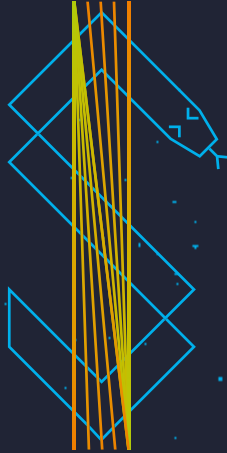


2022
SALON SANTÉ



THE *FLUID* PATIENT

REDEFINING HOLISTIC
HEALTHCARE NEEDS

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STATUS QUO

The healthcare system of the future will be person-centred. Advances in precision medicine and access to medical data are opening up new ways to personalise the treatment of complex diseases. Systematic evaluation of clinical treatment results serves as the basis for ensuring and improving the quality of therapy.

Yet this evaluation means extending the focus beyond disease to adapt healthcare to meet the requirements of the 21st century. As the scope of 'unmet medical need' increases, the healthcare system and society in general will not only have to deal with challenging infectious diseases and age-related degenerative disorders, but also with conditions arising from people's lifestyle and environment.

At the same time, we need to assess quality related to these requirements. When it comes to mental disorders or non-communicable diseases, we must define and record biomedical criteria as well as emotional and social factors as integral components of health. A holistic understanding of health involves not only treating diseases, but also promoting a healthy lifestyle, warding off disease through prevention, and offering needs-based palliative care in patients' final stage of life. In contrast to the traditional approach, prevention will increasingly become a key factor in the healthcare

system. The focus will no longer be primarily on clinical centres, but rather on everyday care.

Another key aspect involves understanding patients' needs. Regaining health requires more than static models based on unchanging needs. A future-oriented understanding of health must therefore not only take multiple dimensions of health into account, but even more, consider the momentum with which requirements change. These requirements change over the course of a person's life depending on their health status. This means that quality assessment can no longer be based on a static, crystalline model, but must consider 'fluid patients'. This requires different quality indicators to be taken into account.

With increasing ways to quantify our health status and behaviour digitally, new prospects are emerging for determining and measuring needs. Today, a vision of holistic measurement and quality control of treatments is at the focus of these efforts. This vision is connected with some challenges, however. Not all quality criteria can be recorded using traditional medical diagnostics. On the other hand, when it comes to complex disease presentations for which the requirements also change over time, it is often impossible to draw clear conclusions about requirements.

When designing a future-oriented healthcare system that is consistently person-centred, three key questions arise:

- 1 What criteria and data can and should be recorded to assess a person's health status – and the quality of medical services?
- 2 How can and should everyday life be included in these assessments?
- 3 What roles and responsibilities emerge from the focus on 'fluid' patients?

These questions were at the focus of the 2022 Salon Santé event, which was organised jointly by Interpharma and Think Tank W.I.R.E. As the starting point for debating the requirements associated with 'fluid patients', the scientific principles for quality assessment were summarised using a holistic definition of health from the literature and were discussed in detail with international experts. The resulting analyses were used to draw up ideas for dealing with changing patient needs. These ideas were then examined in greater detail and expounded upon with the Salon Santé participants. This document summarises the key findings, aiming to share the key future debates related to all aspects of the healthcare system of the future with additional experts, decision-makers, policy-makers and the general public.

FUNDAMENTALS

MEASURING
HEALTH
DYNAMICALLY

To evaluate the quality of medical services, we first need criteria we can use to evaluate the success of a therapy or intervention. Traditionally, these quality criteria have been geared towards evidence-based clinical data. But the benefit of an intervention that can be proven by way of statistics does not necessarily provide added value that is perceived by the patient. For instance, an oncological therapy may positively impact the development of a tumour, but negatively affect the patient's emotional state. Traditionally, such influences have not been recorded, or not to a great enough extent. This is because service providers have not paid enough attention to factors benefiting the patient's subjective point of view, considering them instead to be non-evidence-based sources of data. However, in reality, this discrepancy between the proven and perceived benefits of treatment often leads to dissatisfied patients, additional follow-up examinations and treatments and ultimately to higher costs.

Principles of quality assessment in medicine

The concept of value-based healthcare (VBHC),¹ as originally proposed by Porter and Teisberg, offers a way to optimise patient benefits. VBHC involves measuring the quality of patient-related treatment results and correlating them with the costs for achieving these results along the treatment pathway. With VBHC, patient-reported outcome measures (PROMs) are mainly used to measure patients' subjective perspective of their health status and the quality of results and intervention. PROMs have recently been extended to include patient-reported experience measures (PREMS),² which are based on validated questionnaires filled in by patients and used to complement the evidence-based clinical data, or clinician-reported outcomes (CROs).² While PROMS depict the patient's treatment-related health status, PREMS focus on process-oriented patient experiences of a treatment, such as communication with medical and nursing staff, waiting time, coordination and the discharge process.²

Projects for introducing PROMS are under way throughout Europe, primarily in the fields of oncology and orthopaedics.² Yet no healthcare systems to date have implemented PROMs across the board for basic healthcare. Throughout the world, there are similar obstacles when putting PROMs into practice in everyday clinical routine,³ such as the fact that questionnaires fail to focus on patients because they are too long or complex.³

An important topic missing in VBHC-based outcome measurement is the recording and integration of external health determinants, which comprise all health-related risk factors. These include a person's genetics, as well as their social and economic environment, their physical surroundings, and their individual characteristics and behaviours.⁴ A distinction can be made between internal and external health determinants: internal determinants include a person's individual genetic predisposition, which still today cannot be influenced by highly invasive interventions in their genetic make-up or can be influenced to only a very limited extent. External health determinants concern the external living conditions in which we live, including air and water quality and even infrastructure. A society can control its living conditions to some extent by adapting the environment or its individual behaviours in order to reduce and prevent risks or actively promote health. Without the integration of these non-therapy-related determinants in medical databases, however, there is an overall risk of bias and misinterpretation of treatment results.⁵

Using digital solutions to measure health in depth

PROMS are an important component of quality assessment when the aim is to make healthcare delivery person-centred. In view of the future, possibilities for involving patients through the use of digital solutions will become even more widespread, making assessment even easier and more effective. This

gives rise to a further component of a data-based healthcare system integrating both clinical data and individual needs and requirements.

The COVID-19 pandemic has made people more willing to measure themselves. Along with the availability of tracking applications in smartphones, opportunities will emerge for systematically recording individual preferences in future. Comparing the healthcare scene with markets for consumer goods shows that with feedback and relevant preference-related data, personalised offers can be created that bring about identifiable benefits for customers. Online shops use such data to create precise profiles of customers and their needs and develop personalised offers. In other industries, too, this data is becoming increasingly valuable for future business models. For instance, a growing number of insurance companies are using behaviour-related data to more accurately assess the risks of their customers – and reflect behaviours in their insurance policies.

Technology giants are the drivers of the growing digital health service delivery sector, investing some USD 4 billion in 2021 alone.⁶ Since 2017, the FDA has approved more than 40 health apps reviewed under the rules for medical devices.⁷ They claim to help with problems including addiction, diabetes, back pain, anxiety, ADHD and asthma. In addition, digital applications are also already being used to record PROMs and prove their efficacy, as well as for self-management and therapy management.⁸ Solutions such as these for identifying and assessing individual risks and patients' health status have the potential to promote patient-centred care if they can be aptly interfaced with established healthcare structures and payment models.

Limits of quantification

When taking a holistic perspective of the opportunities and limitations of individual measurement and the change

requirements of fluid patients, we must keep in mind several limitations.

People's lack of or low level of willingness to undergo continuous measurement

- Longitudinal data recording requires people to commit to undergoing regular measurements both when they are healthy and when they are unwell. It is already hard enough to convince patients to answer lengthy questionnaires when they are in hospital. If this is already the case in a clinical setting, then extensive, systematic recording of the people's everyday health status is unlikely to garner widespread acceptance.

High complexity and costs for deriving relevant data findings

- In-depth data recording does not automatically translate into more benefits or more accurate findings. When dealing with complex systems, for instance when observing the influence of nutrition on health or for multifactorial conditions, in many cases no clear-cut correlations can be determined. In addition, recording, collecting and processing quality-tested data is time-consuming, cost-intensive and in many cases not reimbursed.

Limits of standardisation

- Not all quality indicators can be measured or standardised or can be subject to uniform assessment through individual perception. In particular, for certain emotional or social impact factors, no generally valid criteria can be determined. At the same time, a highly specific outcome measurement makes analysing data at the collective level more difficult for comparing benchmarks and defining suggestions for improvement.

Ethical risks of total surveillance

- The meticulous collection of everyday data gives rise to the risk of compromised privacy or misuse. China's social scoring system shows how comprehensive measurement of individual behaviour purportedly leads to more security, but first and foremost accounts for control. Applications in democratic systems also have these risks, albeit to a lesser extent.

Ethical and medical risks of overdiagnosis

- The ongoing trend of overdiagnosis through overdetection is leading to too many irrelevant diagnoses for a person today.⁹ This is continually shifting intervention thresholds towards disease, which in turn causes more and more people to be overtreated and medicalised.⁹ The result is not just unfair distribution of limited resources within the healthcare system, but also a risk for patients themselves.⁹

It is neither feasible nor desirable to completely capture all of a person's health indicators. The increasing individual 'measurement burden' is at the focus, which is becoming a growing burden for patients and citizens of a digital society. Continuous measurement calls for a high level of discipline and threatens to become unwanted surveillance with a loss of privacy. The promises of more accurate prognoses and better health through comprehensive measurement are only valid to a limited extent, because predictive medicine is unable to deliver unequivocal correlations due to the complexity of chronic multimorbidities and because of the risk of overdiagnosis, which labels ever more people as ill.

It is important to develop a realistic target that takes future expectations for the multi-dimensional and changing needs of fluid patients into account, while also allowing for practical application.

SOLUTION

ESTABLISHING
HORIZONTAL
PRECISION
MEDICINE

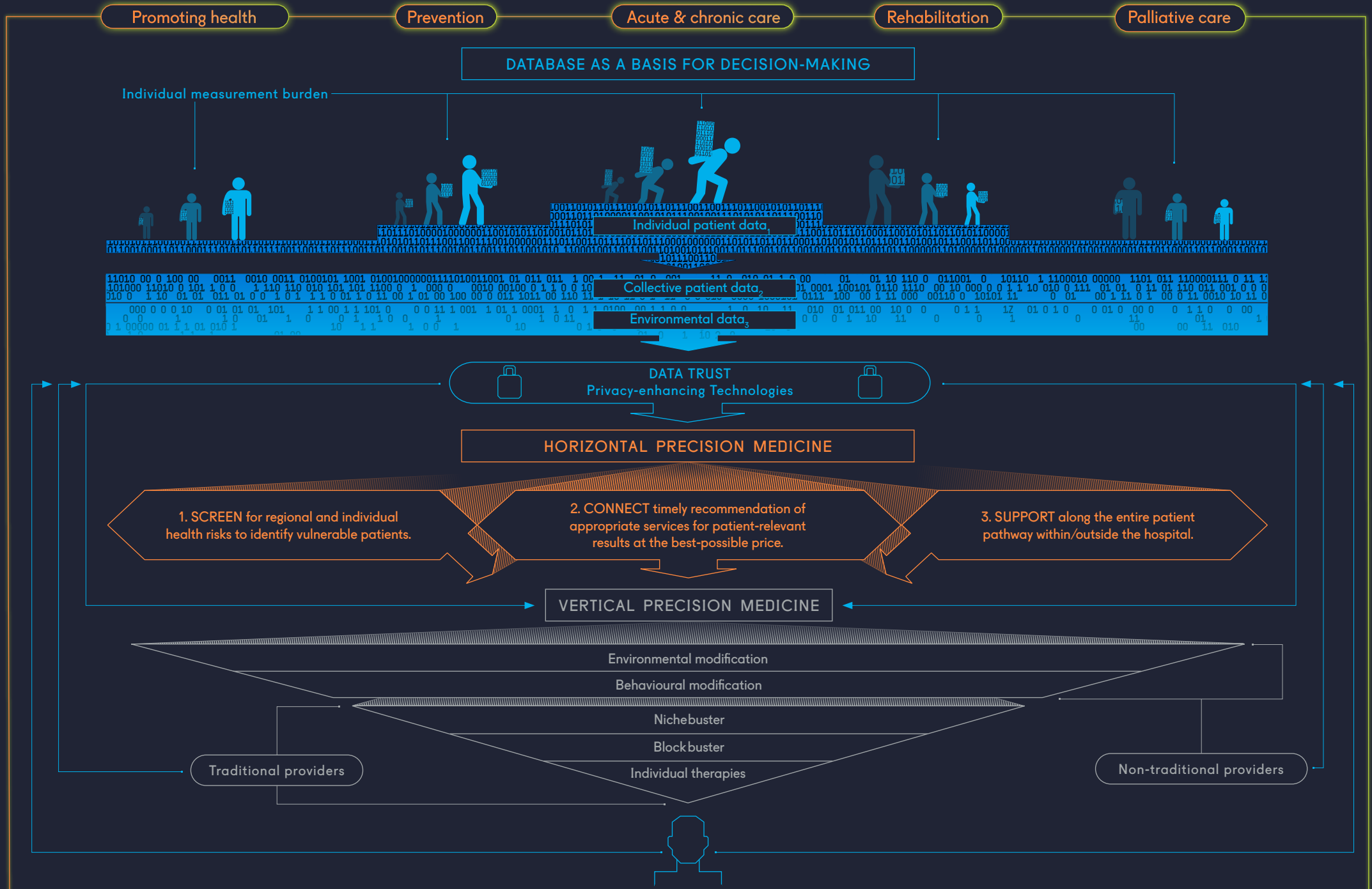
When designing a future-oriented healthcare system, we need to systematically assess the requirements of fluid patients, while also defining principles that meet economic and ethical requirements.

In addition to the established research focus on 'vertical' precision medicine, which investigates individual isolated health functions in the individual disease areas in ever greater detail, we need in-depth understanding of how processes in a health continuum are horizontally interrelated among different functions such as health promotion and disease prevention, recovery, rehabilitation and palliative care.

'Horizontal precision medicine' thus aims to find the right combination of therapy for the right patient at the right time and at the right price along the entire health continuum. This requires in-depth understanding of both how the quality of medical care can be measured along the different health functions and how dynamic needs change in the transitions between health functions and life stages. This type of system is based on the consistent collection and integration of key medical data in an electronic health record with interoperable datasets, which enables different users access to the data – provided the data owners have given their consent. To this end, 'data trust' structures could play an important role. These structures enable secure storage of data as well as regulated and controlled sharing of data if desired.

To meet the future requirements of fluid patients, and deploy the available resources in the long term, we have identified three areas of activity.

CONCEPT OF HORIZONTAL PRECISION MEDICINE AND OPTIMISED MEASUREMENT BURDEN



1. Medical data, genetics, socio-economic data, behaviour data. 2. Anonymised for secondary data use. 3. For example, heat waves and wastewater composition



Minimising the individual measurement burden

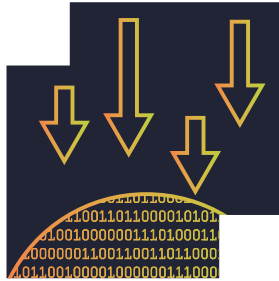
Selective rather than exhaustive data capture focusing on health-related data that provides benefits as the basis for efficiency and added value for patients.

Longitudinal data recording requires people to regularly have themselves measured both when they are healthy and when they are unwell. However, even in a clinical setting, adherence is a huge challenge. People have no desire to fill in time-consuming questionnaires that do not make them feel they will get the help they need. If this is already the case in a clinical setting, then extensive, systematic recording of people's everyday health status is unlikely to garner widespread acceptance. Another problem that results from in-depth data collection and has a negative effect on society is the ongoing trend towards overdetection, with the risk that too many and irrelevant diagnoses will be made, causing more and more people to be overtreated and medicalised. Such overdiagnosis leads to inequitable distribution of limited resources within the healthcare system and in many cases, poses a risk for the patients themselves.⁹ These developments actually harm the entire population by counteracting efforts to achieve high-quality yet affordable healthcare.

To this end, the fundamental notion of current data strategies must be adapted to minimise the measurement burden for people rather than maximise measurement. This can be achieved in three steps: first, we have to selectively use only data types for which there is a clear correlation to an impact on a person's health status. These filtered findings should be integrated from research on an ongoing basis. Second, priorities need to be shifted from 'generating even more data' to 'using existing data more expediently', because a huge range of data already exists globally. This is important, so we can lay the foundations of the process for creating and evaluating data value in a structured and benefit-oriented manner before burdening people with uncontrolled data collection that delivers only marginal benefits. Third, data should be used which is collected unobtrusively and nearly automatically when people interact with digital services and products, such as when they pay for products in the supermarket or when they use digital health applications or wearables. However, it is essential that data is only collected in this way if users have explicitly granted their consent.

"If we want to engage people in measurement, we need measures that are simple, actionable, and meaningfully focused on patients. We need to ask if people are getting well or more able. We need to ask people if their health care is improving their health and life. We can do this by asking about Capability, Comfort, and Calm. If we ask people too many things, or if we ask questions that aren't really about their health goals, they won't answer."

Dr. Elizabeth Teisberg



Keep external risk factors in mind

Recording and integrating external health determinants helps detect health risks early on without monitoring people.

In addition to assessing individual risks identified by medical diagnoses, environmental factors should be systematically taken into account. Systematic recording of demographic, socio-economic or geographic contexts helps identify external risk factors at an early stage. For example, heat waves in cities, noise emissions or the density of fast-food chains can be translated into local risk landscapes. This type of mapping would enable us to identify regions with population groups that are at risk and underserved and to achieve relevant targeted measures for health promotion and prevention by adapting behaviour or the surroundings.

Including such data gives rise to three major benefits: first, people can optimise their health through customised behavioural adaptation, in so doing keeping their individual measurement burden to a minimum. Second, the general risk of biases and misinterpretation of treatment results can be minimised by linking up such non-therapy-related determinants with medical databases. Third, the data enables us to identify the population groups with the poorest health, which not only promotes fair and efficient use of existing resources, but also

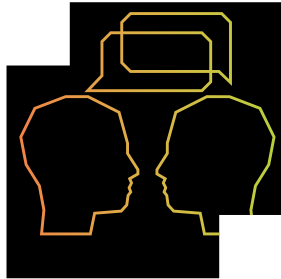
ensures that funds are used to maximum effect in order to improve the average health of the overall population.

In the future, such data could even be used to create individual 'digital twin' models that, coupled with existing data on an individual's state of health, provide personal recommendations – without needing people to be digitally monitored.

By detecting external risks and the associated future requirements for the healthcare system early and systematically, we can therefore make health services and products more proactive and user-oriented and promote fair and efficient use of existing resources.

“What we need is an aggregation of individualised and anonymised external health determinants and possibly a new relationship to data privacy.”

Dr. Med. Florian Rüter



Establishing human coordination and translation

New health professionals known as 'Health NATRAS' (health navigators and translators) help translate and integrate patients' needs for digital systems, acting as navigators and providing support along treatment pathways across the entire health continuum.

Humans are often able to correctly interpret conditions that are difficult to put into words, such as well-being or feelings, because they draw on their experience and knowledge. Machines, however, can only act correctly if information is clear. The limits of digital solutions become obvious, for example, when it comes to describing ambivalent experiences after a medical procedure. The context of the experience will still have to be recognised and interpreted through interpersonal relationships in the future, for example during personal evaluations and consultations at home. In view of the limitations of digital assistance systems, these findings must be translated into clear information models so results can be depicted correctly. In a final step, findings obtained in this manner must not only be stripped of medical jargon and explained in a way patients can understand, but must also be coupled with recommendations they can put into practice in their everyday lives. This enables efficient coordination, where patients are connected to the right health providers

and they feel that they are receiving the help they need at the right moment.

Interface functions such as this, with translation and coordination responsibilities, should be designed by a new group of health professionals known as 'Health NATRAS', who combine the strengths of digital tools with human engagement and emotional relationship building. This permits us to capture quality more accurately, provide human help and guidance at the right moment and ensure that this is maintained over the longer term across different treatment pathways and stages of life. NATRAS improve the efficiency of the overall system by acting as coaches who take the time to help patients navigate the healthcare system efficiently and provide long-term consultation, but also deftly interweave, simplify and stabilise digital and analogue processes at human-machine interfaces.

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Salon Santé promotes interdisciplinary dialogue to help the Swiss healthcare system evolve and advance innovations in society, research and policy-making. A select group of decision-makers, managers and experts take part in the event as thought leaders for further development of the Swiss healthcare system. The dialogue is conducted under the Chatham House Rule.

The annual event focuses on new trends and technologies with the potential to fundamentally change the structures of the Swiss healthcare system. The dialogue will make a key contribution to shaping the further development of the healthcare system through detailed understanding of future health needs. It thus serves as the foundation for sustainably handling the future challenges and opportunities in the healthcare system.

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