


Strategic Oversight Across Real-World Health Data Initiatives in a Complex Health Data Space: A Call for Collective Responsibility

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Keywords: Landscaping, European Health Data Space, Interoperability Challenges, Information Scattering.

Abstract: Reusing real-world health data is useful, but challenging. Multiple initiatives exist and more are continuously arising to overcome these challenges, but the strategic oversight across these initiatives is lacking, which leads to a fragmented ecosystem. An overview of which initiatives that work on unlocking real-world health data, making this data accessible for research and/or innovation and/or policy and getting an idea about which aspect of the ecosystem the initiatives are working on would be very helpful. It could help in figuring out how initiatives can work in synergy in order that consortia can be formed more efficiently. We tried to create an overview, resulting in a static list, but have thereby run into many problems and difficulties and have noticed that the information is even more scattered than expected, and often ambiguous and unclear. This paper highlights the need for strategic oversight in our complex health data space, defines key challenges and focuses on solutions and strategies for overcoming these challenges, and aims to guide the future of health data research and innovation on a global scale, offering a valuable resource for stakeholders in the field.

1 REUSING REAL-WORLD HEALTH DATA IS USEFUL, BUT CHALLENGING


1.1 Europe Acknowledges Great Promise in the Reuse of Health Data


The European Commission has been working for several years on a strategy for data sharing. In this context, in February 2022, the Data Act, which is a proposed regulation that clarifies who is allowed to create value from data and under which conditions, was adopted by the European Commission (*link to Data Act: <https://digital-strategy.ec.europa.eu/en/policies/data-act>*). With a specific focus on the healthcare domain, Europe has been making continuous efforts aiming at enhancing the harmonization and integration of health data, which is needed in order to be able to create a digitized and connected healthcare system, as foreseen in the

European Health Data Space (EHDS) regulation (*link to EHDS regulation: https://health.ec.europa.eu/publications/proposal-regulation-european-health-data-space_en*). The EHDS regulation aims at unleashing the full potential of health data by supporting the reuse of health data for better healthcare delivery, better research, innovation and policy making.

1.2 Several Socio-Technical Challenges Are Obstructing Us from Scaling Reusing Health Data

Several socio-technical challenges obstruct us from reaching the true potential of reusing real-world health data, such as the level of awareness and understanding on the use and/or importance of real-world health data differs between individuals, different stakeholders have different needs, finding and assessing health data sources is challenging and time-consuming, limited interoperability and the combined complexity of governance, ethical and

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legal barriers, as well as technical challenges in data management and analyses, impacts the execution of large-scale initiatives. This section takes a closer look at these problems and potential solutions.

1.2.1 Limited Awareness Leads to Limited Engagement

The level of awareness and understanding of the use and/or importance of real-world health data differs between individuals, resulting in different levels of engagement to contribute to the health data space. In our experience, healthcare professionals or citizens are often not motivated to consistently collect and share health data in a structured way, and regulators are reluctant to acknowledge evidence generated through non-controlled observational studies. On the other hand, individuals can be engaged but not sufficiently educated or trained to make informed decisions (e.g. a director of a hospital that is willing to invest in an improved data management strategy, but is struggling with so-called ‘analysis-paralysis’ because they have no clue where to start). Examples of activities that can be done to overcome this challenge include (i) Advocating the message “Health data - why should you care?” and showcasing the impact of reusing health data by sharing success stories from collaborative projects, presented in a way that resonates with a layman audience; (ii) Develop and disseminate educational resources (with different target audiences in mind); (iii) Facilitate interactions and collaborations and promote knowledge exchange by organizing workshops, conferences and other networking events. By raising awareness, educating, and demonstrating the benefits of health data, we can bridge the gap in understanding and encourage broader engagement in the health data space.

1.2.2 Different Stakeholders Have Different Needs, Which Makes Large Collaborative Efforts Complex and Time-Consuming

Relevant stakeholders include, e.g. citizens, healthcare professionals, researchers (private and public), data custodians, industry and regulators. Meeting the varied needs of different stakeholders often requires complex coordination efforts. This complexity can slow down decision-making processes and the execution of large collaborative efforts. To mitigate this, fostering a better understanding and empathy among the various stakeholders is crucial. This can be achieved by (i)

promoting more conversations and interactions between different stakeholder groups, facilitating a deeper appreciation of their unique perspectives and requirements; (ii) documenting and disseminating the strategies used within successful multi-stakeholder projects in order to create a valuable knowledge repository that can be leveraged by others facing similar challenges.

1.2.3 Low Adoption of FAIR Guiding Principles

As stated by Wilkinson et al. (Wilkinson M.D., 2016), FAIRness -in which FAIR means Findable, Accessible, Interoperable and Reusable- is a prerequisite for proper data management and data stewardship. It is important that real-world health data is FAIR in the long-term as well (Holub P., 2018). Finding and assessing health data sources is challenging and time-consuming. Metadata catalogues can empower end-users to assess and compare metadata associated with health data sources. Some examples of metadata that are of interest include information about the (i) organizational set-up and governance model of the data source; (ii) type of data collected (categorizing data sources by type, such as electronic health records, -omics data, or medical images, allows users to quickly identify datasets relevant to their research or analytical needs); (iii) number of unique patient records; (iv) detailed information about the specific variables or data elements collected; (v) basic information related to data quality, such as validity, completeness, accuracy, and any quality control measures in place. Additionally, health data sources are heterogeneous in size, maturity and depth, reducing their potential of reusing it. Heterogeneous data from various resources are difficult to integrate, thereby limiting the interoperability. One approach to tackle this issue involves the formulation of guidelines that serve as a framework for standardizing data sources and harmonizing their structure. Additionally, the development, implementation, and widespread adoption of data standards or common data models are pivotal steps to ensure that health data sources are more readily accessible and also compatible, resulting in enhanced potential for reuse and interconnectivity.

1.2.4 The Combined Complexity of Governance, Ethical and Legal Barriers, as Well as Technical Challenges in Health Data Handling and Analyses, Impacts the Execution of Large-Scale Initiatives

Some examples of potential solutions to overcome this moving forward include: (i) Developing and implementing advanced cutting-edge technologies that enable secure and privacy-preserving analysis of health data; (ii) Documenting and streamlining governance procedures and encouraging sharing of successful ethical and legal frameworks that have proven effective in similar projects; (iii) Adjusting ethical and legal frameworks in collaboration with funding agencies, policymakers and researchers if necessary.

2 STRATEGIC OVERSIGHT ACROSS INITIATIVES IS USEFUL, BUT CHALLENGING TO ACHIEVE

Multiple 'health data initiatives' (in short: initiatives) exist -and more are continuously arising- to overcome the challenges discussed in the previous section. However, the strategic oversight across these initiatives is lacking. In the context of this paper, the term 'initiative' is used to encompass all plans, projects, or studies dedicated to addressing one or more of the socio-technical challenges listed. We focus on initiatives that still exist today and are more than 'just an idea or concept note'.

2.1 Strategic Oversight Across Initiatives Is of Utmost Importance

An overview of which initiatives that work on unlocking real-world health data, making this data accessible for research and/or innovation and/or policy and getting an idea about which aspect of the ecosystem the initiatives are working on would be very useful, because of a variety of reasons, including but not limited to:

(i) Guiding newcomers: One of the main reasons for emphasizing strategic oversight across health data initiatives is to offer a fast and comprehensive overview of the complexity of our health data space. This is especially invaluable for less experienced stakeholders. Navigating this intricate landscape can be daunting, and an overview could serve as a guiding

beacon, ensuring that those entering this complex space find direction and fundamental understanding rather than feeling lost.

(ii) Knowledge leveraging and preventing redundancy: Currently, the immense challenges posed within our health data ecosystem are often tackled in isolated silos, leading to a redundant 'reinventing the wheel' paradigm. By promoting knowledge transfer and best practices, such oversight could ensure efficient utilization of resources. Moreover, it could enable a collective learning process, significantly reducing duplication of efforts.

(iii) Analysing an initiative network: A holistic view of how initiatives interconnect and the common challenges they face is essential. It promotes collaboration, highlights areas where collective solutions are needed, and fosters a sense of unity in addressing health data challenges.

(iv) Identifying gaps: Strategic oversight can pinpoint gaps and shortcomings in the current health data landscape, enabling targeted efforts to fill these voids and enhance the overall quality and coverage of available data.

(v) Influencing policy: A comprehensive overview facilitates the development of policy preparatory documentation, which can influence policy decisions and regulations that shape the health data landscape.

(vi) Forming consortia efficiently: For efficient consortium formation, it is essential to know which initiatives already exist, their specific focuses, current status, and levels of advancement. This knowledge forms the foundation for strategic collaboration and innovation in the health data ecosystem.

2.2 The Health Data Landscape Is Inherently Complex. Hence, Achieving Strategic Oversight Is Challenging and Time-Consuming, but at Least We Tried

We kick-started 2023 with the good intention to try to come up with a strategic oversight of existing initiatives using a comprehensive and multi-faceted approach. It could help in figuring out how initiatives can collaborate in a better way, how they can work in synergy in order that consortia can be formed more efficiently. Additionally, it could open the eyes of regulators and the government, leading to policy preparatory documentation and be able to influence policy. A rigorous literature review and internet scanning served as the initial screening process for identifying existing initiatives. Between January 2023 and April 2023, several search strings in several

search engines were applied using different keywords. The sources searched were PubMed, Google Scholar, Medline NLM, Cochrane, Scopus and Cordis. The keywords used in the literature search were: real world data; real world data AND infrastructure; data infrastructure; (real world) data infrastructure AND Europe; real world data strategy; real world data and inventory; FAIR data ecosystem; Digitization AND health AND RWD; FAIR data management; secondary reuse AND health data; data science strategy; data-driven medicine; data sharing infrastructures; Big data and health; real world data initiative; real-world data AND health AND initiative.

Specific inclusion and exclusion criteria were defined for the scoping review. To be considered for this review, studies had to meet the following inclusion criteria: English-language articles; the articles had to be reviews, systematic reviews or meta-analyses. Studies that were published more than 5 years ago were excluded.

Next to this literature research, a general Google search was performed to find initiatives that work on unlocking real-world health data, making real-world health data accessible for research and/or innovation and/or policy. Additionally, information and documents we received during the past months and years from our network were checked and evaluated on eligibility. This review allowed us to form a preliminary shortlist of initiatives while gaining a broader understanding of the field's landscape. Subsequently, during the period of May to August 2023, 13 semi-structured interviews were conducted with authorities in the field of data spaces, health data management and analyses to better understand which information they considered critical to be gathered from various health data initiatives. In addition, we solicited these experts' opinions regarding how such an exercise could become sufficiently exhaustive to be useful, and could be kept up-to-date with minimal effort from all stakeholders involved. The semi-structured interviews, supported with an interview guide that was used in a flexible way, gave much opportunity for the respondents to speak very openly. All interviews were done by Lotte Geys, who had no personal connection with the experts. Interviews took between 45 minutes and 1 hour and were recorded (Google Meet) and transcribed verbatim.

The interviews were set-up in Google Meet and the experts were asked the following: (i) their opinions on the idea of setting up a living library of existing initiatives, (ii) which questions from end users the living library should be able to answer, (iii) which initiatives they know about, (iv) who we could

possibly talk to in order to better carry out our research and achieve our goal. Personal data was collected from participants and processed in accordance with the General Data Protection Regulation (GDPR). This research was conducted and seen as a task carried out in the public interest. This study received approval from the UHasselt Social ("Sociaal-Maatschappelijke") ethical committee (SMEC) (REC/SMEC/2022-2023/33).

2.3 To Date, It Is Impossible to Achieve This Strategic Oversight Because of Various Reasons

While striving hard for several months to achieve our set goal towards providing strategic oversight across initiatives, in the end, we were left deeply frustrated because of 3 main reasons.

First of all, the information we need about the initiatives is, most of the time, not available in the public domain. Table 1 presents an overview of the information deemed essential by experts for assessing the value, impact and strategic positioning of health data initiatives. The aim of an initiative, the data they focus on, the way they work, what they exactly do, etc., is often only vaguely described or not to be found at all.

Secondly, a lot of initiatives are interlinked or change their name and scope over time without properly documenting these changes. It's often very confusing how they are linked or not clear that a certain initiative originates from another one. It turns out to be impossible to know for each initiative how they originated and what it stands for. Many initiatives started from a grant that expired after a few years, but the initiative itself turned out to be successful. These initiatives then often survive but choose to work under a new name, potentially with a new legal entity. This becomes very complex for people who are trying to understand the ecosystem and trying to get an overview of what is going on. To give a concrete example: the Population Health Information Research Infrastructure (PHIRI) initiative allows for better coordinated European efforts across national and European stakeholders. PHIRI aims to generate the best available evidence for research on health and well-being of populations as impacted by COVID-19 to underpin decision-making. It was born from two former initiatives: BRIDGE Health and the Joint Action on Health Information (InfAct) projects, which both have a whole history. On top of that, PHIRI launched a "spin-off initiative": its Health Information Portal, which is a one-stop shop facilitating access to

Table 1: Essential Information for evaluating Health Data Initiatives. Through semi-structured interviews with experts in the field, we inquired which information they considered critical to be gathered from various health data initiatives. This table presents an overview of the information deemed essential by experts for assessing the value, impact and strategic positioning of health data initiatives.

Category	More specifically
Data	Data type Granularity Centralized vs federated Coding Numbers Data quality Missing data Link to prospective data Standards Category of health data How to apply for data access How to contribute
Stakeholders	Which stakeholders are involved? Who is it accessible to? Also for industry? Also for commercial purposes? Looking for partners? How many and type of partners? Who is the initiator, who are participating organizations?
Scope of the initiative	Objectives What are their strengths? What specific socio-technical challenges are they focusing on? (E.g. standardization, infrastructure, legal point of view, business modeling)? Geographical scope (E.g. Europe, global vs specific region)
Costs/Financial aspect	Free of charge or not Funding
Governance of the initiative	Links with other initiatives
General information	Publications Contact details

population health and healthcare data, information and expertise in Europe. Unfortunately, PHIRI ended in November 2023, and it could be that they will continue to exist with another name, putting it at risk of complicating it even more for people to understand. This is just one initiative, but considering that we found 67 initiatives (10.5281/zenodo.10451144) and there are even more, one might understand that it becomes impossible to

keep track of, especially when their websites are not very detailed either.

And last, but not least, we were continuously haunted by the question ‘where to start and where to stop’. Initially, we wanted to include as many initiatives as possible. But the more we progressed, the more overwhelmed we were. The term “initiative” can be interpreted in many different ways, making it difficult to define precise inclusion/exclusion criteria.

3 OUR RESULTS AND HIGHLIGHTED INITIATIVES FROM OUR IMPERFECT VENTURE

While we acknowledge that achieving a complete overview is impossible (see reasons above in 2.3), we believe the list of initiatives v2023 (10.5281/zenodo.10451144) serves as a valuable starting point for those navigating the complex landscape of health data initiatives. For each initiative, details about the covered regions, associated countries, website links, and whether the initiative is specific to healthcare or encompasses multiple domains are presented, as available. We share it with the hope of assisting others in their quest for clarity. *Important Disclaimer:* we acknowledge that this list is neither exhaustive nor free from bias, influenced by their geographical location and their research emphasis on chronic disorders. However, this list offers a starting point to address the issues discussed in this position paper, aiming to provide readers with insights gained after extensive online exploration. The list resulting from our work can assist individuals seeking clarity on the evolving landscape of health data initiatives. While a comprehensive overview remains elusive, this list serves as a valuable resource to navigate the intricate ecosystem. In this section, we will provide more details on some highlighted initiatives to explain some interesting emerging trends we have noticed during our extensive landscaping exercise.

3.1 Initiatives Focused on Tackling Data Heterogeneity - Data Standards and Common Data Models

As mentioned earlier, health data is heterogeneous in size, maturity and depth, reducing their potential of reusing it (limited interoperability). To reduce

heterogeneity, the health informatics community is focusing on the development and adoption of data standards (e.g. Logical Observation Identifiers Names and Codes (LOINC), International Classification of Diseases (ICD), and SNOMED Clinical Terms (CT)) and common data models (CDMs). Different initiatives are developing and/or adopting different CDMs, potentially obstructing the interconnection of these initiatives over time.

OMOP is an abbreviation of ‘Observational Medical Outcomes Partnership’ and is a common data model for observational healthcare data managed by the Observational Health Data Sciences and Informatics community (OHDSI: OHDSI.org). More than 810 million unique patient records have been mapped to the OMOP CDM, clearly showcasing the wide adoption of this CDM. The OMOP CDM is implemented within two important European large-scale collaborative efforts: the European Health Data and Evidence Network (EHDEN.eu) and the Data Analysis and Real-world Interrogation Network in the European Union (DARWIN.org). EHDEN, established in 2018, aims to build a network and infrastructure that uses harmonized health data to gain real-world evidence. It currently compasses 187 data partners from 29 different countries. DARWIN, a federated data coordination network established by the European Medicine Agency, aspires to deliver real-world evidence from across Europe on diseases, populations and the uses and performance of medicines (pharmacovigilance studies).

3.2 Initiatives Focused on Education and Awareness Raising

Data Saves Lives (datasaveslives.eu) is a multi-stakeholder initiative with the aim of raising wider patient and public awareness about the importance of health data, improving understanding of how it is used and establishing a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe. It is led by European Patients’ Forum (eu-patient.eu) and European Institute for Innovation through Health Data (i-HD.eu). Data Saves Lives aspires to share relevant information and best practice examples about the use of health data and generate easy-to-use materials about the basic concept related to the data journey. The portal of data.europe.eu, aiming to be the central point of access to European open data, educates citizens and organizations about the opportunities that arise from the availability of open data with their “Academy tab”. An inspiring new trend within recently approved programmes within Horizon

Europe (HE) and Innovative Medicine and Health Initiative (IMI/IMI) is to disseminate lessons learned more broadly to the public (e.g. EHDEN Academy (academy.ehden.eu) and other initiatives within the Big Data For Better Outcomes roadmap (bd4bo.eu)).

3.3 Initiatives Focused on a Specific Set of Data Types

Distinct categories of data require tailored technical solutions for data management, storage and analyses. InterRAI (interrai.org) is a partnership of researchers and practitioners in more than 35 countries committed to improving healthcare for people in long-term care by tackling the challenges that arise with handling so-called ‘resident assessment instruments’ (RAI). RAIs are scientifically validated instruments enabling an assessment of the degree of dependency and the care needs of individuals. The Health Outcome Observatory (H2O; health-outcomes-observatory.eu) aspires to create a standardized data governance and infrastructure system across Europe with a specific focus on patient-reported information. Within the European Strategy Forum on Research Infrastructures (ESFRI.eu) roadmap, two initiatives are focusing on tackling two specific sets of data types: ELIXIR (elixir-europe.org), focusing on -omics data (e.g. genomics, proteomics) and EBRAINS (ebrains.eu) with a specific focus on brain-related data (e.g. neuroimaging data). Interestingly, ESFRI is currently working on a landscape analysis which will provide an overview of the European transnational research infrastructure ecosystem. The Landscape Analysis will include research infrastructure services, technology, instrumentation and data aspects, as well as societal and economic impact; it covers national, European and global scales and will be published online in December 2023.

3.4 Initiatives Focused on a Specific Disease Area of Interest

While the existence of broader, disease-independent initiatives is undoubtedly advantageous, the importance of preserving disease-specific initiatives cannot be overstated. These specialized initiatives are indispensable because of their domain expertise and knowledge needed to meet disease-specific requirements. Additionally, these initiatives are crucial to improve the disease-specific community engagement, and communication and collaboration between stakeholders involved. Some interesting initiatives showcasing this are: the Multiple Sclerosis Data Alliance (msdataalliance.com); PIONEER

focusing on prostate cancer (prostate-pioneer.eu), the European Platform on Rare Disease Registration, the Haematological Outcomes Network in Europe (HONEUR, portal.honneur.org) and the European Society for Blood and Marrow Transplantation (EBMT.org).

3.5 Initiatives Focused on Streamlining Governance Principles

The project entitled ‘Towards European Health Data Space’ (TEHDAS; tehdas.eu) plays a pivotal role in addressing the challenge of streamlining governance principles within and across member states in the context of the EHDS regulation. TEHDAS helps EU member states and the European Commission to develop and promote concepts for the secondary use of health data to benefit public health and health research and innovation in Europe. At the level of the member states, national data authorities have already been installed to act as the single-point-of-entry responsible for orchestrating the reuse of health data in a specific country. Examples include the Finnish Social and Health Data Permit Authority (findata.fi) and the French Health Data Hub (health-data-hub.fr). In October 2022, the HealthData@EU Pilot project started (ehds2pilot.eu), bringing together 17 partners including health data access bodies, health data sharing infrastructures and European agencies. The HealthData@EU Pilot project is a two-year-long European project co-financed by the EU4Health programme. It will build a pilot version of the EHDS infrastructure for the secondary use of health data.

3.6 Initiatives not Focusing Specifically on Health, but that Could Deliver Interesting Insights to Be Leveraged to the Health Domain

The socio-technical challenges that we face in the health data space are similar in other domains. Therefore, it is interesting to follow and align with some initiatives that have a broader scope. Examples funded by the European Commission include: the Data Spaces Support Center (DSSC, dssc.eu), the European Open Science Cloud (EOSC; eoscportal.eu) and Open Digitising European Industries (opendei.eu). The DSSC explores the needs of data space initiatives, defines common requirements and establishes best practices to accelerate the formation of sovereign data spaces as a crucial element of digital transformation in all areas. One of the key objectives of the DSSC is to establish a Network of Stakeholders that aims to build a strong and innovative data

ecosystem in Europe through the development of common data spaces in strategic economic sectors and domains. OpenDEI focuses on “Platforms and Pilots” to support the implementation of next-generation digital platforms in four basic industrial domains: manufacturing, agriculture, energy and healthcare. The ambition of EOSC is to provide European researchers, innovators, companies and citizens with a federated and open multi-disciplinary environment where they can publish, find and reuse data, tools and services for research, innovation and educational purposes. EOSC ultimately aims to develop a Web of FAIR Data and services for science in Europe upon which a wide range of value-added services can be built. These range from visualization and analytics to long-term information preservation or the monitoring of the uptake of open science practices.

There are some interesting arising initiatives that focus mainly on some of the more technical challenges requiring privacy-preserving decentralized storage and analytics like federated learning. Besides the already previously mentioned health-specific initiatives ELIXIR, EHDEN, OHDSI and EBRAINS, SOLID (solidproject.org) and GAIA-X (gaia-x.eu) are more general initiatives worth considering to learn more about in this area. Solid is a technical specification that allows citizens to store their data securely in decentralized, private data stores called “pods”. Gaia-X strives towards developing and implementing a federated system linking many cloud service providers and users together in a transparent environment that will drive the European data economy. Within the Gaia-x initiative, the International Data Spaces (IDS; internationaldataspaces.org) initiative aims at cross-sectoral data sovereignty and data interoperability.

4 CONCLUSIONS AND CALL-TO-ACTIONS TO THE ECOSYSTEM

Our health data landscape is a mess and that is a problem. Strategic oversight across initiatives is crucial, because it could provide valuable guidance to newcomers, promote efficient resource utilization, identify common challenges, help fill gaps, influence policy making and facilitate and speed-up consortium formation. Striving to accomplish this strategic oversight has been a challenging journey that left us deeply frustrated. Although we did not expect it to be easy, we have noticed that the information is even

more scattered than expected and is often ambiguous and unclear.

However, we are hopeful that together we can overcome some of these challenges moving forward. To accomplish this, we suggest concrete call-to-actions for different actors:

- Specific for the actors involved in the set-up and implementation of the European Health Data Space: Install multiple teams (e.g. at least one per country) that safeguards the strategic oversight within a member state and make sure that orchestration and knowledge leveraging across member states is facilitated. Libraries or scientific reports providing strategic oversight are only useful when they are kept up-to-date and the efforts required to accomplish that should not be underestimated.
- Specific for funders of large-scale collaborative efforts: Regularly scan the landscape for existing initiatives and encourage initiatives that request funding to continue to work on top of previously delivered results and successes (ideally without pushing them to change their name). Currently, innovation appears to be meaning that you have to do something ‘new’, pushing consortia to be ‘unique’ and again start from scratch, leading to the ‘reinventing the wheel’ paradigm we see happening at the moment. We believe that we can only truly scale-up health data research if we start focusing on the adoption and implementation of existing solutions and principles instead of continuously developing new solutions.
- Specific for the individuals leading these initiatives: Make sure that at least your websites are providing detailed information about the what, (for) who, why and how of the initiatives, as well as whether the initiative is a still ongoing effort, whether or not acting under a new name. In addition, be open to understanding more about and learning from other initiatives, even if they appear to be (at first glance) in competition with your own aspirations.

Together with the acquired experience resulting from this landscaping exercise, we hope that the static list we compiled ([10.5281/zenodo.10451144](https://zenodo.org/record/10451144)) can contribute to a start in creating policy preparation documentation that will lead to clear guidelines on

how to proceed and work together in synergy and move the data ecosystem in the right direction.

ACKNOWLEDGEMENTS

We would like to thank all the experts who generously contributed their insights and expertise during the interviews. Their valuable input has been instrumental in shaping our thoughts formulated in this position paper. This work was supported by Research Foundation - Flanders (FWO) for ELIXIR Belgium (1000323N).

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