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Original Research

How ready are endocrine scientists to share retrospective clinical data for research: a perspective from the European Network for the Study of Adrenal Tumors

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Abstract

Objective: Individual patients' data sharing requires interoperability, security, ethical, and legal compliance. The aim was to assess the landscape and sharing capacities between endocrine researchers.

Design: A standardized survey (SurveyMonkey®) with 67 questions was sent to European Network for the Study of Adrenal Tumors centers.

Methods: Answers were counted as absolute numbers and percentages. Comparisons between inclusiveness target countries (ITC) and non-ITC (defined by Cooperation in Science & Technology Action) were performed using Fisher's exact test.

Results: Seventy-three centers from 34 countries answered the survey. Electronic health record (EHR) systems are now the main source of data (90%). However, significant variability was reported, entailing >35 EHR providers, and variable data collected. Variable stakeholders' implication

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for enabling data sharing was reported, with more lawyers ($P = .023$), patient representatives ($P < .001$), ethicists ($P = .002$), methodologists ($P = .023$), and information technology experts ($P < .001$) in non-ITC centers. Implication of information technologies experts for data collection and sharing was underwhelming (33%). Funding for clinical research was higher in non-ITC than in ITC for clinical trials ($P = .01$) and for registry-based and cohort studies ($P = .05$). However, for retrospective studies addressing a specific clinical question, the funding was either very low (<10%) or nonexistent for both ITC and non-ITC (37% and 46%, respectively), with no dedicated funding for information technology (86%) and ethical and regulatory aspects (88%).

Conclusions: In the absence of dedicated funding for retrospective research, current requirements for data sharing are obstacles.

Keywords: data sharing, adrenal tumors, endocrinology, legal framework, information technologies

Significance

Despite their research expertise, ENSAT centers report difficulties in sharing clinical data. This real-life evaluation throughout Europe contrasts with the official efforts and statements for clinical data sharing at the European level. Especially with the evolution of technological and regulatory requirements, the lack of dedicated funding has now become a major limitation for retrospective clinical research, despite its importance. For the future retrospective analyses, academic investigators need to continue sharing simple clinical data without specific funding and with reasonable administrative burden. Therefore, academic institutions should provide and standardize sponsorships and agreements between centers. Simple and versatile information technology tools exist and should be promoted. Transient data collections could also contribute to avoiding costly permanent data collections.

Introduction

Clinical data can be shared in the setting of a prospective clinical trial, of a registry, or of a multicentric retrospective clinical study. For prospective clinical trials, electronic case report forms are designed specifically for the research question. Data are then centralized for the analysis and discarded at the end of the study. For registries, a limited set of variables are collected in multiple centers. Scientific questions are then asked, depending on the variables available and their informativeness. For multicentric retrospective clinical studies, a set of variables is defined to address specifically a clinical question. Participating centers then provide the necessary data. Data are then collected centrally for the analysis and discarded at the end of the study. While prospective clinical trials and registries benefit from dedicated funding, multicentric retrospective clinical studies correspond to a long tradition of nonfunded academic clinical research, with thousands of research questions addressed through the transient sharing of pseudonymized clinical data between academic centers. Though not properly evaluated, this nonfunded research reusing retrospective routine care data corresponds to a large proportion of publications, especially in the field of rare diseases. However, in the current legal and research environment, this simple nonfunded setting for data sharing and sharing is challenged. Beyond patient and ethics committee agreements, several novel requirements now apply, related to the rapidly evolving regulations, technologies, and practices. Any simple retrospective research now requires institutional sponsorship, legal agreements between participating centers, and an interoperable secure data sharing infrastructure.

Several initiatives have been proposed to process a wide range of health data and provide a health specific framework for clinical data sharing in Europe. The European Health Data Space (EHDS) has been launched to provide a trustworthy option, building on the General Data Protection Regulation (GDPR), proposed Data Governance Act, Data Act, and European Union (EU) Network and Information Systems Directive (European Commission 2023). However, several concerns arise regarding the supervision of data holders and users which may lead to power asymmetry,[1] heterogeneity and multiplicity of data sources with different coverage and quality levels,[2] and the size of EHDS, which could entail diminished safeguards for patients and citizens without providing any collective good.[3,4]

Most EU projects exploring data frameworks are dedicated to specific medical domains. With the objective of addressing the fragmentation of patient data throughout Europe, the European Joint Program on Rare Diseases (EJP-RD) has delivered a virtual platform to discover, query, and standardize patient registries, and genomics and multiomics repositories, targeting the use of a "single door."[5,6] Similar initiatives have been raised in cancer, with common data models that are mostly based or translated into the Observational Medical Outcomes Partnership (OMOP) standard[7,8] and global projects like the European Initiative to Understand Cancer (UNCAN), addressing major challenges related to cross-border and transdisciplinary research.[9] However, from the point of view of "bed side" researchers, a question may arise: do these initiatives fully cover the specificities of retrospective clinical research, such as the need for specific variables for each research question, the multiplicity of the research questions, the stiffness to adapt quickly to the most relevant clinical aspects, and the lack of dedicated funding?

This work is part of the Cooperation in Science & Technology (COST) Action Harmonisation (CA20122), aiming at promoting adrenal research in Europe through the harmonization of clinical, research, technical, and regulatory practices, in a bottom-up approach starting directly from physicians' and researchers' insight. The first step, presented here, was to establish the landscape of opportunities and constraints for data sharing and use. For that aim, we addressed a questionnaire to the principal investigators (PIs) of the European Network for the Study of Adrenal Tumors (ENSAT). The ENSAT is a research network founded in 2002, with the aim to improve the understanding and management of adrenal tumors across Europe.[10] At the European level, the ENSAT network incentivized continuous multicentric data sharing and use through 80 centers representing 38 countries from the European region. Through various multicentric European research programs like the Seventh Framework Programme of the European Community

for research and technological development including demonstration activities (FP7), Horizon2020, and now COST Action Harmonisation (CA20122), ENSAT has become a community of expert physicians and researchers, used to sharing data at the European level for addressing various research questions. Within the field of endocrine sciences, adrenal tumors have several characteristics, which make them a domain of interest with respect to data sharing and use: low prevalence of certain adrenal tumor types, clinical and molecular heterogeneity, diverse grades of severity, different metastatic potential, and new research directions, which need to be explored in the quest of biomarkers and treatments. In this paper, members of the ENSAT network were asked to explore the diversity of the European adrenal tumor data management, sharing, and use capacity through the prism of legal, information technology, and ethical details in order to identify ways to facilitate easier data sharing across different centers in Europe.

Methods

An online survey was sent to 140 clinical and research centers in 36 countries. Each center was invited to participate by a formal email with a link to the questionnaire provided through a web service SurveyMonkey®. Apart from the initial email, 3 additional reminder mails were sent to all participants with the link to the survey. The survey was filled out once by a dedicated person or a team in a receiving center and was submitted. Data were extracted in a table format for subsequent analysis.

Participating centers

Participating centers included 140 ENSAT centers also participating in the COST Action 20122 (CA20122) Harmonisation. Centers included public and private hospitals and research centers. Participating centers were either from inclusiveness target countries (ITC) or non-ITC, as defined by COST.[11] Participating ITCs include Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Moldova, Montenegro, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Turkey, and the Republic of North Macedonia. Participating non-ITC countries include Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Luxembourg, The Netherlands, Norway, Spain, Sweden, Switzerland, Israel, and the United Kingdom. The study protocol got approval by the institutional review board of the coordinating institution of the CA20122 Harmonisation (num 380-59-10106-22-111/149; class 641-01/22-02/01, Zagreb, 19.09.2022).

Structured questionnaire

A total of 67 questions (Table S1) for the structured questionnaire were formulated by an expert team consisting of medical doctors, basic and translational scientists, data and artificial intelligence (AI) experts, and ethics and legal experts working in the field of endocrinology. All but 2 questions had multiple choice answers. The questions in the survey were grouped into the following categories: 6 general questions, 7 questions related to ethical committees and legal data management, 7 questions related to IT considerations, 15 questions on electronic health records (EHRs), 9 questions on data warehousing, 10 questions on stakeholders around medical data, 5 questions related to clinical data use for research, 5 questions regarding funding for clinical research, and 3 open questions about IT, ethical issues, and data collection (Table S1).

Statistical analysis

All survey responses were collected and analyzed using R statistical software v. 4.2.2. Descriptive data were reported as absolute numbers and percentages for categorical variables. For numerical variables, we used either mean and SD or median and interquartile interval depending on the distribution. Comparisons of categorical variables were done using Fisher's exact test. For graphic organization of the data, we used bar charts. Comparison of answers between ITC and non-ITC is provided when any difference was statistically significant. Otherwise, the reporting is limited to a global description encompassing both ITC and non-ITC. $P < 5\%$ was considered as significant.

Results

Participation around Europe

A total of 73 centers representing 34 countries and 69 different cities submitted full responses to the survey (Figure 1; Table S2). The ITC center participation was 43% ($N = 31/73$) and non-ITC was 57% ($N = 42/73$). Response rate was 52.14% ($N = 73/140$). Median response rate to the 67 questions was 72/73 (99%, range 82%-100%).

Most survey participants came from public clinical centers ($N = 68/73$, 93%), and some of them associated with a research center ($N = 6/73$, 8%). There were also 3 standalone research centers and 3 private practice centers, all 3 in non-ITC. Clinical experts were the main contributors to the survey in all centers but 3 (ITC $N = 31/31$, 100%; non-ITC $N = 39/42$, 93%). Basic scientists contributed to the survey with 6% ($N = 2/31$) in ITC centers and 24% ($N = 10/42$) in non-ITC centers. Information technology experts also contributed to the survey, but to a significantly lesser extent than clinicians, in 19% ($N = 6/31$) in ITC centers and 10% ($N = 4/42$) in non-ITC centers, while ethics experts were involved in 13% ($N = 4/31$) in ITC and 12% ($N = 5/42$) in non-ITC centers.

Clinical information systems are deployed in a majority of centers, but remain highly heterogeneous

Survey participants reported that 66/73 (90%) centers use an EHR in routine practice for collecting patient data. Among these centers, most ITC centers ($N = 20/31$, 65%) and non-ITC centers ($N = 35/42$, 84%) use it systematically. A total of 4 centers (1 ITC and 3 non-ITCs) stated that they never use any type of EHR or text processing software, while 4 ITC centers and 2 non-ITC centers reported using other text processing software in routine practice.

In the 66 centers using an EHR, a total of 35 different EHR vendors have implemented their systems in our surveyed centers, while 6 participants could not state the name of the company or system. A total of 7 EHR systems are used in more than 1 country and 3 are used in more than 2 countries in Europe. Of note, ITC and non-ITC centers do not share any common EHR company. Finally, survey participants reported the use of different EHR companies within the same country in 10/15 countries with at least 2 centers answering the survey.

All but 4 centers generate digital documents for patients with adrenal tumors ($N = 69/73$, 94.4%). Those typed reports

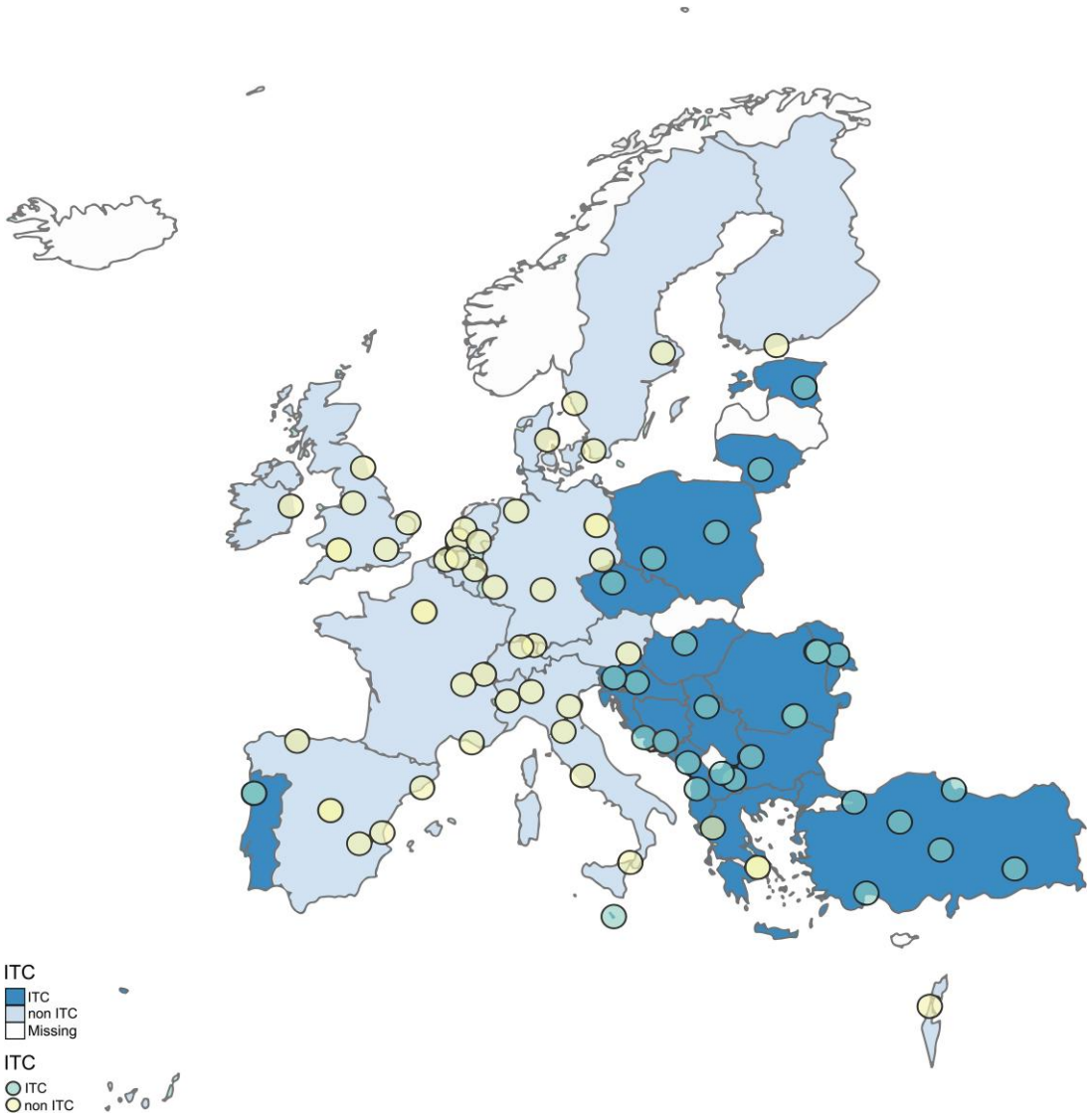

Figure 1. Geographic representation of participating centers in Europe. ITC, inclusiveness target country; non-ITC, non-inclusiveness target country.

contain data on diagnosis, outcomes, treatments, complications, comorbidities, medical imaging data through either text reports or images, pathology reports, genetic and molecular biology data, and hormone levels, with no significant difference between their content in the ITC and non-ITC. A small portion of the reports for patients also contain clinical images ($N = 5/69$, 7%).

The EHR systems store all these data in a structured format or free text. Clinical images are included into the EHR in only a few ITC centers (ITC $N = 6/31$, 19%; non-ITC $N = 26/42$, 62%; $P < .001$), while genetic/molecular biology data are more often present in ITC than non-ITC (ITC $N = 13/31$, 42%; non-ITC $N = 33/42$, 79%; $P = .003$), with no differences for other data types (Table 1).

Survey participants were then asked about the simplest way for them to extract clinical data for research from their EHR. The dominant way would be using the copy-paste function in the EHR ($N = 34/73$, 47%). Of note, the non-ITC centers also considered PDF text processing ($N = 9/41$, 23%) or saving in a word processing program ($N = 11/41$, 27%) along with the standard copy-paste option. Technically, the possibility of retrospective data collection from a current EHR dates back to 1997. This starting date is significantly different between ITC and non-ITC. Indeed, significantly less data are available in ITC centers in their EHR prior to 2015 while

Table 1. Data types available in the electronic health record (EHR)

Data type	Overall, $N = 73$[a]	ITC, $N = 31$[a]	Non-ITC, $N = 42$[a]	*P*-value[b]
Diagnosis	66 (90%)	27 (87%)	39 (93%)	.44
Outcome	60 (82%)	23 (74%)	37 (88%)	.21
Treatments	64 (88%)	26 (84%)	38 (90%)	.48
Complications	63 (86%)	25 (81%)	38 (90%)	.30
Comorbidities	64 (88%)	26 (84%)	38 (90%)	.48
Images (reports)	57 (78%)	22 (71%)	35 (83%)	.26
Images (pictures)	32 (44%)	6 (19%)	26 (62%)	<.001
Genetics/molecular biology	46 (63%)	13 (42%)	33 (79%)	.003
Hormone values	62 (85%)	24 (77%)	38 (90%)	.18
Pathology	61 (84%)	22 (71%)	39 (93%)	.44
None (I have no EHR)	7 (10%)	9 (29%)	4 (10%)	.06

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country.
[a]N (%).
[b]Fisher's exact test.

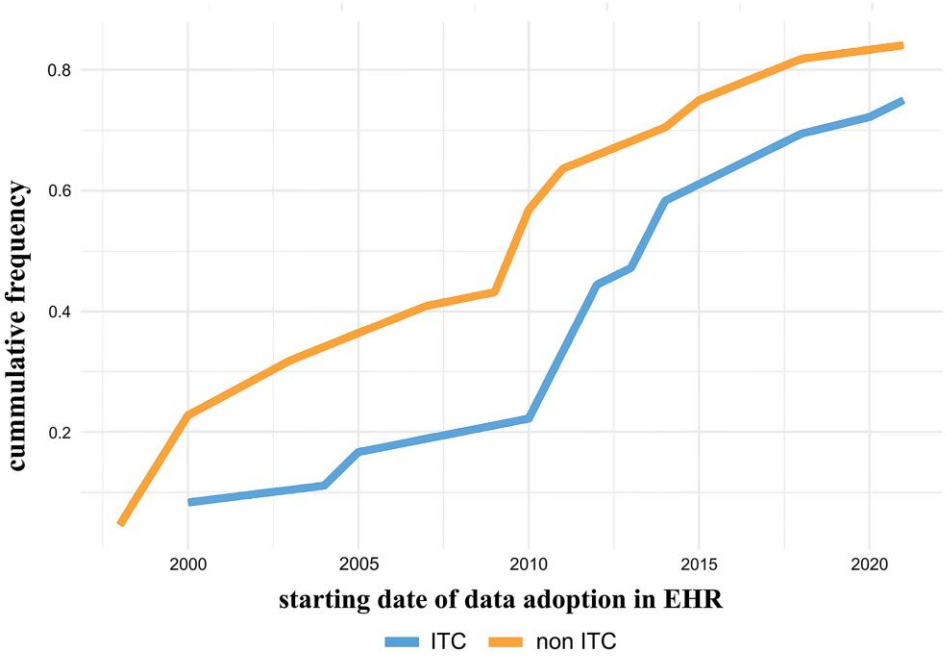

Figure 2. Cumulative proportion of adrenal centers using EHRs for clinical data collection. ITC, inclusiveness target country; non-ITC, non-inclusiveness target country; EHRs, electronic health records.

Table 2. The use of medical thesauri in the surveyed centers

Use of a medical thesaurus	Overall, $N = 72$[a]	ITC, $N = 31$[a]	Non-ITC, $N = 41$[a]	*P*-value[b]
For collecting clinical information in routine practice (always)	9 (12%)	6 (19%)	3 (7%)	.16
For collecting clinical information in routine practice (sometimes)	13 (18%)	6 (19%)	7 (17%)	>.9
For collecting clinical information for clinical research (sometimes)	8 (11%)	4 (13%)	4 (10%)	.72
For reporting clinical activity to get your hospital funded (always)	6 (8%)	3 (10%)	3 (7%)	>.9
For reporting clinical activity to get your hospital funded (sometimes)	1 (1%)	0 (0%)	1 (2%)	>.9
Never	46 (64%)	18 (58%)	28 (68%)	.46

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country.
[a]N (%).
[b]Fisher's exact test.

more than 40% of non-ITC centers have data available from 2007. However, the pace of EHR data adoption since 2015 is similar in ITC and non-ITC centers, and data from 2020 and beyond are available in 80% of all centers regardless of their ITC status (Figure 2).

The level of data structure for clinical research is variable

Around half of the surveyed participants were not aware of any natural language processing (NLP) tools for automatically processing free text information in their institution ($N = 37/72$, 51%).

Survey participants were then asked about the use of medical thesauri. More than half of ITC and non-ITC centers never use a standardized medical terminology in the perspective of standardizing data for future clinical research (ITC $N = 46/72$, 64%). Only 6 ITC centers and 3 non-ITC centers always collect clinical information coded to medical thesauri (Table 2). Globally, there was no significant difference in the use of medical thesauri between the ITC and non-ITC centers.

Only 2 centers reported having reports in a language different from their official language more often. In other centers, whether ITC or non-ITC, the integration of medical reports in foreign languages was an exception, rather than the norm.

The estimated time for collecting a theoretical set of 10 simple clinical variables on adrenal tumor patients with the current tools is currently estimated between 10 min ($N = 39/72$, 54%) and 30 min ($N = 19/72$, 26%). Insufficient information technology tools ($N = 23/72$, 32%) and staff shortage ($N = 34/72$, 47%) were considered as the most important drawbacks in the process of adrenal tumor data collection irrespective of the ethical and legal aspects.

Repositories of patients' data were reported available by more than two-thirds of the surveyed participants ($N = 45/67$, 78%). They were corresponding either to structured or unstructured data collections, managed either by the information technology department or personally by the survey participant —with no difference between the ITC and non-ITC centers. Unstructured data collections consisted mostly of collections of spreadsheets, machine-typed paper versions, and handwritten paper documents. The handwritten type of data collection was still used in some ITC centers (ITC $N = 5/30$, 29%; non-ITC 0/37, 0%; $P = .015$; Table 3).

Most data collection is still done manually, with no difference between the ITC and non-ITC centers ($N = 29/45$,

Table 3. Types of data repositories in the surveyed centers

Type of data repositories	Overall, $N = 67$[a]	ITC, $N = 30$[a]	Non-ITC, $N = 37$[a]	P-value[b]
A structured database managed by information technology professionals	19 (28%)	7 (23%)	12 (32%)	.59
A structured database managed by yourself	18 (27%)	8 (27%)	10 (27%)	>.9
An unstructured data collection, consisting into one or a series of spreadsheet documents	11 (16%)	8 (27%)	3 (8%)	.05
An unstructured data collection, consisting into a machine-typed paper version	3 (4%)	2 (7%)	1 (3%)	.58
An unstructured data collection, consisting into a handwritten paper version	5 (7%)	5 (17%)	0 (0%)	.01
No data warehouse	15 (22%)	6 (20%)	9 (24%)	.77
I am not sure	14 (21%)	6 (20%)	8 (22%)	>.9

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country.
[a]N (%).
[b]Fisher's exact test.

Table 4. Responsibility for the management of data usage after initial authorization

Responsibility for the management of data usage	Overall, $N = 69$[a]	ITC, $N = 31$[a]	Non-ITC, $N = 38$[a]	P-value[b]
The head of medical department	16 (23%)	12 (39%)	4 (11%)	.02
The research project PI	46 (67%)	15 (48%)	31 (82%)	.004
Nobody as far as nobody complains	12 (17%)	9 (29%)	3 (8%)	.02
Information technologies professionals	3 (4%)	1 (3%)	2 (5%)	>.9
I don't know	5 (7%)	3 (10%)	2 (5%)	.65

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country; PI, principal investigator.
[a]N (%).
[b]Fisher's exact test.

Table 5. Stakeholders who can block data sharing after obtaining ethical approval and collecting data

Stakeholders who can block data sharing	Overall, $N = 73$[a]	ITC, $N = 31$[a]	Non-ITC, $N = 42$[a]	P-value[b]
Medical doctors in charge of the patient	18 (25%)	9 (29%)	9 (21%)	.58
Medical doctors not in charge of the patient	5 (6.8%)	1 (3%)	4 (10%)	.39
Lawyers	17 (23%)	6 (19%)	11 (26%)	.58
Patients' representatives	7 (9.6%)	1 (3%)	6 (14%)	.22
Hospital representatives	26 (36%)	10 (32%)	16 (38%)	>.9
Government representatives	14 (19%)	6 (19%)	8 (19%)	>.9
Information technologies representatives	8 (11%)	3 (10%)	5 (12%)	>.9
None	30 (41%)	14 (45%)	16 (38%)	.62

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country.
[a]N (%).
[b]Fisher's exact test.

64%). In contrast, automated pipelines have been developed in 31% ($N = 14/45$) of centers with a data repository, with the purpose of transferring data from the EHR to the data repository. Reusing and extracting adrenal tumor data from structured data repositories without going back to the EHR is possible in more than half of centers with this type of data collection ($N = 22/37$, 59%). Concerning the data available for extraction from data repositories, data types were not significantly different among the participating centers and included diagnosis, outcomes, treatments, comorbidities, complications, images, pathology, genetics, and hormone values.

Numerous stakeholders are participating in the data sharing and use process

Beneficiaries

Survey participants reported hospitals and individual researchers as the main beneficiaries in case of patents and financial benefit from research ($N = 44/73$, 60% and $N = 23/73$, 32%, respectively). However, they mostly felt that the researchers were the ones that should be retributed intellectual property over significant findings ($N = 49/73$, 67%), followed by the hospitals ($N = 31/73$, 42%) and physicians ($N = 28/73$, 38%). A majority of survey participants stated that they were not sure if the current valorization of clinical data is fair ($N = 40/73$, 55%). In the surveyed centers, the institutional retribution for data generation and management is mostly through citations in scientific publications ($N = 47/73$, 64%).

Potential obstacles for data sharing and use

Implementation of data sharing and use after initial authorization is mostly managed by the PI ($N = 46/69$, 67%) with a significantly larger role in non-ITC centers (ITC $N = 15/31$, 48%; non-ITC $N = 31/38$, 82%; $P = .004$). The role of the head of the medical department is significantly more relevant for data usage implementation in ITC than in non-ITC centers (ITC $N = 12/31$, 39%; non-ITC $N = 4/38$, 11%; $P = .021$) (Table 4).

Survey participants reported that the process of clinical data sharing and use could be blocked by a participating

Table 6. Ethical committee composition in ITC and non-ITC centers

Ethical committee composition	Overall, $N = 73$[a]	ITC, $N = 31$[a]	Non-ITC, $N = 42$[a]	P-value[b]
Medical doctors	72 (99%)	31 (100%)	41 (98%)	>.9
Lawyers	49 (67%)	16 (52%)	33 (79%)	.023
Patients' representatives	42 (58%)	6 (19%)	36 (86%)	<.001
Pharmacologists (clinical trials)	48 (66%)	17 (55%)	31 (74%)	.13
Ethicists	48 (66%)	14 (45%)	34 (81%)	.002
Methodologists	27 (37%)	5 (16%)	22 (52%)	.002
Information technologies experts	23 (32%)	2 (6%)	21 (50%)	<.001

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country.
[a]N (%).
[b]Fisher's exact test.

Table 7. Implication of Information technologies teams

Implication of information technology teams	Overall, $N = 73$[a]	ITC, $N = 31$[a]	Non-ITC, $N = 42$[a]	P-value[b]
For routine technical problems	68 (93%)	28 (90%)	40 (95%)	.6
For designing or improving specific tools	32 (44%)	11 (35%)	21 (50%)	.2
For data collection	24 (33%)	8 (26%)	16 (38%)	.3
I have never talked to them	5 (6.8%)	3 (10%)	2 (5%)	.6

Abbreviations: ITC, inclusiveness target country; non–ITC, non-inclusiveness target country.
[a]N (%).
[b]Fisher's exact test.

stakeholder in 59% of centers ($N = 43/73$). The type of stakeholder potentially blocking the data sharing process included colleagues (medical doctors), lawyers, patients, hospital, and government representatives and information technology representatives, with no difference between ITC and non-ITC centers (Table 5).

Ethical committees

There are significant differences in the stakeholders participating in ethical committees between ITC and non-ITC centers, since significantly more non-ITC centers' ethical committees include lawyers (ITC $N = 16/31$, 52%; non-ITC $N = 33/42$, 79%; $P = .023$), patient representatives (ITC $N = 6/31$, 19%; non-ITC $N = 36/42$, 86%; $P < .001$), ethics experts (ITC $N = 14/31$, 45%; non-ITC $N = 34/42$, 81%; $P = .002$), methodologists (ITC $N = 5/31$, 16%; non-ITC $N = 22/42$, 52%; $P = .002$), and information technology experts (ITC $N = 2/31$, 6.4%; non-ITC $N = 21/42$, 50%; $P < .001$) (Table 6).

A local or a regional ethical committee was identified as available to all centers. All studies currently require some kind of ethical approval in the surveyed centers. Depending on the type of study, different ethical requirements emerged. Local ethical committees manage the majority of studies in all centers while the regional ethics committee is responsible mostly for clinical trials with no difference in regulations between ITC and non-ITC centers. When it comes to retrospective studies, prospective studies (with/without biobanking), somatic/germline genomic studies, and clinical trials, there was no significant difference between the types of the studies that can be managed by the local ethical committee and ones that should be managed by the regional ethical committees between ITC and non-ITC centers.

The timeframe for obtaining an ethical approval to extract adrenal tumor data from an EHR is reported as quicker in ITC compared to non-ITC centers (within 3 months for ITC $N = 21/30$, 70%; non-ITC $N = 20/38$, 53%; within 6 months for ITC $N = 5/30$, 17%; non-ITC $N = 18/38$, 47%; $P = .01$).

Regarding patient approval for data sharing and use, differences emerge between centers. Opt-out consent based on a generic information—that is, patient's consent obtained by default, but can potentially withdraw their consent if they claim for it—is available only in one-third of the centers ($N = 26/73$, 36%). In centers with opt-out consents available, the type of studies eligible to opt-out was similar between ITC and non-ITC, except for multicentric prospective studies (ITC $N = 8/31$, 26% vs non-ITC $N = 2/42$, 4.7%, $P = .014$).

Information technologies teams in data sharing and use

The majority of participants communicate with their information technologies hospital team for solving routine technical problems ($N = 68/73$, 93%), but more rarely for research data collection ($N = 24/73$, 33%) (Table 7). In addition, two-thirds of the surveyed centers report that they have the ability to establish a collaboration with their information technologies team for the purpose of sharing and using data on adrenal tumor patients if needed. Of note, a few centers reported having no dedicated information technology team in 10% ($N = 3/31$) of the ITC centers and 5% ($N = 2/42$) non-ITC centers.

Patients

Around half of the survey participants think that the patients are properly informed when their data are being used for research ($N = 38/73$, 53%). The main reported motivation for participation would be the trust between the surveyed medical experts and their patients ($N = 45/73$, 61%), desire to help medical progress ($N = 42/73$, 58%), with no differences between ITC and non-ITC. Survey participants also reported that about half of patients fully understand the information related to the research project ($N = 40/73$, 55%). The vast majority of the survey participants reported that they can collect data from all of the patients being managed by their team ($N = 60/72$, 83.3%).

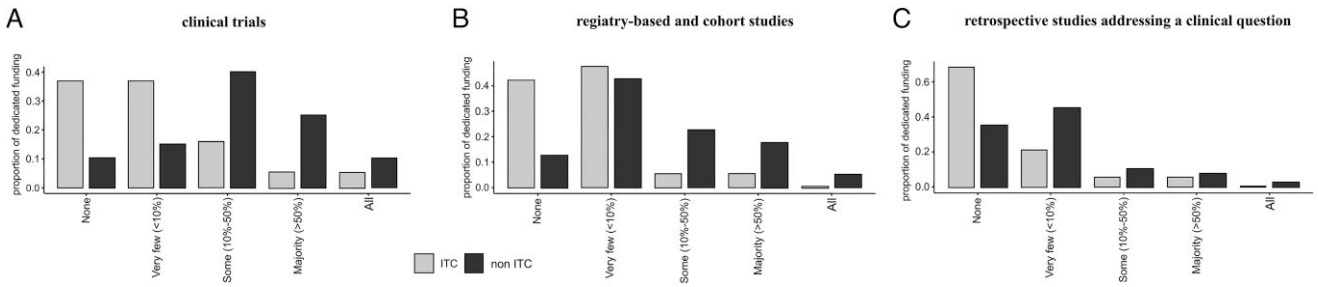

Figure 3. Proportion of clinical studies with dedicated funding. Total number of answers: $N = 19$ for ITC and $N = 40$ non-ITC participants. (A) Proportion of clinical trials with dedicated funding. (B) Proportion of registry-based and cohort studies with dedicated funding. (C) Proportion of retrospective studies addressing a clinical question with dedicated funding. ITC, inclusiveness target country; non-ITC, non-inclusiveness target country.

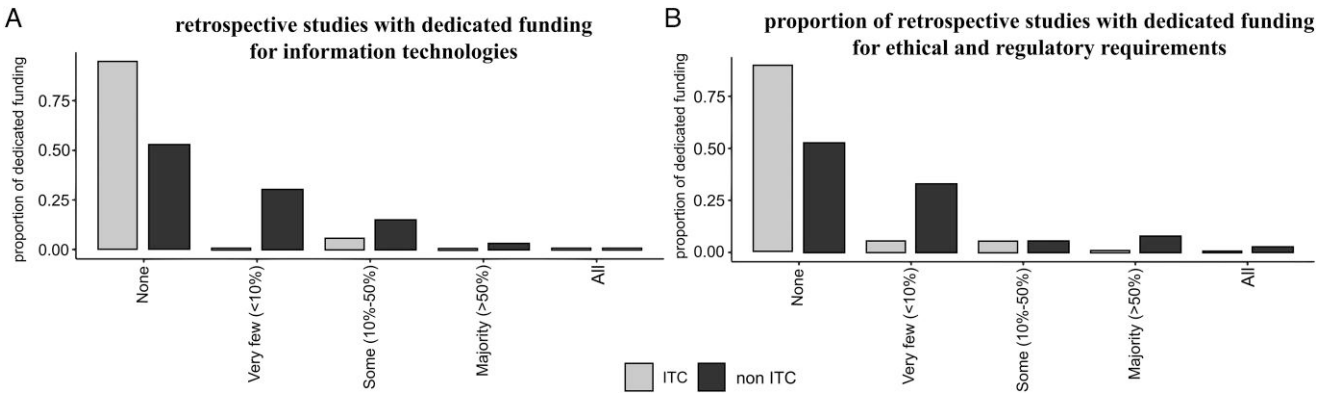

Figure 4. Proportion of retrospective studies with dedicated funding for information technologies, ethical, and regulatory requirements. Total number of answers: $N = 19$ for ITC and $N = 40$ non-ITC participants. (A) Proportion of retrospective studies with dedicated funding for IT. (B) Proportion of retrospective studies with dedicated funding for ethical and regulatory requirements. ITC, inclusiveness target country; non-ITC, non-inclusiveness target country.

Lack of dedicated funding is detrimental for retrospective clinical research at the European level

Specific support for clinical research

Survey participants were asked whether they acquired dedicated funding for clinical trials, for registry-based and cohort studies, and for individual retrospective studies addressing a specific clinical question. Clinical trials were the most funded type of studies. However, only a few ITC and some non-ITC centers had funding for clinical trials, with slightly more funding in non-ITC ($P = .01$, Figure 3A). Registry-based and cohort studies were less funded (Figure 3B). Here again, non-ITC centers had slightly more funding than ITC ($P = .05$, Figure 3B). Finally, the majority of retrospective studies addressing a clinical question were not funded for both ITC and non-ITC, with no difference between both ($P = .17$, Figure 3C).

Specific support for information technologies and ethical and regulatory requirements for retrospective clinical research

Survey participants were then asked whether they had any dedicated support for information technologies, ethics, and regulatory requirements when they performed a retrospective clinical research study. For information technologies, a vast majority of retrospective studies did not have dedicated support in ITC, while some studies had such support in non-ITC centers ($P = .004$, Figure 4A). For ethical and regulatory requirements, a majority of retrospective studies were without dedicated support as well, with slightly more support in non-ITC centers ($P = .03$, Figure 4B).

Discussion

This survey reports on the heterogeneity of the adrenal tumor research landscape, at the level of interoperability and structure across European countries. The survey also addresses the issue of the complexity in implementing data sharing and use. The main novelty of this survey is the physician's perspective, while a vast majority of published information originates from information technologies or public health experts. This original view sheds light on gaps between these different expertise.

In this work, EHRs appear to be available almost everywhere today. Despite being developed and optimized for the primary use in routine care, EHR should also facilitate secondary use of clinical data for research. Continuous efforts are undertaken to deliver methods for mining the rich information present in EHRs and clinical narratives,[12] preserving patient privacy,[13] making databases more harmonized through conceptual models,[14] allowing research hypotheses to be tested safely, cheaply, and quickly on digital models,[15] and making data collected in hospitals reusable for multicentric research.[16] These efforts have gained momentum in the last years and are expected to provide appropriate tools and support for clinicians. However, our ground field data experience reported here does not reflect this enthusiastic view. Especially in spite of deployment almost everywhere, modern EHR solutions focus on patient management while also being incompatible with other data structures and sharing processes. Implementation of advanced interoperability frameworks and FAIR data sharing principles directly to EHR is not trivial and requires

additional layers of solutions.[17] Major EHR companies develop their own domain-agnostic solutions, to reuse patient data for research.[18] However, it is not known whether such tools would be compatible with the specific and dynamic design of variables by expert physicians for their numerous research questions, precluding any type of "one-fits-all" data structure solution. However, improving secondary use of clinical data should not alter the ergonomics of the EHR and more generally of all information and communication technologies. The results of our survey in European countries underline this point and echo the recommendations made by the American Medical Informatics Association and the Association of Medical Directors of Information Systems in the United States, who highlight that information technology solutions and AI should be devoted to improving clinicians' well-being by easing documentation burdens and reducing clinician documentation beyond notes.[19] Similarly, the American Medical Association partners with technology leaders to bring physicians critical insights on information technology application design and ensures that physicians have a voice in shaping AI's role in medicine. The CA20122 Harmonisation consortium also claims that a bottom-up approach based on routinely collected clinical data should be favored in information technology development at the European level.

Clinical research analyses require structured data. While European registry initiatives, aiming at gathering and using clinical data from multiple centers, have emerged in Europe, the experience of the ENSAT network demonstrates that a priori structuring of data is usually not compatible with the specific questions to be answered through clinical data reuse. Our survey demonstrates a remarkable variability in the way clinical data are structured in EHRs. Only a minority of our surveyed centers utilize standardized terminologies such as International Classification of Diseases (ICD),[20] Systematized Nomenclature of Medicine (SNOMED CT),[21] or Human Phenotype Ontology (HPO)[22] to collect signs, symptoms, and diagnoses. Standardized terminologies have required important consensus efforts to be established. Their use for economic monitoring of clinical activity is more and more generalized. For clinical research, ICD codes can be used as clinical variables, for instance for selecting patients to be included into a study. However, to which extent some patients may be missed—in case of multiple diseases, or to which extent ICD codes may miss sensitivity for refined selection of patients remain to be evaluated. Even for easy-to-code and clinically significant information, ICD codes do not warrant good performance.[23]

In this survey, around 50% of participants were not aware of any NLP tools for processing free text in their institution. Natural language processing and more recently large language models quickly emerge as promising tools for automating data structuration.[24] The implementation of such tools in the secured data space of hospitals and their connection to EHRs is ongoing. However, NLP may also go slightly contrary to the bottom-up claim emerging from this survey study, where expert physicians already express the limitation of staff and IT tools for collecting simple data, as reported in our survey. Indeed, the difficulties outlined throughout this work are in large part due to the difficulties of pinning down an exact dictionary that fits the purposes of the different studies in the particular clinical area. If this job is given over to semiautomated NLP or large language model tools, that difficulty will get even greater, at least in the short term, while the technology is still not quite mature and funding not warranted.

For multicentric studies, data sharing and use between centers require the implication of information technology professionals, warranting interoperability and security. In the present survey, only one-third of participants reported communicating with information technology professionals for data collection. This raises the question of how data sharing with external collaborators is currently pursued and to which extent approved solutions for data sharing and use are utilized. Beyond these technical aspects, several major business and clinical aspects were not addressed by this survey, despite their importance for data sharing and use. For instance, major questions remain, related to data value, sustainability, equity, improvement of the complex health data ecosystem, and promotion of public health.[25] Some of these questions will be addressed in the following steps of the Harmonization COST Action.[10] Indeed, a pilot European retrospective research study will be run. The aims will be to reach full compliance in each participating center for data collection, sharing, and reuse and to monitor the effort it takes. This next step should also contribute to raising attention to these poorly documented aspects of data sharing, despite their deep practical impact.

Health systems are an essential component of European social infrastructure, contributing significantly to the wealth of the EU.[26] Part of this wealth is reinjected into research. However, our survey participants report having no funding for the majority of their retrospective clinical research, in spite of their economic value, usually generated through publication-related support to hospitals. The evolution of regulations, including ethical, legal, and technical improvements, now introduces intermediate fees for institutions warranting sponsorship, for their lawyers building the agreements between centers and their information technology experts for safe and efficient data sharing and use. How can we reconcile the absence of immediate funding for retrospective multicentric research and these immediate fees? One solution could be that the government funding to hospitals—especially the funding arising from publications—should account for academic institutionalization of clinical data transactions and federated models of data exchange. The fees could be reduced by establishing standard agreement frames and laws, and the use of simple and safe information technology solutions for structuring and sharing. Physicians should not have to fight to be able to share, especially when the vast majority of their work is in the public interest.

This survey compared ITC and non-ITC countries, showing funding gaps, with significantly less clinical trials with dedicated funding and significantly less funding for information technology and ethical/regulatory aspects of retrospective research in ITC when compared to non-ITC. Lesser accessibility to funding for research prompts lower scientific contributions, expanding the knowledge gap and increasing expert allocation, thus resulting in a lower level of clinical research development. Even within the EU level, medical research funds were shown to be greatly disproportionate with the EU-15 countries obtaining 96.9% of all research funds in comparison to EU-13 countries, with EU-15 countries also having higher amounts per beneficiary and GDP per capita and research excellence as the most significant predictors for EU funding.[27]

Conclusion

This view on clinical data sharing and use by adrenal research scientists reports the broad availability of the EHR in Europe, but also the heterogeneity of this tool and of data structuring.

Beyond difficulties related to the complexity of regulations and the multiplicity of stakeholders, data sharing and use are constrained by funding, in spite of being a productive resource. Sharing data is deeply rooted in clinical research. The current evolution of regulations makes sharing more difficult. Sponsorship and legal agreements are bottlenecks, where future efforts are needed as a priority.

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