MyData: Applying human-centric principles to health data

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Abstract

Modern data legislation increasingly empowers citizens, and therefore patients, with rights to access and control their health data. The mechanisms needed to exercise modern data rights are currently underdeveloped and underserving individuals and societies. MyData is the human-centric approach to shift the power of personal data more equitably into the hands of individuals as part of a fair data economy. In this article, we present different scenarios that apply the MyData principles for human-centric control of health data. These scenarios demonstrate the potential of the human-centric approach for turning data rights into truly actionable points for policymakers, healthcare stakeholders, and medical communicators.

The emergence of the health data economy

The ability to digitalise health records has not only revolutionised the practices of clinicians and healthcare organisations, but it has also started a social change that is radically reforming the relationship between the individual and their health data.[1]

> "Numbers can't speak for themselves, and data sets – no matter their scale – are still objects of human design." Kate Crawford

Integrated, high-quality health data is a potential treasure-trove for healthcare. Diverse actors seek to leverage the digitalisation of healthcare to develop data-driven benefits – a phenomenon that is emerging as the "data economy" (see Figure 1).[2] Ideally, in the health data economy, providers can improve efficiency from seamless, centralised access to longitudinal records all while individuals immediately access and control their health data. However, when health data is framed exclusively in terms of the data economy, it runs the risk of reducing individuals to mere
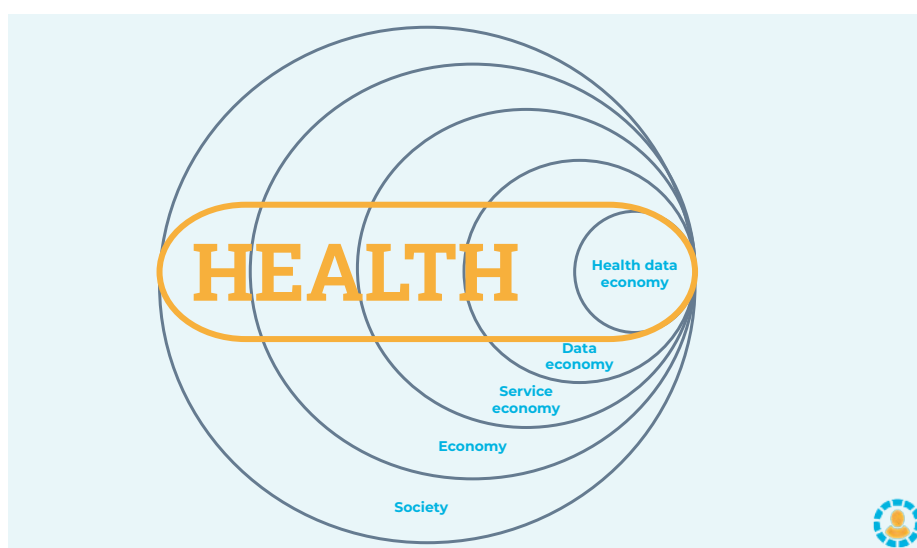

Figure 1. The context of health data in the economy
The health sector as a whole reaches across all aspects of modern economies, while the data economy has emerged as a driving force of innovation behind the service economy. The health data economy has the potential to play an increasingly significant role in both healthcare and the data economy.
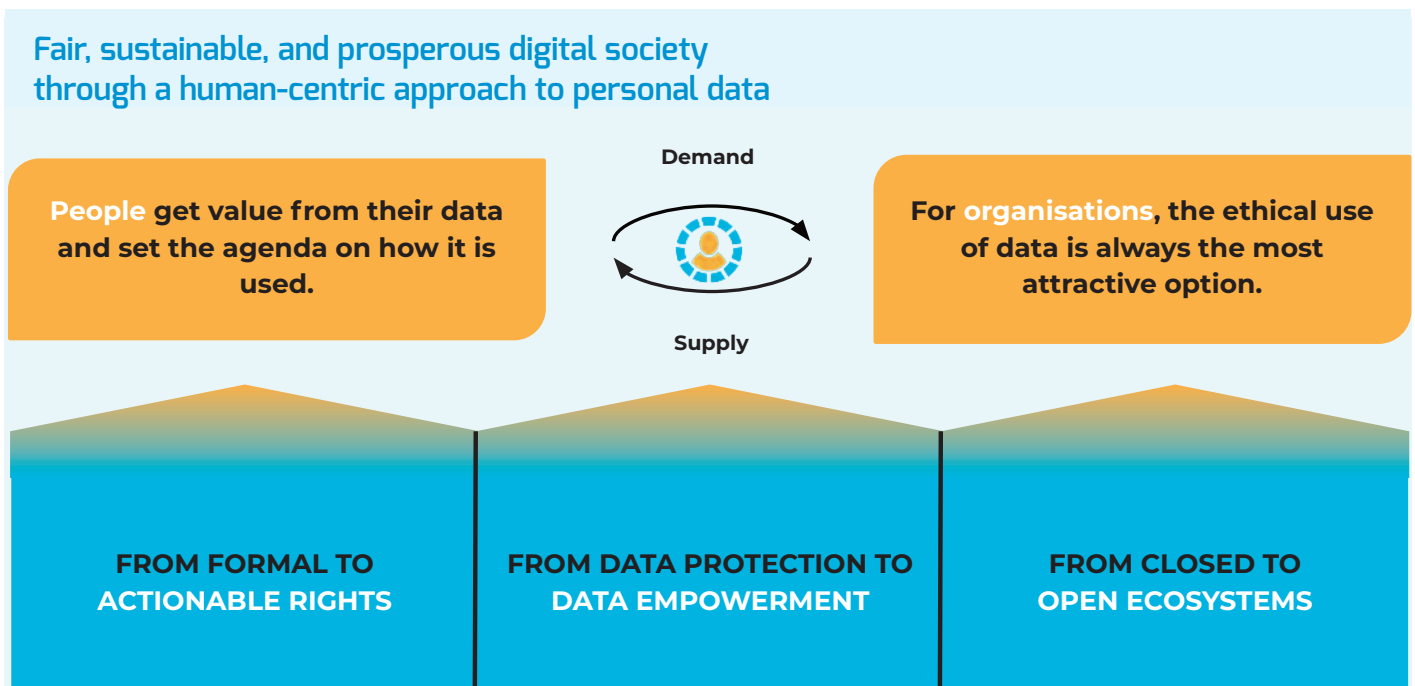
Figure 2. Goals of the MyData approach
To build a fair, sustainable, and prosperous digital society, three shifts are necessary, as represented by the boxes at the bottom of the figure.

market participants. Consideration should be given to the wider societal context beyond the data economy to support human agency and ultimately advocate for the role and rights of citizens.

MyData

MyData is a human-centric approach to personal data.[3] This human-centric paradigm was introduced to support the realisation of "a fair, sustainable, and prosperous digital society, where the sharing of personal data is based on trust as well as a balanced and fair relationship between individuals and organisations" (see Figure 2).[4] MyData Global is a non-profit organisation catalysing the adoption of this approach, aiming to empower people by improving their right to self-determination in all aspects of personal data.[5] Driven from the ground up, the MyData community published a declaration outlining the shifts needed to reach the human-centric paradigm and the principles upon which to build it (see Figure 3).[6] The European Strategy for Data, a recent communication released by the European Commission, endorsed the MyData approach as a promising initiative to actualise human-centricity.[7]

The principles

Multiple, interrelated issues exist in the current *modus operandi* of the health and wellness ecosystem, many of which can be addressed through the MyData principles (see Figure 3). The fractured state of the contemporary health data landscape is one of the fundamentally problematic aspects. The MyData approach to remedy this situation is to adopt the principle of the individual as the point of integration; that is, the individual acts as the central contact point to access and control their data. This approach simplifies the challenges around consent, enables human-centric governance, and creates opportunities for service innovation.

Healthcare organisations are facing risks associated with being data custodians, including the burden of security and the possibility of severe penalties for data breaches and privacy violations.[8] By adopting the principles of transparency and accountability, organisations can prepare for intended and unintended consequences from their use of health data in a manner that creates trust and mitigates risks. Making a conscious shift towards human-centric control of personal data, organisations in the health and wellness sector empower people to be healthier and flourish with the help

of the data available about them.

Modern data protection and privacy legislation grants individuals the rights over their personal data. However, the tools, skills, and opportunities necessary to exercise these rights are often underdeveloped and overlooked. Adopting the principles of interoperability enables the sharing of health data between organisations and individuals, while portability allows individuals to access and use data about them. These two principles can help organisations to comply with existing and emerging legislation, and better serve their customers. In short, the MyData approach is an attractive option for organisations because it ensures individuals are empowered to control their data and promote its best use.[9]

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MyData principles

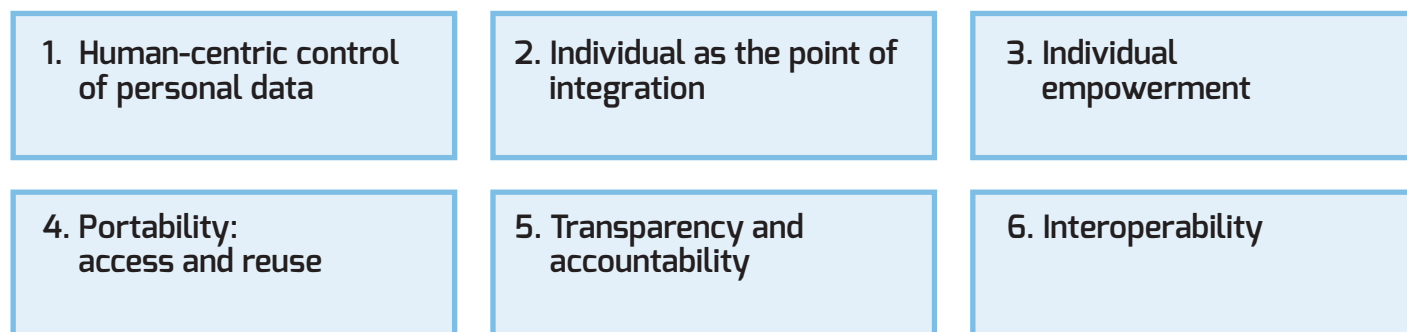|		
1. Human-centric control of personal data	**2. Individual as the point of integration**	**3. Individual empowerment**
4. Portability: access and reuse	**5. Transparency and accountability**	**6. Interoperability**

Figure 3. The six MyData principles

The power of applied MyData thinking

In this section, we demonstrate the power of the MyData approach by discussing four contemporary challenges in healthcare and presenting innovative solutions and initiatives that succeed in addressing these challenges through the adoption of MyData principles.

Health data access and reuse for patients with diabetes

Access to health data has proven beneficial for self-management of complex chronic diseases such as diabetes.[10] Diabetes management tools (e.g., insulin pumps, blood glucose meters, and continuous glucose monitors [CGMs]) provide a rich source of health data, yet, the potential value of this data is not maximised to meet all desired uses by patients. While device manufacturers provide patients with software tools for data use, MyData principles underlie advances in diabetes data reuse by patients for other purposes. In particular, three relevant principles apply: individuals as a point of integration, individuals as autonomous agents in the reuse of their data, and the right of individuals to port their data to their own devices and other services. These principles have come together to give patients the ability to create and use data for purposes beyond those provided by device manufacturers.

The huge variety of tools, grassroots, and non-profit efforts for repurposing diabetes data highlight the progress in this domain. The patient-initiated Nightscout Project is an open-source software project for CGM data portability, enabling coordinated care and data access for caretakers as well as re-display of data on different devices. Patients have also developed open-source tools for "looping" (automated insulin

delivery personalised from CGM data). Remarkably, due in part to government regulation, these efforts made automated insulin available to patients before commercial products were available. Data integration across devices is also enabled with open-source software developed by Tidepool, and the non-profit organisation has launched a project to develop an FDA-regulated version of Loop software.[11] Patients have also been able to donate data to research via a centralised database managed by Tidepool as well as similar patient-led research projects.[12,13] The ability of patients to access and reuse their data as advocated by MyData principles has enabled a remarkable set of innovations beyond what would have otherwise existed.

Empowering individuals with control of their health data

Healthcare is challenging due to the sensitivity of health data, the imbalance of power in the patient-provider relationship, and healthcare providers' historical status as controllers of data. Empowering individuals with control over their health data is a key MyData principle that addresses this problem. When individuals are given control over their data, they are more willing to share their health information.[14] Certain types of health data are more sensitive, such as those related to mental health or substance use disorder, and require an individual to decide what can be shared, with whom, for what purpose, and for how long. Understanding individuals' perceptions regarding what specifically matters for their privacy is essential.

A form of control is enacted through informed consent, which has been at the centre of human subject research since the Declaration of Helsinki in 1964.[15] However, consent terms and privacy policies often include lengthy legal

text that is not conducive to engaging individuals in informed decision making. Lack of meaningful choices can cause an individual to deny consent or avoid medical services out of fears of discrimination or abuse of power. For medical providers, timely access to the right data at the right time is paramount, and the scope of access is dependent on the context. For example, data accessible to a physician during a regular visit can differ from data available during substance use disorder treatment. Emerging platforms empower individuals by integrating their privacy concerns into data flow based on context while enabling centralised control over health data.[16,17]

To provide individuals with a central point of contact to manage their data, open-source solutions for personal data stores are becoming increasingly relevant.[18,19] Innovations which empower individuals with control over their health data are crucial for balancing power in the data economy.

Data interoperability

Data interoperability standardises interfaces, data syntax, and the semantics of the underlying data, going beyond technical integration to ensure that data has the same meaning wherever it is used. It provides the best opportunity for the use of health data and appropriate standards across different types of systems as advocated for by the MyData principles. The ability to integrate universally at the data level is known as semantic harmonisation, and this provides full data portability. This is desirable because storing data together with the tools necessary for interpretation makes it easier for a wide range of services to access the information. A good example of a storage tool that achieves this is a Semantic Container.[20] Tightly controlled data formats also improve interoperability capabilities from new
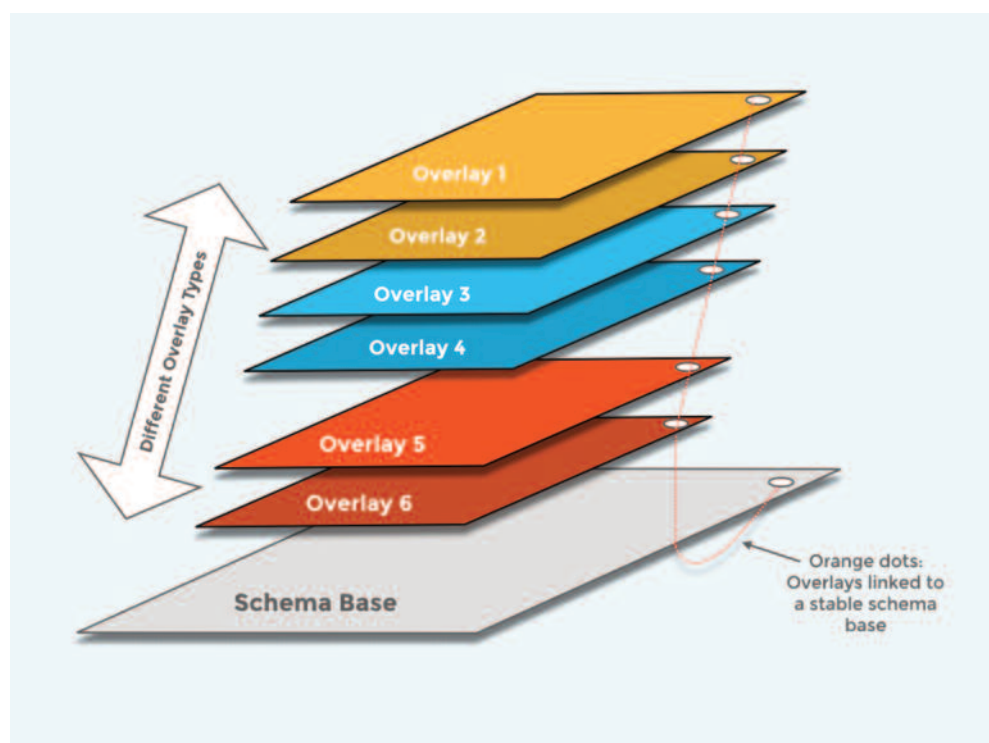
Figure 4. Overlays capture architecture can enable object interoperability within an industry sector
This architecture presents a schema base and interoperable overlays. Different overlays represent the specific needs of a particular application or organisation with, for example, dedicated formats, character sets, or information overlays. Multiple parties can interact with and contribute to the overlays without having to change the schema base definition.

applications such as Internet of Things devices.[21]

A universal approach to a unified data language would provide data subjects with the opportunity to request enriched data, in a standard format for self-governed usage, from trusted brokers such as national governments, insurers, or healthcare providers. A layered capture architecture (see Figure 4) can facilitate data harmonisation beyond the confines of a single organisation by enabling a number of parties to contribute to multi-source data pools. This level of object interoperability and subsequent language unification will provide increasing efficiency and effectiveness within the healthcare sector.

A core component to facilitate a unified data language is object interoperability using a schema with a layered architecture.[22] By introducing layered task-orientated objects (or "overlays") multiple parties can interact with the same base object by simply creating their own set of linked overlays to fulfil the requirements of their particular use case. With schema base definitions a stable foundation is established to capture health data in a standardised way.

Any specific machine-readable task, rule or definition relating to the semantics of the source data can be encapsulated into a data capture object. To maintain the reusability of data capture objects, each item should remain accessible to all developers interacting with the network. Although there must always be an auditable trace back to the public identifier of the original issuer of a data capture object, that actor never needs to govern who has access to those published items. All actors will benefit from the availability of data capture objects in open form which, alongside a human-centric design ethos, helps to drive interoperability through standardisation.

Establishing trust between stakeholders for health data use

Traditionally, trust between patients and their caregivers is a necessary part of medicine and healing. However, this trust has been abused in some cases, and as a result, new data policies are in place to protect patients.[23] With an increase of health data, the relationship between clinicians, healthcare organisations, and patients is evolving and questions of how trust can be achieved are necessary as part of a fair health data economy.

As the generation of health data often involves multiple parties, it can become difficult to determine who governs data, which impedes data use. One way to rebuild trust between healthcare systems, data vendors, and individuals is for stakeholders to embrace the MyData principle of transparency and accountability. Although informed consent provides specific terms and conditions for data use, there are often grey areas where data can potentially be used beyond the scope of the agreement. Traceable health information services allow individuals to have full access and control of health data about themselves through a transparent data management process.[24] The accountability of data flow reduces individuals' worries about data misuse.

Because health data can be copied with ease, special measures are necessary to ensure terms of use. Digital watermarking provides an elegant way to foster transparency and accountability in data transfers, increasing trust between
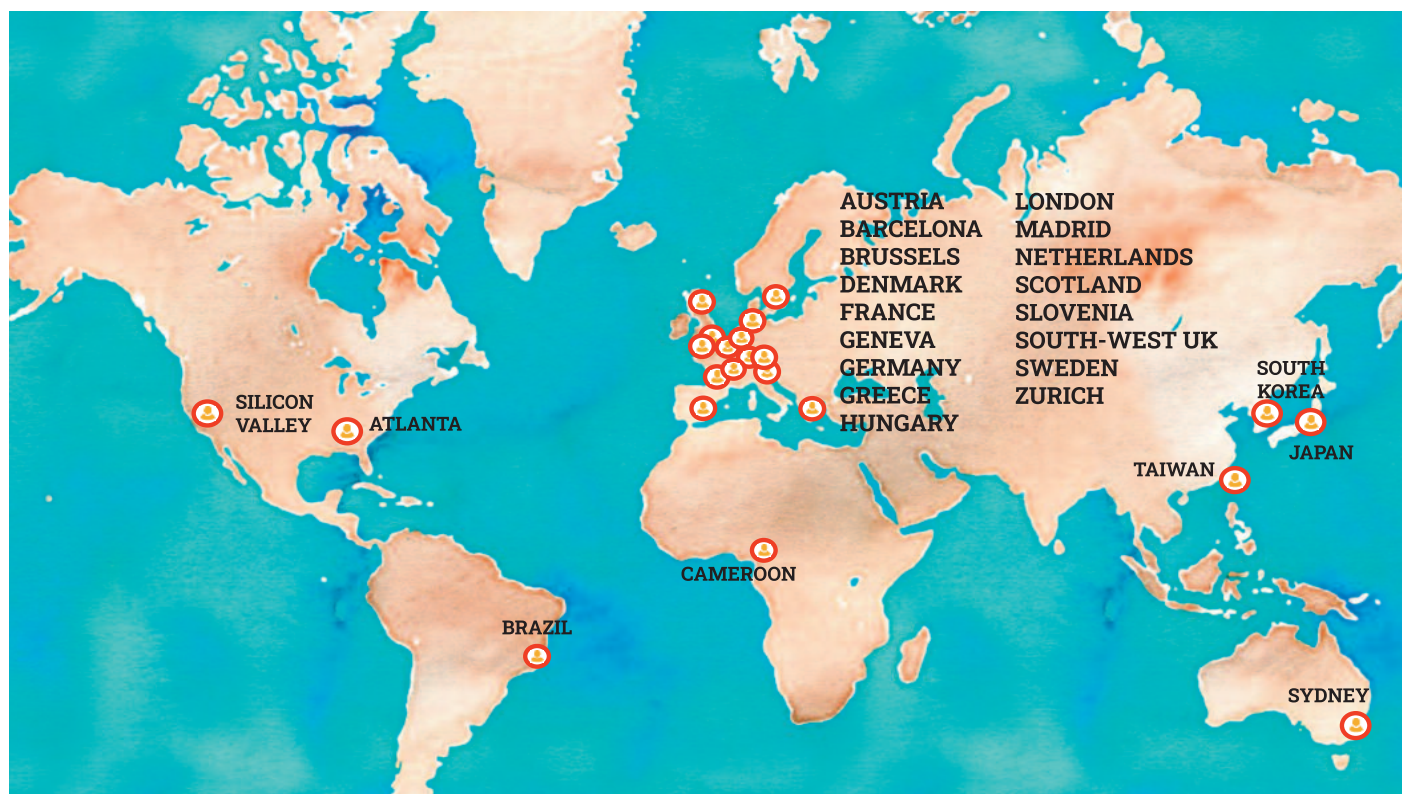
AUSTRIA   LONDON
BARCELONA   MADRID
BRUSSELS   NETHERLANDS
DENMARK   SCOTLAND
FRANCE   SLOVENIA
GENEVA   SOUTH-WEST UK
GERMANY   SWEDEN
GREECE   ZURICH
HUNGARY

SILICON VALLEY   ATLANTA   SOUTH KOREA   JAPAN   TAIWAN   CAMEROON   BRAZIL   SYDNEY

Figure 5. Locations of MyData hubs

individuals and healthcare stakeholders. The individual benefits by proving lawful access to the data all while building trust through transparency mechanisms. In practice, Semantic Containers provide an open-source implementation for digital watermarking.[20] Ultimately, traceability of health data invokes the necessary level of trust to encourage data sharing on a global scale for societal benefit.

The imminent role of MyData in the data economy

MyData for healthcare stakeholders

The four areas of application outlined above clearly reveal the interplay between individuals and organisations of the healthcare sector. While we have shown that technologies are emerging to support these dynamic relationships, in each case, it is human-centric design thinking that achieves the balance required for a sustainable model. The initiatives, companies, and services presented here expose a world where new tools for exchanging health data are in the process of being adopted. These tools are starting to open up the large health data repositories and monopolies by making the individual the point of integration. From the point of view of

healthcare organisations, the health economic arguments for these human-centric approaches are undeniable–they reduce regulatory burden and risk, provide access to new sources of data, and build equity with individuals.

MyData for policymakers

Data protection regulations in many countries increasingly provide rights to individuals; however, this should not be seen as the sole driver for providing increased access to and control over health data. Considerable benefits also arise from data sharing, portability, and use. The European Commission's data strategy supports a common health data space as crucial for "advances in preventing, detecting, and curing diseases as well as for informed, evidence-based decisions to improve the accessibility, effectiveness, and sustainability of the healthcare systems".[7] Adopting the MyData principles from the top down would continue to support the individual as the point of integration for developing this shared health data space.

MyData for medical communicators

The approach advocated by MyData is to focus on human factors as central to the activities of the

health data economy. Since medical communicators traditionally gather and disseminate health information from trustworthy sources, they are in an excellent position to convey the importance of best data practices in the medical field with confidence and sensitivity. Understanding the expectations, opportunities, and risks that individuals face is critical in the creation of informative materials for public dissemination. Medical writers should recognise the data rights of individuals and use MyData principles as a resource to empower human-centric communications.

Conclusion

The role of health data in the data economy as the source of predictive, preventive, personalised, and participatory power is an emerging phenomenon. Leveraging the abundance of health data as a source of value for relevant stakeholders can only be materialised through deliberate actions by policymakers, support from medical writers for disseminating best data practices, and innovative data management models embraced by organisations.[25] All healthcare actors have a vested interest in empowering individuals to improve health and wellness while advancing the health data economy. This should be approached

in a fair, transparent, and sustainable manner as advocated for by the MyData principles.

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Disclaimers

The opinions expressed in this article are the author's own and not necessarily shared by their employer or EMWA.

Conflicts of interest

The authors declare that they are all active members of MyData Global ry. MPB is also an elected member of the MyData Global ry board. VL is also actively employed by MyData Global ry.

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MyData Health thematic group information

MyData Global is a registered association whose mission is to advocate for a human-centric approach to personal data. With just over two dozen hubs currently established on five continents, MyData Global represents hundreds of individuals and dozens of organisations as members (see Figure 5). As part of the MyData Global organisation, the thematic group for health data is a diverse collection of like-minded individuals with a wide range of expertise and experience on the health-related aspects of personal data. Our interests and activities are inspired by health topics ranging from debating the status of genomic data, to knowledge creation on interoperability and data sharing. We advocate for the human-centric MyData principles and are an inclusive community. If you would like to learn more, or are interested in joining our community, you can find us on the online communication platform Slack for MyData[4] and on Twitter.