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Streamlining the ethical-legal governance of cross-border health data sharing during global health emergencies

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Abstract

Global health emergencies often lead to a proliferation of health-related research and resultant data, which is shared across borders to help control the outbreak of disease and support decision-making regarding public health interventions. However, efforts to share data can be hindered by diverse international ethical and legal frameworks. The frameworks aim to govern coordinated processing, sharing and transfer of health data across borders thus placing burdens on researchers who are willing or obligated to share data. In this paper, we investigate ethical values and legal principles that can be applied to ensure a more streamlined approach in the governance of cross-border health data sharing during global health emergencies. A scoping review approach was used to better understand emerging evidence about issues related to the ethical and legal governance of cross-border health data sharing. We first highlight the challenges of sharing health data across borders. We then discuss how the challenges might be overcome through the application of ethical values and legal principles that have been identified in literature. This is followed by a proposal for possible ways of streamlining the governance of health data sharing from ethical and legal perspectives in a bid to better prepare for future global health emergencies and promote the responsible sharing of health data.

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Keywords
Cross-border, data sharing, global health emergencies, governance, health data, ethical and legal challenges

Introduction

The World Health Organization (WHO) has often repeated calls for rapid access to "both raw and analyzed data or other pertinent research findings" to ensure an effective response to major disease outbreaks (Modjarrad et al., 2016: 2). Disease outbreaks can lead to public health emergencies of international concern if the emergence of the disease is unexpected and leads to serious public health impact (WHO, 2005; Annex 1). In such circumstances, the development of effective communication channels between the health system and other stakeholders within and between different countries is critical to enable rapid responses in emergency situations (Gustavsen et al., 2016). Global health emergencies often lead to a proliferation of health-related research to generate important data. The need for rapid collection and sharing of data during public health emergencies, as witnessed during the Ebola outbreaks in West Africa and the global COVID-19 pandemic have led to data being shared across national borders to help control the outbreak of diseases and support decision-making in public health interventions (Cullinan and Roberts, 2020; Liverani et al., 2018; Tacconelli et al., 2022). Data sharing helps to ensure scientific rigor and creates opportunities for better and more accurate results (Inter Academy Partnership, 2022; Townsend, 2022), and generalizability of research findings (Tacconelli et al., 2022). However, efforts to share data can be hindered by diverse international ethical and legal frameworks. The frameworks aim to govern coordinated processing, sharing and transfer of health data across borders thus placing burdens on researchers who are willing or obligated to share data (Brand et al., 2022; Mahomed et al., 2022). Even within the European Union where the Regulation (EU) 2016/679 (General Data Protection Regulation or the GDPR) was in force, there were challenges in cross-border data sharing due to lack of consensus on the interpretation of the GDPR (Tacconelli et al., 2022). This has led to the proposal for a European Digital Health Space (EDHS) in 2022 to facilitate data sharing across borders (European Parliament, 2022). The challenges highlight the need for guidelines on data sharing to be clear to guarantee the protection of personal information (WHO, 2022) and avert other related potential harms.

Guidelines should also ensure equitable data sharing since norms that maximize the utility of the data, such as rapid and real-time data sharing, currently seem to be prioritized, thus causing tensions with equally important equitable norms such as researcher recognition and equitable access to data (Pratt and Bull, 2021). Failure to ensure equity often leads to exploitation and conflicts of interest (Bull and Bhagwandin, 2020), which in turn causes tensions and inequalities that tend to emerge during public health emergencies. This was seen during the COVID-19 pandemic when low- and middle-income countries (LMICs) that participated in research and provided samples, and other forms of data ended up paying more for the vaccines when compared to their high-income country counterparts (Singh et al., 2022). This demonstrates inequality when it comes to sharing data, samples and the benefits that result from research. It also raises ethical concerns due to differential treatment of LMICs when compared to higher-income countries. These issues could have been provided for in sample and data sharing agreements, if guidelines had been followed.

Current literature has highlighted the challenges of cross-border health data sharing during global health emergencies and proposed possible solutions to overcome the identified challenges (ASSAf, 2021; Tacconelli et al., 2022). However, the proposed solutions “such as federated data analysis (or federated learning) and the adoption of common standards for data encoding and sharing” only partially address the challenges (Tacconelli et al., 2022: 2). It is thus unclear what efforts have been made to streamline the governance of data sharing during global health emergencies and what ethical values and legal principles should be applied to ensure a streamlined approach in the governance of cross-border data sharing within collaborative research projects. This study aims to answer the question “what ethical values and legal principles can be applied to ensure a more streamlined approach in the governance of cross-border health data sharing during global health emergencies?” The specific objectives of the study are:

- To identify the challenges of cross-border health data sharing during global health emergencies.
- To identify proposals from current literature for overcoming ethical and legal challenges of cross-border data sharing.
- To map the ethical values and legal principles that can inform a more streamlined approach in the governance of cross-border health data sharing during global health emergencies.

In this paper, we discuss the ethical and legal challenges in cross-border data sharing and ethical values and legal principles that have been identified in current literature to overcome the challenges. This is followed by a proposal for possible ways of streamlining the governance of health data sharing from ethical and legal perspectives in a bid to better prepare for future global health emergencies and enable responsible sharing of health data.

Scoping review methodology

A scoping review approach was used to better understand emerging evidence on issues relating to ethical and legal governance of cross-border health data sharing in global health emergencies. Scoping reviews enable researchers to synthesize diverse bodies of knowledge and describe their relevance, range, and nature. We followed the methodological framework of Arksey and O'Mally (2005) for scoping review studies. Arksey and O'Malley outline five steps to conduct such reviews which include: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarizing, and reporting the results.

Search strategy

Searches were conducted on the Google Scholar search engine and four databases: Pub-med, Web of Science, Scopus, and Medline. Full texts of peer-reviewed articles were located and screened. The search terms used were: "health data AND pandemics OR health emergencies," "health data AND ethical issues," "health data AND legal issues," "health data AND cross-border sharing," "health data AND governance," "health data AND streamlining governance."

Selection process

The inclusion and exclusion criteria outlined in Table 1 below were used to assign a value of "include," "exclude," or "maybe" to the identified articles to ascertain whether the article should be included in the review or not. Further, Figure 1 elaborates on the strategy that was used to include and exclude the articles in relation to Table 1. In a situation where it was not possible to decide based on the title and abstract alone, the full article was reviewed. When the first reviewer (LM) was unsure of whether to include an article a second reviewer (PA) reviewed the article, and this was resolved by the full article being retrieved and re-read in each case. After removing duplicates and excluding articles that did not match the search criteria, a total of 23 articles were included in the analysis. A summary of the characteristics of the 23 articles selected for review can be found in Table 2.

Data analysis

All articles were read and re-read to explore and understand raw data. Further, it was important to be as inclusive as possible given the limited evidence currently available on legal and ethical issues on cross-border health data sharing during public health emergencies. In this regard, we included original research articles where authors had used different methods to conduct their studies. A total of 23 articles were selected for review. While individually drawing from each article was important, it was also essential to compare themes and to synthesize the results.

Table 1. Exclusion and inclusion criteria.

Exclusion criteria	Description	Inclusion criteria	Description
Topic	General research or commentary on public health emergencies	Topic	Describes ethical and legal aspects of cross border health data sharing during global health emergencies
Language	Non-English	Language	English
Publication date	Pre-2015	Publication date	From 2015 to 2023
Publication type	Non-peer reviewed articles, books, theses, reports	Publication type	Peer reviewed articles
Type of study	Research letters, editorials, scoping reviews, systematic reviews, literature reviews, etc.	Type of study	Original research, primary data

Results

We located 23 original articles that described research on the legal and ethical challenges relating to cross-border health sharing data during global health emergencies. The selected articles were published between 2015 and 2023. We chose this period to enable us to include articles that focus on the most recent global public health emergencies that raised data sharing concerns. Most (14) of the articles were published during and after the COVID-19 pandemic. The studies presented work undertaken in different regions, North America (Jiménez and Kozo, 2022), Africa (Anane-Sarpong et al., 2020; Chirawurah et al., 2022; Kiwuwa-Muyingo et al., 2023; Stuart et al., 2023; Walker et al., 2022); European Union (de Kok et al., 2023; Holub et al., 2020; Lalova-Spinks et al., 2022; Natsiavas et al., 2021, 2022; Sperle et al., 2023; Tacconelli et al., 2022; Van Kolfschooten, 2019); and Asia (Liverani et al., 2018; Tsukayama et al., 2023). Some of the articles presented data from more than one region (Durrance-Bagale et al., 2022; Edelstein et al., 2018; Kickbusch et al., 2021; Lee et al., 2020; Watson et al., 2023). The published articles collected data using a range of methodologies including questionnaires, interviews, review of policy documents, screening health records and bio-banking research infrastructure.

Themes

The four primary themes that emerged from the analysis of 23 articles are outlined below.

Theme 1. Data quality, security, and risk

Despite expectations to use and share public health data, it is difficult to attain (van Panhuis et al., 2014). The analyzed articles identified different challenges pertaining

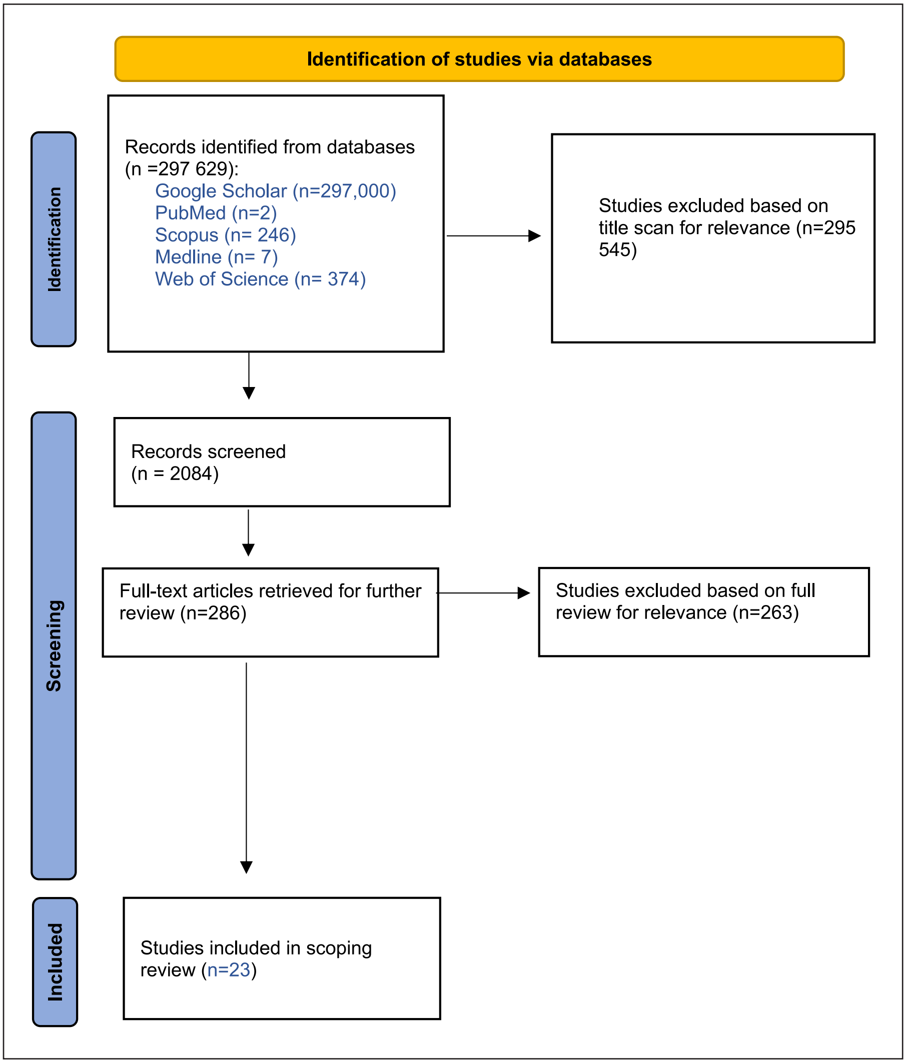

Figure 1. PRISMA flowchart.

to data quality during public health emergencies, including management, data interoperability as well as monitoring and analysis. The absence of datasets and information in standardized formats presents major challenges to the effective management of public health interventions. Moreover, sharing health data across borders raises security concerns and the need to minimize breaches can become challenging (Li et al., 2022). The development of information technology has increased the network security risks to both infrastructure and to data in general. In addition, the growing use of new technologies such as artificial intelligence also contribute to increased

Table 2. List of reviewed articles including authors, research aims, samples, methods used and findings.

Author name(s)	Title	Research aim	Methodology	Findings
Sperle et al. (2023)	COVID-19 cross-border case and contact tracing activities—experiences and lessons learnt, Germany, April–December 2020.	To describe cross-border COVID-19 case and contact tracing activities including lessons learnt by public health authorities (PHA) to adapt the procedures accordingly.	Data was collected on cases, contacts, dates of exposure, and/or SARS-CoV-2 positive test results and exposure setting. The authors performed descriptive analyses of events from April 6, 2020 to December 31, 2020. Interviews were conducted with PHA to understand experiences and lessons learnt, applying a thematic approach for qualitative analysis.	Main challenges identified through five interviews were missing data or delayed accessibility particularly from flights, and lack of clear and easy to use communication channels. More and better trained staff were mentioned as ideas for improving future pandemic response preparedness.
Lawpoolsri et al. (2018)	Data quality and timeliness of outbreak reporting system among countries in Greater Mekong subregion: Challenges for international data sharing.	To evaluate timeliness and data quality of national outbreak reporting for four countries in the Mekong Basin Disease Surveillance network (MBDS).	This study used secondary aggregated data at provincial level from public health surveillance reports. The Ministry of Health of the four countries provided permission to use the data.	The hierarchical structure of the reporting system, data collection method, and country's resources could affect the data quality and timeliness of the national outbreak reporting system. Differences in data quality and timeliness of outbreak reporting system among member countries should be considered when planning data sharing strategies within a regional network.
Lee et al. (2020)	Global Infectious Disease Surveillance and Case Tracking System for COVID-19: Development Study.	To design a global infectious disease surveillance and case tracking system that can facilitate the detection and control of COVID-19.	The International Patient Summary (IPS; an electronic health record that contains essential health care information about a patient) was used. The IPS was designed to support the used case scenario for unplanned cross-border care. The design, scope, utility, and potential for reuse of the IPS for unplanned cross-border care make it suitable for situations like COVID-19.	The COVID-19 surveillance system was designed based on blockchain architecture. The IPS was used to exchange case study information among physicians. After being verified, physicians can upload IPS files and receive IPS data from other global cases. The system includes a daily IPS uploading and enhancement plan, which covers real-time uploading through the interoperation of the clinic system, with the module based on the Open Application Programming Interface architecture.
Durrance-Bagale et al. (2022)	"Science is only half of it": Expert perspectives on operationalizing infectious disease control cooperation in the ASEAN region.	To examine perspectives of experts working with regional disease control bodies on how to operationalize regional infectious disease control cooperation and inform the ASEAN Centre for Public Health Emergencies and Emerging Diseases (ACPHEED) operationalization.	A qualitative study, using semi-structured interviews with experts on regional disease control.	The international infectious disease community has learned valuable lessons from the COVID-19 pandemic, not least the necessity of pooling human, financial and technological resources, constructing positive working relationships with neighbors, and sharing data. Without this kind of regional cooperation, infectious diseases will continue to threaten our future, and the next pandemic may have even more far-reaching effects.

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Table 2. (Continued)

Author name(s)	Title	Research aim	Methodology	Findings
Van Kolfschooten (2019)	EU Coordination of Serious Cross-Border Threats to Health: The Implications for Protection of Informed Consent in National Pandemic Policies.	To examine whether the right to informed consent is adequately safeguarded in the context of EU policy on pandemic preparedness and response in Europe.	Examines both the EU's and the Dutch government's countermeasures in the EU and the Netherlands respectively during the 2013–2016 Ebola outbreak.	This results in a tension between public health and individual rights in the EU, especially with regard to the right to informed consent, a central right in health law. In response to the 2013–2016 Ebola outbreak in West Africa, the EU introduced several preventive and responsive measures in the Member States to prevent the pandemic from spreading to the EU. The case study analysis of Dutch pandemic policies established in reaction to this outbreak shows that national pandemic policies are substantially shaped by EU actions, which has implications for the protection of the individual right to informed consent in the Member States.
Walker et al. (2022)	Cross-border collaboration and capacity- building for improved health emergency response planning in Southern Africa.	To strengthen collaboration among the countries in implementing public health emergency response strategies.	The study presents findings from project participants' perspectives on whether and how the project supported improved regional collaboration for emergency responses to public health events, and their perceptions of how the project strengthened their border health systems. Country delegates were convened in multi-sectoral regional and sub-regional meetings and workshops to facilitate cross-border public health information-sharing and co-ordination, and to align surveillance for emergency preparedness and response.	Procedures were drafted to: strengthen cross-border and multi-sectoral communication; prioritize points of entry for cross-border co-ordination; map population movement patterns; and identify national and regional border health priorities. Training focused on points of entry to enhance planning for future disease outbreaks by introducing the Population Connectivity Across Borders Toolkit for analyzing population movement data to guide the design of public health interventions.
Jiménez and Kozo (2022)	The Development of a Collaborative Binational Strategy to Support the San Diego-Tijuana Transborder Community During the COVID-19 Pandemic.	To implement a formal structure to facilitate cross-border COVID-19 communication, coordination, and collaboration.	Describes how the development of a Collaborative Binational Strategy led to coordinated outreach and initiatives that addressed access and equity in the transborder region.	Through examples, the article illustrates how regional leaders in San Diego and Tijuana harnessed existing transborder partnerships to collaboratively build infrastructure and communication pathways to exchange data, guidance, troubleshoot shared challenges, build capacity, and establish cross-border testing and vaccine opportunities.
Tsukayama et al. (2023)	Public health emergency operations center operations and coordination among Thailand, Cambodia, Lao PDR, and Malaysia during the COVID-19 pandemic.	To examine the coordination mechanisms between national and sub-national Public Health Emergency Operations Centers (PHEOCs) in Thailand, Cambodia, Lao People's Democratic Republic, and Malaysia (TCLM countries) during the COVID-19 pandemic.	Information was collected on PHEOC structures, functions, and cross-border communications in three stages: a literature review of national PHEOC and emergency preparedness capacities; questionnaire responses from stakeholders to describe PHEOC activity at the national level; and meetings with emergency response staff in five border provinces of Thailand to assess communications between sub-national PHEOCs across country borders.	The findings showed that each of the countries has demonstrated a commitment to strengthening their national PHEOCs and improving cross-border communication in the face of the COVID-19 pandemic. Strong existing relationships between TCLM countries assisted in activating a coordinated pandemic response, but gaps remain in efficient data sharing, workforce capacity, and the utilization of consistent communication platforms among countries. Lessons learned from the pandemic can be used to further strengthen countries' preparedness for future health emergencies, in line with World Health Organization (WHO) and International Health Regulations (2005) and regional plans to build health security in the Southeast Asia region.

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Table 2. (Continued)

Author name(s)	Title	Research aim	Methodology	Findings
Chirawurah et al. (2022)	Interactions Among Cross-Border Contiguous Communities and Implications for Managing Pandemics—The case of Ghana and Burkina Faso During the Ebola Outbreak in West Africa: A Qualitative Study.	To understand the nature of contiguous border communities' interactions and to seek community solutions for building efficient and resilient health systems to combat a possible Ebola outbreak in Ghana and Burkina Faso and the control of future pandemics.	A qualitative cross sectional study design using focused group discussions and key informant interviews involving six focused groups and 46 key informants were conducted amongst six Kasem-speaking contiguous border communities, three-each in Ghana and Burkina Faso.	Findings of interactions consisted of social interactions such as marriage ceremonies; traditional and religious practices; informal trade; and health seeking behavior in the study communities. Collaborative disease surveillance systems; constructive dialogue involving community traditional leaders; incorporation of health education into social, traditional, and religious activities; retraining of health personnel; effective communication including networking; and inter-governmental collaborations were identified as solutions to the effective control of the Ebola outbreak and for future public health interventions in general.
Kiwuwa-Muyingo et al. (2023)	Enabling data sharing and utilization for African population health data using OHDSI tools with an OMOP-common data model.	To create a standard mechanism for collecting, documenting, and disseminating COVID-19 related data or metadata, which makes the use and reuse a challenge.	Methods are divided into four categories: platform governance, capacity development (meta)data pipeline best practices, and integration with place-based attributes.	The INSPIRE PaaS for COVID-19 data leverages the cloud gateway for both individual research organizations and for data networks. Individual research institutions may choose to use the PaaS to access the FAIR data management, data analysis and data sharing capabilities which come with the OMOP CDM.
Watson et al. (2023)	Delivering on NIH data sharing requirements: avoiding Open Data in Appearance Only.	To propose a framework that states the main risks associated with data sharing, systematically present risk mitigation strategies and provide examples through a healthcare lens.	This framework was informed by critical aspects of both the Open Data Institute and the NIH's 2023 Data Management and Sharing Policy plan guidelines.	The examination of legal, technical, reputational, and commercial categories, found barriers to data sharing ranging from misinterpretation of General Data Privacy Rule to lack of technical personnel able to execute large data transfers. From this, it was deduced that at numerous touchpoints, data sharing is presently too disincentivized to become the norm.
Tacconelli et al. (2022)	Challenges of data sharing in European COVID-19 projects: A learning opportunity for advancing pandemic preparedness and response.	to focus on compliance with the General Data Protection Regulation (GDPR) and ethics approvals when sharing data across national borders.	An analysis of direct experience of four projects funded under the Horizon 2020 programme, namely ReCoDID, ORCHESTRA, unCoVer and SYNCHROS. The projects provide insight into the complexities of sharing patient level data from observational cohorts.	Procedures for data mapping; submission of new international codes to standards organization; federated approach; and centralized data curation.
Kickbusch et al. (2021)	The Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world.	To outline the governance approaches and initiatives that are required to shape health futures and transform UHC in an age of increasing digital transformations.	Shaped by an inclusive and participatory process, with the writing of the report taking place alongside broader efforts to inspire global public and private stakeholders and involve the imaginations and voices of youth.	Decision makers, health professionals, and researchers consider—and address—digital technologies as increasingly important determinants of health. The need to build a governance architecture that creates trust in digital health by enfranchising patients and vulnerable groups. A new approach to the collection and use of health data based on the concept of data solidarity.
Anane-Sarpong et al. (2020)	Ethical principles for promoting health research data sharing with sub-Saharan Africa.	To discuss mandatory data-sharing in relation to peculiar challenges faced by sub-Saharan African scientists and to suggest ethical principles for rethinking and reframing solutions.	This article is written to align the authors' experiences in working in sub-Saharan Africa with relevant literature to explore most typical risks that face science and scientists in the region.	Proposes six principles which mirror guidelines from the Institute of Medicine and encapsulate principles from the Emanuel Framework, Nairobi Data Sharing Principles, and the COHRED guidelines.

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Table 2. (Continued)

Author name(s)	Title	Research aim	Methodology	Findings
Stuart et al. (2023)	Public health research using cell phone derived mobility data in sub-Saharan Africa: Ethical issues.	To address ethical issues that arise with one particularly powerful form of such big data research: the use of cell phone data to track human mobility patterns in efforts to improve public health in SSA.	This research utilizes call data records (CDRs) that cell phone companies passively collect in real time from millions of clients.	This study empirically elucidated numerous key legal and ethical issues related to GDPR compliance in the context of (cross-border) clinical research. It showed that the lack of legal harmonization remains the biggest challenge in the field, and that it is present not only at the level of the interplay of key EU legislative acts and national implementation of the GDPR, but also when it comes to interpretation at local, regional and institutional levels.
Lalova-Spinks et al. (2022)	Challenges related to data protection in clinical research before and during the COVID-19 pandemic: An exploratory study.	To gain insights into the experience of key clinical research stakeholders (investigators, ethics committees (ECs), and data protection officers (DPOs)/legal experts working with clinical research sponsors) across the EU and the UK on the main challenges related to data protection in clinical research before and during the pandemic.	The study consisted of an online survey and follow-up semi-structured interviews. Data collection occurred between April and December 2021. Survey data was analyzed descriptively, and the interviews underwent a framework analysis.	Out of the targeted 28 countries (EU and UK), 25 were represented in the survey. The majority of stakeholders were based in Western Europe. This study empirically elucidated numerous key legal and ethical issues related to GDPR compliance in the context of (cross-border) clinical research. It showed that lack of legal harmonization remains the biggest challenge not only at the level of the interplay of key EU legislative acts and national implementation of the GDPR, but also when it comes to interpretation at local, regional, and institutional levels. Moreover, the role of ECs in data protection was further explored and possible ways forward for its normative delineation were discussed.
Natsiavas et al. (2021)	Developing an infrastructure for secure patient summary exchange in the EU context: Lessons learned from the KONFIDO project.	To provide a toolkit supporting secure cross-border health data exchange.	Key user scenarios were elaborated both in terms of threat analysis and legal challenges. Moreover, KONFIDO developed a toolkit aiming to enhance the security of OpenNCP, the reference implementation framework.	The main project outcomes are highlighted and the "Lessons Learned," the technical challenges and the EU context.
de Kok et al. (2023)	A guide to sharing open healthcare data under the General Data Protection Regulation.	To explore four successful open ICU healthcare databases to determine how open healthcare data can be shared appropriately in the EU.	A questionnaire was constructed based on the Delphi method. Then, follow-up questions were discussed with experts from the four databases. These experts encountered similar challenges and regarded ethical and legal aspects to be the most challenging.	The study found that all four databases had to account for similar challenges of sharing open health data. The most significant identified challenges were the ethical and legal aspects due to the sensitivity of healthcare data, forcing these open data projects to abide by the applicable privacy and data protection laws and regulations. Consequently, data anonymization and pseudonymization were performed, although each database implemented this differently.
Edelstein et al. (2018)	Strengthening Global Public Health Surveillance through Data and Benefit Sharing.	To explore equitable sharing of public health surveillance data.	An expert consultation conducted by Chatham House.	An expert consultation conducted by Chatham House outlined seven principles to encourage the process of equitable data sharing: (1) building trust; (2) articulating the value; (3) planning for data sharing; (4) achieving quality data; (5) understanding the legal context; (6) creating data-sharing agreements; and (7) monitoring and evaluation.

(Continued)

Table 2. (Continued)

Author name(s)	Title	Research aim	Methodology	Findings
Ntafi et al. (2022)	The legal aspect of interoperability of cross border electronic health services: A study of the European and national legal framework.	To focus on an innovative way on the influence of health policy in the law-making process and discusses traditional political science answers such as the degree of centralization of a country's health system, its financial healthcare organization.	A review of EU legislation, policy initiatives and relevant judgments of the European Court of Justice (ECJ) and the European Court of Human Rights (ECHR) concerning personal medical data.	A model of legal interoperability for cross-border eHealth services is proposed for policy makers at EU level based on the following major domains: protection and security of data, transparency, and liability, further analyzed in multiple axes and combined with EU targets, policy priorities and basic European legal principles.
Paganoni (2021)	Cross-border health data from legislation to implementation a critical discursive approach to COVID-19 responses.	To illustrate the role of the linguistic and discursive framing of the values and priorities.	The data set under analysis is composed of seven official documents at EU level, dealing with healthcare provision and characterized by a noticeable degree of interdiscursivity between different domains (legal, institutional, medical, technical).	The authors observe that interoperability is discursively encoded through a number of words and phrases that emphasize common intent and sharing of workflows.
Çami et al. (2023)	Navigating Cross-Border Challenges in Biobanking: Analyzing Eu Legislation, ECJ Case Law, and the Role of Private International Law.	To examine important legal precedents established by the European Court of Justice (ECJ) and explore the field of Private International Law.	This article offers a comprehensive analysis of the complexities surrounding cross-border biobanking within the European Union (EU), focusing on EU legislation and the notable legal precedents set by the European Court of Justice (ECJ). Additionally, it examines the efficacy of utilizing Private International Law mechanisms to navigate the legal intricacies inherent in biobanking activities.	The study highlights the potential of international conventions and treaties in promoting harmonization in cross-border biobanking practices. By illuminating how legal theories and frameworks can facilitate efficient cross-border biobanking collaborations.
Liverani et al. (2018)	Sharing public health data and information across borders: lessons from Southeast Asia.	To explore these issues, 60 interviews were conducted with domestic and international stakeholders in Cambodia and Vietnam, selected amongst those who were involved in regional public health programmes and networks.	60 interviews were conducted with domestic and international stakeholders in Cambodia and Vietnam, selected amongst those who were involved in regional public health programmes and networks.	Findings from this study document ways in which the movement of data and information from production sites to other places can be challenging due to different standards and practices, language barriers, different national structures, and rules that govern the circulation of health information inside and outside countries, imbalances in capacities and power, and sustainability of financing arrangements.

risks (Berger and Schneck, 2019). Yet, some public health emergencies, such as the COVID-19 pandemic, are time sensitive and therefore this information may need to be accessed immediately. Tsukayame et al. (2023) noted that there were differences in IT capacity and systems, which complicated data sharing within the Asian region. They noted that lack of standardized communication methods led to inconsistency in information sharing between countries (Tsukayama et al., 2023). Lawpoolsri et al. (2018), on the other hand, reported inconsistent data formats and missing variables, which compromised the quality of data in the Greater Mekong subregion. Similarly, Sperle et al. (2023) reported the need for good quality data to come up with a generalizable sample size in order to mitigate risks during health emergencies. Additionally, for good quality data to be collected, financial, human, and technical resources are required. Some studies also underscored the need for human resources such as better trained staff who collect good quality data (Sperle et al., 2023; Walker et al., 2022; Watson et al., 2023).

Theme 2: Ethics and protection of privacy in health data sharing

It was also evident from the analyzed articles that technologies can be used to discover and assess pathways of diseases during health emergencies (Kiwuwa-Muyingo et al., 2023), and expedite health interventions and treatment in ways that adhere to ethical standards. These standards include obtaining patients' informed consent and protecting privacy by de-identifying data (Van Kolfschooten, 2019; Watson et al., 2023). Vital for the handling of personal data is that data processing must be lawful, clear, and fair (Mulder and Tudorica, 2019). Personal information is regarded as sensitive and confidential data when it might possibly impact an individual's fundamental rights and freedoms. Van Kolfschooten (2019) highlights the importance of the right to informed consent and the need to safeguard this in the context of the European Union and international policy, particularly in pandemic preparedness and responses in the EU region. Similarly, Watson et al. (2023) reiterate that patients sometimes share their personal information with little to no gain. Health data is sensitive since it relates to the data subjects' health and engagement with health services. The data can also comprise population-level aggregated data regarding burdens of disease and the usage of health services (World Health Organization, 2021). Consequently, the correct balance should be struck between safeguarding the rights of data subjects and the sharing of data responsibly during global health emergencies to facilitate data driven approaches to healthcare and research. The need for this balanced approach has led to increased calls for standardized governance frameworks for data sharing (Bennett et al., 2020; IAP, 2022; Seastedt et al., 2022) to ensure data access and interoperability of heterogeneous health-related data (Tacconelli et al., 2022). This leads to the next theme of data sharing agreements.

Theme 3: Data sharing agreements

Some of the reviewed articles identified strong cross-border coordination mechanisms that lead to positive results when health data is shared across borders (Durrance-Bagale et al., 2022; Jiménez and Kozo, 2022; Tsukayama et al., 2023). Walker et al. (2022) discussed the development of legal frameworks in the Southern African Development Community (SADC) region outlining the roles and responsibilities of countries, the conditions under which the countries share data, as well as the way the data is used. This allowed a transparent process, which built trust and solidarity amongst stakeholders and partners. Durrance-Bagale et al. (2022) elaborated on how the building of partnerships and collaborations is key to the success of regional networks and further builds trust and transparency. This is essential when data is being shared across borders as legal frameworks can be well organized to allow easy access to data (Durrance-Bagale et al., 2022; Walker et al., 2022). Existing governance frameworks that are insufficiently equipped to deal with the complexities of international data sharing are a concern since they tend to perpetuate inequalities due to piece-meal decision-making, which does not consider the roles of multiple stakeholders in the data ecosystem (Kaye et al., 2018). These governance structures are designed to protect personal data within national borders, which can slow down data sharing due to the additional bureaucratic layers that a national focus creates. Kaye et al. (2018) observe that applying territorial governance to broader areas perpetuates existing inequalities as it obscures the contributions of different stakeholders to the data stream, thus underlining the importance of suitable data agreements.

Theme 4: Political commitment, transparency, and accountability

Maintaining transparency and accountability for data sharing processes, usage and intended outcomes is crucial to ensure that trust amongst all stakeholders is maintained. The need for trust and transparency includes matters relating to political, social, and organizational factors, and citizens’ engagement (Abboud et al., 2021). One of the challenges of maintaining transparency emerges from sharing data through informal networks, thus restricting other users from accessing the data (Pisani et al., 2018). This problem has been addressed by institutions and research groups through the establishment of data repositories and Data Access Committees that transparently regulate access and enable cross-border data sharing (Parker et al., 2019). Further, some of the articles underscored the importance of political commitment and data sharing. In the interviews conducted by Durrance-Bagale et al. (2022) with key experts, some respondents highlighted the importance of politicians being involved from the beginning with the associated and administrative support, as this helps to ensure that every stakeholder clearly understands the process and outcome.

Discussion

Proposals for overcoming ethical and legal challenges in cross-border health data sharing

It is clear from this scoping review that there is no one solution for overcoming the identified ethical and legal challenges in cross-border health data sharing during public health emergencies. The challenges ranging from lack of quality safety guidelines, data quality, differences in IT capacity within countries, limited budgets for collecting quality data, lack of memoranda of understanding for sharing information, and human resources capacity building have been noted (Holub et al., 2020; Sperle et al., 2023; Tsukayama et al., 2023; Watson et al., 2023). These challenges show that there is a need to streamline the existing systems to facilitate cross-border health data sharing. Current developments in information and communication technology have also improved ways of sharing information rapidly through user-friendly systems, which are available globally (Fegan et al., 2011). Accordingly, governance frameworks need to be more efficient and effective in enabling cross-border data sharing in ways that comply with ethical and legal standards.

Quality data should be shared rapidly during public health emergencies (Sane and Edelstein, 2015), yet the barriers that are identified in this review may impede the sharing of data. These barriers mainly include insufficiently equipped governance frameworks, lack of cultural sensitivity, inequitable data-sharing practices, lack of enabling frameworks for sharing data, and concerns relating to security, transparency, and accountability.

Issues relating to data ownership, data interoperability, different guidelines and loss of trust tend to complicate sharing health data during public health emergencies. Furthermore, missing details in the collected data, lack of training and inadequate preparation can raise ethical concerns as elaborated by Sperle et al. (2023). In many cases, during health emergencies, there are no plans for long-term use of the collected data, but this position is changing as noted by Holub et al. (2020) with the European biobanking infrastructure; during the COVID-19 pandemic biobanks were able to preserve valuable biological materials complemented by detailed health-related data for future research purposes (Holub et al., 2020). Pre-existing relationships are key to ensuring respect and well-functioning data sharing systems amongst professionals.

Technical barriers, as mentioned in some articles (Lawpoolsri et al., 2018; Tsukayama et al., 2023), are a huge concern. Inadequate data collection and lack of standardization, as well as shared protocols across agencies and surveillance locations, means that there is varying data quality and incompatibility in the different databases. Consequently, data is not always comprehensive or sometimes lacks variables that are important. Furthermore, language barriers have also been reported (Abboud et al., 2021) as contributing to barriers in cross-border data sharing.

Enabling regulatory frameworks for data sharing

The standardization and automation of data would make sharing health data easier and cheaper as this would be less demanding to clean up and help to ensure that the quality of the data is up to standard (Abboud et al, 2021; Lawpoolsri et al, 2018; Sane and Edelstein, 2015). It is important to note that data sharing also entails the ability to collect high-quality data, thus the need for a capable and skilled workforce.

Legal barriers can also impede health data sharing due to strict personal data protection laws that prevent data from being shared, as well as unclear legal frameworks in which exceptions to data protection on health grounds are not explicit (Kaplan, 2016; Sane and Edelstein, 2015). These gray areas become problematic as public health institutions are uncertain about sharing health data. Furthermore, lack of official or unofficial data sharing agreements across borders, and proprietary claims over data, obstruct transparent cross-border health data sharing. The main concerns raised about the regulatory frameworks relate to “lack of well-defined guidelines for data sharing, knowledge of legal regulations or technical resources to standardize and share data” (Tacconelli et al., 2022: 6). In such scenarios, legal frameworks have the possibility of overcoming technical barriers by promoting capacity building. The SADC region, for example, has developed the SADC Model law, which guides Member States on how to develop and draft data protection laws (Musoni, 2022). Additionally, the EU Decision on cross-border threats has developed public health capacity by ensuring member states’ compliance with regional standards (European Union, 2013). The regulation on the creation of the European Health Data Space, for example, has led to recommendations that can support an enabling environment for seamless data sharing to promote healthcare and research (European Parliament, 2022; Zoi et al., 2021). The European Health Data Space (EHDS) incorporates federated interrogation networks that allow remote analysis of data by researchers without data being transferred, thus ensuring protection of data subjects’ privacy (Zoi et al., 2021). Additionally, the EHDS has led to specific proposals for “common governance mechanisms (policies, guidelines, code of conduct and agreements)” that are useful for moving toward a streamlined governance system to overcome legal and ethical barriers in cross-border data sharing (Zoi et al., 2021: 8). These regional initiatives are a step in the right direction for developing a more streamlined approach, which is necessary for addressing the concerns that are identified in this paper. The values and principles that can be used for the envisaged approach are summarized below.

Streamlining the governance of health data sharing

Compliance with ethical values and the FAIR principles. The values of equity, trust, reciprocity, and accountability can be used to streamline the governance of data sharing by encouraging stakeholders to comply with the FAIR principles, namely making data findable, accessible, interoperable, and reusable (Wilkinson et al., 2016), which can be challenging during public health emergencies. A streamlined approach that is based on the aforementioned values should have the attributes of being able to maximize the use of data and ensuring productive cross-border data flows and the protection of data subjects' rights (Bitange and Thegeya, 2022). Moreover, the approach can ensure an equitable framework by being fair, efficient, and fostering accountability. Although the FAIR principles have been endorsed by many data sharing stakeholders, there are still challenges regarding data reuse, especially in health-related research, which may arise from the need to ensure confidentiality and privacy. Commercial interests and sensitivities should also be handled carefully. To facilitate compliance with these principles, support is needed to develop capacity to generate good quality data and ensure interoperability to enable data sharing (Anane-Sarpong et al., 2020; O'Connell and Plewes, 2015).

Responsible data sharing. The WHO guidelines (2017) oblige all parties who are involved in public health surveillance to share data in a timely fashion (Guideline 15). This calls for responsible data sharing, which requires stakeholders to allow the sharing of as much data as openly as possible and in a timely fashion while maintaining public trust (RDA Guidelines, 2020: para 6.4). Data trusts have been proposed as tools for ensuring trust due to their potential for representing diverse stakeholders' interests and being more flexible to accommodate rapid evolution in technologies (Milne et al., 2022; Smith, 2022). Moreover, stakeholder participation and trust are essential for any programmes that promote data sharing (Smith, 2022). Notably, data sharing itself is said to promote "trust, integrity and completeness in science" (Anane-Sarpong et al., 2020: 87). To this effect data sharing should be promoted while ensuring that data is rapidly available and accessible, ethical, equitable, and reliable.

Two values which underpin responsible data sharing are solidarity and transparency. These values are useful for avoiding punitive actions against stakeholders who share data transparently, as happened to Southern African countries when they shared the genomic sequencing data of the omicron variant of COVID-19 (B.1.1.529) with the global community (Moodley et al., 2022; Petersen et al., 2022). The travel bans that were imposed on Southern African countries after they shared data were based on unfounded fears as the bans did not stop the spread of the variant across the globe.

Cultural sensitivity and privacy regulation. Cultural differences and privacy regulations in cross border health management can bring about huge challenges if not considered (Austin et al., 2021). These challenges can be mitigated by understanding the different cultures and jurisdictions in different regions. Cultural sensitivity can be ensured through stakeholder engagement and trust, which are essential for any programme that promotes data sharing (Smith, 2022). When one is aware of these differences, proper planning can be done so that novel ethical and human rights challenges are dealt with effectively. The main barrier that emerges from privacy regulations relates to the varying approaches to determining the appropriate legal basis for processing data, which can lead to divergent advice from research ethics committees (RECs) that review protocols, thus making cross-border data sharing challenging. The determination of an appropriate legal basis is generally agreed to be the responsibility of the data controllers who are accountable for safeguarding data subjects' rights (Lalova-Spinks et al., 2022). Nonetheless, RECs are expected to assess risks when reviewing protocols and the mandate of RECs in data protection requires further clarification to ensure that the application of different legal bases in cross-border studies does not create inequalities between participants or data subjects from different countries (Lalova-Spinks et al., 2022). Another layer of complexity emerges from the assessment of the compatibility of additional processing of data with the initial purpose for which the data was collected. It is generally agreed that compatibility should be assessed in each case based on the appropriate safeguards that are in place (Wiewiorówski, 2020). A discrepancy exists in this regard when partial compatibility assessment is conducted based on the expectations of the data subjects instead of the existence of appropriate safeguards (Lalova-Spinks et al., 2022).

Policy and practice recommendations

Our findings suggest that policymakers and governments must prioritize the harmonization of legislation for cross-border health data sharing. Legal frameworks must be put in place to support cross-border health data sharing and to safeguard fundamental rights, maintain consistent adherence to ethics standards, enhance security and to protect privacy in the health data ecosystem since health data is sensitive data.

Further, to ensure consistent and high level of data protection, governments should establish clear interoperability policies, which can guide stakeholders in cross-border data sharing based on suitable data sharing agreements.

Researchers need to play an active role in supporting cross-border data sharing while ensuring that high ethical standards are maintained. They can play a crucial role in developing templates for informed consent, which reassure research participants that their personal information will be protected.

The study's strengths and limitations

In this study we considered information from different regions including Africa, Europe, Asia, North America. However, a limitation of the study is that we relied on literature that has been published in English. This may have excluded valuable literature in other languages.

Conclusion

There is a need for health systems to transform the way health data is shared across borders to better prepare for global health pandemics, respond effectively to the changing patterns of diseases, and satisfy multifaceted health care needs while taking into account limited resources. Addressing ethical and legal challenges requires collaborative efforts from communities, researchers, governments, the healthcare industry, and international organizations to ensure fair and responsible cross-border data sharing that is respectful of cultural diversity and individual rights. A streamlined global framework that is informed by the current regional best practices such as the European EHDS may be a feasible approach in dealing with unfairness in data sharing. This could facilitate timely access to data during public health emergencies. The process for developing this framework could be led by an international organization, such as the WHO, to ensure that member states are fully committed to sharing quality data and maintaining high levels of integrity. Moreover, all involved stakeholders should state and acknowledge the different interests they have in the data sharing process. The values, which are identified in this paper can be embedded in the framework to ensure mutual understanding, and address issues relating to risks and benefits of sharing data with all stakeholders, as well as any expectations. This will help to build solidarity, trust, and goodwill in all involved stakeholders. Additionally, regional and sub-national legislation and policies that govern the key elements of data sharing mechanisms should be streamlined to eliminate fragmentation of policies that govern cross-border health data sharing in countries. This will ensure flexibility and development of comprehensive data sharing policies that promote good science.

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Ethical approval

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