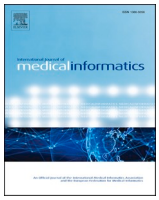
International Journal of Medical Informatics 218 (2026) 106544



Contents lists available at ScienceDirect

International Journal of Medical Informatics

journal homepage: www.elsevier.com/locate/ijmedinf



Short Communication

European cancer data sharing: Analyses of an international survey

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ARTICLE INFO

Keywords:
Health information exchange
Public health infrastructure
Patient generated health data
Data curation

ABSTRACT

Background: Clinical and biomarker data sharing across institutions accelerates cancer research, yet European data sharing practices are not well characterized.
Methods: We surveyed 75 cancer institutions across 23 European countries on data sharing practices, data standards adoption, and perceived challenges.
Results: Most institutions (>80 %) actively share data for research. However, adoption of clinical data standards remains fragmented: only 33 % use Fast Healthcare Interoperability Resources (FHIR) and 21 % use the Observational Medical Outcomes Partnership (OMOP) data model. The top non-technical hurdles were General Data Protection Regulation (GDPR) compliance (31 %) and legal challenges (24 %). The leading technical hurdle was interoperability (35 %). Despite challenges, 77 % of institutions aim to expand sharing capabilities.
Conclusions: Among those surveyed, GDPR compliance and legal complexity are the dominant barriers to European cancer data sharing. Inconsistent data standards adoption poses risks to European Health Data Space (EHDS) implementation. Investments in legal support, interoperability, and personnel are needed to advance cancer research networking.

1. Introduction

Data sharing is foundational to biomedical research. Multi-institution data-sharing collaborations have yielded major advances in cancer research worldwide, including efforts from North America and Asia [1–3] and within Europe specifically [4,5]. Shared data promotes reproducibility, enables follow-up analyses, and is essential for leveraging the emerging artificial intelligence (AI) capabilities in cancer care. In parallel, an expanding literature has focused on the use of health data, examining how privacy regulations, interoperability standards, and institutional incentives shape researchers' ability to access and reuse clinical data across countries and healthcare systems [6–8]. Recent studies have highlighted these challenges within cancer research, where the value of linking clinical, imaging, genomic, and outcomes data is often tempered by legal, technical, and organizational barriers to data sharing [9,10].

European initiatives have demonstrated the feasibility of large-scale, multi-national data sharing. The European Medical Information

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https://doi.org/10.1016/j.ijmedinf.2026.106544
Received 24 March 2026; Received in revised form 5 June 2026; Accepted 9 June 2026
Available online 10 June 2026
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Framework integrated millions of de-identified patient records across countries [11], and the European Health Data and Evidence Network (EHDEN) standardized observational data from 11 countries into a common data model (CDM) [12]. Cancer-specific efforts support coordination across registries, imaging, electronic health records, and genomic data [13,14], though challenges remain in scaling these initiatives. Recent work aiming to articulate best practices for data standardization, quality control, and bias mitigation of health data illustrate the pitfalls and enduring technical challenge in this domain [15,16].

The European Health Data Space (EHDS) aims to facilitate both primary and secondary use of health data across the European Union (EU) [17], while Towards the European Health Data Space (TEHDAS2) works to implement data ontologies and transfer protocols [18]. The road to implementation such initiatives will be shaped by diverse national capabilities and legal standards. For example, a recent use case from an EHDS pilot study aimed to gather mutational signatures and clinical outcomes to study metastatic colorectal cancer but encountered difficulties coordinating ethical approval requests and data access procedures across participating countries [19].

This work aims to address a targeted set of research questions: which types of European institutions contribute to cancer data sharing efforts, what infrastructure is currently utilized, and what are the perceived barriers? Here, we present results from a survey designed to characterize the baseline of cancer data sharing practices across European institutions, covering data standards utilization, sharing scope, and ongoing challenges.

2. Methods

The questionnaire was constructed by the "AI and Infrastructure Task Force" of the EU Joint Action Network of Expertise (JANE). It consisted of 22 questions organized in three themes: institutional information, data storage and sharing, and data processing and technology. A mixture of closed-end and open-ended questions captured both institutional practices and respondent perspectives (see Supplemental Table 1 for the full question list).

Institutions were contacted if they met three criteria: (1) they provided cancer care and/or participate in academic cancer research, (2) they were located within Europe, and (3) they had an employee participating in JANE or the European Network of Comprehensive Cancer Centres (EUcccNET) willing to serve as the primary contact. The survey was sent to 410 individuals at approximately 150 institutions. The data were collected between May and August 2024 via an online form.

The survey collected institutional and respondent-level information only. No patient data, identifiers, or clinical records were accessed at any stage during this work. Respondents — typically clinical, informatics, or research leaders at each institution — provided consent by voluntarily completing the online questionnaire. Response confidentiality was ensured, and data were reported only in aggregate [20]. Free-text responses were reviewed, grouped by similarity, and tabulated. As respondents could select multiple answers, percentage sums may exceed 100 %. Italian institutions had proportionally high representation (20 % of responses); stratification analysis confirmed this did not skew results (see Supplemental Table 2).

3. Results

We obtained responses from 75 institutions across 23 countries (response rate of 20 %, see Fig. 1A). Of these, 73 % participate in clinical trials and 71 % in primary cancer care; most contribute to basic and translational research (Fig. 1B). Approximately 48 % were academic medical centres, 40 % primarily research institutions, and 20 % regional hospitals (Fig. 1C).

Most institutions collect complex data types including medical records (84 %), clinical trial data (75 %), genomic data (67 %), and imaging data (81 %). Data sharing rates for these types were: primary care records (49 %), clinical trials (65 %), genomic data (46 %), and imaging (55 %). The majority (87 %) share data for inter-institutional research. Data type sharing patterns were observed in different combinations and institutions most commonly shared all four data types (Fig. 1D). Among institutions not yet sharing, 77 % aim to expand capabilities. Regarding clinical data standards, only 33 % of institutions used Fast Healthcare Interoperability Resources (FHIR), and 21 % used Observational Medical Outcomes Partnership (OMOP-CDM) for data sharing (see Supplemental Fig. 1), indicating substantial gaps in interoperability.

Hurdles to data sharing were also surveyed. The most common non-technical hurdles were General Data Protection Regulation (GDPR) and privacy compliance (31 %) and general legal challenges (24 %), followed by resourcing constraints and administrative complexity (Fig. 2A). As one respondent stated, "complex and very strict legal and institutional regulations" were the biggest challenge.

Approximately half of respondents relied on external service providers for data sharing (Fig. 2B), using a mix of open-source software (54 %), commercial cloud solutions (52 %), and in-house tools (53 %). The leading technical hurdles were interoperability issues (35 %) and security/privacy protocols (16 %) (Fig. 2C).

4. Discussion

These survey results from 23 countries reveal that while most European cancer institutions (>80 %) actively share data, significant barriers persist. GDPR compliance and legal complexity dominate as the top non-technical hurdles, consistent with findings from the TEHDAS joint action, which identified legal challenges as among the most significant barriers to enabling secondary data use [21]. One respondent noted that "GDPR and very strict interpretation of privacy protection" formed an important barrier, reflecting how varying national interpretations foster institutional cultures of risk-aversion and reluctance to share data, even when the underlying legal basis would permit it [22]. Our free-text responses repeatedly pointed to this dynamic, with legal and compliance risk-aversion emerging as a primary driver of custodian reluctance.

The inconsistent adoption of standards such as FHIR (33 %) and OMOP (21 %) is concerning. While EHDS is technology-neutral at the legislative level, the implementing specifications for EEHRxF are expected to make extensive use of HL7 FHIR profiles with primary-use interoperability requirements phased in from 2029 and 2031 [17]. Prior work has shown that standardized CDM adoption across institutions, while challenging, yields substantial benefits for multinational research [12,23]. Protocols designed for patient-mediated, cross-border electronic health record exchange offers concrete patterns for FHIR-based interoperability that institutions could adopt [24]. Targeted investment in interoperability infrastructure and qualified personnel is needed, as respondents also highlighted staffing constraints as a key barrier [25]. Emerging approaches such as federated learning may offer privacy-preserving alternatives to direct data transfer [26,27].

The survey was impacted by limitations including bias towards larger cancer institutions, responses submitted by individuals associated with the JANE or EUcccNET networks, and the self-reported nature of the survey which reflects individual or functional perspectives. As a cross-sectional study, the survey captures practices as of mid-2024 and does not track adoption patterns over time related to emerging tools, governance, or policy changes. Several known contributors to data custodian reluctance to share were not assessed by our survey — including data-misuse concerns, research incentives, and gate-keeping — but likely also play a role and warrant separate study [28,29]. The self-reported nature of our survey results may have been impacted by recall bias and higher rates of engagement from digitally engaged institutions. Despite these limitations, the responses clearly reflect important aspects of the European cancer data sharing landscape, given

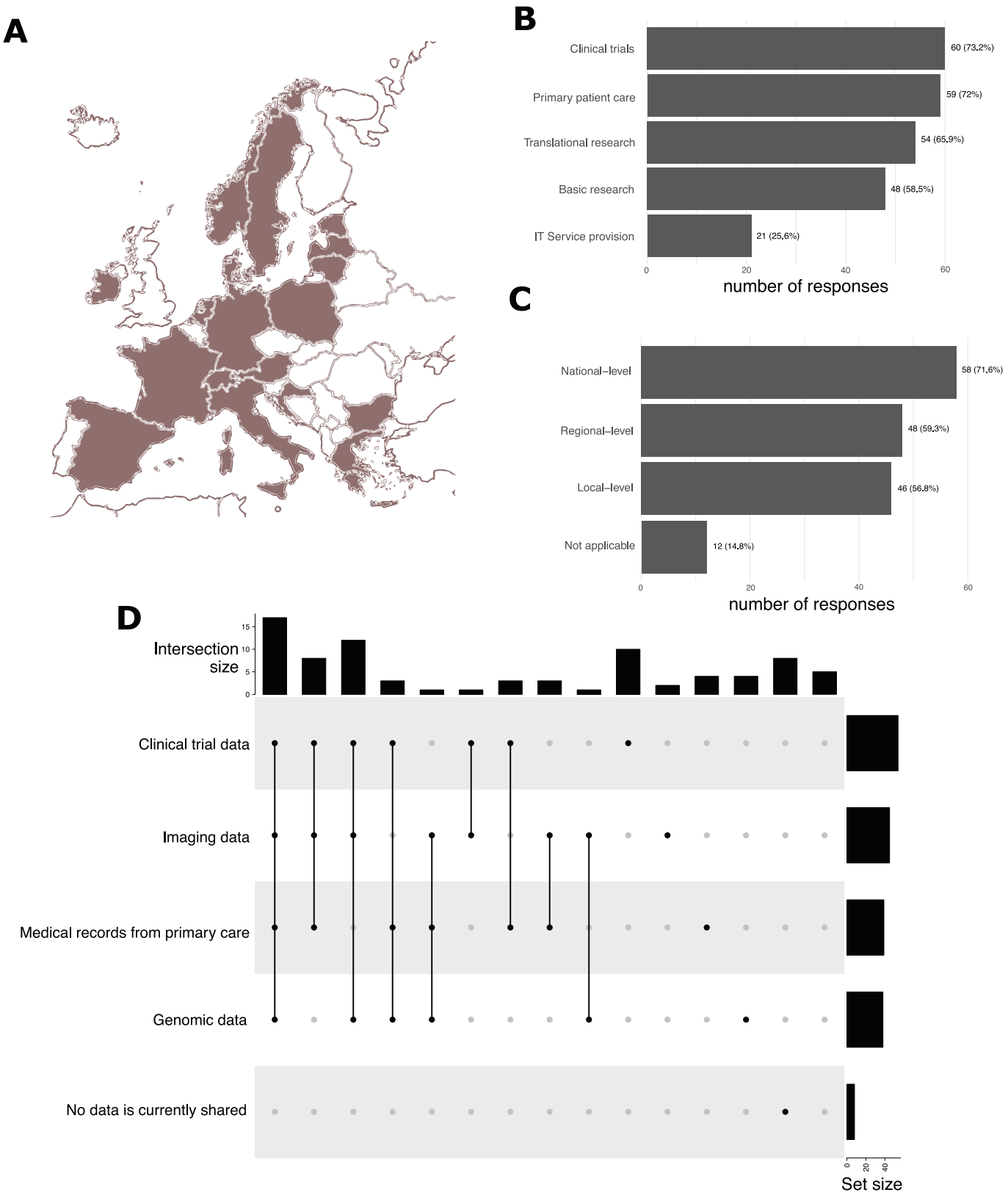


Fig. 1. Institutional activities, data types stored, and data shared among survey respondents. A) Depiction of European countries with at least one institution participating in the survey, B) top most reported data types that reflect the institutions' involvement with cancer data. Selection of more than one data type was allowed for each respondent. C) Proportion of institutions delivering patient care capabilities at a local, regional, or national level, D) Data types currently being shared with external collaborators for research purposes. Each row of the plot corresponds to one data type that is shared externally by some institutions. Columns of the graph depict the frequency of combinations of data types.

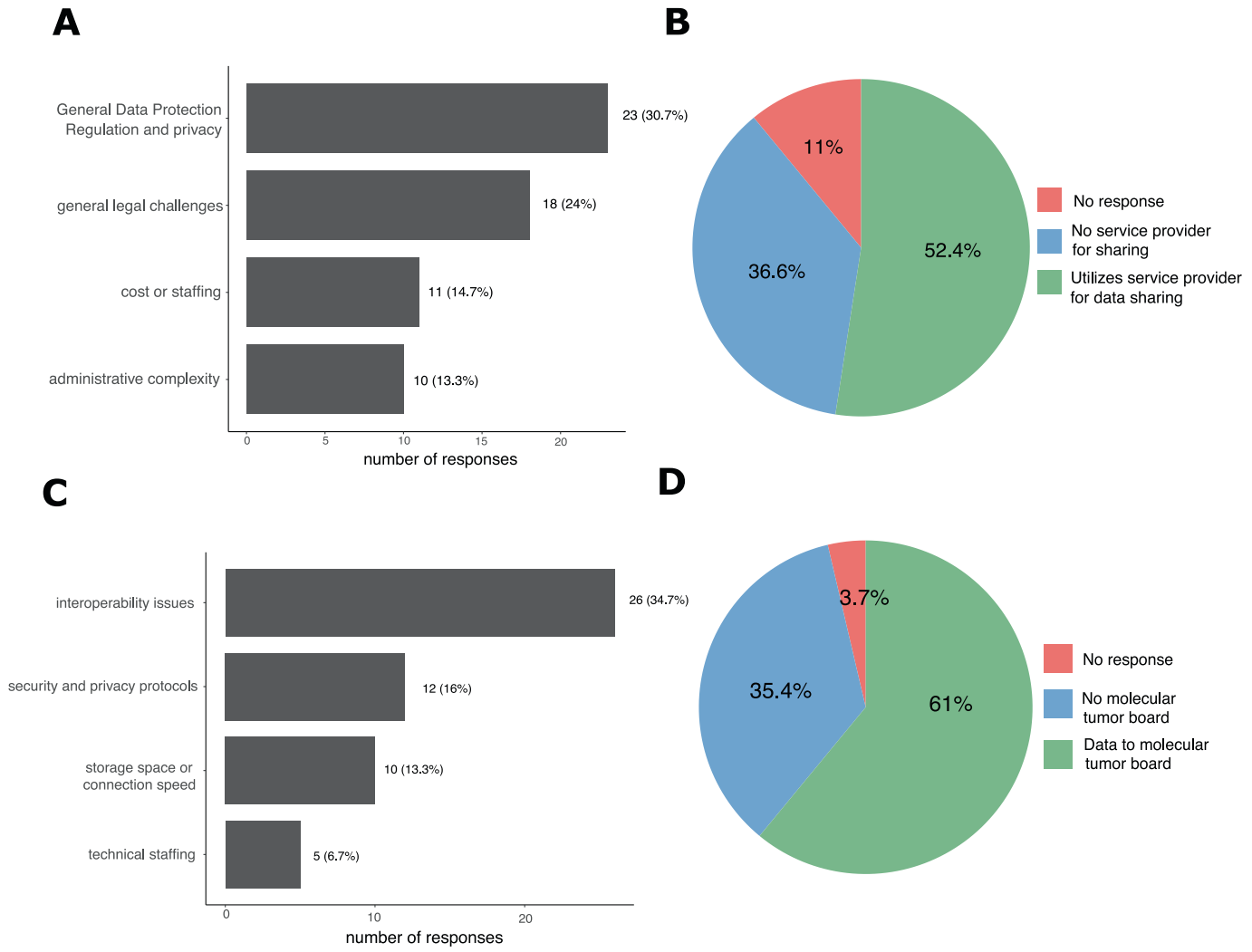


Fig. 2. A) Most frequently reported non-technical hurdles that hinder cancer data sharing for research, B) utilization of service providers for data sharing, C) Most frequently reported technical hurdles that hinder cancer data sharing for research, D) Proportion of respondents sharing genomic data with molecular tumor boards.

a significant number of respondents reporting similar answers.

5. Conclusion

This survey of 75 European cancer institutions across 23 countries reveals that GDPR compliance and legal complexity are the primary barriers to data sharing for research, surpassing technical challenges. Inconsistent adoption of clinical data standards threatens EHDS implementation timelines. The EU requires strategic investments in legal support and interoperability infrastructure. As privacy-preserving computation [30] and generative AI tools rapidly enter clinical research workflows, future surveys should track their adoption alongside emerging ethical and governance considerations [31,32]. Future surveys based on institutional self-reporting could also be complemented by government- or funder-driven accounts of cancer data sharing.

6. Declarations

Our study consists of a descriptive survey of healthcare professionals' experiences and perceptions of cancer data sharing. The study did not involve interventions, collection of health information about individual patients, or biomedical research on disease. No direct personal indefinable information was collected from any survey respondent. During the preparation of this work, the authors used Claude Opus 4.7 to shorten the draft text to fit the length requirement. The authors reviewed and edited the output as needed and take full responsibility for the content of the published article.

CRediT authorship contribution statement

Larson Hogstrom: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Arvydas Laurinavicius:** Writing – review & editing, Formal analysis, Conceptualization. **Miguel Giraldez Alvarez:** Writing – review & editing, Formal analysis, Conceptualization. **Sigve Nakken:** Writing – review & editing, Supervision, Formal analysis, Conceptualization. **Ingrid Jenny Guldvik:** Writing – review & editing, Formal analysis, Conceptualization. **Carlos Miguez Sanchez:** Writing – review & editing, Formal analysis, Conceptualization. **Olga Papadodima:** Writing – review & editing, Formal analysis, Conceptualization. **Konstantinos Voutetakis:** Writing – review & editing, Formal analysis, Conceptualization. **Per Magnus Mæhle:** Writing – review & editing, Formal analysis, Conceptualization. **Norman Zerbe:** Writing – review & editing, Formal analysis, Conceptualization. **Mario Šekerija:** Writing – review & editing, Formal analysis, Conceptualization. **Ane Fullaondo:** Writing – review & editing, Formal analysis, Conceptualization. **Eivind Hovig:** Writing – review & editing, Supervision, Project administration,

Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Funding

Funded by the European Union under Grant Agreement no. 101075328 – Joint Action JANE. Views and opinions expressed are those of the author(s) only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Eivind Hovig reports financial support was provided by European Union. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank the JANE Coordination Team including Annalisa Trama and Joanne Fleming for their support in identifying survey participants.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijmedinf.2026.106544.

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