

SALON SANTÉ

CTRL	SHRE	DEL
CONTROL	SHARE	DELETE

UNLOCKING THE VALUE OF HEALTH DATA

QUOTES

»Data sharing makes it possible to replace the control arm (placebo group) with real-world data in clinical trials.«

»The transparency that comes with sharing data may not be desired by some stakeholders, as it enables control of services (e.g. doctors).«

»Sharing data enables early intervention through protective measures to prevent a potential outbreak of diseases.«

»People are too lazy to actively share their data. An opt-out solution would be an efficient approach.«

»There is a lack of cooperatively developed open standards – ideally managed by a neutral non-profit organization.«

»Providers must allow digitally enabled decision-making as it is central to demonstrating the benefits of shared data through use cases.«

»There is an international absence of data coding/standardization. For example, the same drug is named differently in different countries. For Switzerland, international integration seems important.«

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Switzerland's healthcare system is in a state of upheaval. An increase in chronic diseases, the need to manage infectious diseases, digital transformation requirements, and changing values of the 21st century are presenting new challenges to existing structures and players – to the healthcare system itself, but also to patients and citizens.

This is where the Salon Santé comes in. It has facilitated a future-oriented, interdisciplinary dialogue about future framework conditions, opportunities, and challenges regarding sustainable innovation in the Swiss healthcare system. Following the 18th- and 19th-century salon culture, the Salon Santé has promoted direct dialogue as

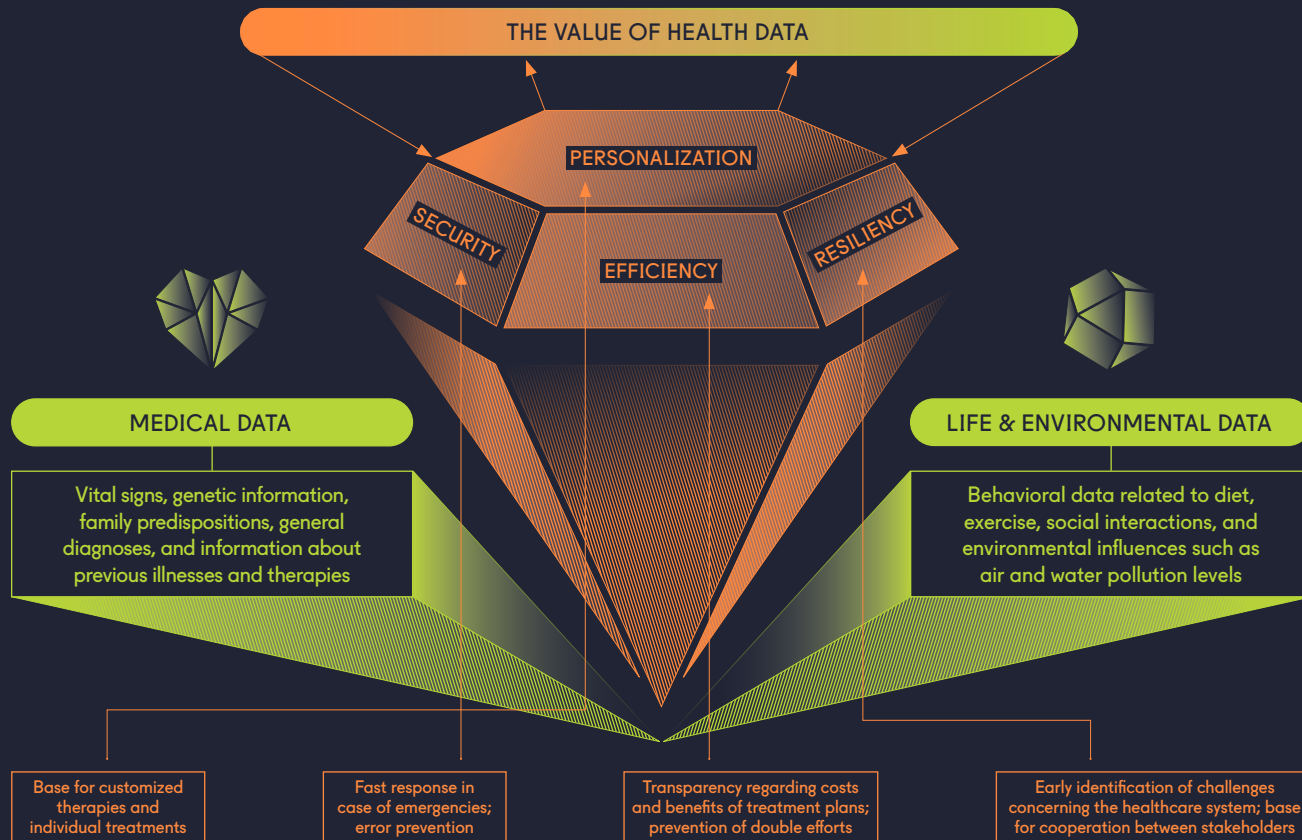
a counter position to the current virtualization of social exchanges.

A selected group of decision makers, scientists, politicians, thought leaders, and doers from life science, medicine, insurance, and other industries have met to shape the future of healthcare. They have assessed opportunities and risks while searching for overarching ideas and solutions for the Swiss healthcare ecosystem of the 21st century.

The Salon Santé has been an initiative of Interpharma in collaboration with the think tank W.I.R.E.

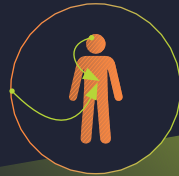
BASELINE

THE HEALTHCARE SYSTEM IS BECOMING MORE DATA-DRIVEN. HUMAN HEALTH HAS PROVEN ITSELF TO BE A DYNAMIC VARIABLE IN A CONSTANT AND MULTI-FACTORIAL STATE OF CHANGE. THEREFORE, ALL DATA CAN POTENTIALLY BE HEALTH DATA AND SERVE AS THE FOUNDATION FOR GREATER PERSONALIZATION, EFFICIENCY, SAFETY, AND RESILIENCY.



OBJECTIVE

A SIGNIFICANT PART OF THE DATA'S VALUE IS, HOWEVER, ONLY REVEALED BY LINKING INDIVIDUAL DATA, EMBEDDING IT INTO HEALTH TRAJECTORIES OVER TIME, AND BUNDLING IT INTO COLLECTIVE SETS.



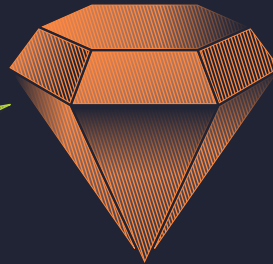
COMBINING MEDICAL, LIFESTYLE, AND ENVIRONMENTAL DATA

Snapshot of the overall health status

By linking vital data with genetic predispositions, dietary as well as exercise habits, and pollution levels at the place of residence, correlations to diseases and health developments can be determined.

ADDED VALUE: personalized treatments, safety through transparency

Data ownership: individual person



JOINING INDIVIDUAL DATA TO COLLECTIVE DATA SETS

Comparison of health development between individuals and groups

By associating individual data to collective data sets, health developments can be compared between individuals and groups.

ADDED VALUE: recognition of overlapping patterns, important base for rare diseases, further utilization for public health

Data ownership: the collective



TEMPORAL LINKING OF MEDICAL, LIFESTYLE, AND ENVIRONMENTAL DATA

Long-term tracking regarding the overall health status

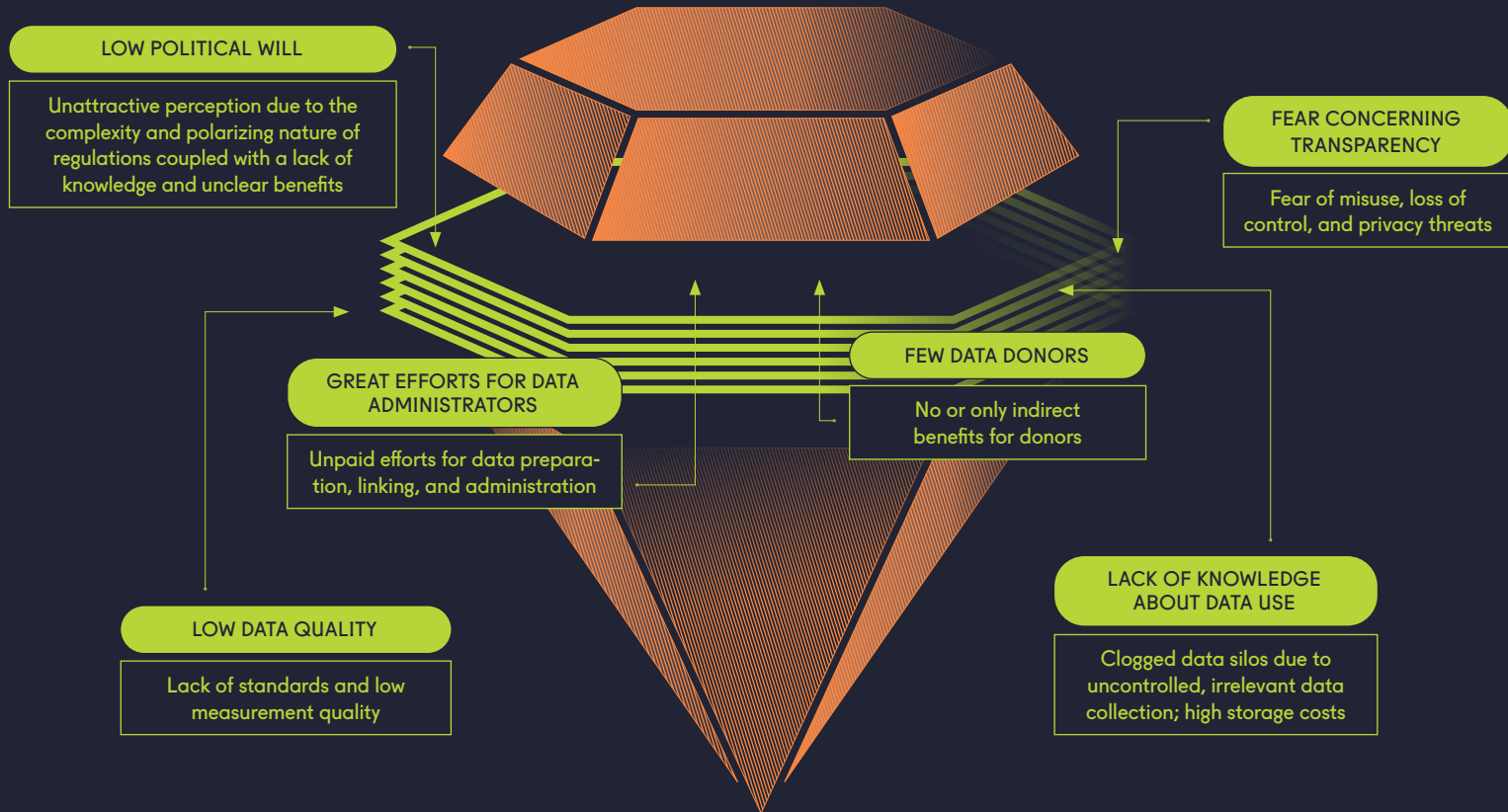
By analyzing the change of various health determinants (vital signs, behavior, and environmental factors) over time, insights can be gained.

ADDED VALUE: understanding long-term consequences, central base for preventive measures and therapies

Data ownership: individual person

BARRIERS

LOSS OF CONTROL, FEAR OF TRANSPARENCY, A LACK OF FRAMEWORK CONDITIONS, AND AN UNCLEAR COST-BENEFIT RATIO MAKE IT DIFFICULT OR IMPOSSIBLE TO SHARE, LINK, AND STORE DATA.



POSSIBLE SOLUTIONS

TO EXPLOIT THE VALUE OF HEALTH DATA AND CREATE A FUTURE-ORIENTED HEALTHCARE SYSTEM IN THE MEDIUM AND LONG TERM, NEW REGULATORY, ECONOMIC, AND TECHNICAL FOUNDATIONS ARE NEEDED.

1.



ENABLING ACCESS TO A CENTRAL, OPEN DATA INFRASTRUCTURE

- Designing a secure and centralized technical infrastructure by private or public organizations to maintain and increase data quality and interoperability
- Fostering purposeful and temporary data access with guaranteed privacy, transparency, and individual or collective control

2.



EMPOWERING CONTROL OVER DATA THROUGH A REGULATORY FRAMEWORK TARGETING RIGHTS, RESPONSIBILITIES, ETHICS, AND SECURITY

- Developing regulations, laws, and policies on data privacy to prevent misuse, discrimination, and unethical use
- Finding a balance between individual rights and collective benefits such as a possible responsibility to share data as part of the collective good

3.



USING INCENTIVE SYSTEMS TO SHARE, LINK, AND ADMINISTER DATA FOR INDIVIDUALS AND ORGANIZATIONS

- Developing incentive systems for organizations and individuals to increase willingness to share, link, and administer data
- Creating differentiated incentive systems that appeal to the broad masses by considering different compensation needs (money, status, solidarity, individual and collective benefits)

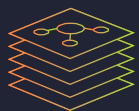
4.



INCREASING INVESTMENTS INTO DATA CURATION

- Compensating organizations for curating data as a collective good
- Initiating a common understanding of the public's and private organizations' roles

5.

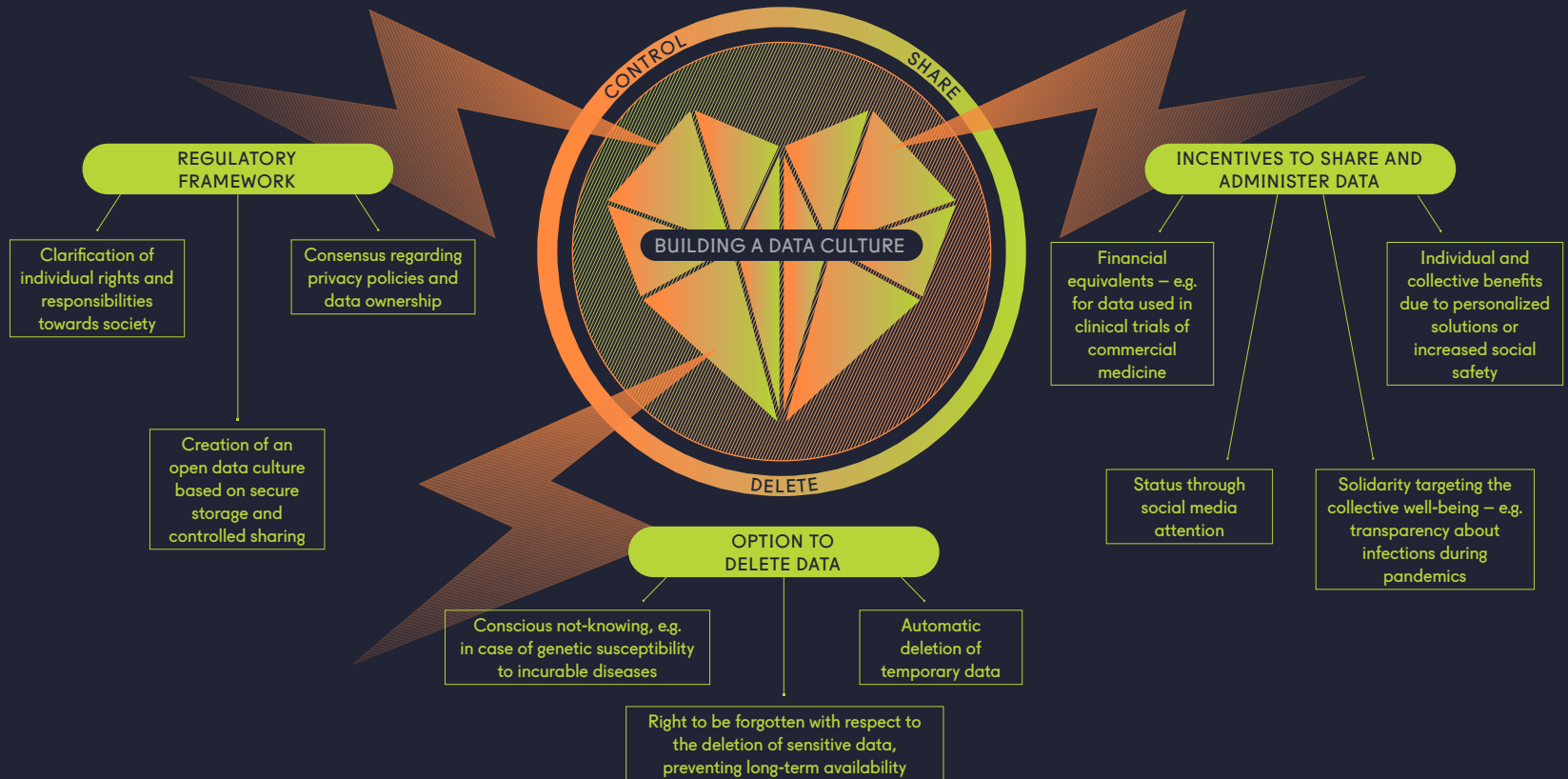


ESTABLISHING DATA TRUSTEES TO MANAGE AND DELETE DATA RELIABLY

- Building reliable governance structures through data fiduciaries to enable more effective forms of individual data management and to increase trust
- Respecting individual rights of non-knowledge and oblivion – e.g. the deletion of individual data

OUTLOOK

IN THE FUTURE HEALTHCARE SYSTEM, DONATING DATA BECOMES THE NEW BLOOD DONATION. BUILDING A »DATA CULTURE« REQUIRES TARGETED INCENTIVES FOR PARTICIPATION. FURTHERMORE, A TRANSITION TO A DATA USE CYCLE IS NEEDED. THE PREREQUISITES INCLUDE BUILDING A FOUNDATION OF TRUST BASED ON RIGHTS, RESPONSIBILITIES, ETHICS, AND SECURITY.



EXECUTIVE SUMMARY

Safe and efficiently personalized medicine and a resilient healthcare system depend on data. By broadening the definition of health, everyday data is moving to the center of our health – next to medical data such as blood pressure. What we eat, which series we watch on Netflix, where we live, and who our friends are, influence our state of health.

Nevertheless, data is not per se the gold of the 21st century. On the one hand, a large part of available data is of insufficient quality, and on the other hand, not all data can be used to derive relevant findings for individuals or society. However, it is clear that without access to data, it will not be possible to meet the demands of a future, quality and cost-conscious healthcare system.

To build a sustainable, data-based health ecosystem, data must be shared, linked, and administered. Only then can value for individuals and society be leveraged and used.

The extent of the added value depends on the data's quality and how it can be integrated into an overall health and tem-

poral context. Data integration is impacted by two dimensions. Vertical integration ensures the linkage of individual data across different domains. Horizontal integration combines data along the time axis, thus mapping an individual's health development and treatment over time. Moreover, bundling individual data into collective data further extends the added value.

This is, however, precisely where the challenges lie: Data is not shared or only insufficiently shared and administered at the moment. Reasons are fear of transparency, a lack of technical and regulatory structures, and an unclear cost-benefit ratio.

As part of the Salon Santé 2021, the foundations were created to overcome the challenges to use health data sustainably for the benefit of people and society in the long term.

Building a »data culture« which enables data to be shared, controlled, but also deleted cyclically has become an indispensable prerequisite.

W.I.R.E.

WEB FOR INTERDISCIPLINARY RESEARCH AND EXPERTISE

THINK TANK FOR BUSINESS, SCIENCE AND SOCIETY

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THINK TANK W.I.R.E.

W.I.R.E. is an independent think tank curating the future at the interface of science and practice. Its approach is built on a systematic early recognition of relevant developments and their translation into long-term strategies and fields of action for private and public organizations and their decision makers. As an interdisciplinary platform, W.I.R.E. has differentiated itself since its founding in 2007 through an overarching understanding of the economy and society and uses its knowledge to develop long-term decision-making bases, ideas, and new solutions. The think tank is connected to an international network of thought leaders and decision makers and maintains partnerships with leading companies, universities, and designers.

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INTERPHARMA

Interpharma is the research-based pharmaceutical industry's association in Switzerland. The 23 member companies account for more than 90 percent of patented medicines' market share in Switzerland. They invest 6.5 billion Swiss francs annually in research and development in Switzerland. Interpharma is a driving force behind an efficient and high-quality healthcare system that offers patients fast access to innovative therapies and the best possible care. At home and abroad, Interpharma works to ensure that patients receive first-class healthcare, that innovation is rewarded, and that the industry can make a significant contribution to prosperity, growth, and competitiveness in Switzerland.

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