

In the “Trusted Health Ecosystems” project we are creating a concept and a product vision for a national health platform of the future. This text is part of the overall concept which is published at www.trusted-health-ecosystems.org.

Objectives and conceptual premises

At the center of our vision are patients and anyone using the healthcare system. In the course of the digital transformation process and of bio-technological advancements, users will be confronted with an increasingly broad spectrum of treatment options, a growing number of entities, and new technologies. The number of decisions that need to be made increases with the complexity of the system, and alongside options for participation, personal responsibility also increases. Given the level of interaction people now have with social media and fake news, there are major challenges where individual decision making is concerned, because good decisions always require good information.

By selecting and bundling information and service offers, the national health platform should facilitate access to trustworthy offers. The intent is to support patients in making informed decisions and being active and co-productive with regard to treatment processes. A further aim is to improve healthcare overall by creating a digital trust space that guarantees data privacy, data security, and informational self-determination, while also promoting data solidarity in parallel. Our concept for a national health platform is based on these 10 premises:

1. Creating trust

Trust in digital systems and associated responsible institutions within healthcare is limited. And not without reason, as our health-related data is particularly sensitive. Many individuals are concerned that their data could get into the wrong hands.

The digital ecosystem should therefore create an uncompromising level of trust in the areas of **data sovereignty, protection, and security**. In addition, it is also important to use algorithmic systems in as transparent a manner as possible and to define clear responsibilities in relation to the effects of these systems.

A central and unique characteristic of the ecosystem outlined here is **quality-based selection of information and service providers** as well as targeted avoidance of misinformation. The reliability and trustworthiness of the information and services provided through the platform is part of the brand's essence and, alongside data sovereignty, constitutes an important prerequisite for building trust.

2. Promoting health literacy

The core service in the new ecosystem reacts to empirical evidence on health literacy among Europe's population. According to surveys, more than half of the population has considerable difficulty **finding, understanding, evaluating, acting on, and making decisions related to relevant information on their health**. The national healthcare platform should effectively support users in identifying information that is **relevant, quality assured, and easy to understand**.

With the aid of data analyses, the ecosystem will be **tailored to the user**, generate region-based references, and anticipate **situational support- and information-related user needs**. The information and services provided should not only relate to medical aspects but should also meet the entire spectrum of requirements that arise when **coping with illness in everyday life**, families, schools, vocational-education and work life, and social and leisure situations.

3. Providing benefits

The success or failure of a platform is closely tied to the size of a community and its rate of growth. Consequently, barriers to participation must be removed and **the greatest possible benefits must be provided for patients**. This can only happen when these are a focal point of product development right from the start.

In parallel, where providers of information and digital services are concerned, acceptance of the digital ecosystem must be created. Therefore, the platform must generate **benefits and incentives for participating actors while respecting their autonomy**. The challenge with regard to the ecosystem's design therefore lies in generating tangible added value for all sides.

4. Strengthening data solidarity

Through the operation of the platform, **new data, data flows, and interfaces** arise that serve not only to optimize in-house offers, but also to deliver important infor-

mation for managing healthcare delivery. Effective use of these data can constitute a strong contribution to improving care and further **developing the healthcare system toward a system that learns**.

Such analyses require a high **degree of data permeability** between the care landscape, research, and systems development. The national healthcare platform is intended to open new options here and provide compliance solutions for sharing data and making **data solidarity** a reality.

5. Taking target groups into account

The platform concept focuses on the supraordinate patient target group, or on all of the people using the healthcare system. The structure of the platform should be oriented around the target state of healthcare-related participation. Therefore, it is important to do justice to the high levels of diversity among the different target groups, and, above all, to take into account the **vulnerable groups** that are frequently affected by or threatened with illness. This includes people of low socio-cultural and -economic resources, migrants, and individuals with chronic illnesses and disabilities.

In order to do justice to the highly differentiated needs of these groups, alongside **provision of multi-lingual access** to information, it must be ensured that content is sensitive to culture and diversity. In parallel, through personalized offers, opportunities should be created for adapting information and services to individual preferences.

6. Ensuring cooperative product development

To create an optimal user experience, product development and design should put user needs in the spotlight. This requires **systematic assessment of the needs, skills, and desires** of different target groups. This can be done through the use of interviews, questionnaires, focus groups, and studies. Even in the process for **participatory product development**, potential users can play a role in delivering important information for design. Just as important are regularly occurring **user tests**, based on which products can be continually optimized.

When involving different user groups, special importance must be given to **younger generations**, as young people will be the primary users of a digital healthcare system of the future; they should not only be included in the development process, but should also be given the opportunity to actively participate (**meaningful youth engagement**).

7. Making sure no one is left behind

In spite of all efforts to create a digital offer that is both as user friendly as possible and that has the lowest possible barriers to entry, an effort must be made to include individuals with **minimal digital readiness** and **limited access** to digital systems, and to counter reinforcement or even the **creation of inequality** (digital health divide).

This can only happen if the barriers between the digital and analog world are fluid: Thus, the benefits and opportunities of the national healthcare platform must be accessible through integration in **personal counseling and information services**, as well as through other channels, such as in the context of medical treatment; via patient guides; and through institutional services, such as the Independent Patient Counseling Service.

8. Institutionalizing sponsorship

Sustainable financing and institutional anchoring deliver the basis for the implementation of a digital ecosystem and the associated reorganization of the information architecture in healthcare. Therefore, the ecosystem design will be anchored in a model for a **legally secure, actionable, and independent support structure**. This model will identify **different funding perspectives** and design an institutional framework for the establishment, ongoing operation, and further development of the digital ecosystem.

The sponsoring institution should be **approved** by all participating stakeholders in the ecosystem, and it should remain **committed to the interests of patients**. Furthermore, it should be taken into account that **government information activities** are subject to special legal requirements. If necessary, it may be appropriate to have certain tasks within the ecosystem be performed by different companies or bodies and to organize the **ecosystem as an umbrella organization**.

9. Strengthening competition

In the digital ecosystem outlined here, the in-house creation and provision of information and services is not part of the platform operator's spectrum of tasks. Rather, the platform offers information and service providers the opportunity to participate in the ecosystem. Efforts must be made to ensure that **companies on the market are not excluded or put at a disadvantage**. On the contrary, the declared goal should be to tap the **innovative power of the European health tech economy** for the platform.

In terms of the data strategy, the national healthcare platform is also expected to make a decisive difference from commercial providers, as it should **not aim to**

achieve a monopoly on data. On the contrary, databases and interfaces could be provided by public institutions as part of an **open data strategy** in order to prevent cutthroat competition.

10. Thinking internationally

We are developing our concept for a national healthcare platform as a prototype for the **German healthcare system**. Digital transformation is however not a national phenomenon, and it knows no borders. Just the opposite: It merges national healthcare systems into a global healthcare market in which new challenges arise that require international strategies for solutions and collaboration.

Consequently, we are coordinating our platform strategy with international partner organizations, aligning ourselves with **European interoperability standards**, and thinking about the international scaling of our platform strategy right from the start. In the long term, within Europe, we envision a merger of national healthcare platforms to a **federated platform ecosystem**.

Contact: Dr. Sebastian Schmidt-Kaehler

Legal notice

© Bertelsmann Stiftung,
September 2023

Bertelsmann Stiftung
Carl-Bertelsmann-Straße 256
33311 Gütersloh
Tel. +49 5241 81-0
www.bertelsmann-stiftung.de

Responsible for content
Dr. Sebastian Schmidt-Kaehler