DATA MESH AS A GOVERNANCE MODEL FOR THE EUROPEAN HEALTH DATA SPACE

Potential Benefits and Trade-Offs

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Supervisor/s:

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Abstract

Current Digital Health technologies generate and capture large amounts of data at unprecedented speeds and in various formats. Advances in technology have enabled precise data collection, increased storage capacity, and greater processing power. As a result of this technological breakthrough, new applications in healthcare, such as summarising consultations and medical data, providing diagnostic support, and advancing drug discovery and research, have begun to emerge. However, strict restrictions on access and sharing remain due to the high sensitivity and heavy regulation of health data. To improve sharing and data reuse while safeguarding current data protection laws, the European Union member states will implement the European Health Data Space. This rules-based ecosystem will enable member states and institutions to make data available for research and public health decision-making without infringing data protection regulations. During the implementation and adoption phases of the EHDS, a clear and streamlined collaboration system is required to define roles and responsibilities and enhance efficiency. To this end, Data Mesh as a governance model is a strong candidate to promote efficiency within multilateral teams.

Keywords: Data Mesh, EHDS, Data Sharing, Health.
JEL Classification codes: I18, C80

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Glossary

EHDS – European Health Data Space

DM – Data Mesh

EU – European Union

EC – European Commission

GDPR – General Data Protection Regulation

NIS – Network and Information Systems Directive

TEHDS2 – Towards European Health Data Space 2

IT – Information Technology

Introduction

Advances in digital health technologies enable data to be captured, stored, and processed at scales previously unattainable before the age of Big Data. Every digital device nowadays is both a data producer and a data consumer of diverse types of information. Health-related devices are no exception, from wearable smartwatches to the heavy diagnostic equipment at a hospital. Data is captured, stored, and processed at greater volume, variety and speed than before (Raghupathi & Raghupathi, 2014). To extract meaningful information from data patterns, mathematical and statistical algorithms were developed, from which inferences were drawn. However, with advances in computing hardware, computationally intensive methods, such as Machine Learning and AI, can now learn from data, extract patterns, and make predictions and detections with far greater accuracy and on more complex problems than before. AI applications and other data uses continue to press for more infrastructural resources and, equally importantly, better governance (Hassan, 2025).

In the healthcare sector, due to its heavy regulation, data is often difficult to access, share, and reuse (de Kok et al., 2023). If this data could be made available while respecting data protection rules and basic rights, it could be a critical boost to medical research across the European Union (EU) member states and of great potential benefit for the healthcare of its citizens. With this in mind, the European Commission (EC) proposed the creation of the European Health Data Space (EHDS), which aims to simplify data access, sharing and reuse while respecting data regulations in place (GDPR, EU Data Governance Act, Data Act, NIS) (European Parliament & Council of the European Union, 2025). Reusability is also important for well-informed public health decision making (European Parliament & Council of the European Union, 2025). Ongoing initiatives, such as those under TEHDS2 (Sitra, 2024), are laying the foundation for technical guidelines and collaboration under the EHDS. However, a smooth implementation is key to the successful adoption of new IT systems. This is achieved by establishing a clear and efficient collaboration framework with well-defined roles and responsibilities and efficient processes (Ali et al., 2022).

Data Mesh is a tech-agnostic framework that establishes clear roles and responsibilities within data and IT teams, treating data as a “product” with “contracts” or specification protocols that determine the specifics of the data to be accessed or shared (Dehghani, 2019). In this way, it is aimed at minimising ambiguity, clarifying collaboration and improving efficiency.

Chapter 1 - Background Information

This chapter aims to inform the reader about the two key topics that underlie this thesis: the European Health Data Space (EHDS) and Data Mesh (DM). The following information provides a concise introduction to the next chapter, which has a more practical, applied nature.

1.1 European Health Data Space

The European Health Data Space (EHDS) is a European Union (EU) initiative that aims to establish clear guidelines for the access, sharing, and reuse of health data while respecting existing data protection laws (European Parliament & Council of the European Union, 2025). The official document establishing the EHDS regulation states that its purpose is to provide individuals with access to and control over their personal health data and to enable its secondary use. It also enables broader use of electronic health data to benefit society, including research, innovation, policymaking, preparedness and response to health threats such as future pandemics, patient safety, personalised medicine, official statistics, and regulatory activities. Furthermore, the Regulation aims to strengthen the internal market by establishing a consistent legal and technical framework for the development, marketing, and use of electronic health record (EHR) systems, in line with EU values.

The expected benefits would be manyfold:

- Citizens would have immediate, cost-free access to their electronic health data in a common European format. They will be able to add information, correct errors, restrict access and obtain information on how their data is being used.

- Health Professionals will have faster access to patients' health records, even across borders, and better interoperability between systems, thus reducing administrative burden.

- Researchers will have access to large amounts of health data, be informed of its availability and quality, and obtain it at a low cost and with high effectiveness.

- Regulators and Policy-makers will have easier access to health data with transparency and cost-effectiveness for the benefit of public health and health systems.

- Industry will benefit from improved standardisation and interoperability, thus enabling the use of data for research and innovation.

1.2 Data Mesh

Data Mesh is a socio-technical framework that redefines how data is produced, owned, and shared. Zhamak Dehgani authored the data-mesh concept organisation (Dehghani, 2019), a decentralised collaboration structure in which the responsibility for data lies with the domains that generate and handle it. Instead of a centralised data team working on all enterprise data, domain teams manage their own data products and make them available for consumption across the organisation. Data mesh has four key principles:

1. Domain-Oriented Data and Decentralised Data Ownership: Data ownership is distributed to domain teams, who manage data within their domain, thus improving accountability, scalability and delivery time.

2. Data as a Product: Data is handled as a product with clear ownership, standards, and documentation. Domain teams are responsible for maintaining data and its quality for downstream users.

3. Self-Service Data Platform: A self-service platform provides standardised tools and capabilities (e.g. data cataloguing, lineage) that enable domain teams to publish, discover and consume data products independently.

4. Federated Governance: Governance is distributed across domains through a federated model, ensuring standard application in areas like compliance, interoperability and security while allowing local autonomy.

In order to operationalise this concept, Dehgani proposes a specific architecture for the teams, divided according to their specific responsibilities:

- Governance Group: defines policies and standards to ensure interoperability, security, privacy and compliance across all domains.

- Enabling Team: Supports domains by providing guidance, training, best practices and reference examples.

- Data Platform team: Builds and maintains the data platform, provides tools and infrastructure needed for domains to manage data products independently.

- Domain Team: Owns and builds data products within a domain, applying domain expertise to ensure data quality, reliability and usability.

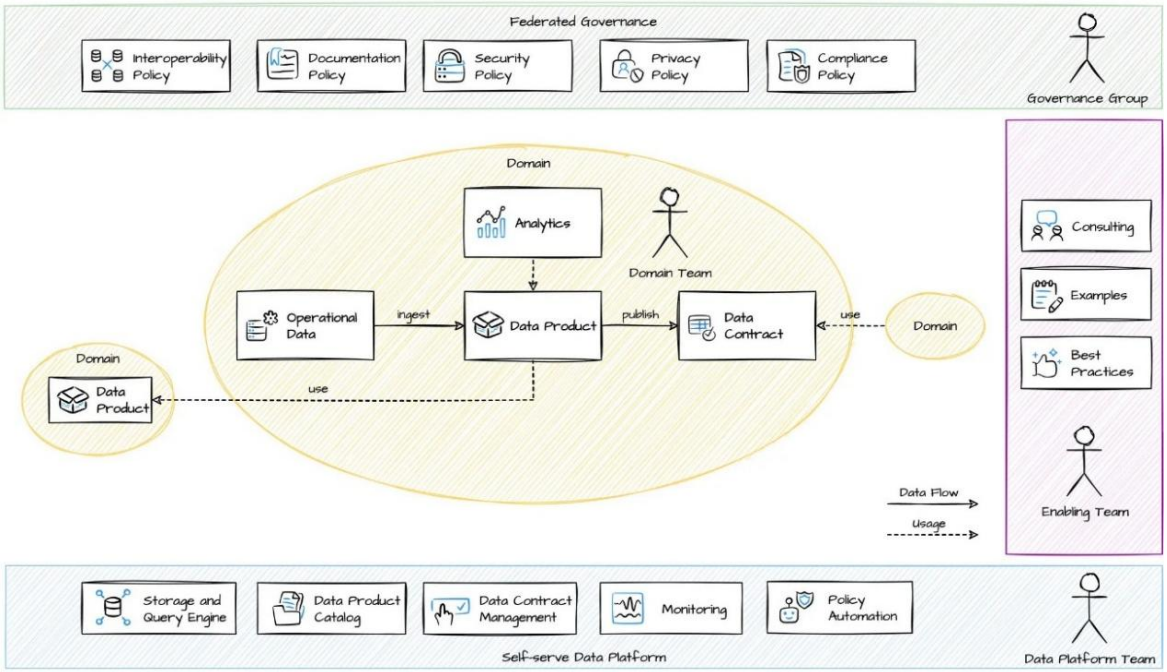


Figure 1.1- Data Mesh Architecture. Adapted from Christ, Visengeriyeva, & Harrer (n.d.).

1.3 Key Definitions

- Data Product: A data product is an item that contains data (i.e. a Dataset) that is formatted, designed and documented and maintained according to rules established by the Governance team. It also includes metadata, semantics, lineage and other properties that contribute to its availability, discoverability and usability (Dehghani, 2019).

- Data Contract: A data contract formally establishes the expectations between data producers and consumers. It defines properties that are key to transmissibility and understanding such as schema, data descriptions, constraints and rules for schema evolution and compatibility. Contracts are often developed and enforced in the data pipelines with appropriate monitoring and systems that catch errors or incompatibilities and alert users (Dehghani, 2019).

- Domain Ownership: Data is managed by the same domain teams that generate it. These teams are responsible for the life cycle of the data products of that domain which include modelling, publishing and maintenance. In this way, data is close and aligned with business users' knowledge, which improves quality and reduced the risk of bottleneck processes in a central team (Dehghani, 2019).

Chapter 2 - Current Challenges

EHDS offers numerous advantages and benefits; however, the Healthcare sector still faces well-known challenges that will need to be addressed with its implementation. These current challenges include:

- Data Fragmentation and Silos: Within the EU, health data is often siloed and fragmented across various institutions, registries, and systems. The use and reuse of data are therefore very limited and highly bureaucratic, with no clear overarching guidelines for access and connectivity until EHDS. (European Commission, 2022; European Commission, 2025).

- Low Technical and Semantic Interoperability: The fragmented landscape of health data and disparity in digital maturity across organisations impact connectivity and interoperability. This issue is expected to be alleviated by the implementation of the EHDS. However, adoption would be most successful if accompanied by a streamlined framework for implementing and working under this new paradigm.

- Lack of Unified Governance: Implementing a novel unified system requires a unified governance framework and guidelines for operating it. Inter-organisational and interdisciplinary connections would benefit from a shared set of guidelines to support more effective collaborations.

Although some of the most important data challenges the Healthcare sector faces today are expected to be alleviated by the implementation of the EHDS, having a clear, standardised framework for efficient collaboration would be of great value for its implementation and everyday use. As the digital transition accelerates, establishing effective standards for the usage of digital collaboration tools becomes increasingly important (de Kok et al., 2023) Data Mesh is the suggested approach to address these challenges by decentralising data ownership and enabling domain teams to manage, share, and access data as a product across the organisation (Dehghani, 2019). This framework minimises bottlenecks related to centralised data platforms and enables scalable cross-functional collaboration (Gartner, 2022). This allows teams to work with consistent, high-quality data in context, strengthening alignment and improving decision-making across departments (Gartner, 2022).

Chapter 3 - Objectives and Methods

The objective of this thesis is to propose the application of Data Mesh (DM) principles to the European Health Data Space (EHDS). Implementing DM together with EHDS could enhance realisation, increase adoption rates, and streamline recurring processes. To evaluate the potential outcomes and synergies between DM and EHDS, three Use Cases (UCs) are presented, illustrating practical applications across the primary and secondary uses of data and governance. To enrich the discussion and collect data, a prospective questionnaire was issued to assess the applicability of DM in real working contexts (see Annex A). The questionnaire comprises 20 multiple-choice questions (see Table 5.1). The first 2 questions are used to collect demographic data, such as Profession and Familiarity with DM concepts. These questions were used to segregate the data from the other 18 questions, which were organised in groups of 6 for each of the three use cases. Here, the response type was multiple choice via a 1-5 Likert Scale in the form of level of agreement (1: Strongly disagree, 2: Disagree, 3: Neither agree nor disagree, 4: Agree, 5: Strongly agree) with statements and related to each use case. For the data analysis, an exploratory method was used in the form of a visualisation, produced in Python 3.11. In this way, the scores can be more easily visualised and interpreted by professional category. The questionnaire was open for 30 days and required respondents to complete all questions before submission. In this way, data quality and completeness were ensured.

This study is exploratory by nature, limited by a small sample size and constraints with participant engagement. Its primary goal is to uncover initial patterns, relationships, and insights that can guide future research. As an exploratory effort, especially given the emerging and understudied topic of this thesis, the results should be seen as preliminary. They provide a basis for further studies with larger, more diverse samples that can produce stronger evidence.

Chapter 4 - Data Mesh and the European Health Data Space

4.1 Use Cases

In this chapter, three use cases will be presented, representing the primary, secondary and governance use of data. For illustration purposes, each use case will be presented from the perspectives of Patients, Academia and Public Health. By encompassing three different views, the aim is to demonstrate the applicability of Data Mesh with EHDS:

1. Patient (Primary use): Cross-Border Patient Care and Continuity of Treatment. This use case explores the potential benefits from the patient's point of view and how the system can work with Data Mesh in order to optimize communication and improve service delivery. This is especially useful in caring for international EU patients where communication between systems across borders is needed.

2. Academia and Research (Secondary use): Health Research and Data Sharing for Academic and Research institutions. Academic and Research Institutions, such as Universities and R&D centres, can benefit immensely from data access and sharing under EHDS. Applying Data Mesh principles can improve governance and improve exchanges. Research would benefit from a greater and more relevant data pool, which in turn will enable the relevance and impact of the produced research.



Figure 4.1 - Use cases for integration of Data Mesh with EHDS. Adapted with images from Freepik. (n.d.), First Aid Plus. (n.d.), alexextrememail. (n.d.).

3. Public Health (Governance use): Monitoring and Crisis Response. The EHDS has the potential to improve data transmissibility in emergency situations without compromising security. Introducing Data Mesh principles in the preparation for these scenarios can improve process clarity and reliability, thus improving the mitigation and resolution of critical occurrences.

4.2 Questionnaire Results

A total of 29 responses were collected; 14 (48%) from Clinicians, 5 (17%) from Data-IT, 4 (14%) from Researchers (Academics), 1 (3%) from Public Administrators, 2 (7%) from Legal/Data Protection officers and 3 (10%) from Student/other professional roles. According to this data, 48% of respondents reported unfamiliarity with Data Mesh, which can be explained by the fact that it is a relatively recent concept (2019) and has not yet seen widespread adoption, especially in the Health Sector. Nevertheless, 52% admitted some level of familiarity with it up to a moderate level. The overall results are shown in Figure 4.3 in the form of radar plots. These kinds of plots allow for visualising scores of multiple questions (see Table 4.1 for the questions description) by a common scale Likert scale (Likert, 1932).

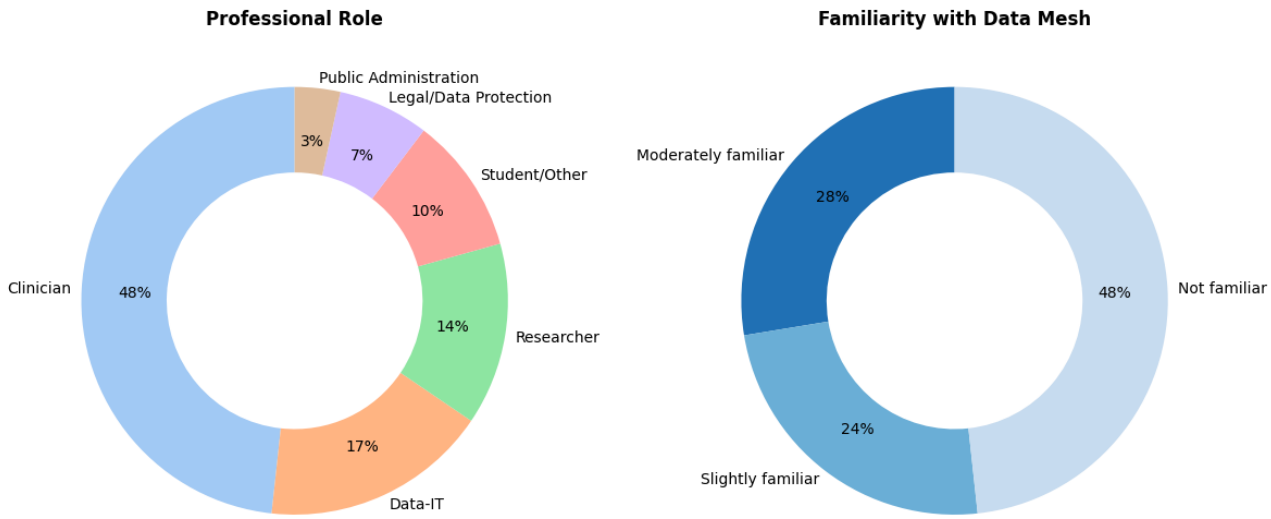


Figure 4.2 - Distribution of the respondents by professional role and familiarity with DM (Generated with Python 3.11).

The results (see Figure 4.2) indicate a general consensus across professional roles on the current problems in health data systems: unclear ownership, fragmented data flows and silos, interoperability barriers and difficulties working with GDPR. There is also consistent support for Data Mesh principles such as domain-oriented approaches, decentralized architectures and ownership as well as for standardized data products. Clinicians mainly emphasize operational constrains, Researchers/Academics focus on standards and reproducibility, Data-IT professionals highlight architectural limitations and legal experts stress regulatory complexity and implementation barriers.

Table 4.1 - Questions by group and label.

Question group	Label	Question - Level of agreement
Profession	Q1	What is your professional role?
Familiarity	Q2	How familiar are you with Data Mesh principles?
Cross-Border Patient Treatment	Q3_1	Data ownership responsibilities between healthcare providers in different countries are unclear.
Cross-Border Patient Treatment	Q3_2	Data flows between organisations in different countries are difficult to manage.
Cross-Border Patient Treatment	Q3_3	Semantic interoperability (terminology, coding systems) is a major barrier.
Cross-Border Patient Treatment	Q3_4	Accountability for data quality in cross-border treatment is not clearly assigned.
Cross-Border Patient Treatment	Q3_5	Translating GDPR and EHDS requirements into operational technical solutions is difficult.
Cross-Border Patient Treatment	Q3_6	Assigning domain-based data ownership would improve cross-border care
Health Research	Q4_1	Data ownership and stewardship responsibilities for research datasets are unclear.
Health Research	Q4_2	Data access approval processes are overly complex and slow.
Health Research	Q4_3	Heterogeneous data models and standards limit cross-country research.
Health Research	Q4_4	Data quality issues reduce the reproducibility of research results.
Health Research	Q4_5	Translating GDPR and EHDS secondary-use requirements into technical safeguards is difficult.
Health Research	Q4_6	Treating research datasets as standardised “data products” would improve discoverability and reuse.
Public Health & Crisis Response	Q5_1	Data ownership responsibilities during public health crises are unclear.
Public Health & Crisis Response	Q5_2	Organisational silos hinder public health data integration.
Public Health & Crisis Response	Q5_3	Real-time data sharing is insufficient for effective crisis response.
Public Health & Crisis Response	Q5_4	Data quality issues significantly affect crisis decision-making.
Public Health & Crisis Response	Q5_5	Regulatory uncertainty slows emergency data sharing.
Public Health & Crisis Response	Q5_6	A federated (decentralized) data architecture would improve cross-border crisis coordination.

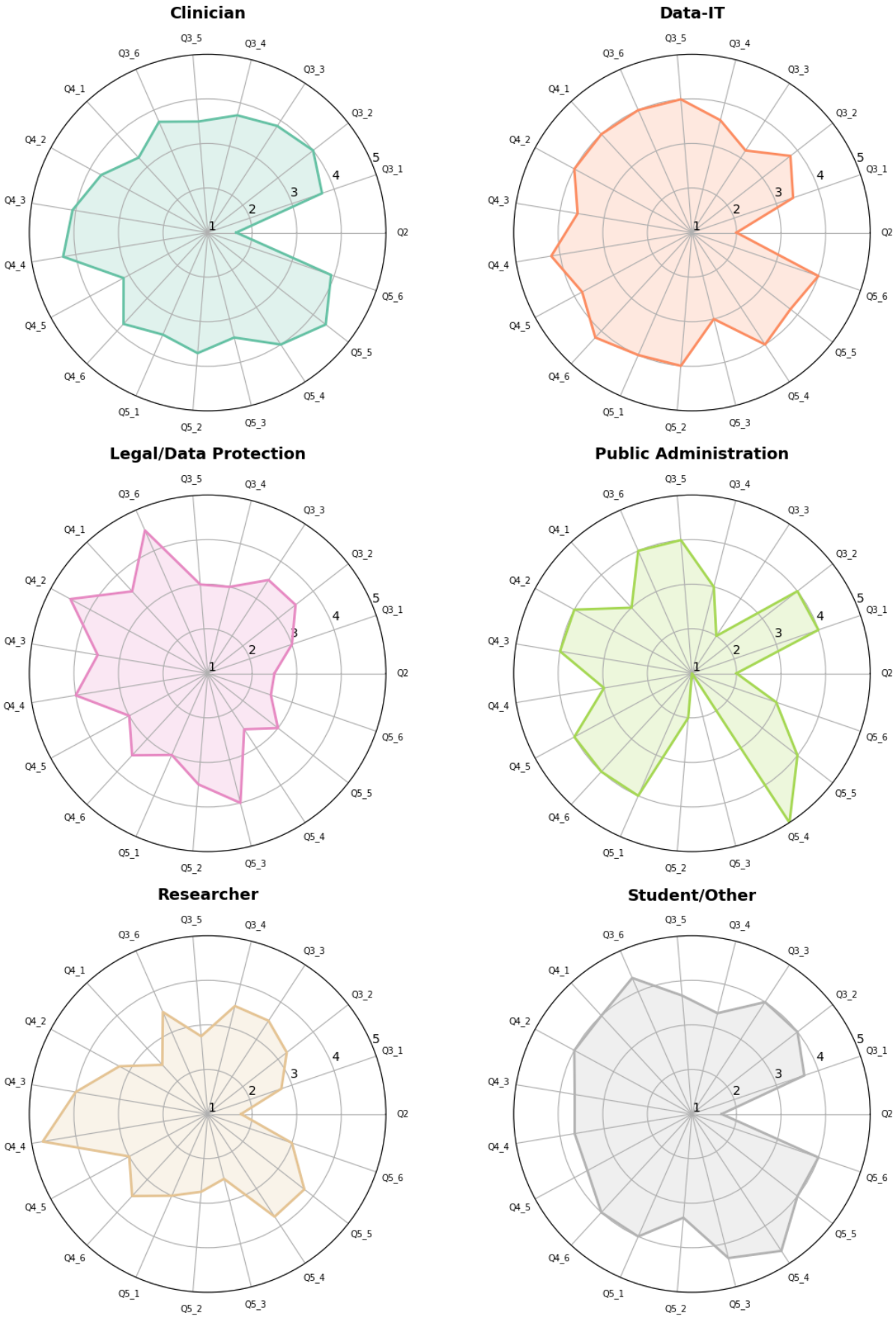


Figure 4.3 Score charts by professional role (generated with Python 3.11).

4.3 Primary Use: Cross-Border Patient Care and Continuity of Treatment

The free movement of citizens within the EU has led to a significant increase in cross-border healthcare interactions. Directive 2011/24/EU (European Parliament & Council of the European Union, 2011) on patients' rights in cross-border healthcare formally establishes the legal framework for accessing healthcare services across Member States. Consequently, medical procedures such as diagnoses, treatments, and follow-up consultations are often carried out, resulting in a notable rise across different national health systems. While this enhances patient choice and access to specialised care, it also fragments health data. Clinical records, laboratory results, imaging exams, and prescription histories may be stored across various systems within member states, often with differing semantics and limited interoperability. These issues can result in incomplete access to patients' medical histories, leading to duplicate tests, prescription errors, and delayed treatments (Kripalani et al., 2007; WHO, 2019). Such challenges have been addressed through the introduction of the eHealth Digital Service (eHDSI), which enables data sharing and ePrescriptions. However, interoperability remains inconsistent across Member States, with healthcare professionals frequently citing limited access to high-quality, reliable data about their patients (European Commission, 2022). The EHDS project aims to improve data access by harmonising legal and technical frameworks across the EU. Nonetheless, operational challenges still persist, such as:

- Data ownership and accountability.
- Scalability across heterogeneous national infrastructures.
- Alignment with national health governance models.
- Compliance with the General Data Protection Regulation (GDPR).

Under the Data Mesh paradigm, data ownership is decentralised to domain-oriented teams, which are responsible for maintaining data products with high standards of quality and interoperability. Healthcare institutions can act as domain owners, responsible for producing interoperable data products in accordance with EHDS specifications. Such domains may include systems in EHRs and laboratories, pharmacy and medication data, patient history, and insurance and reimbursement systems. This collaborative structure maintains autonomy while meeting interoperability and accessibility standards.

A Data Mesh-informed EHDS brings potential benefits, such as:

- Improved Continuity of Care: Access to patient summaries, thereby reducing information gaps during care transitions. Research indicates that continuity of information improves patient outcomes and reduces hospitalisation rates (Haggerty et al., 2003).

- Reduction of Medical Errors: Medication errors are a major cause of preventable harm (WHO, 2019). The availability of prescription data across borders helps to minimise adverse drug reactions and duplicate prescriptions.

- Clear Accountability: Clear ownership enables responsibility and compliance with data deliveries, quality and access. Research demonstrates that clear accountability structures are essential for establishing trust in distributed architectures (Janssen & van der Voort, 2020).

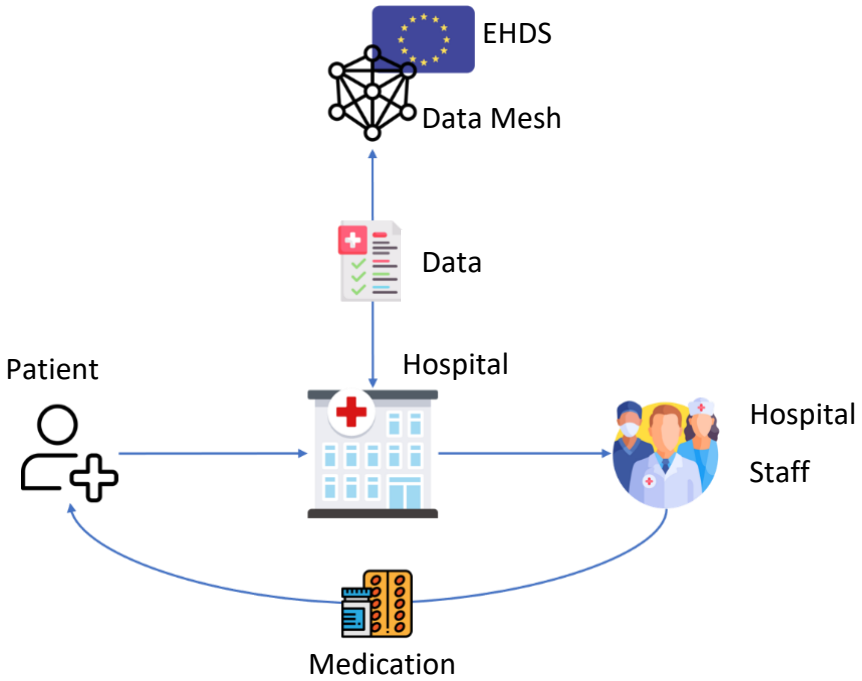


Figure 4.4 – Illustration for primary use of data with
EHDS and DM. Adapted with icons from Flaticon (n.d.)

4.4 Secondary Use: Academia and Research

Access to large, high-quality databases that represent diverse characteristics across populations, regions, and health systems is critical for conducting good research and producing robust evidence. Research projects are often hindered by a lack of available data due to fragmentation and complex administrative processes for data access. In this regard, the European Health Data Space (EHDS) explicitly addresses these challenges by establishing a legal foundation for the secondary use of health data. However, EHDS foundations for rights of access, governance, and safeguards can be complemented by a clear technical and organisational framework such as Data Mesh. Data Mesh promotes data ownership, federated governance, and sharing data as a product, which functionally improves its use by clearly establishing ownership, technical definitions, expectations, and integration into sharing workflows. Under this use case, domains can be identified as Hospital and Clinical registries, Biobanks and genomic databases and National Health Statistics Authority. Each domain is responsible for collecting and sharing curated, research-ready data products, rather than raw operational data. As a result, research data products would be characterised by standardised data specifications, data quality and lineage requirements, defined update cycles and versioning. EHDS owns the access permits and their specific purposes, while Data Mesh governs how data is curated, published, and reused across domains.

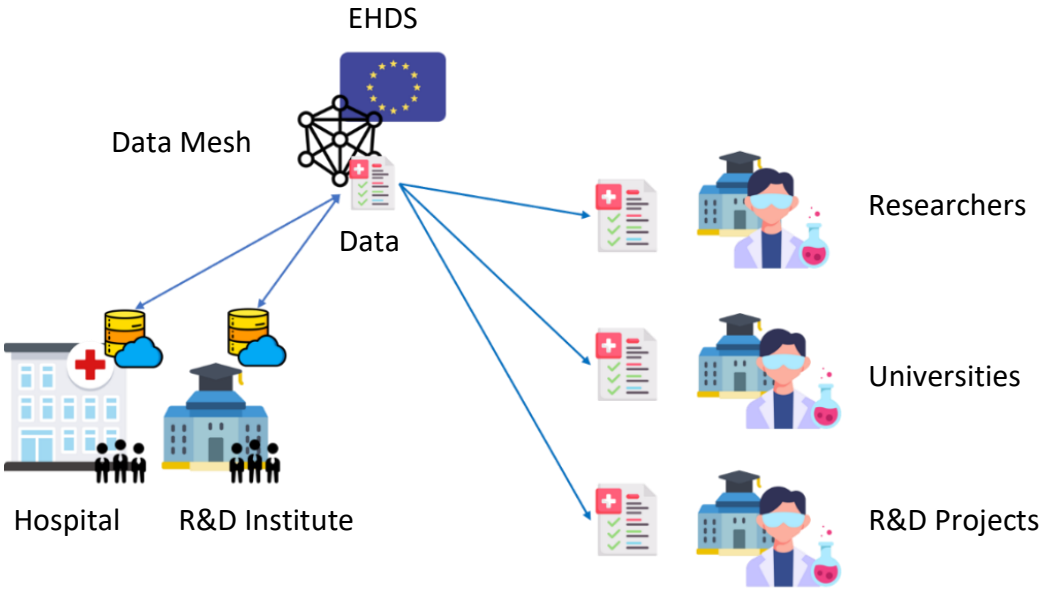


Figure 4.5 - Illustration for secondary use of data with EHDS and DM.
Adapted with icons from Flaticon (n.d.)

4.5 Governance Use: Public Health Monitoring and Crisis Response

Public health crises, such as disease outbreaks and pandemics, require rapid yet comprehensive access to reliable data. This challenge is compounded when crises like this need to be managed in coordination between different states. Centralised data sources and inefficient data flows can lead to suboptimal coordinated efforts and crisis response. EHDS provides a legal basis for public health data exchange, but practical data integration remains challenging during emergencies. As a socio-technical approach, Data Mesh provides a clear ownership and collaboration grid that various services and teams can rely on. For instance, in a disease outbreak scenario, key domains for data collection and ownership can be established, such as:

- Diagnostic laboratories.
- Hospitals and ICU units.
- Vaccination centres.
- Regional and national public health authorities.

Each of the domains above publishes data in a standardised format as its data product, which can then be requested and consumed by another platform or team, depending on needs. Data storage and access would follow clear guidelines established and acknowledged by all teams and domains qualified to access it. This architecture is characterised by decentralised ingestion pipelines, standardised data models defined by EHDS, domain-owned data quality and timeliness metrics and a centralised analytics hub for decision making. Having a centralised analytics hub for data reporting may seem to contradict the federated nature of Data Mesh; however, it is essential to provide the central government and authorities with a unified source of truth to inform their decisions.

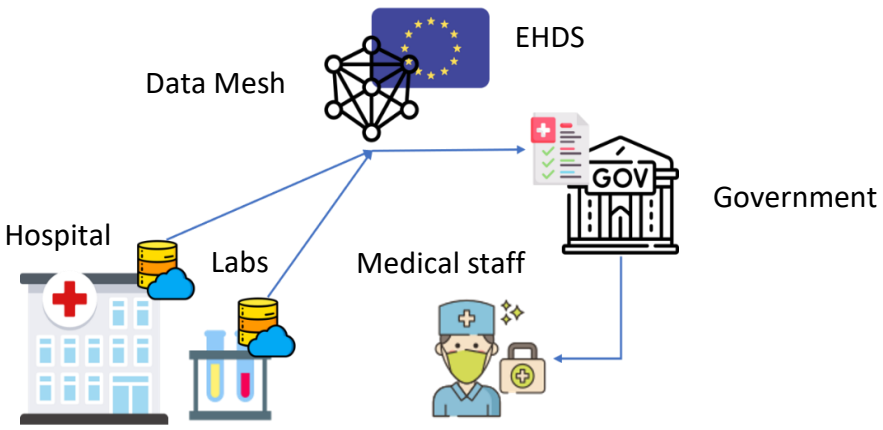


Figure 4.6 - Illustration for governance with EHDS for DM.
Adapted with icons from Flaticon (n.d.)

Discussion

One of the greatest challenges of the EHDS is to balance decentralized data stewardship with centralized regulatory and legal accountability (van Drumpt et al. 2025). In order to address this challenge, it could be beneficial to combine key concepts from multiple governance frameworks. For instance, key DM ideas such as ‘domain ownership’ and ‘data as a product’ could be implemented locally while, at a higher level, ‘Data Trusts’ concept (van Drumpt et al. 2025) could address non-technical aspects such as consents, opt-outs and other ethical and legal requirements that would serve national Health Data Access Bodies. This degree of flexibility could enable local domain teams to operate more efficiently while addressing needs for compliance and oversight from centralized EHDS organization structure. Additionally, modern technical approaches such as Data Fabric (Buleje et al., 2023) can bring new foundational capabilities such as intelligent data discovery, automated cataloguing, lineage tracking and compliance monitoring that could significantly improve technical and organizational processes.

Digital maturity is another key factor on EHDS adoption across Europe. It is to be expected that countries with different levels of digital development can also differ in levels of implementation and participation within EHDS. Readiness of the underlying infrastructure may represent an important bottleneck for data availability and transit, even when there is legal alignment (Salmatani et al., 2026). Furthermore, local preferences (like permits and opt-outs) for data sharing and reuse will likely differ from state to state, effectively creating a diverse mosaic of data availability levels rather than a uniform level of access. These key aspects will likely remain applicable for new member states in the case of future EU enlargement.

In summary, taking the necessary steps to improve local readiness is essential towards EHDS implementation. Infrastructure and resource provisioning, digital maturity development as well as public educational campaigns on the core values, objectives and collective benefits of EHDS can provide a good substrate for a wider and successful adoption.

Conclusion

Data Mesh has the potential to enhance the functioning of EHDS, making it more robust from the governance point of view by clarifying collaboration, ownership and establishing mechanisms that improve data usage and sharing. However, working with Data Mesh can also difficulties and new trade-offs. While enabling scalability and data access, it can also introduce complexity into the organisational structure. In this regard, it is important to be flexible and adapt the implementation to the organisation's reality in order to optimise efficiency while minimising entropy. Data Mesh introduces important trade-offs to consider (see the table below). For instance, decentralisation brings autonomy to domain teams; however, it can add another layer of complexity to the organisational structure if not properly implemented or inappropriate in that particular case. In essence, trade-offs and feasibility need to be evaluated before committing to implementing Data Mesh.

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Table 5.1 Trade-offs of Data Mesh implementation with EHDS.

Trade-off	Advantage	Disadvantage
Autonomy vs Control	Faster decisions, domain alignment	Governance and consistency challenges
Flexibility vs Standardisation	Tailored data products	Risk of duplication and inconsistency
Short-term vs Long-term	Scalable and sustainable architecture	High initial cost and complexity

In some cases, it may be necessary to adjust the underlying technical infrastructure to enable implementation, which can lead to a higher initial cost and greater complexity than expected. However, a mid-way working solution can be achieved by decentralising logical data ownership (domains) but maintaining a centralised ownership of infrastructure (Bode et al., 2023). However, to achieve additional benefits, this infrastructure needs to execute requests as seamlessly as possible to maintain agility. In this case, recent data engineering applications, such as Data Factory, can be beneficial, as they reduce development effort and streamline data flows. In other words, adapt the implementation strategy to fit organisational reality and include new technologies when reliable and feasible.

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Annexes

Annex A - Questionnaire

Welcome! This survey is part of a thesis exploring how Data Mesh principles can support the implementation of the European Health Data Space (EHDS) in the European Union. The survey takes about 4 minutes to complete. All responses are confidential, and no personal data is collected. Thank you for your time!

Q1 What is your professional role?

- ○ Clinician / Healthcare professional
- ○ Data / IT professional
- ○ Researcher / Academic
- ○ Policy maker / Public administration
- ○ Legal / Compliance / Data protection
- ○ Student
- ○ Other

Q2 How familiar are you with Data Mesh principles?

- ○ Not familiar
- ○ Slightly familiar
- ○ Moderately familiar
- ○ Very familiar
- ○ Expert

Q3 Please indicate your level of agreement with the following statements about Cross-Border Patient Treatment.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Data ownership responsibilities between healthcare providers in different countries are unclear.					
Data flows between organizations in different countries are difficult to manage.					
Semantic interoperability (terminology, coding systems) is a major barrier.					
Accountability for data quality in cross-border treatment is not clearly assigned.					
Translating GDPR and EHDS requirements into operational technical solutions is difficult.					
Assigning domain-based data ownership would improve cross-border care					

Q4 Please indicate your level of agreement with the following statements about Health Research.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Data ownership and stewardship responsibilities for research datasets are unclear.					
Data access approval processes are overly complex and slow.					
Heterogeneous data models and standards limit cross-country research.					
Data quality issues reduce reproducibility of research results.					
Translating GDPR and EHDS secondary-use requirements into technical safeguards is difficult.					
Treating research datasets as “data products” would improve discoverability and reuse.					

Q5 Please indicate your level of agreement with the following statements about Public Health & Crisis Response.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Data ownership responsibilities during public health crises are unclear.					
Organizational silos hinder public health data integration.					
Real-time data sharing is insufficient for effective crisis response.					
Data quality issues significantly affect crisis decision-making.					
Regulatory uncertainty slows emergency data sharing.					
A federated data architecture would improve cross-border crisis coordination.					

Annex B - ***Form: Use of Artificial Intelligence (AI) Tools in Academic Work***

Formulário: Uso de Ferramentas de Inteligência Artificial (IA)

O Conselho Científico do Iscte aprovou, em reunião plenária de 21 de abril de 2026, o Guia para uma Utilização Responsável da Inteligência Artificial em Trabalhos Académicos. O presente formulário constitui parte integrante do Guia e deve ser incluído como anexo aos trabalhos finais de mestrado ou tese de doutoramento.

The Scientific Council of Iscte approved, at its plenary meeting of 21 April 2026, the Guide for the Responsible Use of Artificial Intelligence in Academic Work. This form constitutes an integral part of the Guide and must be included as an appendix to the final Master's dissertation or doctoral thesis.

1. Declaração e Transparência I ***Declaration and Transparency***

Não foram utilizadas ferramentas de IA no manuscrito. *No AI tools were used in the manuscript*.	X
Foram utilizadas ferramentas de IA no manuscrito e: *AI tools were used in the manuscript and*:	
Declarei explicitamente o uso de ferramentas de IA no manuscrito. *I have explicitly declared the use of AI tools in the manuscript*.	☐
Indiquei o nome da ferramenta e, sempre que possível, a versão. *I have indicated the name of the tool and, where possible, the version*.	☐
Descrevi claramente para que finalidade a IA foi utilizada (ex.: revisão linguística, apoio à análise, organização preliminar, simulação de dados). *I have clearly described the purpose for which the AI was used (e.g. linguistic review, analysis support, preliminary organisation, data simulation)*.	☐

2. Autoria e Responsabilidade I ***Authorship and Responsibility***

Assumo responsabilidade integral pelo texto, dados, análises, interpretações e referências. *I take full responsibility for the text, data, analyses, interpretations and references.*	X

3. Uso de IA na Redação e no Conteúdo Científico I ***The Use of AI in Writing and Scientific Content***

A IA não foi utilizada para fabricar dados, resultados empíricos ou conclusões. *AI was not used to fabricate data, empirical results or conclusions.*	X
Qualquer texto gerado ou reformulado com apoio de IA foi criticamente revisto por mim. *Any text generated or rewritten with the aid of AI has been critically reviewed by me*.	X

Foram explicitados limites, enviesamentos potenciais e decisões interpretativas humanas.
Limitations, potential biases and human interpretative decisions have been made explicit. X

4. IA como Parte do Método (Assinalar apenas se aplicável) I ***AI as Part of the Method*** *(Tick only if applicable)*

O uso de IA como parte do método foi justificado do ponto de vista de produção do conhecimento.
The use of AI as part of the method was justified from the perspective of knowledge production. ☐

Os procedimentos foram descritos de forma clara e transparente.
The procedures have been described clearly and transparently. ☐

Foram explicitados limites, enviesamentos potenciais e decisões interpretativas humanas.
Limitations, potential biases and human interpretative decisions have been made explicit. ☐

5. Investigação Qualitativa, Entrevistas e Etnografia (Assinalar apenas se aplicável) I ***Qualitative Research, Interviews and Ethnography*** *(Tick only if applicable)*

A IA não teve acesso a transcrições integrais de entrevistas, notas de campo, diários etnográficos ou observações participantes.
AI did not have access to full interview transcripts, field notes, ethnographic diaries or participant observations. ☐

A IA não foi utilizada para gerar discurso, narrativas empíricas ou descrições etnográficas simuladas.
AI was not used to generate discourse, empirical narratives or simulated ethnographic descriptions. ☐

Qualquer apoio de IA à análise qualitativa (ex.: sugestões exploratórias de códigos ou temas) foi:
Any AI support for qualitative analysis (e.g. exploratory suggestions for codes or themes) was:

Descrito na secção de Metodologia.
Described in the Methodology section. ☐

Interpretado e validado por mim.
Interpreted and validated by me. ☐

Utilizado em conformidade com os termos de consentimento informado.
Used in accordance with the terms of informed consent. ☐

6. Proteção de Dados e Ética I *Data Protection and Ethics*

Nenhum dado pessoal, sensível ou identificável foi introduzido em ferramentas de IA. *No personal, sensitive or identifiable data was entered into AI tools*.	X
O uso de IA é compatível com as normas éticas da investigação científica e com a legislação de proteção de dados aplicável. *The use of AI complies with the ethical standards of scientific research and with the applicable data protection legislation.*	X

Declaro que:
I hereby declare that:

Toda a informação prestada neste formulário é verdadeira. *All information provided in this form is true and accurate.*	X
Estou consciente de que a utilização indevida de ferramentas de Inteligência Artificial, a ausência de declaração do seu uso quando este ocorreu, bem como a prestação de declaração falsa ou enganosa sobre a sua utilização, constituem condutas suscetíveis de configurar infração aos deveres académicos previstos no Regulamento Disciplinar de Discentes, no Código de Conduta Académica do Iscte e no Código de Ética e de Conduta. *I understand that the improper use of Artificial Intelligence tools, failure to declare their use when such use has occurred, as well as making a false or misleading statement regarding their use, may constitute a breach of the academic duties set out in the Student Disciplinary Regulations, the Iscte Academic Code of Conduct, and the Code of Ethics and Conduct.*	X

Data I *Date* 29/09/2026

Nome I *Name* Daniel Castro