BDI

universität Witten/Herdecke | Institute for Digital Transformation in Healthcare

A Collaborative Health Data Space

Preliminary Study

Bundesverband der Deutschen Industrie e.V. | Institute for Digital Transformation in Healthcare GmbH

Initiative „Gesundheit digital“

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Unlocking an industry-led digital transformation to accelerate a European healthcare of tomorrow

Our vision: Data-driven Innovation in Healthcare

What if our healthcare system would prevent patients from suffering rather than treating and managing diseases? #RealWorldEvidence

What if we could offer every patient individualized products – specifically configured for their individual needs and conditions? #SecondaryUseOfPatientData

What if we could truly maximize patient safety and product quality through collaborating along the whole value chain? #DataDrivenProducts

What if we could tear down intersectoral and national barriers to work on a European mission to provide the best healthcare possible? #DigitalCollaboration

To explore the opportunities and obstacles of data sharing within the healthcare industry, we conducted a preliminary study

Our vision: Data-driven Innovation in Healthcare

Industry Challenges

To **enable** and implement solutions towards a **personalized healthcare of the future**, organizations are **dependent on a range of intersectoral and divers data sets.**

However, **relevant data** currently is **stored in data silos and proprietary systems** and **hard to access** for industry players.

Additional factors (e.g. **lack of interoperability**, legal and **regulatory hurdles**, a **complex stakeholder situation**, or a **lack of collaboration formats**) impose further challenges and barriers to data sharing

Exploring data sharing opportunities towards collaborative innovation

Status Quo

- Other industries have succeeded in building collaborative data spaces in which data can be shared securely while preserving the data sovereignity of the participating partners
- Driven by the recent Covid-19 pandemic, various healthcare initiatives[1] and research projects[2] are emerging that aim to make data more accessible and promote the intersectoral exchange and collaboration

Preliminary Study

- To gain a sound understanding of the opportunities and obstacles of data sharing within the healthcare system, we conducted a preliminary study
- The study explains aspects of data sharing in general as well as with reference to the partcularities of the EU healthcare systems

Goal of the study is to explore data sharing opportunities for the healthcare industry

[1] e.g. European Health Data Space (EHDS), Medizininformatik-Initiative
[2] e.g. HEALTH-X dataLOFT, TEAM-X

Our study was supported by various industry partners to truly understand market challenges and perspectives

Our vision: Data-driven Innovation in Healthcare

Sound research methodologies paired with industry expertise

Study Setup

Our study is based on a **qualitative research approach** including **(1) a market analysis and (2) expert interviews** with our supporters as well as additional healthcare actors (e.g. self-governing bodies, Health IT providers, medical law, data space providers from other industries)

Supporters

Lilly, Roche, MSD, janssen, BAYER, Pfizer, sanofi, GlaxoSmithKline, SIEMENS Healthineers, vfa., BRAINLAB, Medtronic, bvitg, BPI, bitkom

Exemplary report excerpt

Methodology

Market analysis of data sharing initiatives including underlying frameworks/ standards for enabling data sharing and ecosystems that implement data sharing solutions

Expert interviews to gain deep industry knowledge including challenges, perceptions and best practices around data sharing

Building of a **use case library** based on desk research and industry contribution

A Collaborative Data Space aims to enable data sharing while maintaining data sovereignity of all parties involved

Study Results

Data Sharing Initiatives

- We identified two different groups of data sharing initiatives
  1. Standard-setting framework initiatives (n=7)
  2. Ecosystems that implement data sharing solutions (n=42)

Framework Initiatives *(excerpt)*

IDSA · HYPERLEDGER FOUNDATION · ECLIPSE FOUNDATION · TEHDAS · gaia-x · iSHARE

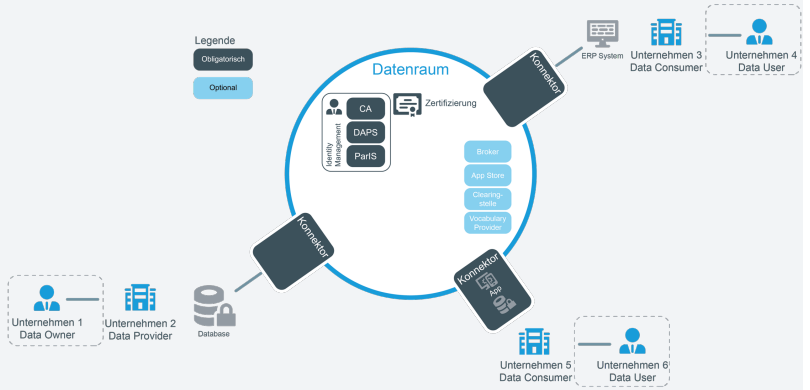
Creating trust by securing data sovereignity

Concept Of A Collaborative Data Space

Characteristics

- Securing **data sovereignity** to create **trust**
- Promotion and enabling of **interoperability**
- **Connecting** private and public **stakeholders**
- Focus on **data quality**

A collaborative data space consists of **clearly defined functions and roles**[1]



[1] Description based on the Reference Architecture Model of the International Data Spaces Association e.V. (compatible with nearly all framework initaitives)

Our use case library demonstrates the demand for a Collaborative Health Data Space – however, use cases vary in complexity and feasibility

Study Results

Structuring Healthcare use cases submitted by industry partners

Healthcare Use Case

- Our **use case intake** (based on desk research and from industry contribution) shows a **significant demand** for a Collaborative Health Data Space
- Particularly relevant use cases offer **added value for the involved stakeholders** but are no **differentiator** for a single organization
- Use cases **vary in complexity** due to their depth of healthcare and level of innovation

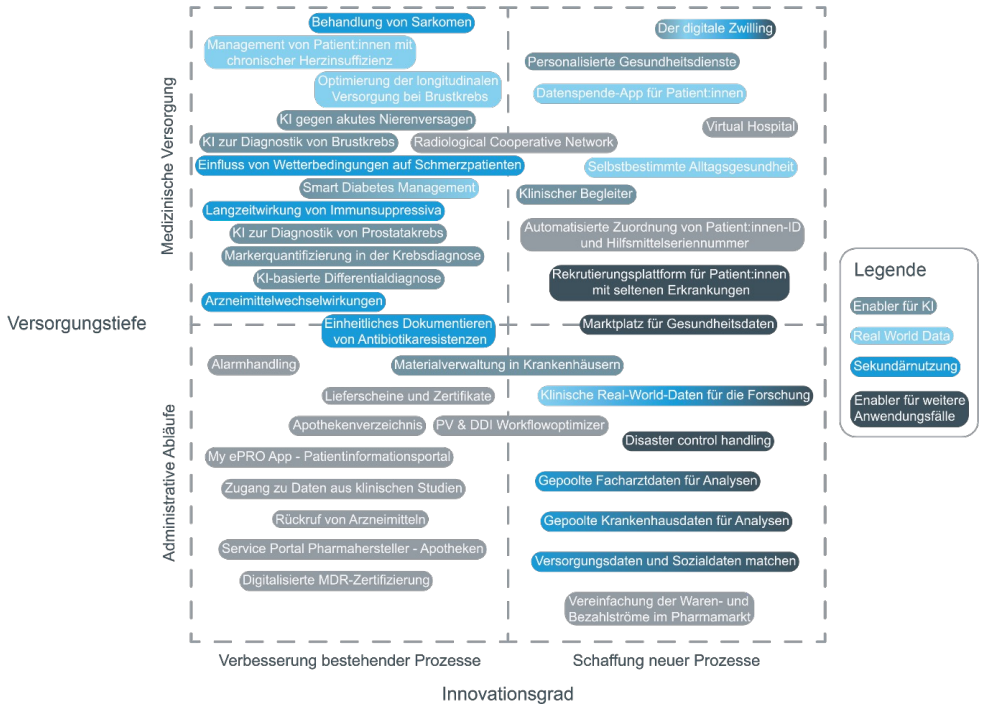
Distinguishing characteristics

All use cases can be clustered based on two features

Depth of healthcare
- Medical care
- Business processes

Level of innovation
- Optimizing current processes
- Creating of new processes

Healthcare-Innovation-Matrix



Therefore, we recommend a strategic approach in consecutive phases that starts with the most pragmatic use cases upfront

Study Results

Advocating for a pragmatic and strategic approach to delivering value

Challenges

- **Use case complexities include** the type and number of stakeholders involved, regulatory requirements/ barriers, sensitivity of data, etc.
- A strategic approach **helps structuring divers stakeholder interests** and therefore enables a pragmatic and **focused implementation**
- The recommended phases shall **guide decision-making**, but need to **remain flexible** due to dynamic market conditions

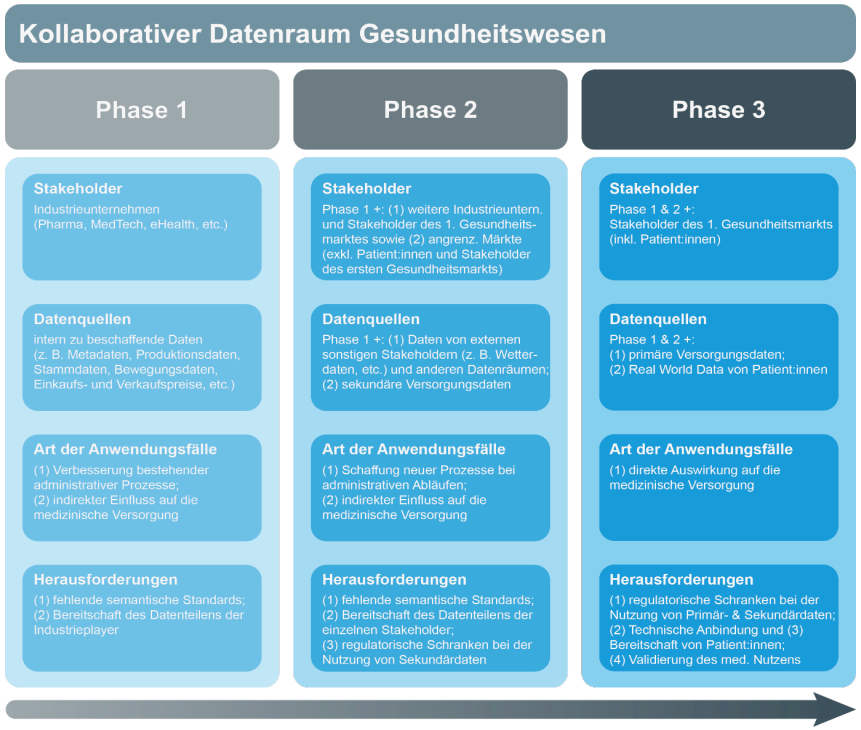
Our Phase Model

1 **Phase 1** includes industry stakeholders only and data domains that can easily be shared

2 **Phase 2** additionally includes stakeholders of the second healthcare market and people‘s lifestyle data

3 **Phase 3** additionally includes stakeholders of the first healthcare market and patient data

Data Space Phase Model



To get started, a dedicated collaboration strucutre is needed

Study Results

Collaboration is King – roles & responsibilities need to be defined

Challenges

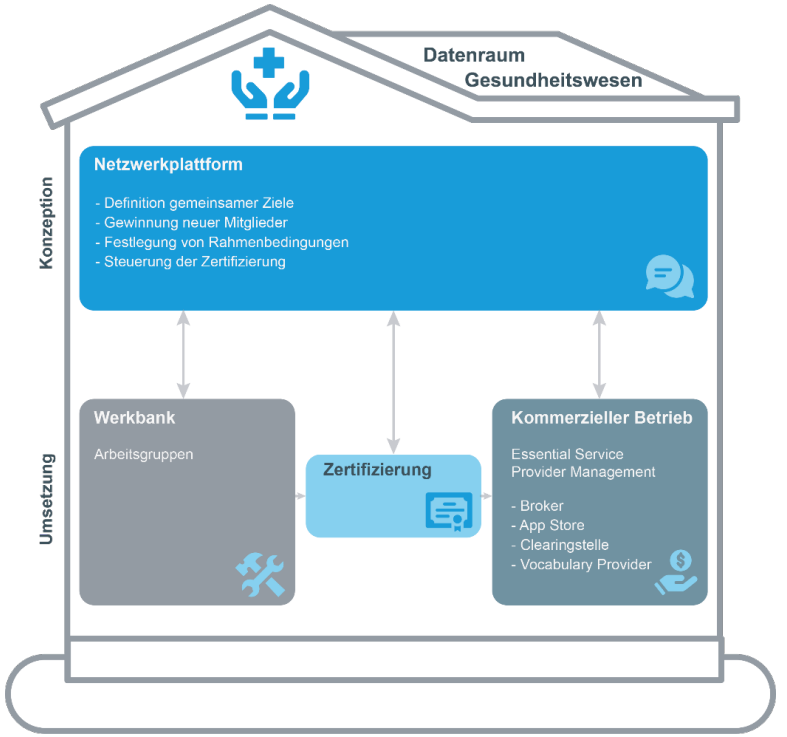
- The healthcare market consists of **very divers stakeholders** (payers, providers, health IT, pharma, medTech, pharmacies, etc.)
- **Platforms** that legally govern digital collaboration **are missing**
- Also, a digital culture that includes the **willingness to share data is not yet developed**
- However, a Collaborated Data Space **requires certain bodies** (e.g. for certification) **to ensure** and enforce **data sovereignity**

Our Collaboration Concept

Our proposed collaboration structure consists of two levels:

1. **Conceptualization**
   A network platform consisting of leading industry players (a minimum of legal formalization is necessary to regulate roles & responsiblities)
2. **Implementation**
   Different roles are needed to develop and operate the data space and to certify solutions and participants

Collaboration House



Wrap-up & Summary

Twoards Creating A Collaborated Health Data Space

Our preliminary study lays out a conceptual basis to move forward with

- The **future of healthcare requires a collaborative approach** to data that includes e.g. interoperability, data sharing between all parties involved and access to patient data.
- Collaborative data spaces **enable data sharing while creating trust** between all participants
- **Data sovereignity can be maintained** and technically enforced
- However, a collaborative platform between all relevant actors (and a corresponding digital culture) is still missing
- For use cases **to qualify for a collaborative platform**, they must **contain a solution that benefits multiple stakeholders** rather than creating a differentiator for a single corporation
- **Relevant use cases differ** in terms of complexity, feasibility and attractiveness for certain stakeholders
- **A structured approach to developing a Collaborative Health Data Space and delivering value through use cases is needed**

Outlook & Recommendations

Twoards Creating A Collaborated Health Data Space

Achievements so far

- ✓ The preliminary study containing a **preliminary framework for building a Collaborative Health Data Space is finalized**
- ✓ Potential **use cases have been collected**, clustered and structured
- ✓ **A network of experts has been** identified and **involved** in the project
- ✓ A **strong community of industry partners** has been activated

„Collaboration allows us to know more than we are capable of knowing by ourselves.“

Let‘s just do it - let‘s build a data space!

Open Questions

- Which use cases should be prioritized?
- What is the most feasible and pragmatic way to build a data space?
- Which partners will take the lead and form a collaboration platform?
- What resources are needed to get started?
- How and when to communicate to politics?

Proposed Next Steps

1. **Scoping of a MVP product „Collaborative Health Data Space“** including feasible use cases and technological requirements
2. **Building of a collaboration structure (simultaneously)** that enables a framework for safe, legal and effective data sharing
3. **MVP Development** (first version of a „Collaborative Health Data Space“) based on 1-3 use cases