

Navigating in the depths of data sea

The DSL DE Ship's Log



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Birgit Bauer

Founder and project coordinator Data Saves Lives Germany

Health Data – Let’s talk about it!

It is undisputed that health data play a crucial role in public health, and this has been the case for quite some time. They are a topic for the entire society, now and in the future. They provide knowledge that helps in providing faster and more effective patient care, preventive measures, and in making healthcare systems more efficient and effective. Therefore, at the very least, we all need to understand what health data are and the benefits they can bring to patients and healthy individuals.

It must be clear that the time is now. Time is of the essence, the data flow is ongoing, and our societal task is to follow this flow. Consequently, there is a significant need for information among patient organizations, patients, and citizens. We need clear information and public discussion.

Data Saves Lives Germany talks about health data. Independently, comprehensively, and neutrally. As a nonprofit initiative driven by patients, we inform and discuss with all stakeholders in healthcare, especially with patient organizations and patients. We are critical, always objective and we always provide solutions. It is necessary for us to stand together now, have public discussions about this topic, inform the public, and ensure that patients and citizens can make informed and conscious decisions about their health data and how to share it. Importantly, we want to clarify: With Data Saves Lives Germany, we do not aim to persuade but to ensure that the significance of the topic is understood.

With this DSL DE Ship’s log, we have created an information source that illustrates what is necessary and initiated a toolkit for patient organizations to help organize simple actions that enable active engagement with the topic. With the DSL DE Logbuch, we aim to make the data flow experiential and understandable for patients and citizens. We provide knowledge, information, and tools that can help initiate the discussion about health data and learn more.

Over the past months, we have spoken with many people and organized the insights from these discussions. This has resulted in a collection of knowledge, ideas, and voices that might offer you support while navigating the sea of data, or at the very least, keep you well-informed.

**If you have any questions,
please feel free to reach out to us.**



Opening message

Data saves lives! Optimal healthcare will only be possible in the future through sufficient health data. This applies to the diagnosis and treatment of diseases as well as the innovation and development of medicinal products and medical devices. Extensive analysis of anonymised treatment data, for example, improves treatment outcomes for very rare cancers and enables patients to have a better life expectancy. Scientific research using health data can also aid in finding cures for previously incurable diseases.

However, this potential is still vastly underutilized in Germany. In comparison with other countries, both European and worldwide, we have a significant amount of catching up to do. At the same time, the data we use that stems from other countries is not representative of the German population and thus is less useful. With the nationwide introduction of electronic health records, we will improve patient care and also provide comprehensive and representative data for research. In order to obtain consent to use data, it is crucial that patients can trust that their data will be protected.

This trust is grounded in the fact that patients are provided with comprehensive information on how the privacy of their data is ensured and on the benefits of using health data. Data Saves Lives Deutschland, an initiative supported by the Federal Ministry of Health, delivers this information in a comprehensible and meaningful manner – at eye level and by patients for patients. Moreover, Data Saves Lives Deutschland supports patient organizations in making the discussion on using health data useful, transparent and informative. Our shared goal is the optimal use of data in the interest of the patients while simultaneously protecting the individuals' privacy. Initiatives like Data Saves Lives Deutschland make a significant contribution toward us achieving this goal together.

A handwritten signature in blue ink, appearing to read 'K. Lauterbach', written in a cursive style.

Prof. Dr. Karl Lauterbach
Minister of Health
Member of the German Bundestag





Understanding Improved Use of Health Data as a Great Opportunity

Why do we need health data, why should we share them, and what is particularly important about this to you?

Health data are essential for accurately assessing the medical condition of patients and facilitating communication among healthcare providers. In the interest of optimal healthcare, it is essential that there are no obstacles and that no information is lost. This is why storing health data, such as in electronic health records (EHRs), makes so much sense.

Furthermore, the simplified analysis of shared data can be especially beneficial for critically ill individuals. It accelerates research processes and allows the results to be applied in a faster treatment,

aligning with evidence-based medicine principles. With an aging population and rising incidences of so-called „common diseases“ like obesity, diabetes, and hypertension, improved data utilization can strengthen prevention and health literacy. This is achieved by identifying health risks early and communicating them to those who are affected. In the end, the patients themselves can benefit the most from an improved health data utilization.

Stefan Schwartzke

Federal Government Commissioner
for Patients' Affairs



Data Saves Lives: From European to National Level

Health data are central to a stable healthcare system. Growing, aging populations with more chronic diseases pose diverse challenges to healthcare. Therefore, approaches for better patient care are necessary, even with limited budgets.

This is where Data Saves Lives comes in. Data Saves Lives raises awareness among the public about health data and promotes responsible handling of them. Under the leadership of the European Patients' Forum (EPF), the European initiative informs about best practices and enables open dialogue. The goal: to meet patient needs and strengthen healthcare systems.

Data Saves Lives Germany, the first national branch, provides patient organizations with a platform to access necessary resources, thus fostering a flourishing dialogue. We welcome this important exchange and hope it inspires further national initiatives spreading the message with the idea of Data Saves Lives.

Ingrid Weindorfer

European Patient Forum
Project Manager



THE BIG ANALYSIS

Attitudes towards sharing health data in the population have been regularly surveyed in recent years. While these surveys often meet the requirements of representativeness, they frequently stay on the surface due to their questioning methods. Detailed insights into subgroups or specific motives often remain undiscovered.

As we were preparing for our first online session on the topic of electronic health records and the recently published digitization strategy of the Federal Ministry of Health (BMG) was being widely discussed in the media, we observed how various actors and groups influenced the specific topic of electronic health records (EHRs), both in terms of content and tone. Within the context of EHRs, the issue of health data already occupied a significant space and was strongly associated with it.

In our initial observation, we noticed that the individual health status significantly influences the willingness to share data, as well as the specific demands that come with data sharing.

To further evaluate this thesis and formulate clear and concrete recommendations for policymakers and decision-makers in the healthcare system based on the findings, we conducted several workshops with different groups using various methods in 2023.

We distinguished three groups:

1. Patients

For this group, we conducted a total of three workshops with representatives from patient organizations and patient influencers present on-site during the Roche Patient Summer Summit (June 23–24 in Grenzach).

2. Experts

During the Data for Health conference organized by the Federal Ministry of Health on June 20–21 in Berlin, we conducted a barcamp session as a workshop with interested experts.

3. Citizens

The citizen group represents the seemingly largest segment under consideration. Therefore, we incorporated existing representative studies. We attempted to deepen the insights through our own survey and a workshop held during the open day at the Federal Ministry of Health (BMG).

The approach for all three groups was identical in the questions asked:

- Inquiry about the basic willingness to share health data (yes/no/no opinion). We asked this question quantitatively to obtain an unfiltered opinion before the discussion.
- What are your desires when it comes to sharing health data? We inquired about the positive aspects and specific expectations.
- What are your concerns and fears regarding sharing health data? We gathered critical points and limiting factors.

Part 1 – Patients

Few target groups are as heterogeneous as patients. Whether acutely or chronically ill, or lightly or severely affected, these factors significantly determine their daily interactions with the German healthcare system and the resulting experiences.

Our analysis focuses on chronically ill individuals, as they consistently leave health data in the system and, in particular, evaluate the sharing of health data from this perspective. This group represents approximately 40–50% of the German population (including sources such as RKI, Journal of Health Monitoring Issue 3/2021).

On June 23, during the Roche Patient Summer Summit, we had the opportunity to interview 61 patients in three workshops based on our defined questions.

Tabular representation of the basic willingness to share health data:

	Yes	No	No Opinion
Workshop 1	17	0	0
Workshop 2	20	1	3
Workshop 3	20	0	0

All three workshops were consistent in their responses regarding the relevant points, so we summarize the results across all three workshops (the specific mentions are documented).

Patients' Desires Regarding Handling and Sharing of Health Data:

Transparency in Data Handling:

A frequently mentioned aspect was transparency about who can access health data and what specific results are achieved through the use of the data. The more concrete this line of use is for a person living with an illness, the stronger the motivation to continue sharing health data.

I want to see what comes out of it

Autonomy:

The health literacy of chronically ill individuals leads to the desire for autonomy in handling their own data. Autonomy is understood as the ability to decide which data to share with whom. This autonomy is explicitly seen in relation to diagnoses (e.g., HIV infection, depression), which can have stigmatizing characteristics.

For me, it's a data donation: I provide it – under clear conditions

Uniformity in Standards:

To create a real situation in which the use of health data benefits patients, binding standards for data and data processing are required.



We need uniform standards – Quality criteria are very important



What does my dentist need to know that I suffer from depression



Anonymized vs. Pseudo-anonymized Data:

Regarding anonymized health data, everyone was open to both commercial and non-commercial use.

However, when it comes to the use of pseudo-anonymized data, there is ambivalence: on one hand, there is a fear that the use of pseudo-anonymized data might compromise one's own anonymity. On the other hand, there is the occasional idea that if anonymity were voluntarily waived (under defined conditions), networking with patients with similar health conditions might be possible. This could be helpful in the case of rare diseases, allowing individuals to connect with others who would otherwise be difficult to identify.

Commercial Use of Health Data:

In general, the patient groups do not fundamentally oppose the processing of health data for commercial purposes. The majority of the group is well aware of the significance of this point, as they are familiar with the benefits such as the development of new therapies. However, in the case of commercial use, there is an expectation of value in return for the patients. This value could, for example, consist of returning the results from commercial use in the form of information.



I want to see what comes out of it



A data match brings me new contacts with a similar fate



Concerns and Fears of Patients Regarding the Sharing of Health Data:

Transparency of Personal Data:

There are concerns about negative consequences with health insurance companies or other institutions if access to personal data is not controllable. Similarly, patients should be able to control the access of healthcare professionals to their health data.

Data Protection / Access Rights:

The desire for transparency is accompanied by the fear of data misuse. Both aspects are inseparable and are most frequently mentioned. Unrestricted access without the consent and control of patients is rejected.



I want to retain my autonomy over who can see what



Part 2 – Experts

During the Data for Health conference organized by the Federal Ministry of Health (BMG) in June 2023 in Berlin, we were able to conduct a barcamp session with interested experts. The overarching questions we posed to the 10 participants were: “What is important from the perspective of patients when it comes to

sharing health data ...”, “What can the wishes and concerns be?”

The intention was to minimize a purely technical or academic perspective by projecting it onto the patient groups. Everyone in the group was generally willing to share health data.

Graphic Recordings from the Conference on Health Data and the Results from Various Barcamp Sessions (including DSL DE):



Source: <https://projektraeger.dlr.de/media/events/dfh23/index.html>

The premise of the experts regarding the handling and sharing of health data:

Be inclusive:

The group advocated for inclusion on two levels. Firstly, it was noted in the previous discourse on the topic that some groups within the healthcare system, such as the nursing sector or physiotherapists, were hardly or not at all considered in the development of concepts for sharing health data. Secondly, data models should be designed to work for various demographic groups, cultures, and diseases. Access for family members and accompanying individuals is also considered a crucial factor in practice.



Expert workshop "Data for Health" Conference 2023



***Data have to be accessible
for family members:
understandability + user friendly***



Be transparent:

Who, where, and how can access health data, and who is allowed to do so, must be absolutely transparent for the patient's side. The extent of their involvement determines how well data systems can be filled with information.



***Regarding the use of data:
there is a big risk in data
selling, data shouldn't be sold***



Communication is key!

Communication was the most frequently mentioned factor for the success of a functional data strategy in the discussion. It ranged from early education about what health data is, to a utilitarian and emotional storytelling about the use of health data. Emphasis was placed on the communication being understandable and trust-building for the citizens.



***Statistics is one thing:
but valuable + right
communication helps more
to understand = storytelling!***



Part 3 – Citizens



In the largest group under consideration, we examined existing representative survey results, conducted our own smaller survey, and directly inquired about their attitudes through a workshop (Open Day at the Federal Ministry of Health) shortly after their recruitment:

- Workshop with citizens at the Open Day of the Federal Ministry of Health (August 19/20 in Berlin)
- Data Saves Lives Survey 2023 (online and non-representative)
- Screening of existing survey results from 2022/2023 regarding the sharing of health data

Similar to the other two groups, we focus on both the willingness to share health data and the associated desires and concerns. A clear separation from the patient's perception is not possible, as no study specifically targets individuals who have never been ill or are not chronically ill.

Workshop with Citizens at the Open Day of the Federal Ministry of Health (August 19/20 in Berlin)

As part of the Open Day event, a session titled “Data for Health: Health Data for Better Patient Care” was offered in collaboration with the Federal Ministry of Health (BMG). More than 20 individuals participated in the event, with 17 of them expressing their agreement to share health data (17 Yes – 3 No – 2 Maybe).

The participants' desires reflect a need for:

- Understanding: What happens during the processing of health data, and who is involved?
- Clear Benefits: What benefits arise from the processing of health data? These benefits are assumed and should be clearly communicable.
- Participation in terms of personal control: Who can use and process health data?

Concerns mainly revolved around data security and data quality:

- Ensuring data protection against hacking and misuse and transparent communication about who can access the data. Autonomy for users must be guaranteed.
- Uniformity and standards of data are crucial to generating usable results.

Data Saves Lives Survey 2023 (online and non-representative)

At the end of 2022, we initiated an online survey, which we continually incorporate into our content to consistently assess the relevant topics related to health data. The survey will remain open to detect trends and questions early on. The current number of fully completed questionnaires does not yet meet the requirements for representative statements.

Here is the link to the survey.



Based on the responses received so far, several points can be noted:

- With over 60% agreement, there is a high willingness to share health data.
- A positive impact on medical research and clinical studies is acknowledged. Negative consequences are rarely seen but not completely ruled out.
- Sharing personal data such as age or ethnic background, along with health data, predominantly raises concerns.
- The medical team (e.g., doctors, therapists) of an individual, as well as hospitals and patient groups where one interacts, enjoy the highest level of trust, alongside research data centers.

Screening of Existing Survey Results from 2022/2023 Regarding the Sharing of Health Data

In the past two years, several representative surveys have been conducted, which, among other things, have examined the willingness to share health data and the associated dimensions. These results provide additional insights into the attitudes of the general population in Germany and, due to the larger sample sizes, have good validity.

Self Tracking Report 2022 by ePatient Analytics

Based on 5,000 respondents in Germany, the study focuses on how health is digitally measured and the attitudes individuals show toward their health data.

Here are the results:

- Over 75% find the idea of a government research database with anonymized health data very good or good.
- Preventive measures based on a digital patient record with personal health data are perceived as good to very good by over 70%.
- More than 55% do not know how to handle the measurement and analysis of data fundamentally.

The survey clearly indicates a very high need for information regarding data handling. The abstract concept of using health data does not prevent a widespread recognition of its high utility.

Source: <https://epatient-analytics.com/>

Phyigital Patient of the Future – Deloitte Digital August 2022

In the Europe-wide survey, conducted across 11 countries with a representative sample of 1.000 respondents in each country, the aim was to demonstrate whether individuals with higher digital affinity exhibit different attitudes toward health data. Based on the questionnaire and defined markers for digital affinity, a comparison was made between the traditional patient type and the digital type (Phyigital).

Results:

- The Phyigital patient type is typically female, a Millennial, and nearly one-third of them have two chronic illnesses. This group represents approximately 9% of the population in Germany.
- Motives for sharing health data include both financial and non-financial benefits. For instance, they see the support in drug development (26% for traditional patients and 40% for Phyigital patients), but both groups are stronger when individual prevention and personalized therapies are delivered as outputs (e. g., 39% for traditional patients and 49% for Phyigital patients regarding prevention).
- Notably, there is a high anticipation of financial incentives, such as discounts on health insurance and other healthcare services (e. g., 35% for traditional patients and 42% for Phyigital patients regarding discounts on health insurance premiums).

Although the division into two different patient types is complex at first, it still shows a higher overall willingness to share data. The data provided should bring personal benefits such as better prevention and care, as well as financial advantages, to both the public and the donating individuals in the future.

Source: <https://www2.deloitte.com/content/dam/Deloitte/pt/Documents/life-sciences-health-care/Phyigital-Patient-of-the-future-2022.pdf>

Consumer attitudes to health data sharing – BEUC (European Consumer Organisation) 2023

In this recent Europe-wide survey of consumers, the focus is on the conditions for sharing health data (over 1.000 respondents in Germany).

Here are the results:

- The willingness to share data is highest for clear contexts related to one's own health status (60% for "care purposes").
- Healthcare providers such as general practitioners are seen as central recipients for health data (88% for "My GP").
- When it comes to processing health data for medical research or public health projects, healthcare professionals (HCPs) are the most trusted entities by a large margin (71% and 70% respectively).

The emerging picture from this survey is clear: respondents want to differentiate which types of data are shared with whom. There is a distinct divide between groups and organizations processing health data, ranging from direct medical contacts to commercial providers and digital tech companies.

Source: https://www.beuc.eu/sites/default/files/publications/BEUC-X-2023-051_consumer_attitudes_to_health_data.pdf

Illness increases the value of health data and the expectations placed on the healthcare system



Patients



Citizens

Data protection



Secure protection of personal data throughout the entire collection and processing chain

Transparency and Autonomy



Manageability of individual data, manageability of visibility, and data sharing by users themselves

Information and Communication



Easily accessible, understandable, and responsive information offerings for various user groups

Cashback/win-win-win



In commercial use of data, direct individual benefits on the level of illness or incentives for insured individuals

Standardization/Interoperability



Making data usable to create operational value

Our recommendations for handling health data:

1 A comprehensive and targeted communication strategy

All stakeholders in healthcare are urged to develop a coordinated communication strategy together. This strategy should help patients and citizens develop their digital health literacy to make informed decisions about sharing health data.

2 Establishment and inclusion of citizen and patient councils in decision-making bodies

We advocate for the establishment of a patient council directly in the relevant departments of the Federal Ministry of Health and other bodies that make decisions or advise on health data. Patient organizations and independent patient representatives have significant expertise and can add considerable value to consultations and decisions.

3 Users of health data are obligated to inform about their research findings

The release of health data is not solely based on the often-mentioned altruism. All researchers using health data commit to making these available in a neutral portal in an understandable and user-friendly summary, regardless of the results. Patient organizations and patient representatives can also help in formulating texts transparently, understandably, and neutrally.

4 Data sharing should be made attractive with incentives

It is evident that citizens expect compensation for sharing their data. We recommend the development of appropriate offers such as bonus points, etc., for healthcare services offered by health insurance companies. Therefore, we suggest considering such possibilities and developing strategies for them promptly.

5 Those who economically benefit from data should provide value in return for everyone

To obtain consent from patients and citizens to freely share health data for economic use, we recommend a voluntary commitment from users to establish a neutral, non-profit organization. This organization should aim to promote health literacy in all aspects of dealing with digitalization and data.

NUMBERS, DATA, FACTS: 1 YEAR OF DSL GERMANY

Our social media activities and successes

Platform	Follower	Posts	Impressions
X (twitter)	176	464	46 000
Instagram	267	264	31 000
LinkedIn	463	57	26 000
YouTube	9	7	437
all	915	792	103 437

Our primary target audience includes patient organizations as multipliers and interested patients who are engaged through self-generated content, fostering organic growth without advertising budgets.

Cited date October 2023.
Source: Hootsuite Analytics + Platform Analytics.

DSL DE Online Sessions 2022/2023

So far, we have conducted a total of five DSL DE online sessions:

- Launch DSL DE
- ePA 1 and ePA 2
- Patient Registries
- PROMs

All our DSL DE online sessions have been attended by an average of 30 participants, 70% of whom come from the realm of patient organizations.

After each event, we make all the sessions available on our YouTube channel. So far, we have recorded around 400 views of the videos.

Our attended and co-hosted events

2022

- Bitkom-Conference
- Data Sharing – Healing People, Conference by the Bavarian State Ministry of Health and Care and the Academy of Sciences
- Health Data Conference Porto – i~HD

2023

- European Association of e-Pharmacies (eaep), Berlin
- Patient Engagement Open Forum (PEOF) Baveno – DSL DE and DSL EU
- Data for Health Conference by the BMG
- Bitkom – Digitalization Working Group

- Stakeholder Meeting by the Federal Ministry of Digital and Transport (BMDV)
- Open House Day at the BMG
- Future of Health Insights by Temedica and Microsoft, September 2023
- HIMSS Europe 2023
- Health Day by Careum Foundation
- Patient Summer Summit/Roche Pharma Germany

At these events, we were either involved in panel discussions or led our own sessions such as lectures or workshops. All outcomes have been integrated into our comprehensive analysis.

LET'S TALK!



Start your own discussion about health data sharing!

Health Data are, as we all know, not the easiest thing in the world. The topic of 'Sharing Health Data' is associated with many false information, doubts, concerns, or issues that need to be cleared up. We all need information to understand the topic. But how?

Our suggestion:

Start your own discussion – we provide you with the DSL armbands for interaction with your community. Our ARMBANDS are a brief guide for discussion rounds on sharing health data:

Three core questions structure the dialogue

1. Would you share your health data – yes – no – maybe?
2. What concerns do you have when it comes to sharing health data?
3. What concerns or desires do you have regarding the topic, for example, what would you expect from the health insurance or patient organization? What is your need to approach the topic?

What is ideally needed for the exchange?

- ✓ A person who is knowledgeable about the topic and preferably gives a brief presentation on the topic. Alternatively, you can also use the materials we offer on our website!
- ✓ A space that can be divided into three groups if necessary. This is useful for groups with more than 20 participants.
- ✓ 3 flip charts or surfaces for the three questions
- ✓ Paper (e.g., sticky notes) in three colors and pens
- ✓ A person to moderate, ask the questions, and two assistants to take notes
- ✓ Approximately 30 minutes of active time
- ✓ A group of up to 20 participants – this ensures that everyone can have a say. If necessary, others can discuss slightly apart, allowing the main discussion to proceed undisturbed.

You can use the results for further discussions or in the form of blog posts or social media posts.

VOICES ON BOARD



The voice of a patient organization: Melanom Info Deutschland e. V.

Together for Progress:
Melanom Info Deutschland – MID e.V. advocates the use of health data for research.

Melanom Info Deutschland firmly supports the vision of improved cancer research and treatment. In line with this vision, we are determined to provide health data for medical research. This data collection forms the foundation for groundbreaking discoveries that can ultimately contribute to saving lives and significantly improving the quality of life for cancer patients.

We are aware that the protection of the privacy of those affected is of utmost importance. Therefore, we emphasize the need to take all necessary measures to ensure the anonymity and security of the collected health data. We advocate for transparent information policies where those affected are fully informed about how their data will be used and the benefits this can have for cancer research as a whole. This also includes the rapid, widespread introduction of electronic health records (EHR), ensuring that patient data, in aggregated form, is with the affected individuals and they have access to it from the beginning.

Sharing health data enables researchers to identify patterns, better understand disease progressions, and develop personalized treatment approaches. New breakthroughs in immunotherapy, genomic analysis, and innovative treatment approaches are accelerated through this process. By sharing our data, we contribute to speeding up scientific progress and help medicine gain a deeper understanding of cancer and its combat.

For melanoma patients, new treatment options, including immunotherapies and targeted therapies, have been available for more than ten years. While these therapies work for some, they don't for others – some experience severe, sometimes permanent side effects, while others are spared. Data collections could help us solve these problems more quickly; for instance, more tailored follow-up plans (adapted to individual risk) could be created. For other patients at low risk, money and radiation exposure could thus be saved. Moreover, the question of which genetic characteristics of a tumor are more likely to lead to metastases and which family members should be examined precisely because melanomas occur frequently could be much better researched.

In today's era of high technology and data analysis, we cannot afford to miss out on the potentials that health data offer. Therefore, Melanom Info Deutschland warmly invites all those affected to join this call. Together, we can make a difference – for ourselves, for future generations of cancer patients, and for the future of medical cancer research.

Astrid Doppler und Katharina Kaminski
Founders and Chairpersons of
Melanom Info Deutschland – MID e.V.





The use of data is becoming decoupled from the system

The results of the first Self-Tracking Report for Germany have turned the image of the state of digitization in the healthcare system upside down. The Self-Tracking Report was conducted by EPatient Analytic GmbH with the support of Prof. Sylvia Thun and Prof. Klaus Hurrelmann, revealing the nation's status regarding digitalization in healthcare. The results clearly show that citizens have increasingly embraced the so-called platform medicine. This means they are increasingly using online services from doctors, online diagnosis and data-based online therapies. Considering that for decades, the majority of the population's vital data

has been migrating abroad through smartphones, trackers, and similar devices, this appears to be a concerning failure on the part of the government, reflecting a digitalization of the healthcare system that has been delayed for 20 years. If this does not change, there is a fear that in the future, there will be two types of healthcare systems in Germany: a modern, data-based one where patients have control, and one that is increasingly losing efficiency.

Alexander Schachinger
Managing Director EPatient
Analytics GmbH



Patient Data: Essential for Progress!

Since its initiation in 2001 by the German Multiple Sclerosis Society (DMSG), the Multiple Sclerosis (MS) Register aims to depict the situation of people with MS in Germany. The MS Register data, collaboratively used by partners from science, healthcare, and patient advocacy, contribute to identifying and addressing gaps in care and increasing knowledge about MS and its therapies. One focus is on patient/therapy safety, where the motto "Good data at the right time help save lives" is particularly applicable. In addressing the diverse questions

handled by the MS Register, it is essential to capture health data through healthcare providers and, increasingly, through patients themselves. This can only happen with the consent of patients. Only patients who understand the value of health data in improving healthcare are willing to "donate" their health data.

Alexander Stahmann
Managing Director MS Forschungs-
und Projektentwicklungs-gGmbH





Patient-centeredness through health data

Our healthcare system is at risk of falling behind. In an era of advanced technologies, outdated systems often hinder swift access to crucial patient information. These obstacles can even impact the quality of patient care. But there is hope. Developments like Real-World Evidence (RWE), Electronic Health Records (EHRs), and health apps could be the solution. These not only allow access to current data but also place the patient at the center. Imagine a healthcare system that is always up-to-date, tailored to real patient data

and needs. By smartly integrating these technologies, we can revolutionize medicine. Our ultimate goal? A patient-centered, data-driven healthcare where each individual receives precisely the care they need.

Benjamin Friedrich

Chief Medical Officer & Co-Founder
Temedica, Member of the Advisory
board of DSL DE



The Research Perspective

Interestingly, health is a concept that only enters our daily lives when we are no longer healthy. Each day, we generate data about our health – some of us more, some of us less. However, only a fraction of this data is currently made available to the healthcare professionals that take care about us. This leads to a loss of valuable knowledge, particularly when considering that the average doctor's visit in Germany lasts only 7.6 minutes. In the future, prevention, detection, and treatment of (chronic) diseases will be significantly enhanced through data-driven research, also because subjective assessments should be complemented with objective data. What do we need to implement this? Digital biomarkers that

can assist in detecting diseases earlier and thus help to partly relieve us of filling burdensome questionnaires. Personalized medicine that truly helps to make individualized decisions. And, of course: Real data donated by people with and without diseases, which are inevitably required to develop innovative models. Additionally, more researchers are needed who engage in this exciting new research field bridging medicine, data science, and innovation research.

Prof. Dr. Moritz Göldner

Assistant Professor for Data-Driven
Innovation at the TUHH





Why is the research-based pharmaceutical industry dependent on health data?

Health data is constantly generated in everyday life, e.g. during treatments and in research. Our digital companions (such as smartwatches, fitness trackers) have fundamentally changed our understanding of handling and utilizing data. However, this data is not an end in itself. It can serve to maintain or restore individual health or contribute to modern healthcare.

Hence, regulated access to health data for private research, which accounts for approximately 70% of research activities in Germany, is a significant contribution to a data-based and thus needs-based and patient-oriented healthcare. Current legislative developments enabling the collection and integration of structured data with good data quality contributes to this goal.

Well-prepared datasets from patient care, for example, provide an overview of the healthcare

events in specific disease fields and the application of therapies in medical practice. The meaningful use of such data would facilitate the research of severe and chronic diseases and, based on this, the development of new drugs or help identify previously unknown or rare diseases. The development of personalized therapies also relies on health data.

Moreover, the use of health data by healthcare companies has been subject to the highest standards for decades, fully complying with the respective data protection regulations.

Ulf Birke

Health policy at Verband forschender Arzneimittelhersteller (vfa), Member of the Advisory board of DSL DE



Non-profit, independent, neutral – Data Saves Lives Germany

Data Saves Lives Germany was established in 2022 by Birgit Bauer, founder and managing director of the “European Digital Health Academy gGmbH”, in collaboration with the team of Data Saves Lives Europe, the main project. The project operates as a non-profit organization, and patients have been closely involved from the beginning.

The advisory board of DSL DE consists of various representatives from different organizations in the healthcare/health data sector. The board reflects the diverse perspectives that we need to consider and incorporate into our work.

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Staying one step ahead of diseases with health data

Because of our health data, we have the opportunity to create the medicine we have long dreamed of: empathetic, efficient, and preventive. Do you know the power your data holds for your well-being?

Data and the knowledge gained through data insights have changed the course of medical history. Today, there is a chance to create another protective barrier for our health – a barrier made of health data.

One example is biomarkers – various characteristics and traits that can be measured in the body, e.g., through blood tests or sensors – are like fingerprints of our health. In the age of digitalization, these health parameters can be captured in real-time directly from the body and the environment using intelligent wearable devices like smartwatches and fitness trackers. Having access to them, doctors will be able to predict diseases or detect them at the earliest stage instead of reacting when the first symptoms occur. The doctor will become the architect of a person's health and a coach of an individual's well-being. This transition to preventive medicine will be enhanced by artificial intelligence continuously and anonymously analyzing our data.

In the future, we will take control of our health data because our data is our property. We could outsource our health data to entities such as data platforms (data funds) or insurance companies, just as we rely on banks to manage our finances. They will then turn insights from data into health benefits like rewards for physical activity or preventive health services.

AI-driven virtual health advisors will be able to monitor our health day and night via our smartphones or sensors, enabling them to understand our needs better and provide precise tips on how to live healthily. When the first signs of developing

a disease occur – even if we are not aware of them – we will be promptly contacted by a doctor. They will intervene to protect our health, not only to cure us. Patients will receive continuous care, also when being at home. It means the comfort that someone controls our health care 24/7.

Thanks to health data, a new form of communal healthcare will arise with a mix of human and digital support. Ultimately, the human touch will be just as important as it is today. Local pharmacies will continue to be the first point of contact when it comes to medication use or assistance with minor health problems. But they also get connected to the health data infrastructure, supplementing care offered by healthcare professionals.

Data has enabled humans to travel to Mars. Similarly, it will allow managing health and well-being from birth to death, making a healthy life possible for everyone. Before scientists like Robert Koch, Rudolf Virchow, and Marie Curie made groundbreaking discoveries in the 19th and 20th centuries, sick people were often at the mercy of their fate. Today, we can actively shape the future – if we let health data work in our favor.

Artur Olesch
Digital Health Journalist





Improvement of medical and human care in Germany

In addition to Birgit Bauer, Ihno Fokken is the second driving force behind Data Saves Lives Germany. Through his agency Friesische Freiheit, he has been supporting the project from the beginning, providing assistance at all levels, including moderating online sessions.

“At Friesische Freiheit, our mission is to support projects that help improve medical and human care

in Germany. Data Saves Lives embodies precisely that: helping people make informed decisions about handling health data through education and discourse.”

Ihno Fokken

Founder and Managing Director,
Friesische Freiheit GmbH



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