels of control with high and low needs for control

Control	High level	Disenfranchisement, optimisation of measured values	Increase in solidarity
	Low level	Voluntary solidarity	Misuse, collapse of solidarity
		Low	High
		Need for control	

Table 3, Source: GDI 2021

But more trust and less control can pay off. Examples like the one mentioned earlier (see page X) about homeless people with alcohol issues demonstrate this. They are more likely to overcome their alcohol addiction if you provide them with accommodation without setting any conditions than if you demand abstinence first and offer accommodation as an incentive. Contrary to the widespread cliché that donated money would be used to buy alcohol, money provided to development cooperation projects without any conditions attached actually results in a reduction of alcohol consumption by the recipients.<sup>88</sup> Dutch care organisation Buurtzorg (see page X) shows that it is also possible to simply trust caregivers to do their job well instead of forcing them to meticulously register all care steps and perhaps monitor them with sophisticated technology in the future.

## Framework conditions for tolerant solidarity

The proper degree of control and solidarity conditions is not a fixed parameter that needs to be found, but something that can be influenced. What does it take for a development towards more tolerant conditions for solidarity, as described in the “Big Self” or “Big Community” scenarios, to become possible? What institu-

tional conditions are necessary? Several such examples were mentioned in the scenarios. The two main directions are:

- > Empowering individuals to use health data
- > Promoting the readiness to share data

### Empowering individuals to use health data

In the scenarios with few conditions, i.e. also little behavioural control, people need to lead healthy lives of their own accord. Health data can help with this, whether in the form of predictions or feedback on one's own behaviour through self-monitoring. This is primarily because, as the volume of data continues to grow, the ability to classify and understand this data becomes more and more important.

<sup>88</sup> Evans, D. K., & Popova, A. (2017). Cash transfers and temptation goods. *Economic Development and Cultural Change*, 65(2), 189-221.

Consequently, to enable the scenarios with tolerant conditions for solidarity, the *promotion of health and data literacy* is necessary. The important notions here are “health literacy” and “data literacy”. People need to learn to read statistics, interpret probabilities, understand the importance of data sharing and the risks involved (see page X). In addition, health literacy is necessary, for example, to be able to imagine what a prognosis for adult-onset diabetes even means. Despite datafication, it is important to learn to read body signals, for example to sense when you have eaten enough. This capacity for introspection can be trained that to datafication and does not necessarily have to be replaced by it. These competences can and should be taught by various institutions, be it school, one’s family physician, one’s insurance company, the workplace, citizen science communities or other online forums.

People need sufficient *resources* (material, time-related, mental) to be able to deal with their health data in the first place and then act on it (see page x). To support this, the government can fight poverty, for example. Employers can offer opportunities for exercise, such as yoga classes at work, retailers can communicate nutritional values of food in an easily understandable way.

In order for people to care about their health in a responsible manner, they must also be treated as responsible citizens and *provided with transparent information*. A negative example in this regard was when masks were falsely labelled as useless by officials at the beginning of the pandemic to prevent panic buying of masks.<sup>89</sup>

### **Promoting the readiness to share data**

The scenarios with a high degree of control have the advantage that a lot of data is collected and aggregated, which is valuable for science, the economy and for public health measures. In the scenarios with little control, on the other hand, voluntary data donations must be promoted in order to harness the wealth of health data.

Those who share their data need first and foremost the confidence that they will not suffer any disadvantages as a result. This requires clear *data protection guidelines* and knowledge of them by the population. In case there is a data leak and/or personal data is misused, people need to know how and where they can get help. *Data discrimination insurance* (see page x) would be a possible institution to help and compensate victims of discrimination. The creation of *data cooperatives* (see page x) could be supported through start-up funding by the government, companies or foundations to give people more control over their own data.

People will not share their data if do not see an advantage in it for themselves and/or society. This is particularly true if others seem to be making a profit from their data. Those who make their data available for research will find the resulting scientific articles in journals that are difficult for private individuals – and not in *open access journals* (see page x). Or the data is used for the development of medicines which are strictly protected by *patents* and very expensive (see page x). Often, promising trial data is not released even if it did not lead to the devel-

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<sup>89</sup> <https://bit.ly/soli-bag> (source: nzz.ch; retrieved: 27 October 2021)

opment of any new medicines, although others could continue to use it for research on them – to the benefit of all.<sup>90</sup> Those who expect people to share data should set a good example themselves. The government, companies and the scientific community should make more *open data available* to the general public, be it data on air quality, publication in open access journals including the publication of raw data or information on the ecological footprint of individual products in a standardised, open data format.

Last but not least, *use cases and success stories* should be communicated about the ways in which data can be used to benefit individual persons themselves and others (see page x). This is the task of all actors in the data society – scientists, companies, the government, the media as well as individuals.

## Contextualizing trends and political demands

For most people, solidarity is not the dominant feeling when the health insurance contribution are payed. A different perspective emerges when the solidarity system is placed in a larger context. When comparing it to the American health care system, it may well be that Europeans are proud that mothers do not have to return to work two weeks after giving birth or that mentally ill people do not end up on the street.

For this reason, it is important to place individual political demands as well as technological developments in a larger context and to consider what effects they might have and what images of humanity they are based on. Contextualizing trends and political demands on the basis of the scenarios does not mean, of course, that every state intervention will necessarily end in a total surveillance state and every liberalization in the complete erosion of all solidarity. But these are dangers that need to be kept in mind and for which this study offers a framework. It should help to facilitate the discussion about what is and what could be, what is desirable and what is not, and with what mix of the four scenarios and which underlying image of humanity the datafied healthcare system of the future should be designed together.

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<sup>90</sup> <https://bit.ly/soli-pfizer> (source: washingtonpost.com; retrieved: 27 October 2021)

## Experts

The following experts contributed to the success of the study through interviews, discussions and feedback. Their ideas are incorporated throughout the text and not only in the passages where they are quoted. We thank them for sharing their valuable experience with us.

**Dr. Alessandro Blasimme**, bioethicist, ETH Zurich

**Dr. Luca Chiapperino**, Lecturer in Science and Technology Studies, University of Lausanne

**Dr. Katrin Cramer**, Director Personalized Health Informatics and Director SPHN Data Coordination Center, Swiss Institute for Bioinformatics

**Cornelia Diethelm**, Center for Digital Responsibility

**Prof. Markus Freitag**, political scientist, University of Bern

**Dr. Andrea Gerfin**, Sanitas health insurance foundation

**André Gollietz**, Founding Partner Zetamind AG and president of the Swiss Data Alliance

**Dr. Bastian Greshake Tzovaras**, Director of Research, Open Humans

**Prof. Ernst Hafen**, ETH Zürich

**Isabel Knobel**, Co-Head Europe Program, Foraus

**Antti Piirainen**, Findata

**Prof. Barbara Prainsack**, political scientist, University of Vienna

**Prof. Stefan Selke**, Chair of “Social Change” and “Transformative & Public Science”, Furtwangen University of Applied Sciences

**Dr. Isabelle Vautravers**, Sanitas health insurance foundation

**Stefan Wild**, board member, pharmaSuisse

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**Dr. Isabelle Baur**, Research assistant, Kompetenzzentrum Medizin - Ethik - Recht Helvetiae. University of Zürich

**Sigrid Beer-Borst**, Research Associate, Disease Registry Section, Federal Office of Public Health

**Prof. Dr. Andréa Belliger**, Institute for Communication and Leadership IKF

**Philip Bessermann**, Project Manager, Sensor Advice

**Adrian Demleitner**, Scientific Software Developer in Digital Humanities, University of Basel

**Dominik Fässler**, Project Manager, Gesundheitsförderung Schweiz

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