Decentralized Health Data Management

An overview of solutions empowering individuals to own, share and benefit from their health data.

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About the sponsoring organisations

Etheros HealthData Foundation

Etheros HealthData Foundation (EHF) is a US-incorporated nonprofit organization, dedicated to enabling individuals globally to own, share, and benefit from their health data. Its goal is to foster a shift towards a more equitable, inclusive, and personalized healthcare future.

Website: https://etheroshealthdata.org/

Crypto Valley

Crypto Valley association (CVA) is a leading blockchain and crypto ecosystem in Switzerland, representing more than 250 corporations and 900 individual members. It is fostering growth, collaboration and integrity in the global blockchain economy since 2017.

Website: https://cryptovalley.swiss/

About the co-authors

Carmen Cucul is a healthcare consultant, member of CVA and advisor to EHF. She brings 15+ years experience in digital innovation, blockchain and AI from nonprofits, pharmaceutical sector, and investment spaces

Hui Huang is the co-founder of Etheros HealthData Foundation. She has 20+ years experience in data science, health economics, and outcomes research from pharmaceutical and consulting sectors

Lu Zheng is the co-founder of Etheros HealthData Foundation and Head of Value-Based Partnership and Digital Health, Europe & Canada at Takeda. She has 20+ years experience in patient-centered digital innovation and strategy

Thomas Egelhof is Chief Radiologist, Merian Iselin - Clinic for Orthopedics & Surgery in Switzerland and member of CVA. His vast healthcare experience blends with a strong passion for AI and blockchain

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Introduction

Context and initiators

Currently, over 30% of all data generated globally pertains to healthcare. Despite this, a significant portion of health data is controlled and managed not by the individuals who produce it but by entities such as hospitals, pharmaceutical firms, research institutions, and insurance companies. Moreover, according to healthcare experts, between 90-95% of data generated by hospitals alone remains siloed, its utility confined to its primary use and rarely shared or leveraged more broadly. Last but not least, 95% of rare diseases lack safe, effective treatments, partly due to lack of sufficient data to power clinical trials / research. All of the above point towards the need for health data to be generated, shared and rewarded in a different way: a way which is more sustainable, equitable and relevant for healthcare systems.

In a promising development, the emergence of health and wellness applications, wearables, and decentralized technologies like blockchain have begun to empower individuals with ownership, sharing capabilities, and the opportunity to derive value from their health data. While the movement towards decentralized health data management is in its nascent stages, we have undertaken to highlight and promote the efforts being made in this domain by organizations worldwide.

This report, detailing solutions that enable individuals to own, share and benefit from their health data, is a collaborative effort by the Crypto Valley Association's (CVA) Sustainability Working Group and the Etheros HealthData Foundation (EHF).

CVA is a leading blockchain and crypto ecosystem in Switzerland, representing more than 250 corporations and 900 individual members. The Sustainability Working Group within CVA focuses on encouraging cooperation, research, and the exchange of best practices at the confluence of sustainability, blockchain, and artificial intelligence. Given the relevance of healthcare to both Sustainable Development Goals (SDG) and Environmental, Social, and Governance (ESG) practices, exploring decentralized health data management solutions, particularly those utilizing blockchain technology, is of interest to the CVA Sustainability Working Group.

EHF is a US-incorporated nonprofit organization, dedicated to enabling individuals globally to own, share, and benefit from their health data. The goal is to foster a shift towards a more equitable, inclusive, and personalized healthcare future. This report is a key component of Etheros' foundational research, facilitating the dissemination of best practices and identifying areas where the Foundation can make further contributions.

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Objectives and Target Audience

This report aims to identify and to promote existing decentralized health data management solutions. These are defined as products and services facilitating individuals to:

- Store their health data, encompassing information from wearables, patient reported outcomes (PROs), medical records, laboratory results and more
- Share aforementioned health data to chosen entities, whether they be researchers, healthcare professionals, friends and family or others
- Benefit from sharing their data, potentially through rewards such as tokens, badges, or access to discounted or complimentary value-adding products or services

We have generated this report with three objectives and target audiences in mind:

1. For general public, our goal is to empower them to take ownership of their health data by sharing ready-to-use decentralized health data management platforms and applications
2. For entrepreneurs and product teams, this report aims to disseminate knowledge, tools, and best practices in the creation of user-friendly, value-adding, secure, scalable and interconnected decentralized health data management solutions
3. For broader ecosystem stakeholders, such as patient organizations, research institutions, healthcare specialists, providers, insurers, technology startups, we strive to spotlight specific areas of opportunity, articulate recommendations to advance the domain of decentralized health data management and inspire collaboration with CVA and EHF

Content Overview

The content of this report is crafted to strategically align with the three objectives previously identified, presenting a structured approach to decentralized health data management solutions.

Chapter 1: "Pillars of Decentralized Health Data Management" is dedicated to sharing knowledge, tools, and best practices in the realm of decentralized health data management. It is divided into three main sections: Own, Share, and Benefit, each introduced with a foreword by a co-author of this report. These introductions aim to contextualize the importance of each pillar, outline the associated challenges, and propose visions for success. Additionally, we incorporate "knowledge blobs", to delve into theoretical concepts vital for the advancement of each topic. This chapter also contains insightful interviews with leaders and entrepreneurs in the field, sharing their experiences, achievements, and lessons learnt.

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Chapter 2: "Compendium of Solutions in Decentralized Health Data Management" focuses on promoting existing decentralized health data management solutions, fulfilling the report's main goal. Through concise and clear "**one pager" overviews**, we outline various applications, platforms, and digital services identified during our research. Each example follows a standardized template that includes an overview, target audience, geographic coverage, major partnerships, and technical specifications of the product or service offered. The highlighted solutions span multiple **continents** and **use cases -** from health & wellness to genomic research, rare diseases and beyond - showcasing the diversity and potential within this emerging sector.

Chapter 3: "Future Opportunities for Decentralized Health Data Management" addresses our objective of identifying opportunities and formulating actionable recommendations to expand the field. It distills the insights collected from expert interviews and the documented solutions into five concrete areas for growth: enhancing **public awareness & health education**, establishing more **data sharing marketplaces**, advocating the use of **standards for interoperability**, using **artificial intelligence** to curate health data and leveraging **scalable technologies** for global impact.

Methodology

In the compilation of this report, the co-authors have engaged in desk and literature research, examining a variety of publicly available sources such as research papers, company websites, press releases, interviews and app interfaces. This endeavor has been complemented by interviews with leading figures in the decentralized health data management sector. While this report is not designed as a scholarly or scientific manuscript, it has been developed with research best practices in mind, conforming to applicable copyright legislation and the principles of peer review.

With respect to disclaimers, it is pertinent to clarify that the projects featured in this report have been selected based on an assessment conducted in good faith, reliant upon publicly accessible information and alignment with the thematic scope of this report. The catalog of existing solutions highlighted through case studies does not purport to be exhaustive, as it was dependent on the availability of public information and access to representatives of the respective solutions, at the time this research was conducted. Furthermore, this document is not intended to act as an inducement or invitation for investment in the entities discussed herein. The reference to companies and their initiatives is intended solely for informational purposes and should not be considered an endorsement. Prospective investors are advised to undertake thorough due diligence independently.

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Key Contributors

This research was carried out by four dedicated individuals from the Crypto Valley Association and Etheros HealthData Foundation, bonded by their shared commitment to empowering individuals to own, share and benefit from their health data. Their diverse expertise has significantly enriched this study: Carmen Cucul offers extensive experience in digital innovation and blockchain from her work in nonprofits and the pharmaceutical sector. Hui Huang brings a wealth of expertise in data science, health economics, and outcomes research to the exploration of decentralized healthcare data management. Drawing on over two decades in biopharma industry and market access consulting, she aims to redefine the value of data based on its societal utility and impact. Lu Zheng adds insight from her background in academia, the pharmaceutical industry, and consulting, focusing on patient services, digital health, and value-based partnerships. Thomas Egelhof elevates the project with his vast experience as a healthcare professional in radiology, a central interface of modern medicine, and his unwavering passion for artificial intelligence and blockchain technology.

We extend our deepest gratitude to the leaders and entrepreneurs interviewed for this project, who provided invaluable perspectives on the challenges and prospects of decentralized health data management: Chrissa McFarlane (Founder & CEO of Patientory), Ahmed Abdulla (CEO of Digipharm) and Annie Axelle (Head of Partnerships at Afya Rekod). Their teams, along with others who supplied documentation and reviewed solution overviews, have been instrumental in this endeavor.
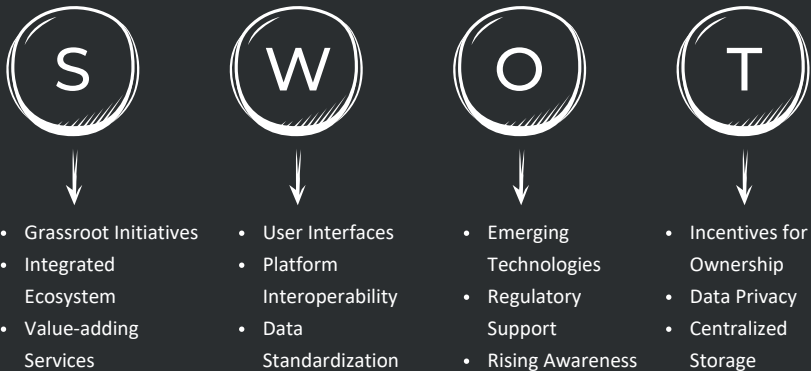
Special thanks are due to our peer reviewers and contributors: Michele Soavi (COO/CSO of ImpactScope and Chair of CVA's Sustainability Working Group), Casper Paardekooper (Partner at Vintura), Fiona Thwaites (CEO / CMO of Jennis.com), Robert Turrall (Web3, Blockchain & AI Advisor and Swiss NFT Association Ambassador), as well as EHF volunteers: Yafei Liu, Liam Bloom, Christian Kokoros and Richard Zhong—whose rigorous scrutiny and fresh perspectives helped refine our insights and highlight overlooked aspects.

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Executive Summary

In order to have an equitable, inclusive and sustainable healthcare system that thrives in a world of data, digitization and automation, a new paradigm is required. The new paradigm ought to redefine the value of data in the healthcare system (from economic impact to societal utility) and to realign how incentive accrue in its value-creation chain (from data processors to data generators: individuals). We call this new paradigm "decentralized health data management". Without societal utility as an "end" and empowerment of individual as a "means", we will continue to experience the bottlenecks of the current system: lack of treatments for many diseases (especially rare and genetic), deterioration of public health standards, under-resourcing and inefficiencies in healthcare delivery services.

A world where decentralized health data management works is a world where individuals are able to own, share and benefit from their own health data. This requires the availability of a critical mass of health data management solutions and marketplaces that are user-friendly, comprehensive, secure, global and interconnected. Additionally, a decentralized system requires the entire ecosystem of stakeholders to work collaboratively in areas such as public awareness and empowerment, use of data standards and interoperable systems or the introduction of supporting legislation.

Concluding this report we have identified a series of strengths and opportunities already available in this nascent sector, as well as risks and obstacles for entrepreneurs and product teams in bringing state of the art solutions to users.

S	W	O	T
• Grassroot Initiatives	• User Interfaces	• Emerging Technologies	• Incentives for Ownership
• Integrated Ecosystem	• Platform Interoperability	• Regulatory Support	• Data Privacy
• Value-adding Services	• Data Standardization	• Rising Awareness	• Centralized Storage

We encourage the general public to download and test some of the solutions presented in Chapter 2, and thus become part of the decentralized health data management transformation. Product teams and broader ecosystem stakeholders who are interested in collaborating and/or participating in CVA's and EHF's future activities should reach out to us at info@crytovalley.swiss and forum@etheroshealthdata.org.

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Chapter I

Pillars of Decentralized Health Data management

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Introduction

This chapter is dedicated to sharing knowledge, tools, and best practices in the realm of decentralized health data management.

It is divided into three main sections: Own, Share, and Benefit, each introduced with a foreword by a co-author of this report. These introductions aim to contextualize the importance of each pillar, outline the associated challenges, and propose visions for success.

Additionally, we incorporate "knowledge blobs", to delve into some of the theoretical concepts we deemed important for a better understanding of each topic.

This chapter also contains insightful interviews with leaders and entrepreneurs in the field, sharing their experiences, achievements, and lessons learnt.

Target audience: broader ecosystem stakeholders, entrepreneurs and product teams, general public.

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1.1 Own Your Health Data

Foreword: Thomas Egelhof

Chief Radiologist, Merian Iselin - Clinic for Orthopedics & Surgery, Switzerland and CVA member

"Health data are crucial for effective health management, embodying not just medical details but also socioeconomic, environmental, and behavioral insights. The existing healthcare systems, however, grapple with challenges in accuracy, cost-efficiency, data security, interoperability, and auditability. The current structure hinders the seamless exchange and standardization of information, complicating collaboration among stakeholders such as individuals, patients, health providers, research entities, and the industry, each with distinct needs and standards.

Historically, before the 1980s, health data were manually recorded and stored in voluminous clinical archives, leading to data loss and retrieval challenges. With technological advances, data processing shifted to computers, stored on floppy disks and magnetic tapes, yet technical and software mismatches persisted, complicating data access. Nowadays, medical records are primarily stored in electronic server archives. However, the reliance on centralized systems means that if a patient changes their doctor or hospital, their data become nearly inaccessible to other medical professionals due to varying software, technological requirements, and functionalities across medical storage systems. This lack of uniformity obstructs the storage, retrieval, and distribution of patient data among different providers.

Moreover, the integration of data from wearables and connected medical devices is essential for a comprehensive health assessment, necessitating that records be up-to-date, traceable, and tamper-proof. Increasingly, patients desire to access, manage, and share their health information securely, driving a demand for more participation, empowerment, better treatment acceptance, and outcomes.

The healthcare industry's current data management systems struggle to simultaneously provide privacy, security, and transparency. Technologies such as blockchain offer a promising solution to these challenges, heralding a shift towards a patient and customer-centered system by enhancing the management and accessibility of health data. I am confident that this report will provide inspiration for innovative approaches to a better, people and patient centric health data management system."

Disclaimer: The views expressed in this foreword are those of the author and do not necessarily reflect those of the employer, Merian Iselin - Clinic for Orthopedics & Surgery.

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Info blob: blockchain for decentralized health data ownership

Blockchain is a digital ledger of transactions that is duplicated and distributed across a network of decentralized computer systems. Each block in the chain contains a number of transactions, and every time a new transaction occurs on the blockchain, a record of that transaction is added to every participant's ledger, as well as to the next block (thus the "chain"). Blockchain technology has been designed to be decentralized and secure, making it nearly impossible to alter past transactions, thereby ensuring transparency and trust.

Within the decentralized health data management space, blockchain technology has the potential to bring several benefits:
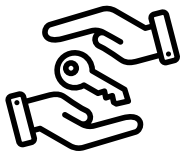
Enhanced Data Ownership and Control: In blockchain, users can decide who accesses their data, under what conditions, and for how long. This is facilitated through digital keys and permissions via smart contracts

Secure Data Sharing: Cryptographic hash functions create a tamper-resistant chain of data blocks by employing public-private key encryption, which ensures data access only to those with authorized keys

Incentivized Data Sharing: Individuals can be incentivized to share their data for research or other beneficial purposes through tokens or other reward mechanisms, such as being part of a Decentralized Autonomous Organisation

Other benefits of blockchain's use in decentralized, patient-driven health data management:
- **Improved Privacy:** With blockchain, personal health information can be anonymized before being shared (e.g by using zero-knowledge proof protocols)
- **Increased Trust and Transparency:** The immutability of blockchain ensures that once data is entered, it cannot be altered or deleted
- **Facilitated Interoperability:** Blockchain standards can be used by different healthcare stakeholders to access and share health data more seamlessly
- **Empowering Patient-Centered Research:** Patients can directly contribute to medical research and innovation by sharing their health data directly, without intermediaries
- **Enhanced Data Integrity and Quality:** Blockchain's consensus mechanisms ensure that data added to the network is verified and validated by multiple parties

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Interview: Chrissa McFarlane

Founder & CEO, Patientory (USA)
Interviewed by Carmen Cucul

Can you describe the problem Patientory aims to solve and why you decided to focus on this particular challenge?

My journey to creating Patientory was deeply influenced by both my professional background in telemedicine and a challenging experience within my own family. A relative struggled for over a decade to get a clear diagnosis, being passed from one healthcare provider to another without a definitive answer. This highlighted a significant issue in the U.S. healthcare system: the fragmented nature of medical records and the lack of patient control over their own health data.

We launched Patientory in 2015, initially not on blockchain. The turning point came a year later, inspired by the advances and potential we saw in **blockchain technology,** particularly through platforms like Ethereum. Their success showed us how blockchain could ensure secure and transparent management of health data. This technology seemed the perfect fit to bridge the gap in health data management, aiming to give patients like my relative the ownership and seamless access to their medical history they so much needed. While we aimed to empower chronic patients at first, we found that our platform attracted crypto enthusiasts and health-conscious individuals as early adopters, which broadened our vision of who could benefit from Patientory's capabilities.

Could you delve into Patientory's product offerings, particularly focusing on the user interface, technical aspects, and data management?

Patientory is designed to empower users by connecting them with their health data and providing actionable insights through our advanced **AI-driven chatbot**. This chatbot serves as a digital health coach, offering personalized health recommendations to users, who can also earn Patientory tokens (PTOY) by following these suggestions. In addition, the app allows users within the U.S. to **access their medical records**, contributed by our healthcare institution partners, and enables them to integrate data from wearable devices. Furthermore, the application alerts users to **clinical trials** they're eligible for, rewarding participation with PTOY tokens; one such example was Moderna's COVID19 vaccine trial. With 50,000 sign-ups, Patientory's aim is to establish itself as a **holistic health management tool.** In terms of design, our approach was intentional: we wanted an app that didn't intimidate users but instead felt like a daily companion.

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Our **technical backbone** is built on a proprietary private, permissioned blockchain, ensuring the secure and private handling of health data. Importantly, we opt not to store data directly on the blockchain. Instead, we leverage decentralized storage solutions, enhancing the security and privacy of user information. Digital Identities (DIDs) are employed to further protect user identities, ensuring a secure environment for health data management. This infrastructure underpins our application's functionality, from securing medical records to facilitating the AI chatbot's personalized health recommendations, all within a framework designed for scalability and user privacy.

Looking ahead, our roadmap is focused on **expansion and innovation**. We aim to extend our medical records integration feature beyond the U.S., making Patientory a global tool for health data management. Additionally, we're in the process of developing telemedicine services, such as the already launched CareGLP: a diabetes telehealth service that uses a person's body mass index (BMI) to recommend appropriate support via the app. This initiative is part of our broader strategy to not just manage health data, but to actively improve access to healthcare services, as underscored by our recent fundraising efforts. Our goal is to make Patientory a cornerstone of personal health management and a significant contributor to the broader healthcare ecosystem.

Regarding Patientory's business model, how would you describe its value proposition, target audience, and the incentive mechanisms for users? How is the initiative financed?

At Patientory, we've constructed a **business model** that resonates deeply with our vision for healthcare — a sector where every individual has complete control and ownership of their health data. Our value proposition is twofold: for the everyday user, it's about empowerment and compensation for their engagement and data, acknowledging that personal health management should be rewarded. This approach appeals to health-conscious individuals, especially those already familiar with web 3.0 concepts, making them our primary target audience. We have seen success in attracting users not only from the USA but also globally, for example English-speaking users in Asia Pacific region. For our partners, like pharmaceutical companies engaging in clinical trials, our platform offers unparalleled speed and efficiency in patient recruitment, addressing the critical challenge where 80% of trials stall due to the difficulty in finding suitable participants.

Financing this initiative began with our pioneering entry into the blockchain space through a token launch sales in 2016, a move that not only secured the necessary funds to build our blockchain infrastructure but also positioned us as innovators at the intersection of healthcare and technology. Since then, we've continued to evolve, raising additional capital through venture capital pre-seed funding specifically for the Patientory Wallet. This component enhances our ecosystem, enabling users to manage their health data and engage with our platform using PTOY tokens. These tokens, integral to our incentive model, are rewarded to users for various activities, including participation in clinical trials (arthritis and diabetes being examples of disease areas where Patientory has contributed data recently) as well as daily health management tasks, especially those connected to users' care plans. The tokens can be

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traded on several exchanges, with plans to expand their availability. Our approach to tokenomics and user engagement aims to keep our community at the heart of everything we do, driving us forward as we continue to redefine the landscape of health data management.

Can you share some roadblocks and key learnings from building Patientory? Would you have approached anything differently in hindsight?

In the early stages of Patientory, we faced significant roadblocks, particularly in securing data partnerships with US healthcare organizations and navigating the complex landscape of blockchain technology. These challenges were not just **technical** but also **educational**, as we had to introduce and advocate for the potential of blockchain within the healthcare sector. This effort required us to not only sell the vision of Patientory but also demystify blockchain for our partners, a task that was both daunting and enlightening.

The journey taught us invaluable lessons, especially regarding the importance of **user experience / user interface** design and the strategic positioning of our platform. We chose to design our app to be welcoming and non-intimidating, moving away from the typical healthcare app aesthetics to make health management integrate seamlessly into user's daily life. Reflecting on our path, I recognize the importance of **managing expectations**, particularly around the adoption rate of blockchain in healthcare. Our initial enthusiasm led us to perhaps overestimate this speed, highlighting the need to start small and prioritize iterative development.

Looking ahead, what is your vision for decentralized health data management, and what factors do you believe are crucial for achieving widespread adoption?
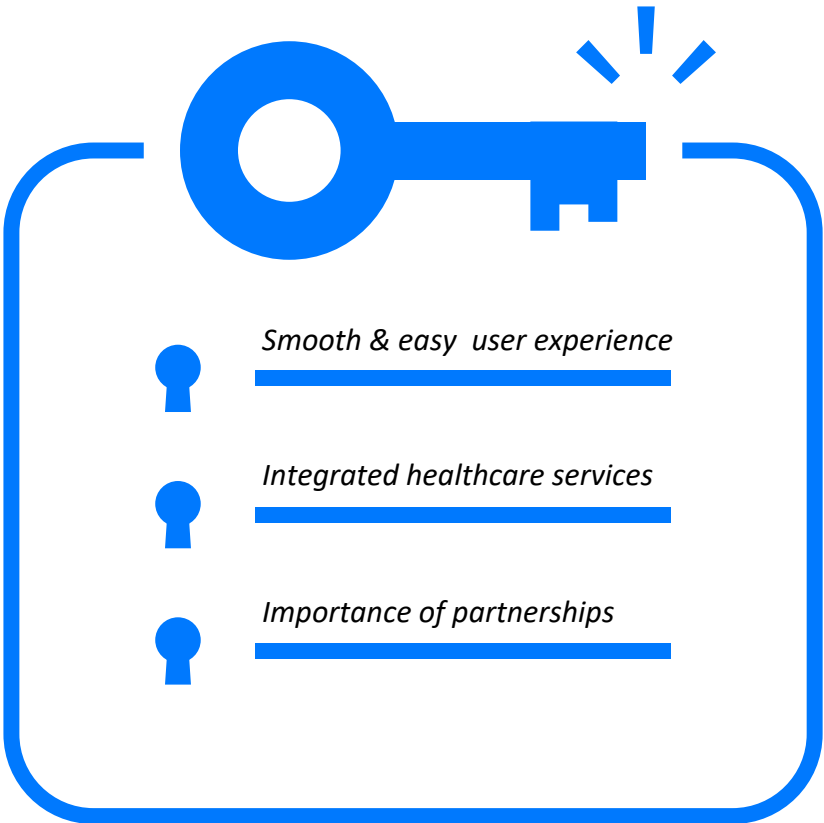
My vision for decentralized health data management is ambitious yet grounded in the realistic potential of emerging technologies. I foresee a future where the vanguard of this transformation comes from regions eager to embrace change, such as **Asia and the Middle East**. Their readiness to integrate cutting-edge solutions in healthcare demonstrates a clear path toward patient-centric data management. Engaging in global forums like Token2049 and Health2030 has solidified my belief that the move away from conventional healthcare systems is not just necessary but imminent. This shift will lean heavily on innovations in telehealth and digital health tools, making healthcare more accessible and tailored to individual needs.

A crucial factor for achieving widespread adoption is the **reimagining of healthcare delivery** itself. Healthcare should not be confined to the walls of hospitals but rather embedded in our daily lives, where every individual takes proactive steps toward their health management, aided by technology. This means the system needs to evolve to meet patients where they are, making health management a personal responsibility supported by easy-to-use, accessible tools. In this envisioned future, decentralized health data management becomes the backbone of a healthcare system that prioritizes patient empowerment, data privacy, and seamless access to care, essentially bringing the healthcare system to individuals, not the other way around.

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Lastly, what kind of support does Patientory need to further integrate into the healthcare ecosystem and achieve its goals?

Strategic partnerships have been pivotal in our journey, exemplified by our designation as a World Economic Forum (WEF) Technology Pioneer, which opened numerous opportunities for dialogue and collaboration for Patientory. Looking ahead, fostering **partnerships** and navigating the complex **regulatory landscape** of healthcare data will be crucial and we welcome any support from eligible stakeholders here. Our engagement with federal organizations and adherence to **data standards** like FHIR underscore our commitment to not just complying with regulations but actively contributing to the development of a more cohesive, patient-centered healthcare system in which data is portable and interoperable.

Visit Patientory at https://patientory.com/

Smooth & easy user experience

Integrated healthcare services

Importance of partnerships

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1.2 Share Your Health Data

Foreword: Lu Zheng

Head of Value-Based Partnerships & Digital Health, Europe & Canada,
Takeda Pharmaceuticals | Co-founder Etheros HealthData Foundation

One of the fundamental challenges in healthcare has been the fragmentation of data across disparate systems and institutions. Health data is often stored in siloed systems that lack interoperability. Different healthcare providers and institutions use disparate electronic health record (EHR) systems that do not seamlessly communicate with one another. This fragmentation hinders the free flow of information and makes it challenging to create a comprehensive view of a patient's health history.

Health data contains highly sensitive and personal information. Concerns about privacy breaches, unauthorized access, and data misuse have led to a cautious approach in sharing health information. The current healthcare ecosystem often lacks adequate incentives for sharing data. Healthcare providers and institutions may be hesitant to share information due to concerns about competitive advantage, liability, or the fear of losing patients to other providers.

Moreover, sharing health data is not just a technological or scientific endeavor; it is a commitment to improving patient outcomes and fostering a patient-centric approach to healthcare. The insights derived from shared health data can empower individuals to take control of their health, enable healthcare providers to make more informed decisions, facilitate an easier and cost effective research and new drug development and ultimately contribute to a more efficient and sustainable healthcare system.

In summary, by forging a path that acknowledges and addresses privacy concerns while unlocking the potential of health data, we can propel healthcare into a new era of innovation, personalized medicine, and improved productivity and sustainability.

Disclaimer: The views expressed in this foreword are those of the author and do not reflect those of the employer, Takeda Pharmaceuticals International AG.

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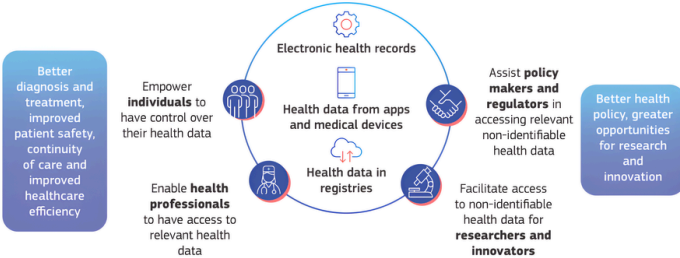
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Info blob: Upcoming European Health Data Space (EHDS) Regulation

The European Health Data Space is a key legislative initiative of the European Union, expected to enter into force as of 2026. It will empower patients to access their health data in an electronic format, including from a different member state to the one in which they live, and allow health professionals to consult their patients' files with their consent, also from other EU countries. Additionally, the Health Data Space would unleash the research potential of health data in an anonymised or pseudonymised format.

Source: European Commission

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Interview: Ahmed Abdulla

CEO, Digipharm (UK)
Interviewed by Carmen Cucul

Can you describe the problem Digipharm and DigiHealth aim to solve and why you decided to focus on this problem?

The journey of Digipharm began with a clear mission: to tackle the inefficiencies and unsustainability in healthcare procurement, especially concerning high-cost drugs. My experience in healthcare economics revealed a stark reality – a disconnect between the cost of therapies and their actual benefits to patients. It was evident that healthcare systems worldwide were grappling with rising costs, yet the value delivered to patients was not proportionate. This challenge became more pronounced with the growth of value-based healthcare (VBHC), an approach that aims to link payments for healthcare services to the achieved patient outcomes.

As we navigated through these challenges, blockchain technology emerged as a beacon of hope. Its promise of transparency, security, and efficiency was perfectly aligned with our vision. Digipharm initially focused on leveraging blockchain to create a business-to-business (B2B) platform, facilitating transparent agreements between manufacturers, insurance companies, governments, and healthcare providers. This platform was designed to make healthcare procurement more efficient, ensuring that contracts and agreements were transparent and beneficial to all parties involved.

However, our vision extended beyond institutional agreements. We recognized a profound opportunity to empower individuals directly through DigiHealth, a business-to-consumer (B2C) solution that serves as a global patient engagement portal. It empowers patients to take ownership of their health data, enabling them to securely manage, share, and leverage this data to participate in research and influence healthcare outcomes. DigiHealth bridges the gap between patient experiences and healthcare delivery, transforming patient interaction with the healthcare system. Patients become active participants in their care, using their health data to inform decisions, access personalized treatments, and advance medical research. DigiHealth heralds a new era of healthcare centered on data ownership and patient empowerment.

Can you tell us a bit about DigiHealth from a product perspective, including the user interface, technical backbone, and data management?

DigiHealth, currently under development and aiming to launch by summer 2024, is designed to bring patients' engagement with their own health data to the next level. Our approach is structured around three pillars, keeping future scalability and patient empowerment in focus.

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User Interface and Functionalities:

The user interface of DigiHealth prioritizes simplicity and engagement, aiming to make the management of health data as intuitive and accessible as possible. We've concentrated on creating a patient-facing application that feels personal and responsive, one that users would be comfortable navigating daily. Key functionalities include the ability to provide remote patient feedback on quality of life and therapy effectiveness through Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs). These features are complemented by established questionnaires, enabling patients to contribute their health data towards personalized research and value-based procurement agreements. Beyond data collection, DigiHealth will offer a suite of integrated services, such as telemedicine consultations, health data storage, and participation in clinical trials or health surveys, all designed to enrich a patient's healthcare journey.

Technical Backbone:

The technical infrastructure of DigiHealth is built on a private blockchain, chosen for its advanced security, efficiency, and ability to handle complex transactions with ease. This blockchain foundation ensures that all patient data is stored securely and that privacy is maintained through encrypted transactions. Our use of blockchain technology is pragmatic, focusing on creating a secure environment for patients to manage and share their health data without compromising on accessibility or ease of use. The platform is designed with interoperability in mind, featuring application programming interfaces (APIs) that facilitate smooth integration with existing healthcare systems and enable comprehensive data analysis.

> *The platform is designed with interoperability in mind, featuring application programming interfaces (APIs) that facilitate smooth integration with existing healthcare systems and enable comprehensive data analysis.*

Data Layer and Management:

The data management strategy of DigiHealth is centered around patient empowerment and data sovereignty. Patients register using Digital Identities (DIDs) and store their health data on the blockchain, encompassing a wide range of information from genetic to medical and lifestyle data. This data is then aggregated into community datasets, with patients having the option to share their data in exchange for rewards, such as digital tokens or non-fungible tokens (NFTs). Our approach ensures that individual data contributes to a larger pool of knowledge while maintaining patient privacy and control. Data cleaning and analysis are performed using AI, ensuring insights are derived efficiently and accurately, supporting both the individual's health journey and broader medical research.

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Could you elaborate on DigiHealth's business model, including its value proposition, target group, incentive schemes, and financing?

DigiHealth, under the umbrella of Digipharm, is crafting a business model that combines the necessity for comprehensive health data management with the innovation of blockchain technology, aiming to serve a broad spectrum of stakeholders within the healthcare ecosystem. At its core, DigiHealth offers a **singular, unified platform** for patients, addressing the cumbersome reality of juggling multiple apps and records for different health conditions. This platform is not just a repository; it's an engagement tool that empowers patients to take control of their health data, offering incentives such as DigiHealth tokens (DGH) and potentially also the possibility of fractional ownership in community datasets through NFTs. These **incentives** complement our broader strategy to enhance patient care and experience through integrated services like telemedicine, health surveys, and device connectivity.

> *At its core, DigiHealth offers a singular, unified platform for patients, addressing the cumbersome reality of juggling multiple apps and records for different health conditions.*

The **value proposition** of DigiHealth extends beyond patients. For researchers and healthcare centers, the platform provides access to a wealth of complementary data that can significantly enrich the analysis of clinical data and health outcomes. This data, encompassing behavioral insights, PROMs / PREMs, genetic information, and more, offers a deeper, more nuanced understanding of patient experiences and the effectiveness of treatments. Manufacturers of drugs and devices also stand to gain from DigiHealth's comprehensive data aggregation, which delivers insights into the real-world efficacy of products, crucial for reimbursement strategies and market access.

Targeting a younger demographic, particularly those under 40 who are accustomed to digital interactions and the sharing economy, DigiHealth is designed for global reach, with an initial focus on key markets such as the UK, EU, and the Middle East. This strategic focus reflects an understanding of the digital native's comfort with data sharing and ownership, underpinned by an interest in digital currencies and web3 technologies. Engagement with this demographic is facilitated through partnerships with hospitals and healthcare providers, ensuring a seamless integration into their health management routines.

Revenue generation for DigiHealth is multifaceted, encompassing license fees from its B2B value-based contracting platform, and a diverse range of B2C income streams. These include monetization of the data shared by users, with a portion of the proceeds returning to them, fees for telemedicine services, and a marketplace where third parties can offer their services. This ecosystem is further enriched by tokenomics and incentive models that reward users for their participation, creating a sustainable cycle of engagement and value creation.

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What sets DigiHealth apart is not just its comprehensive approach to patient data management but its potential to revolutionize healthcare delivery and research. By providing additional **data for value-based contracts** of medicines, diagnostics devices and services, DigiHealth offers a 360-degree view of patient health. This unparalleled insight, combined with the platform's commitment to data security and patient empowerment, positions DigiHealth as a challenger to established health apps such as Apple or Samsung Health, paving the way for a new era in decentralized health data management.

Could you discuss some of the roadblocks and learnings in building DigiHealth?

One of the most significant challenges in developing DigiHealth has been the **scarcity of developers** with the necessary blend of blockchain and healthcare expertise. This scarcity not only makes the development process costly but also time-intensive. Another hurdle has been ensuring the **availability and quality of health data**, which is critical for the platform's success. Our journey taught us the value of long-term thinking, the need for patience and the importance of building a comprehensive ecosystem that encourages all stakeholders to participate actively and benefit mutually.

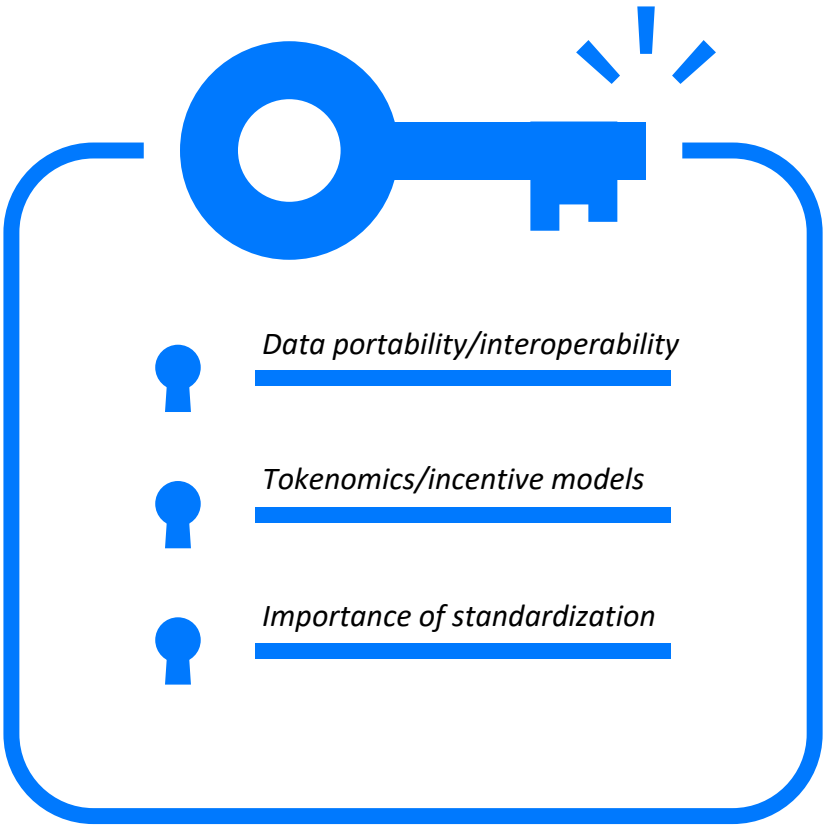### What is your vision for the future of decentralized health data management?

My vision is a future where users don't need intermediaries to submit their data; they would have direct control and the ability to share data with researchers, insurers, etc., using distributed storage solutions. However, realizing this vision is challenging and may take another 5-10 years. In the meantime, we aim to bridge the gap by focusing on transparency, data portability, and improving the blockchain user experience (UX) to encourage mass adoption.

Achieving mass adoption requires more than just technological advancements; it demands a shift in how users **perceive** and engage with their health data. Success stories that highlight the tangible benefits of decentralized health data management will be instrumental in this journey. These stories not only showcase the potential for improved health outcomes but also build trust in the security and efficacy of platforms like DigiHealth. Furthermore, **engaging** with users on their preferred platforms is crucial, whether it's through social media, online communities, or direct partnerships with healthcare providers. This approach, coupled with clear **regulatory frameworks** and continuous improvements in user experience, will pave the way for DigiHealth and similar decentralized health data solutions to become integral parts of the healthcare system.

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Lastly, what support does Digipharm need to grow and integrate into the broader ecosystem?

The most significant support would be from an organization that facilitates the **sharing of best practices** and **standards for interoperability** among different players in the healthcare data space. Currently, there's a sense of fragmentation as everyone pursues their solutions. Establishing compatibility among platforms and enabling data portability will be key to fostering a more integrated and efficient healthcare ecosystem.

Visit Digipharm and DigiHealth at https://www.digipharm.io/

Data portability/interoperability

Tokenomics/incentive models

Importance of standardization

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1.3 Benefit From Your Health Data

 ## *Foreword: Hui Huang*

Founder and CEO, CSD Partners LLC | co-founder Etheros HealthData Foundation

Etheros HealthData Foundation is pioneering a new value system where the worth of health data is determined by its societal utility and impact, rather than traditional economic measures. This shift has profound implications for how we perceive and leverage personal health information. Consider the case of rare disease patients. In current economic paradigms, they may be seen as less productive due to the constraints of their conditions. However, in a data-driven economy, the scarcity and specificity of their health information make it immensely valuable for advancing medical understanding and developing treatments. This new value system recognizes and rewards their unique contributions, promoting equitable rights and benefits for all participants.

Realizing this vision requires a fundamental mindset change. Individuals must recognize the inherent worth of their health data and feel empowered to own and share it within a trusted, rewarding ecosystem. Just as the free exchange of goods transformed economic productivity, as Adam Smith envisioned, the free flow of data can exponentially accelerate scientific progress and healthcare innovation.

However, this transformation raises important philosophical and ethical questions. How do we build legitimate, secure marketplaces that honor individual agency over personal data? How do we quantify and compare the societal utility of different data contributions? How do we ensure equitable outcomes and prevent the exploitation of vulnerable groups? Answering these will be critical to shaping a responsible, inclusive data economy.

Ultimately, this shift is about more than just economic benefits. It's about redefining the very essence of our existence. As our lives become increasingly digitized, our health data becomes an integral part of our identity, a chronicle of our physical, mental and emotional journeys. With proper stewardship, this data can create a form of immortality, ensuring that our experiences, learnings and contributions endure beyond our physical years.

EHF invites everyone to be part of this transformation so we can create a future where every individual's health data is cherished as a vital resource, where sharing it is an empowering act of social good, and where the insights gleaned from it form a lasting legacy for the future.

Disclaimer: The views expressed in this foreword are those of the author and do not reflect those of the employer, CSD Partners LLC.

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Info blob: example of incentives schemes that work in web3.0

Web3 is a fascinating domain in which innovative incentive schemes have been implemented across the value creation chain of transactions and have proven their utility in sectors such as dePIN (decentralized physical infrastructure), gaming and DeFi (decentralized finance).

The value creation chain of a transaction

Initiation

(How is a value-creating transaction being generated?)

Confirmation

(How is this transaction being validated?)

Allocation

(How do parties receive their share of rewards?)

Administration

(How are rewards gained being managed?)

How incentives work across the value chain (web3.0)

Smart Contracts

Digital artefact generated on a blockchain to document a transaction between two or more parties. Most blockchains offer smart contract functionality.

Consensus Mechanisms

Process undertaken by several validators (computers) to confirm transactions were legitimate. Most consensus mechanisms are either Proof of Work (PoW) or Proof of Stake (PoS)

Token/Coins, NFTs

Different means of payment for parties engaged in a smart contract. Some are fungible (tokens / coins such as BTC, ETH, USDT, USDC), others are non-fungible (such as CryptoPunk NFTs).

Exchanges, DAOs

Each party ca use generated rewards on exchanges (buy / sell / stake / loan...) or manage them in a decentralized autonomous organisation (DAO) based on community decisionmaking rules

Examples of web3.0 use cases where incentives work

DePIN
Decentralized Physical Infrastructure

Ex: Wifi Map, Filecoin, Helium Mobile, Render, Akash

Gaming
Play-to-earn platforms

Ex: Axie Infinity, Illuvium, Decentraland, Sandbox

DeFi
Decentralized Finance

Ex: Uniswap, Lido, Maker, Ledger, Binance, Aave

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Interview: Annie Axelle

Head of Partnerships, Afya Rekod (Kenya)
Interviewed by Carmen Cucul

Can you start by telling us about the main problems Afya Rekod is addressing and why you decided to focus on these issues?

Absolutely, Afya Rekod, was established in response to significant challenges in the African healthcare landscape, primarily around health data ownership and accessibility. Traditionally, patients have been inadvertently 'bound' to specific physical location because medical records are kept wherever the diagnosis or treatment takes place. This leads to situations where patients are required to undertake lengthy, costly, time consuming journeys back to hospitals that hold their historical medical records – because no other hospital, clinic or medical centre could access such data. Afya Rekod solves this lack of data transportability and interoperability.

Moreover, the issue of misdiagnosis and subsequent mistreatment is alarmingly common – with 33% of all patients citing this experience – often with tragic and even deadly results. This highlights the critical need for improved data management and health awareness within our healthcare systems.

In response, Afya Rekod was launched in 2019 with a mission to revolutionize how health data is managed by empowering patients to own and control access to their personal health information. Our goal is to ensure that patients can access and transfer their health data freely, reducing dependency on any single healthcare provider and improving healthcare service delivery and outcomes.

Can you tell us a bit about Afya Rekod from a product perspective, including the user interface, technical backbone, and data management?

Afya Rekod's platform is strategically designed around **three core service areas**, each targeting specific gaps within the healthcare delivery and data management ecosystem. First, we have MyRekod, designed to empower them with direct control over their health data. Second, we also have a Health Management Information System (HMIS), tailored for hospitals, particularly those that lack digital infrastructure. Lastly, our health worker module digitizes data collection during their community engagements, and links back to our HMIS for seamless data integration, analysis and reporting, which then is made available to stakeholders. All services are accessed via our mobile app and website.

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MyRekod is the **patient-facing component** of our platform, designed with a user-friendly interface that simplifies the management of health information by the individuals. Patients can scan prescriptions, automatically receive updates on their health records from connected hospitals, and add personal health profiles that can be useful during medical consultations. Additionally, features include the ability to keep a health diary for symptoms monitoring, to access disease-specific educational content prepared by healthcare experts, and to undertake real-time communication with healthcare practitioners. Patients can provide permission-based access and share their data securely with anyone they choose, enhancing the collaborative aspect of patient-centered care.

On the **technical side**, MyRekod is supported by our robust **blockchain** infrastructure. This setup guarantees the immutability and security of the data, crucial for maintaining patient trust and compliance with global data protection regulations. Furthermore, our **artificial intelligence models** generate valuable insights for healthcare delivery stakeholders and optimize our own services.

Can you elaborate on Afya Rekod's business model, including its value proposition, target groups, incentive schemes for data sharing, and financing?

Afya Rekod is primarily **positioned** as a data management company, and our value proposition is twofold: For the business-to-business (B2B) sector, we focus on providing data mobility, interoperable systems, affordable healthcare solutions, and ensuring the continuity of patient care. For the business-to-consumer (B2C) market, our core offering is returning control, access and agency over health data back to the individuals, who are the rightful owners of healthcare data.

Our **target groups** reflect these distinctions. In B2B terms, we serve hospitals, particularly faith-based institutions in rural areas that lack the necessary infrastructure to manage health data effectively. These facilities make up about 60% of healthcare delivery in Kenya alone, highlighting a significant market need. For B2C cases, our platform appeals to health-aware individuals, caregivers, and notably, patients with non-communicable diseases, who represent approximately 80% of our user base.

> *For the business-to-consumer (B2C) market, our core offering is returning control, access, ownership, and agency over health data back to the individuals, who are the rightful owners of healthcare data.*

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Our **business model** incorporates both the B2B and B2C aspects of our activities. Medical institutions are charged fees for the implementation and ongoing operation of our HMIS platform. On the B2C side, while our suite of services is free for patients, doctors pay a subscription fee to access various diagnosis, treatment, referral and monitoring tools. This dual revenue stream supports our sustainable growth, as will, in the future, other types of revenue streams. In addition, we have previously secured Pre-Seed and Seed funding and are preparing, in the near-future, to undertake a Series A capital raise to accelerate the expansion of our proven model.

Currently, Afya Rekod **operates** offices in Kenya, Nigeria, South Africa, and Zambia, and we're planning to expand into Burundi and Malawi this year. Our platform has attracted over 400,000 users, with significant engagement, particularly in Kenya and Nigeria, where majority of users are individuals, while in South Africa, most users are healthcare professionals. This diverse user engagement underscores the broad applicability and need for our services across different healthcare settings and user demographics.

Reflecting on the journey of building Afya Rekod, what have been some significant roadblocks and key lessons learned along the way?

Afya Rekod's journey has been filled with both challenges and invaluable learnings. One of the primary challenges was the **implementation** of our Health Management Information System (HMIS) with large hospitals who often had legacy systems and processes. In response, we have created a collaborative working process with such institutions which provides a clear demonstration of the multiple benefits gained by partnering with Afya Rekod.

This process has delivered some key learnings. Firstly, defining the real **timelines** required for the actual deployment of our systems given all the complexities involved in transitioning from paper to digital systems was not an easy task. Secondly, developing an effective **change management** process, to assist the transition for hospital staff who are accustomed to traditional methods proved out to be essential. Finally, the **connectivity issues** seen in rural areas, where many client organizations are located, required us to better understand how best to deploy online capabilities to ensure our clients can have access to the full functionality of our platform.

In addition to the challenges above, **managing client expectations** has been found to the key to successful implementations. Case in point: different departments within the same hospitals (finance, human resources, enterprise resource planning - ERP) can have different expectations, needs and desired outcomes from the same service, thus reconciling these expectations to seamlessly manage this whole process has been a key learning.

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On the patient front, there remains a significant **lack of awareness** about the individuals' inherent right to own and control their health data. To address this, we have run awareness campaigns and medical camps since launch, to educate patients on the value and importance of healthcare data ownership and how it empowers them to manage their healthcare more effectively.

Moreover, staying attuned to the market needs has been pivotal in the development of products and services. Our use of AI for data curation and prediction has directly responded to these needs, allowing us to provide more tailored and effective solutions.

Looking ahead, what is your vision for the future of decentralized health data management, and what do you think are key success factors to achieve mass adoption?

Our vision at Afya Rekod is for a future where health data management mirrors the simplicity and accessibility of modern banking. Just as we no longer need to visit a bank to check our balances or make transactions, we envision a healthcare system where data is mobile, accessible at one's fingertips and user-controlled. To achieve this, **integration and data portability** across healthcare systems and institutions is essential, allowing individuals to freely and securely access their health data not just within a specific country but indeed across Africa. This is Afya Rekod's ambition.

Supportive regulations are another key success factor. By 2025, we anticipate new regulations that will mandate data interoperability across the continent, through the <u>Digital Health Act</u>. This legislative framework will be pivotal in breaking down existing barriers to data mobility and usage, fostering a more connected and efficient healthcare environment.

Furthermore, for mass adoption, a concerted effort to increase **public trust and awareness** about the benefits of decentralized health data management is required. Educating the populace on how this model not only enhances personal healthcare management but also contributes to the improvement of healthcare systems – and health outcomes as a whole - will be vital. Achieving this will require collaboration among governments, healthcare providers, and technology developers to create a transparent, secure, and user-friendly data ecosystem. Afya Rekod will foster such collaboration.

> *Our vision at Afya Rekod is for a future where health data management mirrors the simplicity and accessibility of modern banking. Just as we no longer need to visit a bank to check our balances or make transactions, we envision a healthcare system where data is mobile and accessible at one's fingertips.*
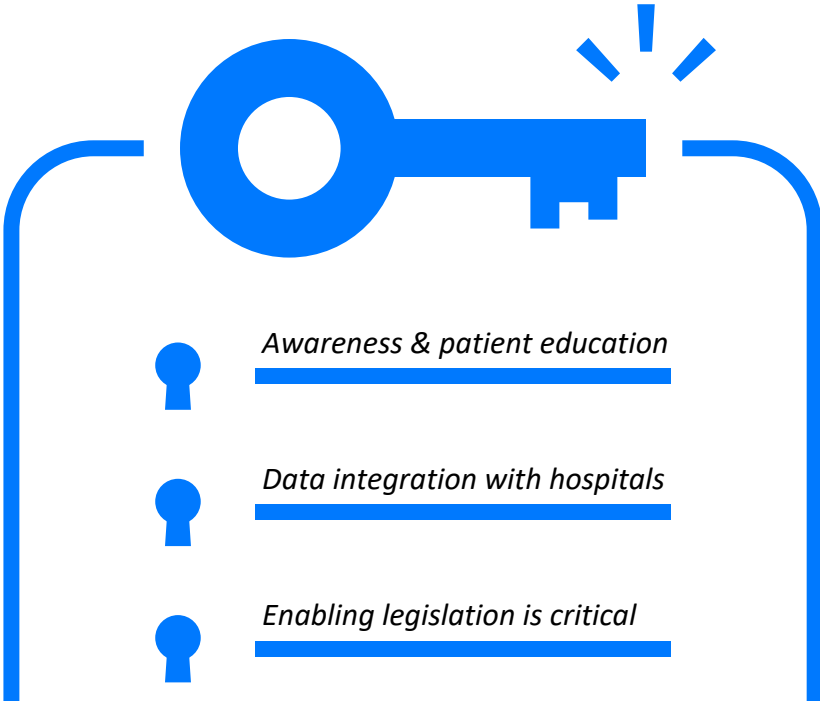
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Lastly, what support does Afya Rekod need to grow and integrate into the broader ecosystem?

To further Afya Rekod's impact and ensure successful integration within the broader health ecosystem, several types of support are essential. First and foremost, forging **partnerships** with organizations that share our vision is critical. These collaborations are vital for sharing resources and extending our reach, particularly in providing public good services like education and awareness about health data management.

Secondly, **financial support** via grant funding would be welcomed, especially for expanding our awareness and educational campaigns. Despite making significant progress, we believe we have covered less than 50% of our target in terms of raising public awareness and enhance our efforts, particularly in rural and underserved areas, by educating individuals on how they can benefit from managing their own health data effectively.

Lastly, supportive **legal and regulatory frameworks** that strengthen interoperability and portability across Africa is critical. As individuals move across countries, their health data should be able to travel with them. AfyaRekod is an advocate in this regard - helping shape the future of healthcare in Africa.

Visit Afya Rekod at https://afyarekod.com/

Awareness & patient education

Data integration with hospitals

Enabling legislation is critical

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Chapter II

Compendium of Solutions in Decentralized Health Data Management

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Introduction

This chapter focuses on promoting existing decentralized health data management solutions, fulfilling the report's main goal. Through concise and clear "one pager" overviews, we outline various applications, platforms, and digital services identified during our research.

Each example follows a standardized template that includes an overview, target audience, geographic coverage, major partnerships, and technical specifications of the product or service offered.

The highlighted solutions span multiple continents and use cases - from health & wellness to genomic research, rare diseases and beyond - showcasing the diversity and potential within this emerging sector.

Target audience: general public, entrepreneurs and product teams, broader ecosystem stakeholders.

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Summary of included solutions

Solution #1: MyRekod (Kenya)
Platform to enable mobility of patient-owned health data
https://afyarekod.com

Solution #2: DigiHealth (UK)
Decentralized platform for healthcare access and data sharing
https://www.digipharm.io

Solution #3: Eka Care (India)
App allowing users to store and access health documents in a secure, encrypted platform (government approved)
https://www.eka.care

Solution #4: Geneial (USA)
Marketplace for sharing genomic data in rare diseases
https://www.geneial.com

Solution #5: Nebula Genomics (USA)
Platform for genomic data sharing and privacy on the blockchain
https://nebula.org

Solution #6: Patientory (USA)
Companion app for secure health data management and sharing
https://patientory.com

Solution #7: Paytm Health Locker (India)
App allowing users to store and access health documents in a secure, encrypted platform (government approved)
https://paytm.com

Solution #8: Care.Wallet (Ukraine)
Integrated, global health tech ecosystem with a patient-facing wallet component
https://solve.care

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2.1: MyRekod (Kenya)

The company: AfyaRekod is a digital health data platform offering an integrated ecosystem composed of a patient app & web portal (MyRekod), a health management information system (HIMS) for hospitals and an app for community health workers.

Link: https://afyarekod.com

Category: Records Management, Health & Wellness, Care Delivery

Target audience: Hospitals lacking infrastructure, Community Health Workers, Individuals who wish to own and move their data

Key Geographies: Kenya, Nigeria, South Africa, Zambia

Key Partnerships: Adanian Labs, GE Healthcare, Machine Intelligence Institute of Africa, Checkups Medical Hub

The Product: Myrekod is a user-friendly app & web portal built on blockchain, which allows individuals to store their health records and share them with whomever they wish, as well as take steps to improve their health. MyRekod has onboarded 400.000 users as of April 2024

Key Features

- Scan a prescription
- Receive health records from hospitals (w/ QR code)
- Share personal health data with others (mobility)
- Add personal health information
- Keep a health diary for symptom monitoring
- Access disease-specific medical education
- Real-time communication with a care provider
- AI-based analysis and reports (for all stakeholders)
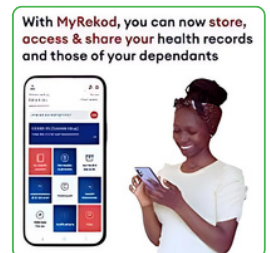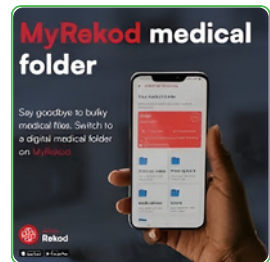
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2.2: DigiHealth (UK)

The company: DigiPharm aims to be the leading value-based healthcare ecosystem dedicated to transforming healthcare procurement and patient engagement. The ecosystem consists of Reimburse, a platform to implement and process value-based contracts for health technologies & services and DigiHealth, a patient portal enabling remote patient feedback on their quality of life.

Link: https://www.digipharm.io/

Category:
Value-based healthcare, Patient reported outcomes, Data Marketplace

Target audience:
Patients, Young and digitally-savvy individuals, Researchers, Healthcare centers

Key Geographies:
UK, Europe, Middle East

Key Partnerships:
ICHOM, NHS, Roche, EIT Health

The Product:
DigiHealth Patient Portal enables remote patient feedback on their quality of life, how well therapies work for them and their experiences when seeking care. To be launched by summer 2024.


Key Features

- ICHOM questionnaires for patient-reported outcomes (PROMs) and experiences (PREMs)
- Provide / share feedback on quality of life (via PROMs and PREMs)
- Share health data with researchers and value-based procurement agreements
- Receive rewards in DGH tokens, NFTs etc.
- Integrated services: telemedicine consultations, health data storage, participation in clinical trials and health surveys
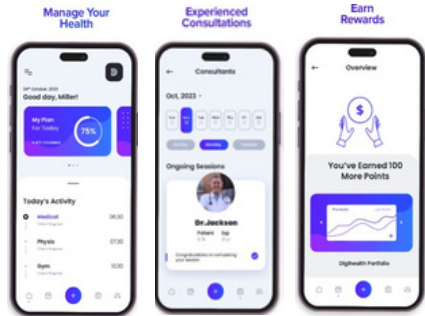
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2.3: Eka Care (India)
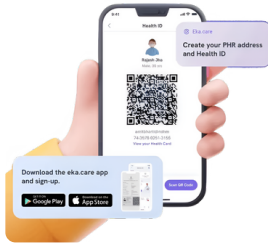
The company: Eka Care is supporting Ayushman Bharat Digital Mission (ABDM) - the digital healthcare initiative of India's National Health Authority, by offering an integrated, connected platform to access digital health services.

Link: **https://www.eka.care/**

Category:
Health & wellness,
Health records
management

Target audience:
Indian patients and their
families (30 million users),
Healthcare providers
(hospitals, care teams)

Key Geographies:
India

Key Partnerships:
IAyushman Bharat
Digital Mission
(ABDM)

! Check Eka Care's 2022 Health Report about health trends in India: https://c.eka.care/insights_2022.pdf

The Product:

Eka.care patient app allows users to open and manage an officially-recognized ABHA health card through which several e-health services can be accessed (e.g. self-assessments, discounted access to health facilities).

Key Features

- Create ABHA (Official Health ID)
- Create a health profile
- Store medical records (including family)
- Consent to share medical records / history
- Access by healthcare professionals (w/ consent)
- Track & assess symptoms
- Track body health via integrated devices
- Find private or public health facilities
- Access tele-consultation and e-pharmacy
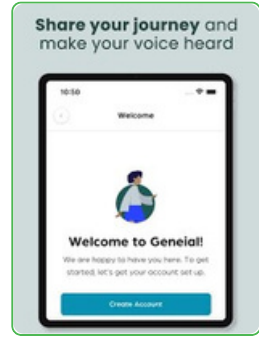- Visualize health data in reports and graphs
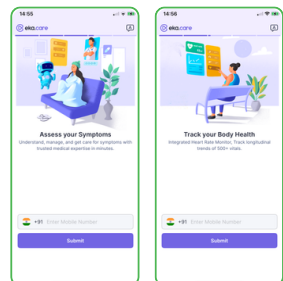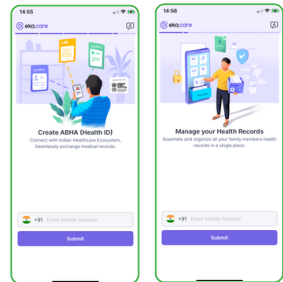
2.4: Geneial (USA)

The company: Genial is shaping the future of genetic medicine, by connecting researchers with diverse patient communities in a marketplace focused on securely exchanging rare and genetic disease data.

Link: https://www.geneial.com/

Category:
Rare diseases, Genomics, Research, Data Marketplace

Target audience:
Patient communities, Healthcare researchers, Individuals suffering from rare and genetic diseases

Key Geographies:
USA

Key Partnerships:
National Institutes of Health (NIH), Xia-Gibbs Society, National Human Genome Research, BCM-HGSC

The Product:

Genial is a marketplace built on a vast and well-encrypted biomedical data network. The "Bridge" allows registry managers and researchers to look for health data and "Advocate" allows individuals to share their data. Platforms is active in 100+ countries.

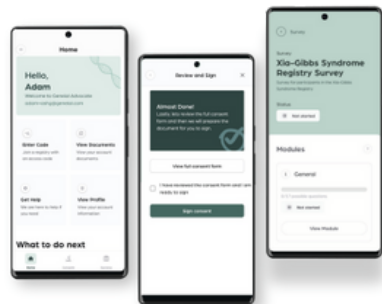| 7%	80%	95%
of people have a rare disease	of rare diseases are genetic	of rare diseases lack an FDA-approved therapy

Key Features

Geneial Bridge:
- Standard Data and Instruments
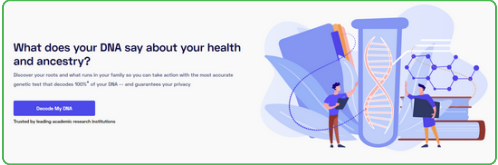- Secure Messaging and Data Exchange
- Consent Management

Geneial Advocate:
- Informed Consent
- Education and Community Engagement
- Contribute to Research
- Control Your Data

Sources: https://www.geneial.com/geneial-launches-new-registry-platform-to-accelerate-genetics-research/

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2.5: Nebula Genomics (USA)

Link: https://nebula.org

The company: Nebula Genomics, a US-based personal (whole) genome sequencing company, has launched a data marketplace to advance genomics scientific research and care delivery by putting individuals at the center.

Category:
Health & wellness, Genomics, Research, Data marketplace

Target audience:
Individuals willing to have their genome sequenced and shared with researchers

Key Geographies:
100+ countries

Key Partnerships:
Bitfury, Insilico Medicine, Veritas Genetics, Oasis Labs

The Product:

The genomics data marketplace is built on blockchain and allows researchers to anonymously access genomics data directly from individuals, by compensating them.
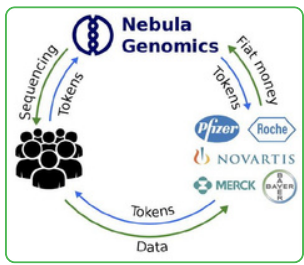
Key Features For Researcher (data buyers):
- Search for records matching criteria
- Submit an offer for sharing data (anonymous)
- Propose compensation (incl. sequencing services)
- Visualize anonymous data, if offer is accepted
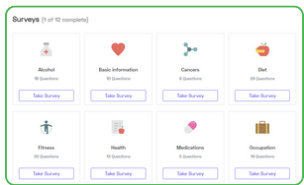
Key Features For Individuals (data providers):
- Create record with overall health parameters
- Take health surveys (e.g. diet, alcohol etc.)
- Store and download raw personal genome (>100Gb)
- High-level reports comparing self to full database
- Review requests and grant/deny access to data
- Receive compensation for data sharing (credits)

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2.6: Patientory (USA)
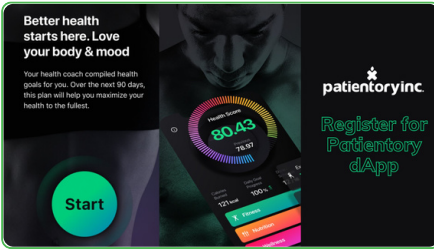
The company: Patientory empowers people with actionable data-driven insights for improved health outcomes and well-being, build a healthier future for all by becoming the home of patient data, built on blockchain.

Link: https://patientory.com/

Category:
Health & wellness, Care Plans, AI

Target audience:
Health-conscious individuals, patients, web3.0 enthusiasts

Key Geographies:
USA, Asia, Middle East

Key Partnerships:
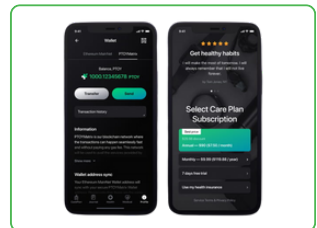Pharma & research organisations, Medtech networks & accelerators, WEF

The Product:

Patientory is a holistic health & wellness management app allowing individuals to track, store, visualize, share and benefit from their own health data through use of advanced AI capabilities. It is available worldwide, however some features are US-specific.

Key Features

- Decentralized digital identity (DID)
- Self-assessment / patient reported outcomes
- Medical Records Storage (US only)
- Integration with wearables / other devices
- Health statistics / reports
- Recommendations to join clinical trials
- AI chatbot - personal health recommendations
- Benefits from medical treatments: Discounted Medications and Pharmacy Savings Card
- Earn & redeem PTOY tokens
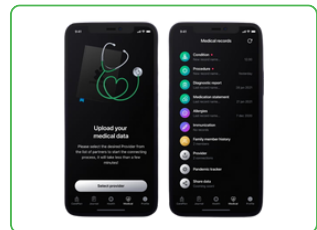
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2.7: Paytm ABHA Health Locker (India)

The company: Paytm, a payments platform in India, is supporting Ayushman Bharat Digital Mission (ABDM) - the digital healthcare initiative of National Health Authority, by enabling patients' access to digital health services.

Link: https://paytm.com/

Category:
HHealth & wellness, Records management

Target audience:
Indian individuals interested to store their medical records and access digital health services

Key Geographies:
India

Key Partnerships:
Ayushman Bharat Digital Mission (ABDM)

The Product:

Paytm ABHA Health Locker is a certified public health medical records app, allowing patients, among others, to create a Health ID, collect their medical records in one place and share them with healthcare providers. It is accessible to Indian individuals in the "Health" section of the overall Paytm app.

Health Card Key Features:

- Create ABHA (Official Health ID)
- Manually upload medical documents
- Collect medical records via QR code
- Organize & analyze medical records

Digital Health Services Key Features:

- Share medical history via QR code
- Book appointments at hospitals (skip queue)
- One-stop-shop app for payments, loans & health

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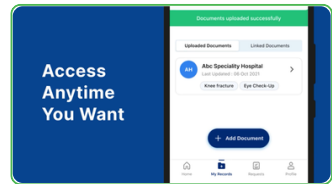
2.8: Care.Wallet (Ukraine)

The company: Solve.care is a global, award-winning telehealth company aiming to deliver better care through decentralization and web3.0. Their integrated offering for better care coordination includes a wallet for patients.

Link: https://solve.care/

Category:
Telehealth, Care coordination, Clinical trials

Target audience:
Institutions (care providers, insurance companies), Individuals willing to share their data for research and services

Key Geographies:
Ukraine (HQ), US, Hungary, Estonia, South Korea, India

Key Partnerships:
Ambisafe, American Research & Policy Institute, Uber Health, Hippocrat Labs (South Korea)


The Product:

Care.Wallet is a life-long companion for users wishing to have better control over their healthcare journey and access web3.0 services, while retaining ownership of their data.

Key Features Care.Wallet for Individuals:
- Complete health profile / questionnaires
- Participate in Care.Trials / Join networks
- View transaction activity with Care.Ledger
- Self-custody of health data (South Korea)
- Setup Care.Circles with friends/family
- Rewards & web3.0 purchases (SOLVE token)
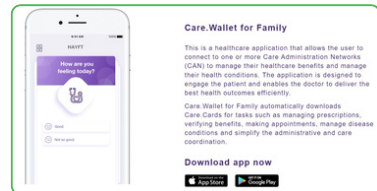
Key Features Care.Wallet for Institutions:
- Care.Trials for research organisations
- Care.Shelter: e-assistance to Ukrainian patients
- Care.Chain: Ethereum-compatible blockchain
- Care.Labs: test new applications on blockchain
- Care.Marketplace: buy/sell telehealth services
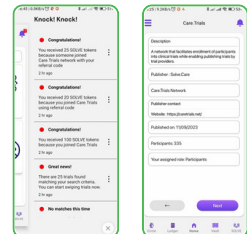
Sources: https://solve.care/press-release/solve-care-releases-care-wallet-2-0/, https://www.youtube.com/watch?v=WAh9d_MxOZ8, https://solve.care/press-release/solve-care-and-hippocrat-forge-strategic-alliance-to-enhance-self-custody-of-healthcare-data-in-korea/

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Chapter III

Future Opportunities for Decentralized Health Data Management

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Introduction

This chapter addresses our objective of identifying opportunities and formulating actionable recommendations to expand the field of decentralized health data management.

It distills the insights collected from expert interviews and the documented solutions into five concrete opportunities for growth:
1. *Enhance public awareness & health education*
2. *Establish more data sharing marketplaces*
3. *Advocate the use of standards for interoperability*
4. *Use artificial intelligence to curate health data*
5. *Leverage scalable technologies for global impact*

Each opportunity is presented by a subject matter expert, detailing their views on why is it important, where else did it succeed and what does it take to achieve the same results in healthcare.

Target audience: entrepreneurs and product teams, broader ecosystem stakeholders.

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3.1 Public Awareness & Health Education

Opinion: Lu Zheng

Head of Value-Based Partnerships & Digital Health, Europe & Canada,
Takeda Pharmaceuticals | Co-founder Etheros HealthData Foundation

Public awareness and health education are critical components in the adoption of decentralized health data management. Our expert interviews underscored the importance of educating the public about the value of their health data and the benefits of taking ownership of it, such as the ability to move from disease management to prevention. Many individuals are unaware of their rights and the potential uses of their health data, while others feel burdened by the tasks associated with self managing their data (as they need to use a new app, collect data from different hospitals and/or devices, communicate frequently with data requesters etc.). These obstacles can lead to a lack of engagement and trust in decentralized solutions.

Looking at other industries, we see several successful examples of public awareness campaigns and community involvement. For instance, environmental campaigns have effectively raised awareness about recycling and sustainability, leading to widespread behavioral changes. The financial industry has also made significant strides with public education on personal finance, empowering people to budget their expenses, invest, and plan for retirement.

For healthcare to replicate these successes in user empowerment, a few things are important:
- **Clear & Transparent Messaging:** Information about decentralized health data management should be conveyed in simple terms. Benefits and risks should also be expressed clearly and transparently, since many of these might be new to individuals around the world.
- **Partnerships:** Collaborating with trusted organizations, including patient advocacy groups, healthcare providers, and community leaders, can lend credibility and amplify the reach of awareness campaigns. It would also allow decentralized mechanisms and empowerment to deploy awareness faster and deeper in society
- **Continuous Engagement:** Ongoing, long-term education and engagement, rather than one-off campaigns, are crucial for inducing sustainable behavioral change. Let's find individuals where they are (in patient forums, on TikTok, in a gym) - and not the other way around. Over time we also expect more people champions to join forces and amplify voices.

Progress in public awareness and health education would be recognizable in terms of growing usage of decentralized health data management solutions and marketplaces around the world. We should also notice policymakers and established healthcare organisations being increasingly supportive of decentralized health data initiatives. Lastly, observable changes in how individuals manage their health data and how much additional quality data becomes available to researchers, would indicate a successful outcome of such campaigns.

Quotes from the young generation

> *Leveraging social media, influencers, short videos - which integrate privacy and data security concerns and highlights the benefits that health data could provide like health consultations, life style coach - would make me want to own and share my data.*
>
> *(Yafei Liu, Master in Quantitative Finance, ETH Zurich, Switzerland)*

> *The younger generation and myself need a campaign that simplifies the process but emphasizes individual value in health data. Younger generation are a blank slate and need to understand that the time to begin compiling and owning their data is now.*
>
> *(Christian Kokoros, Economics Student, Tufts University, USA)*

> *I am already convinced that owning and sharing my health data digitally eliminates the hassle of heavy paperwork and ensures I receive timely and efficient medical care, wherever I am. When I recently moved from Kenya to the United States, I had all my health and treatment data history in MyRekod. Platforms like this exemplify how technology can bridge the gap between different healthcare systems, making global mobility a less daunting experience for individuals with chronic health conditions like me.*
>
> *(Dr. Ruguru Joan Kimani, Postgraduate Student, Duke University, USA and MyRekod Champion)*

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3.2 Data Sharing Marketplaces

Opinion: Carmen Cucul

Healthcare Consultant | Advisor Etheros HealthData Foundation

The concept of data sharing marketplaces is pivotal in realizing the full potential of decentralized health data management. By creating platforms where individuals can securely share their health data with researchers, healthcare providers, and other stakeholders, we can facilitate a more collaborative and efficient healthcare ecosystem. Our interviews with industry experts highlight the untapped potential of health data when aggregated and analyzed at scale. These marketplaces not only empower individuals to control their data but also enable advancements in medical research and personalized healthcare.

> *More than 90 % of rare diseases lack sufficient diagnosis and treatment tools. [...] A second common challenge is the limited sharing of research data.*
> *(European Parliament)*

Within the healthcare space -and throughout this report- we already see promising examples of decentralized data sharing marketplaces, such as Geneial, a community-led biomedical data network to accelerate research for genetic diseases and Nebula Genomics, a genome sequencing company which launched also a data marketplace to advance genomics scientific research. The concept of decentralized marketplaces is also expanding in other industries. For example, JustCarbon allows users to trade & offset their carbon emissions while supporting high-quality carbon removal projects to combat climate change. Similarly, the energy sector has adopted decentralized platforms such as Powerledger to trade renewable energy credits, fostering a more sustainable energy market driven by peer-to-peer economics. All these marketplaces have great potential to grow, however their use is not yet mainstream.

So how do we get to a world where using marketplaces to exchange our health data is as ubiquitous as using marketplaces to exchange our goods or services (think of eBay, Taobao, Upwork, Fiverr)? The first step is probably to reset the expectations around "value" for health data, as EHF argues in this paper. On one hand, data that has societal value (not just economical value) should be equally desirable for researchers and other healthcare ecosystem stakeholders. On the other hand, individuals should also start perceiving their health data as being valuable beyond their main use (i.e. personal care) into secondary use.

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Once the value of health data has been "reset", incentive schemes should adjust, to accelerate its generation and dissemination. For this, the web3 space has pioneered many interesting tools which can be leveraged in healthcare: tokens to reward the provision of data by individuals, consensus mechanisms to incentivize good behaviors by transaction validators, decentralized autonomous organisations (DAOs) to optimize decisionmaking among large groups of users. Many of the examples presented earlier in this opinion already leverage such tools, which is encouraging.

Thirdly, more marketplaces should exist, to cater for different healthcare use cases (e.g. women's health, rare diseases, longevity etc.), by different user profiles (web3 natives, older generation, marginalized populations etc.) and in different parts of the world (USA, Africa, Asia, Europe - given restrictions in data flows and user access).

Should your team be inspired to build such a health data marketplace, here are some considerations derived from literature research:

- **Implement Robust Security and Privacy Measures:** Incorporate advanced encryption methods, such as re-encryption mechanisms and smart contracts, to maintain data privacy and secure transactions. Employ decentralized solutions like IPFS (InterPlanetary File System) to store data off-chain, to enhance data availability and security while maintaining a scalable and decentralized infrastructure.
- **Develop Comprehensive Governance Structures:** Establish decentralized autonomous organizations (DAOs) to manage the marketplace governance, enabling community-driven decision-making and maintaining a transparent and equitable system. Implement arbitration mechanisms using smart contracts and side-contracts to resolve disputes efficiently, ensuring trust and reliability within the marketplace.
- **Ensure Interoperability and Standardization:** Promote the use of standardized protocols and interfaces to facilitate seamless data exchange between different systems and platforms, including the use of APIs for integration. Foster collaboration among different stakeholders, including data providers, consumers, and developers, to create a cohesive ecosystem that supports interoperability and innovation.
- **Focus on Scalability and Efficiency:** Design the marketplace with scalability in mind, utilizing microservices architecture and blockchain scalability solutions such as side-chains or layer-2 protocols to handle increasing data volumes and transaction loads efficiently. Automate processes using smart contracts to streamline data transactions and reduce operational costs.
- **Enhance User Trust and Engagement:** Provide transparent audit trails and provenance tracking to build trust among users by ensuring the authenticity and traceability of data transactions. Implement incentive mechanisms to encourage user participation, such as rewarding data providers with tokens for contributing high-quality data, thereby fostering an active and engaged community.

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3.3 Standards for Interoperability

Opinion: Hui Huang

Founder and CEO, CSD Partners LLC | Co-founder Etheros HealthData Foundation

Standards and interoperability are foundational to the success of decentralized health data management. Without them it is difficult, if not impossible, to exchange, aggregate, and analyze health data effectively. Our research indicates that one of the biggest hurdles in health data management is precisely the lack of standardized data formats and interoperable systems. This is due to the existence of data silos, mistrust, complex data sharing agreements, security concerns, and inconsistent data standards implementation.

Illustrative for the power of standards and interoperability is finance industry's adoption of the SWIFT system. SWIFT has created a standardized protocol for financial transactions, enabling seamless communication between banks worldwide. Similarly, the telecommunications industry's adoption of the GSM standard has allowed for interoperability across different mobile networks globally. These examples show how standardization can drive efficiency, compatibility, and growth in complex systems.

In healthcare, several standards exist, as illustrated in the table below. HL7 and FHIR are the major ones, designed to facilitate the exchange of electronic health records (EHR) and enable interoperability between healthcare systems.

Table: Overview of most important standards for health data interoperability

Standard Name	Type of health data in scope	Regions Using it	Sources
HL7	Clinical data exchange	Globally	HL7 International, HealthIT.gov
FHIR	Clinical data exchange, mobile apps, cloud-based systems	Globally	HL7 FHIR, HealthIT.gov
DICOM	Medical Imaging	Globally	DICOM Standard, RSNA
LOINC	Laboratory tests, clinical observations	Globally	LOINC, Regenstrief Institute
ICD	Disease and health condition classification	Globally (mostly WHO)	WHO ICD, CDC
CDA	Clinical documents (discharge summaries, progress notes etc)	Globally	HL7 CDA, HealthIT.gov
OMOP	Clinical data for research, observational data	Mostly USA and Europe	OHDSI OMOP, OHDSI Europe

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What is required in order for product teams building decentralized health data management solutions to be incentivized and supported to implement data standards from the get-go?

- **Collaborative Development:** Involving a wide range of stakeholders, including healthcare providers, technology developers, and regulatory bodies, in the development and adoption of standards.
- **Regulatory Support:** Strong backing from regulatory bodies to ensure compliance and adoption of interoperability standards.
- **Technological Innovation:** Leveraging advanced technologies, such as blockchain, to enhance data security and ensure integrity during data exchange.
- **Education and Training:** Providing education and training to healthcare professionals and organizations on the importance and implementation of interoperability standards.

As we see, the responsibility of enabling widespread use of data standards lays on the shoulders of the entire healthcare ecosystem, not just product teams and entrepreneurs. Regulators, healthcare providers, pharmaceutical companies, device manufacturers, academia and foundations such as EHF and CVA should also engage in educational initiatives, network collaboration, research and pilot projects, policy advocacy and community building.

As more healthcare platforms and organizations adopt existing standards and achieve greater interoperability, it becomes easier to integrate decentralized solutions that can further enhance data security, patient empowerment, and cross-sector collaboration. The ultimate goal is to create a more connected and efficient healthcare ecosystem that benefits all patients.

> *The responsibility of enabling widespread use of data standards lays on the shoulders of the entire healthcare ecosystem, not just product teams and entrepreneurs*

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3.4 Artificial Intelligence

Opinion: Thomas Egelhof

Chief Radiologist, Merian Iselin - Clinic for Orthopedics & Surgery, Switzerland and CVA member

AI and blockchain are two technologies that have the potential to transform the healthcare industry, by providing new ways of collecting, analyzing, and sharing health data, and by enabling new models of care delivery, collaboration, and innovation. AI has already started to transform the health sector, by enabling faster and more accurate diagnosis, personalized treatment, improved prevention, and enhanced research. However, AI also poses significant challenges, such as data quality, privacy, security, accountability, and social impact.

The transformative potential of AI is enormous:

- Improved diagnosis and prognosis: AI analyzes large and complex data sets, such as medical images, genomic data, and electronic health records, and provide faster and more accurate diagnosis and prognosis for various diseases and conditions. AI algorithms have been developed to analyze mammograms and identify potential signs of breast cancer, assisting radiologists in detecting early-stage cancers and reducing false negatives. Similarly, AI solutions for analyzing CT scans can detect early signs of lung cancer, and those for MRI and CT scans of the brain can detect brain tumors, aneurysms, and other abnormalities.
- Personalized treatment and care: AI tailors treatment and care plans to the individual needs and preferences of each patient, based on their genetic, environmental, and behavioral factors, and monitor their progress and outcomes.
- Enhanced prevention and wellness: AI identifies and predicts risk factors, and provide early intervention and prevention strategies, such as lifestyle recommendations, screening tests, and alerts. AI can also support wellness and well-being, by providing personalized feedback, coaching, and motivation.
- Advanced research and innovation: AI accelerates and improves the discovery and development of new drugs, therapies, and devices, by finding patterns and insights from large data sources, such as clinical trials, scientific literature, and patient feedback.
- Precision medicine: AI plays a significant role in advancing precision medicine, which focuses on tailoring medical treatments to individual patients.

> *AI can generate 20-50% costs & time savings in discovery to preclinical stages of R&D (BCG)*

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- **Genomic analysis:** AI algorithms analyze large sets of genomic data and identify patterns that could help understand diseases at a molecular level. This information can be used to develop personalized treatment plans based on an individual's genetic makeup.
- **Predictive analytics:** AI models predict likelihood of disease progression or treatment response based on an individual's health records, genetic data, and lifestyle factors. This information can help doctors in making informed decisions about personalized treatment strategies.
- **Virtual assistants:** AI-powered virtual assistants provide patients with personalized healthcare information and support. These assistants can answer questions, provide medication reminders, and offer guidance on managing chronic conditions.
- **Remote patient monitoring:** AI systems are developed to monitor patient health remotely. These systems can track vital signs, detect abnormalities, and alert healthcare providers if intervention is required. This enables patients to receive personalized care from the comfort of their homes.
- **Health wearables:** AI technologies integrated into wearable devices, such as smartwatches or fitness trackers, can monitor various health parameters like heart rate, sleep patterns, and physical activity. These devices provide personalized insights to individuals, encouraging them to make healthier choices and take preventive measures.

AI and health data also present challenges and risks, which need addressing and resolution:

- **Quality and availability**: AI depends on the quality and availability of data, which can vary widely across various sources, regions, and populations. Data can be incomplete, inaccurate, biased, or outdated, and affect the performance and reliability of AI systems.
- **Privacy and security:** AI involves the collection, storage, and sharing of sensitive and personal data, which can expose patients and health professionals to potential breaches or misuse of their data. Data privacy and security require adequate policies, standards, and technologies, to protect the data from unauthorized access, modification, or disclosure.
- **Accountability and transparency:** AI involves complex and often opaque algorithms, which can make decisions or recommendations that affect the health and well-being of patients and health professionals. Data accountability and transparency require clear and explainable mechanisms, to ensure that the AI systems are fair, accurate, and trustworthy, and that data owners and users are aware and informed of their rights and responsibilities.
- **Social and ethical impact:** AI has social and ethical implications, such as affecting the roles and relationships of patients and health professionals, creating new opportunities and inequalities, and raising moral and legal questions. Careful and inclusive assessments are required, to ensure that AI systems are aligned with the values and norms of the society, and that the benefits and risks are distributed fairly and equitably.

AI, Blockchain and Health data used in a responsible and ethical manner offer an enormous opportunity to empower patients, improve health and well-being of people and society and will lead to the necessary reform of healthcare systems worldwide.

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3.5 Scalable Technology

Opinion: Robert Turrall

Web3, Blockchain & AI Advisor, Swiss NFT Association Ambassador

Decentralized health data management leverages technologies like blockchain and artificial intelligence to enhance security, privacy, and patient empowerment. These platforms, while transformative, need to be scalable to realize their full potential. Scalability ensures the development of better products, reduces long-term costs, and amplifies impact across the healthcare ecosystem. Though achieving scalability requires careful consideration and investment, the benefits for product teams, their customers, and the broader healthcare system make it a worthwhile endeavor. The arguments and examples below will focus on the use of blockchain and AI, among a multitude of relevant technologies available in this space.

Scalable technologies enable better, cheaper and higher impact decentralized health data management products and services. More specifically, the benefits of scalability are:

- Enhanced Security: Blockchain's immutable and distributed ledger provides robust security, reducing the risk of data breaches. Scalable blockchains can potentially further strengthen data security due to the higher number of validators involved and superior consensus mechanisms. Estonia has become an e-health leader in Europe (also) due to its use of scalable blockchains, allowing citizens and healthcare professionals to access to their e-health records anywhere, anytime, securely.
- Ecosystem Integration: Scalable blockchains enable product teams to tap into broader innovation networks. This connectivity allows for integration with other decentralized applications, enhancing functionality and interoperability. Over the past few years, strong ecosystems have been built around blockchains such as Ethereum, Solana, Hedera Hashgraph, Cosmos etc.
- Competitive Edge: Scalable solutions can position startups to compete easier with established tech giants such as Amazon, Apple, IBM or Meta by offering equal or superior data privacy, security, user experience and value-adding features. DePIN (decentralized physical infrastructure) networks have already showcased the potential in this space, with millions of users providing file storage, sharing internet bandwidths or mapping locations in return for incentives and better services.
- Reduced Long-term Costs: Investing in scalable technology upfront can minimize the need for costly overhauls as user bases grow. Emerging Layer 2 blockchains and other scaling solutions, like state channels and sidechains, promise significant reductions in transaction costs, with some networks now offering nearly zero-cost transactions. For instance, Optimistic and ZK-Rollups aggregate multiple transactions into a single batch, reducing fees and providing near-instant finality.

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- **Global User Base**: Scalable platforms can support users globally, maintaining performance and functionality regardless of geography. This inclusivity enhances the utility of health applications for users who travel or live in different regions, as they can access their health data/services anywhere, ensuring continuity of care and fostering global health networks.
- **Higher Impact**: More users and broader technical footprints mean access to larger datasets. In a world where health data is siloed, unstructured and underused, access to larger datasets can enhance AI's predictive analytics capabilities. This can lead not only to more accurate and personalized health insights but also faster research for new medicines.

For product teams ready to embrace blockchain and AI scalability, here are few implementation considerations:

- **User Centricity and Empowerment:** regardless of the choice of technology, ensuring user's data is secured, private, self-custodied and easily shareable should always be a priority. Secure encryption methods, including homomorphic encryption and federated learning, can be implemented for AI applications to avoid data breaches. Utilization of zero-knowledge proofs (zk-proofs) can now be used to confirm users' health data or identity without revealing it. And solutions such as MedRec, Ocean Protocol or those presented in Chapter 2 provide best practices in how users can own, share and benefit from their data.
- **Interoperability and Collaboration:** Definition or adoption of shared data standards is necessary to facilitate seamless data exchange and portability. Teams can consider the use of blockchain's distributed ledger and smart contract functionalities to automate access permissions. Integration of AI to normalize heterogeneous data sets and structure unstructured clinical notes is also beneficial. Development of APIs that link electronic health record (EHR) systems is almost ubiquitously mandatory. Joining consortia such as the Synaptic Health Alliance, can help manage costs and standardize implementation.
- **Cloud and Hybrid Solutions:** Combination of blockchain with scalable cloud infrastructure is effective for managing large-scale health data, especially when AI models are deployed. BurstIQ, for example, demonstrates how blockchain integrated with cloud infrastructure can manage health data effectively, offering elastic resource allocation for dynamic scaling (hybrid solution). Opting for hybrid solutions balances cloud infrastructure costs with the benefits of dynamic scaling (i.e. the ability to pay only for the resources consumed). Another consideration is to ensure that cloud providers offer HIPAA-compliant services, which are critical for handling Protected Health Information securely and transparently.

The integration of blockchain, Web3 technologies, scalable cloud computing, and AI into healthcare offers transformative opportunities and tangible benefits for all stakeholders. For project teams building decentralized health data management solutions, scalability allows for enhanced security, efficiency and cost savings, making their offerings more competitive and value-adding. For individuals, scalability of underlying technologies translates into products and services that are more insightful, personalized, accessible, portable and integrated. Broader healthcare ecosystem benefits from greater collaboration, accelerated innovation and new economic opportunities derived from standardized, interoperable and secure platforms.

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Conclusions

We live in a healthcare system where health data is siloed, underutilized or lacking altogether. This leads to the unavailability of safe and effective treatments for many diseases (especially rare) and unaffordability of healthcare products/services for several others. In order to have an equitable, inclusive and sustainable healthcare system that thrives in a world of data, digitization and automation, value needs to be assigned -also- to health data that generates societal utility (not just economical) and incentives need to accrue -also- to individuals (not just to institutions). In other words, we need more decentralization and fairness in health data management.

As we have seen throughout this report, we are in the early stages of decentralizing health data management and enabling individuals to truly own, share and benefit from their own data. The journey parallels the early days of internet adoption in the 1990s, facing similar technical, regulatory, and change management challenges. Nevertheless, grassroots initiatives led by entrepreneurs, patient groups, and local communities have surged over the past decade, as highlighted in our interviews and solution overviews. This bottom-up approach is further supported by regulatory frameworks such as the European Health Data Space (EHDS), the Ayushman Bharat Digital Mission in India or Kenya's Digital Health Act, which promote data decentralization and portability.

Summarizing the insights and learnings gathered in preparing this report, we created a SWOT analysis of how we currently see the decentralized health data management space. Strengths & weaknesses are inherent to the solutions / initiatives themselves, opportunities and threats are coming from the external environment.

Strengths:

1. **Grassroots Initiatives**: Our interviews with local entrepreneurs and community leaders revealed a strong understanding of regional healthcare needs and innovative approaches. These grassroots initiatives foster a sense of ownership and trust within the communities they serve, driving adoption and engagement
2. **Integrated Ecosystems:** Many patient-facing apps, as illustrated in our case studies, are part of integrated ecosystems that facilitate the fluid circulation of health data among care providers, insurers, healthcare professionals, and patients. This integration enhances the user experience and improves the efficiency and effectiveness of overall care delivery
3. **Value-Adding Services:** The platforms we studied offer a wide array of value-adding services beyond basic records management. These include telemedicine, self-assessments, health diaries, clinical trial participation, and access to disease education. Patients are empowered with knowledge and tools for better health management.

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Weaknesses:

1. **User Interfaces:** A recurring theme in our expert interviews was the basic nature of user interfaces in many blockchain-based decentralized applications. This limitation, attributed to the early development stage of blockchain technology, can deter users from engaging with these platforms. Improving UX/UI is essential for broader adoption
2. **Platform Interoperability**: Experts highlighted the significant challenge of interoperability between different platforms and user applications. The inability to seamlessly transfer data from one application to another can be a major barrier for individuals wishing to self-manage their health data on a long-term basis
3. **Data Standardization**: The variability in data formats used by hospitals and/or care providers complicates data analysis and medical research, as noted by several interviewees. Standardizing data formats and ensuring consistent data quality across platforms will enhance the usability and value of health data generated in a decentralized manner

Opportunities:

1. **Emerging Technologies**: Our research identified blockchain and artificial intelligence (AI) as scalable and cost-effective solutions for decentralization and automation. Blockchain technology offers secure and transparent data management, while AI can be used for data cleaning, analysis, and generating actionable insights. Both technologies currently undergo major evolutions and enhancements
2. **Regulatory Support:** Increasing regulatory support, as seen in frameworks like the EHDS, Kenya's Digital Health Act, and India's Ayushman Bharat Digital Mission, encourages individual ownership and data portability. These regulations provide a conducive environment for the growth and adoption of decentralized health data management solutions
3. **Rising Awareness**: There is a growing awareness among individuals about the value of their personal data and their rights to own and benefit from it. This trend, driven by movements in other areas like online consumer rights and artist communities, bodes well for the adoption of decentralized health data management.

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Threats:

1. **Incentives for Ownership**: One of the primary challenges identified by our experts is the lack of strong incentives for individuals to manage their own health data. For many, it may seem like an extra effort with unclear benefits. Developing compelling incentives and demonstrating the tangible benefits of self-custody are essential.
2. **Data Privacy:** Ensuring data privacy in a decentralized world remains a significant challenge. The lack of established standards and the early stage of technological developments make decentralized systems vulnerable to hacks and data breaches. Building robust security measures and establishing trust are critical for success.
3. **Centralized Backend Storage:** Despite efforts to decentralize, much of the data still ends up being stored centrally on backend systems like Microsoft or Amazon cloud services. This centralization can reintroduce issues of power concentration and unauthorized data use.

S	**W**	**O**	**T**
1. Grassroot Initiatives 2. Integrated Ecosystem 3. Value-adding Services	1. User Interfaces 2. Platform Interoperability 3. Data Standardization	1. Emerging Technologies 2. Regulatory Support 3. Rising Awareness	1. Incentives for Ownership 2. Data Privacy 3. Centralized Backend Storage

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Supporting Decentralized Health Data Management

To support the decentralization of health data management, Etheros HealthData Foundation (EHF) and Crypto Valley Association (CVA) can take several strategic actions based on the insights from our research and interviews:

- **Raise Public Awareness:** Educate various stakeholders, including patients, patient groups, healthcare providers, regulators, and investors, about the importance of self-management of health data. Awareness campaigns and educational programs can help individuals understand the benefits of owning and managing their health data

- **Create and Disseminate Content:** Continuing to produce and share relevant content, such as this report, can inform and engage stakeholders. Providing up-to-date information, best practices, and case studies will help to build a knowledge base and support informed decision-making in this fast evolving field

- **Support Standardization Efforts:** Contributing to public initiatives aimed at standardizing health data and technology is essential for achieving interoperability and security. Collaborating with entrepreneurs and product teams to promote the use of existing standards will accelerate their own scalability, while delivering a truly user-centric experience

- **Develop Stakeholder Networks:** Establishing forums and communities involving all stakeholders can accelerate the development and scalability of decentralized health data management solutions. Such platform can facilitate the sharing of insights, best practices, and collaborative problem-solving at global level

- **Build New Products:** Identifying and creating new products to address specific geographies or use cases where suitable solutions do not yet exist (such as data marketplaces in specific rare diseases) is another key area for Etheros HealthData Foundation going forward

By engaging in such activities, EHF and CVA can contribute to building a more connected, efficient, and equitable healthcare system that benefits all stakeholders. Through our joint efforts, we can help pave the way for a future where healthcare data is easily accessible, securely shared, and leveraged to improve patient outcomes and drive innovation in the industry.

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Next Steps for the Report

Moving forward, we will continue to refine and expand the insights from this report, focusing on actionable recommendations to drive the adoption and integration of decentralized health data management solutions, as this field evolves. Further research and publications on this theme from both CVA and EHF are to be expected in the coming years.

Additionally, EHF will explore opportunities to build platforms for collaboration and thought leadership among all relevant stakeholders: entrepreneurs and product teams, research and healthcare delivery institutions, patient groups and advocates, healthcare professionals, regulators, etc. EHF will also aim to accelerate ideation and scale-up of promising solutions - especially in underserved disease areas and geographies- by providing access to expertise, networks, services and funding to promising entrepreneurs and intrapreneurs.
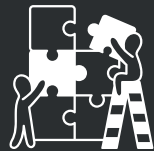
We express our gratitude to all contributors and readers and invite further engagement to advance this transformative vision. We encourage the general public to download and test some of the solutions presented in Chapter 2, and thus become part of the decentralized health data management transformation. Product teams and broader ecosystem stakeholders who are interested in collaborating and/or participating in CVA's and EHF's future activities should reach out to us at info@cryptovalley.swiss and forum@etheroshealthdata.org.

☑ **Use the Apps**   ☑ **Join our Network**   ☑ **Build with Us**

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Crypto Valley

Crypto Valley Association (CVA) is a leading blockchain and crypto ecosystem in Switzerland, representing more than 250 corporations and 900 individual members. It is fostering growth, collaboration and integrity in the global blockchain economy since 2017.

Website: https://cryptovalley.swiss
Email: info@cryptovalley.swiss

Etheros HealthData Foundation

Etheros HealthData Foundation (EHF) is a US-incorporated nonprofit organization, dedicated to enabling individuals globally to own, share, and benefit from their health data. Its goal is to foster a shift towards a more equitable, inclusive, and personalized healthcare future.

Website: https://etheroshealthdata.org
Email: forum@etheroshealthdata.org