

EDITORIAL

Creating a Health Data Marketplace for the Digital Health Era

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Globally, non-communicable chronic diseases (NCDs) such as hypertension and diabetes account for 75% of direct mortality.¹ Concurrently, mental health diseases like dementia have recently become the biggest killer disease in countries like the UK², with no cure, treatment or even effective intervention.³ To address this pressing issue, Healthcare 4.0 introduces a patient-centric paradigm shift, transitioning from traditional reactive medicine to predictive diagnosis and personalized preventive interventions.⁴ This shift leverages on the large volume and variety of health data generated from the growing use of electronic health records (EHR), the internet of medical things (IoMT) and personal wearable devices like the smartwatch, along with the growing capability of predictive and generative algorithms to create value from this health data.

However, unlike Industry 4.0, which extensively benefited from the internet of things (IoT) and sensor-derived data, Healthcare 4.0 has yet to fully capitalize even on EHR datasets, let alone IoMT and wearables-derived data. EHR data are often siloed in centralized databases of various service providers, such as hospitals and clinics, whereas IoMT and wearable-derived data remain in the respective vendor's cloud, with limited and or complex data access and interoperability procedures.⁵ This data inaccessibility and incompatibility undermine the predictive and analytical capabilities of machine learning algorithms and data analytics, limiting medical practitioners' decision-making abilities as well as the 4P vision of Healthcare 4.0—prediction, prevention, personalization, and participation.⁶

From the patient's perspective, restricted access to their health data, negatively impacts their perception towards data ownership and stewardship. This limitation can make patients feel coerced into a passive role in decision-making,

knowledge, and value-creation processes, often leading to non-participation or even non-adherence to medications and physician instructions.⁷

To realize the 4P vision of healthcare 4.0 particularly participation of patients, decentralization and democratization of health data is fundamental. However, adverse incentives of healthcare business models that are driven by organizations with interest in complicated and nontransparent financing mechanisms, prevent such decentralization that empowers patients. We posit that the establishment of a blockchain-based health data marketplace where EHR, IoMT and wearable-derived data can be monetised by selling it to data consumers like medical professionals, researchers, regulators, third-party (e.g. AI service providers) and policymakers can solve this data centralization problem.⁸ Blockchain-like distributed ledger technology (DLT) introduces new opportunities to develop such a health data marketplace. The immutable feature of blockchain enables the attribution of ownership of digital assets (health data in this case) in a highly secure environment, while the smart contract feature provides flexible data stewardship capabilities (i.e. patients can choose which health data attribute to sell to which type of consumer), thus promoting privacy and trust. The smart contract also facilitates efficient and equitable distribution of revenue among the stakeholders (patient, clinics, caregivers etc.), fostering a cooperation-like socioeconomic ecosystem.⁹ Finally, the capability of cross-organization (hospitals, clinics) and technology (IoMT, wearables) data interoperability, traceability and integrity by DLT-like technologies¹⁰ makes them the most suitable candidate on which to build such a marketplace.

In recent years, several blockchain-based Health Data Marketplace have emerged¹¹ with different business models

and service choices. Patientory¹² as a pioneering example facilitates monetization of health data, opportunities to participate in clinical trials, AI and video based health coaching services etc. Here blockchain-like technologies been used to ensure data privacy and security. The platform's interoperability further enhances its value, facilitating seamless data exchange among patients, healthcare providers, and researchers, thereby improving healthcare delivery efficiency. However, despite these successes, Patientory faces challenges in achieving long-term user engagement and satisfaction. This is primarily due to the fact that monetization and generalized static servitization (video coaching service) are not enough for sustainable user engagement. Here, using the user's data the marketplace needs to offer (directly or through third party) a suite of AI or data analytics-based services with personalized and predictive capabilities tailored to adapt with the change of personal lifestyle, health and social conditions. The marketplace also needs to offer a community environment (through metaverse like technologies) through which collective intelligence, community surveillance can be achieved through collaboration and competition.

Integrating wearable-derived patient-generated data with clinical records will allow healthcare providers to use artificial intelligence and improved computing capabilities to analyze large amounts of data and to develop more accurate evidence-based diagnostic tools and treatment plans tailored to individual patients. Health regulators, in particular, stand to benefit significantly from this model. With access to a vast pool of real-world data, regulators can make more informed decisions to improve efficiency, coordination, and accountability that will improve public health. Last but not least, the marketplace model encourages a shift from a service-oriented healthcare system to a knowledge-driven one, where patients are no longer passive recipients of care but active participants in their health journey.

Disclaimer

This editorial is based on the podcast discussion and the paper titled "From Sharing to Selling: Challenges and Opportunities of Establishing Digital Health Data Marketplaces Using Blockchain Technologies." For a more detailed understanding, readers are encouraged to refer to the original paper and listen to the full podcast.

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References

- Zimmermann M. Diet, nutrition, and the prevention of chronic diseases: by the World Health Organization, 1991, 203 pages, softcover. WHO, Geneva. *Am J Clin Nutr.* 1994;60:644–5. <https://doi.org/10.1093/ajcn/60.4.644a>
- Alzheimer's Research UK. Dementia leading cause of death in 2022. [cited 2024 July 07]. Available from: <https://www.alzheimersresearchuk.org/news/dementia-is-the-uks-biggest-killer-we-need-political-action-to-save-lives/#:~:text=Our%20new%20analysis%20shows%20that,can%20save%20people%20from%20dementia>
- van der Flier WM, de Vugt ME, Smets EMA, Blom M, Teunissen CE. Towards a future where Alzheimer's disease pathology is stopped before the onset of dementia. *Nat Aging.* 2023;3:494–505. <https://doi.org/10.1038/s43587-023-00404-2>
- Dash S, Shakyawar SK, Sharma M, Kaushik S. Big data in healthcare: management, analysis and future prospects. *J Big Data.* 2019;6:1–25. <https://doi.org/10.1186/s40537-019-0217-0>
- Wiederrecht G, Darwish S. The healthcare data explosion. [cited 2024 July 07]. Available from: https://www.rbccm.com/en/gib/healthcare/episode/the_healthcare_data_explosion
- Li J, Carayon P. Health care 4.0: a vision for smart and connected health care. *IIEE Transac Healthc Syst Eng.* 2021;11:171–80. <https://doi.org/10.1080/24725579.2021.1884627>
- Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expect.* 2007;10:259–67. <https://doi.org/10.1111/j.1369-7625.2007.00450.x>
- Maher M, Khan I, Prikshat V. Monetisation of digital health data through a gdpr-compliant and blockchain-enabled digital health data marketplace: a proposal to enhance patient's engagement with health data repositories. *Int J Inf Manag Data Insights.* 2023;3:100159. <https://doi.org/10.1016/j.jjime.2023.100159>
- Narayan R, Tidstrom A. Tokenizing cooperation in a blockchain for a transition to circular economy. *J Cleaner Prod.* 2020;263:121437. <https://doi.org/10.1016/j.jclepro.2020.121437>
- Shahaab A, Khan I, Maude R, Hewage C, Wang Y. Public service operational efficiency and blockchain—a case study of Companies House, UK. *Gov Info Quart.* 2023;40(1):101759. <https://doi.org/10.1016/j.giq.2022.101759>
- Built In. Blockchain in healthcare: 18 examples to know [Internet]. [cited 2024 Aug 7]. Available from: <https://builtin.com/blockchain/blockchain-healthcare-applications-companies>

12. Patientory Inc. CASE STUDY: forging the path to consumer directed health through blockchain technology [Internet]. 2019 May 20 [cited 2024 Aug 7]. Available from: <https://patientory.com/blog/2019/05/20/case-study-forging-the-path-to-consumer-directed-health-through-blockchain-technology>

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