Evaluation Section: Data Ownership and Control

This section delves into the theme of "Data Ownership and Control," a critical aspect directly influencing researchers' willingness to share cohort data and shaping the development of effective data sharing platforms. The analysis reveals a strong sense of ownership among researchers over their data, stemming from the substantial investment of time, effort, and resources poured into its collection and curation. This perceived ownership significantly influences their willingness to share and the conditions under which they are willing to relinquish some control.

Subtheme 1: Concerns about Misinterpretation and Misuse

A significant barrier within the broader theme of data ownership is the pervasive concern among researchers regarding the potential misinterpretation and misuse of their data. This anxiety stems from the recognition that individuals unfamiliar with the intricacies of the data – its nuances, context-specific elements, and inherent limitations – may reach erroneous conclusions or utilize the data in ways that were never intended. Researchers emphasize that understanding the context in which the data was collected is paramount to proper interpretation. This includes detailed knowledge of the study design, specific methodologies employed, and potential biases that might have influenced data collection. One researcher vividly explained this concern by stating that "it can go very, very wrong if you don't know this extra information," highlighting the potential for flawed research outcomes when data is analyzed without a full understanding of its origins and limitations [1:2.11]. This concern is further amplified when sharing is extended beyond their immediate research network – researchers express a heightened need for control and oversight to ensure the data's responsible and accurate utilization. They often prefer active collaboration with those seeking to use the data, viewing it as a mechanism to safeguard against misinterpretation. For example, one researcher described their data sharing approach, stating, "The Z proposal, one will be part of the writing team, just to be a guaranteer, for the correct description of the cohort et cetera" [1:2.1]. This underscores the importance researchers place on direct involvement, either their own or that of individuals intimately familiar with the data, to guide analysis, ensure accuracy, and ultimately prevent the dissemination of misleading research findings. This desire for control over data interpretation is rooted in a commitment to scientific rigor and a sense of responsibility for ensuring the data's appropriate use.

Subtheme 2: Strategic Data Sharing for Collaboration and Visibility

The analysis reveals that researchers approach data sharing with a strategic lens, viewing it as a mechanism to foster collaboration, enhance the visibility of their work, and contribute to the advancement of scientific knowledge. This strategic approach stands in contrast to the notion of data sharing as a passive act of making data available; instead, it highlights a desire for active engagement and mutual benefit. Researchers prioritize partnerships where they can actively contribute to the research process. For instance, one researcher stated, "In general, in the past...only the results were shared but not the actual data," highlighting a shift towards greater data sharing, but under the condition of active collaboration [3:2.9]. They seek opportunities to shape research questions, participate in data analysis, and be recognized for their contributions through co-authorship on publications. This desire for active involvement reflects a deep-seated belief that data sharing should be a two-way street, fostering scientific exchange and mutual benefit. Co-authorship emerges as a particularly crucial aspect of this strategic approach. This strategic perspective on data sharing is also intertwined with the desire to enhance the visibility of their research and gain recognition for their work. Through collaborative data sharing, researchers aim to expand the reach of their data, attracting new collaborators and increasing the impact of their research. This strategic approach, balancing openness with the pursuit of scientific

recognition and advancement, has significant implications for how data sharing platforms are designed and utilized.

Subtheme 3: Challenges with Legacy Cohorts and Data Ownership Transition

The longevity inherent in cohort studies, particularly older ones, introduces a unique set of challenges related to data ownership and control. As the original researchers involved in data collection retire or pass away, the process of transitioning data ownership to new generations of researchers becomes increasingly complex. This transfer of ownership is not merely a logistical hurdle; it raises fundamental questions about authorship and the criteria used to determine who can rightfully claim ownership and control over the data. The challenge is particularly pronounced when newer generations of researchers, while possessing the skills and interest to analyze the data, may not have been involved in the original data collection or preparation phases. For instance, one researcher highlighted this dilemma, stating, "The people who collected the data...have retired, some have died already...it is not straightforward how [new researchers] could comply with the first criterion of the ICMJE" [6:2.17]. This discrepancy creates tension with established authorship guidelines, such as those outlined by the International Committee of Medical Journal Editors (ICMJE), which typically require authors to have been substantially involved in data collection or analysis. This tension underscores a potential conflict between upholding traditional authorship criteria and facilitating the continued use and analysis of valuable legacy cohort data.

Subtheme 4: Negotiating Control through Data Access Committees and Agreements

Data Access Committees (DACs) and formal data sharing agreements emerge as critical mechanisms through which researchers negotiate and exert control over their data. They represent a structured approach to balancing the desire for data sharing with the need to protect data integrity, ensure appropriate use, and address potential concerns related to misuse or misinterpretation. DACs act as gatekeepers, responsible for scrutinizing data access requests and ensuring alignment with the study's purpose, ethical guidelines, and the parameters of informed consent obtained from participants. They review proposals, assess the qualifications of those seeking access, and may guide researchers towards collaborative models to mitigate risks associated with misinterpretation or misuse. This role was emphasized by one researcher who stated, "Everyone is free to apply for data but it is scrutinized if it fits with the overall purpose" [1:2.3]. Formal data sharing agreements further solidify the terms of data use. One researcher explained their agreement terms, stating, "the data after a certain time...needs to be deleted from the pc of the person who is doing the analysis. And it’s always that co-authorships from the X study will be involved" [2:2.5]. These agreements serve to protect the interests of both the data generators and those seeking to use the data. However, while these mechanisms are seen as vital for maintaining control, concerns about their potential to introduce bureaucratic hurdles are also acknowledged. The process of proposal review, ethical clearance, and agreement negotiation can be time-consuming, potentially slowing down the research process.

Subtheme 5: The Tension between Openness and Maintaining Competitive Advantage

While researchers generally acknowledge the overarching benefits of open data sharing for scientific progress, they also grapple with the inherent tension between embracing openness and safeguarding their own competitive advantage. This tension reflects a practical consideration within the research landscape – researchers strive to balance a commitment to scientific openness with the strategic pursuit of research goals and recognition for their work. While recognizing the value of data reuse and replication for broader scientific validation, researchers may prioritize

their own research agendas. This sentiment was echoed by another researcher who stated, "The B trial group should have the possibility to write the key publications first and then it’s open" [1:2.2]. They seek to retain control over data analysis, particularly when it aligns directly with their areas of expertise or ongoing research projects. This emphasis on collaboration, rather than pure data sharing, underscores the perceived value of active involvement in research projects and the importance of recognizing the effort invested in data generation. For instance, one researcher expressed, "But to give it out completely to people who have not contributed in any kinds… I don’t know if that is feasible" [3:2.10]. The desire to maintain a level of control over data use is often linked to the substantial effort and resources invested in cohort establishment and data collection. Navigating this tension between openness and competitive advantage requires a nuanced approach that respects both the communal benefits of data sharing and the individual interests of researchers who have invested considerable effort in generating valuable data.

Overall Conclusion: Implications for Data Sharing Platforms

In conclusion, the theme of "Data Ownership and Control" highlights the multifaceted and nuanced perspectives researchers hold regarding the sharing of cohort data. Researchers' sense of ownership over their data significantly influences their willingness to share, the conditions they place on data access, and their preferences for collaborative research models. This theme emphasizes the need for data sharing platforms to move beyond simply providing access to data and instead foster environments that support collaboration, recognize the contributions of data generators, and address researchers' concerns about data misinterpretation and the potential loss of control. Platforms that successfully navigate these complex issues will be better positioned to encourage data sharing and unlock the full potential of cohort data for advancing scientific knowledge.

The Evolving Landscape of Data Sharing Practices and Incentive Structures

This section delves into the evolving landscape of data sharing practices and incentive structures within the research community. It explores how traditional academic reward systems, primarily focused on authorship and impact factor, are increasingly recognized as insufficient for promoting and rewarding the multifaceted efforts involved in data-intensive research. The analysis highlights researchers' desire for more comprehensive systems that acknowledge diverse contributions, including data generation, quality assurance, and collaborative analysis. It emphasizes a growing awareness of the need to transition towards a more collaborative and open research culture, supported by alternative metrics and recognition mechanisms that accurately reflect the value of data sharing and collaborative research practices.

Subtheme 6: Inadequacy of Traditional Authorship Models for Data-Intensive Research

This subtheme examines the limitations of traditional authorship models, particularly the emphasis on first and last authors, in adequately reflecting the collaborative nature of data-intensive research. While first and last author positions retain their importance in signifying leadership and overall project responsibility, the contributions of individuals involved in other crucial aspects, such as data collection, processing, and analysis, often become obscured, particularly in studies involving large consortia and extensive author lists.

Interviewees acknowledge the inherent tension between the collaborative nature of data-intensive research and the traditional authorship model. One participant [1:2.11] criticizes the prevailing attitude that prioritizes first and last authors while diminishing the contributions of middle

authors as "just trash," particularly in large-scale epidemiological studies involving decades of data collection from thousands of participants. This sentiment underscores the inadequacy of the current system in recognizing the essential roles played by researchers throughout the research lifecycle. Another interviewee [2:3.14] expresses a contrasting view, suggesting that authorship should be restricted to those directly involved in data analysis for a specific publication. While acknowledging the efforts of data generators and others, this perspective advocates for alternative forms of recognition, such as listings in the collaborator or acknowledgment sections. This highlights the ongoing debate within the research community regarding appropriate attribution and reward mechanisms for different research contributions.

The emphasis on first and last authorship in research evaluation creates a system where middle authors, despite their significant contributions, may not receive adequate recognition, impacting their career progression and the perceived value of their work. This practice fails to acknowledge the reality of modern research, which often relies on large-scale collaborations and the expertise of individuals across various domains. For example, an interviewee [3:5.16] highlights that while participating in large consortia can lead to high-impact publications, the individual contributions of researchers, especially those listed as middle authors, are often overlooked in evaluations, emphasizing the need for more nuanced recognition mechanisms.

Subtheme 7: Exploring Alternative Crediting Mechanisms and Data-Level Metrics

This subtheme explores the growing interest in alternative crediting mechanisms, such as data authorship, detailed contributor roles, and data-level metrics, to acknowledge and reward the diverse contributions within data-intensive research. These alternative approaches aim to address the limitations of traditional authorship models by providing a more granular and comprehensive representation of individual contributions.

However, there is a lack of consensus among researchers regarding the effectiveness and practical implementation of these alternative mechanisms. Some researchers are optimistic about the potential of data authorship and detailed contributor roles. They recognize the value of these approaches in recognizing the efforts of individuals involved in data generation, quality control, and other essential research activities. For instance, one interviewee [3:8.14] acknowledges the importance of individual recognition and suggests that with increasing research complexity, finding ways to acknowledge diverse contributions, potentially through mechanisms like the CRediT taxonomy, will be crucial.

Conversely, skepticism exists regarding the practical application and impact of these alternative crediting mechanisms on research evaluation. An interviewee [2:3.23] expresses indifference towards detailed contributor roles, stating a preference for directly contacting researchers with specific expertise rather than relying on role descriptions provided in publications. This perspective highlights a potential disconnect between the intended purpose of such mechanisms and their actual utilization by researchers. Further, the lack of standardized implementation and the absence of widespread adoption within the research community raise concerns about the effectiveness of these alternative mechanisms in driving meaningful change.

While alternative crediting mechanisms like data citation hold promise, their implementation remains a topic of debate. An interviewee [6:7.11], while acknowledging data citation initiatives, expresses skepticism about their applicability to complex datasets. This skepticism underscores the need for further development and refinement of alternative crediting systems to ensure their practicality and efficacy across diverse research contexts. The successful implementation of alternative mechanisms requires addressing these practical concerns and fostering wider adoption within the research community.

Subtheme 8: The Need for Funders and Institutions to Realign Incentives and Support Data Sharing

This subtheme emphasizes the pivotal role of funders and academic institutions in promoting a research culture that values and rewards data sharing. By aligning incentives and providing necessary support, these stakeholders can effectively drive the adoption of open science practices. The analysis highlights how funding structures and institutional policies significantly influence researchers' decisions regarding data sharing.

Interviewees acknowledge the significant influence of funders on researchers' data sharing practices. Funders, through their grant allocation processes and requirements, have the power to shape research priorities and practices. As highlighted by one interviewee [4:4.11], the most effective way to encourage researchers to adopt new practices, such as data sharing, is by incorporating them as requirements for receiving research grants. This perspective underscores the importance of clear guidelines and mandates from funding agencies in driving the cultural shift towards open science.

However, the current funding landscape, often focused on project-based grants, poses challenges. One interviewee [4:4.11] points out that researchers often prioritize research projects aligned with available funding opportunities, potentially neglecting equally important research avenues due to a lack of financial support. This funding structure can stifle innovation and limit the scope of research undertaken. This underscores the need for a more diversified funding landscape that supports a wider range of research activities, including data generation, curation, and sharing, to foster a more robust and comprehensive research ecosystem.

Furthermore, while universities recognize the importance of research support roles, funding these positions remains challenging. An interviewee [7: 8.11] highlights the difficulty in securing funding for support staff, such as statisticians, who play a crucial role in data-intensive research. Funders primarily prioritize project-based grants, leaving support roles underfunded and consequently hindering the overall productivity and efficiency of research teams. This funding disparity undermines the sustainability of research infrastructure and highlights the need for funders to recognize and support the crucial role of these often-invisible contributors.

Another significant challenge is the lack of resources allocated for data preparation, a critical step in the data sharing process. Despite the increasing pressure on researchers to share data, they often lack the necessary financial and personnel resources to adequately prepare their data for sharing. As noted by one interviewee [6:6.11], the lack of resources to make data shareable represents a significant barrier. This lack of support makes it challenging for researchers to engage in data sharing initiatives and highlights the urgent need for funders and institutions to provide dedicated resources and infrastructure for data preparation and curation.

Subtheme 9: The Role of Journals in Promoting Transparency and Data Citation

This subtheme explores the influential role of journals in promoting transparency, data citation, and open research practices. By implementing policies that encourage data sharing, journals contribute to a research environment where data accessibility and reusability are valued and rewarded.

Interviewees widely recognize the impact of journal policies on researchers' behavior. One participant [6:6.11] highlights the significant progress made by journals in pushing for data sharing and providing mechanisms for acknowledging data contributions through co-authorship or other contributor roles. Journals can leverage their position to incentivize data sharing further by adopting policies that encourage or mandate data citation, promoting transparency in

authorship contributions, and supporting the use of data repositories. By integrating data-related metrics into the publication process, journals can motivate researchers to make their data accessible and contribute to a more robust and reproducible scientific literature.

Subtheme 10: Leveraging Data Sharing Platforms to Track Data Usage and Contributions

This subtheme emphasizes the potential of data sharing platforms in enhancing transparency, facilitating collaboration, and enabling equitable recognition for data-related contributions. By providing tools to track data usage, promote data reuse, and acknowledge data contributions, these platforms can address some of the challenges associated with traditional research evaluation systems.

Data sharing platforms can contribute to greater transparency and build trust within the research community by providing clear information about data access procedures and usage. As highlighted by one interviewee [1:1.21], a clear and accessible webpage with information on how to access the data is crucial for promoting transparency and facilitating data reuse. Additionally, platforms that enable the tracking of data access requests and monitor data reuse can provide valuable insights into the impact and reach of datasets. This information can be used to demonstrate the value of data sharing and advocate for increased support for data-intensive research. For instance, an interviewee [4: 5.11] highlights that tracking data reuse not only indicates data quality but also showcases good data management practices, ultimately benefiting the original data generators through increased visibility and potential collaborations.

Overall Conclusion

In conclusion, the analysis of the theme "The Evolving Landscape of Data Sharing Practices and Incentive Structures" reveals a research landscape in transition. While traditional academic reward systems centered on authorship and impact factor remain dominant, there is a growing recognition of their inadequacy in reflecting the collaborative nature of data-intensive research. The subthemes explored in this section highlight the multifaceted challenges associated with data sharing and the need for a systemic shift in how research contributions are recognized and rewarded.

The analysis underscores the need to move beyond traditional metrics and embrace alternative crediting mechanisms, such as data citation, detailed contributor roles, and data-level metrics. Furthermore, it emphasizes the crucial role of funders, institutions, and journals in driving this cultural shift by aligning incentives, providing necessary support for data sharing activities, and promoting transparency in research practices.

Navigating Legal and Ethical Considerations in Data Sharing

This section delves into the crucial theme of navigating legal and ethical considerations in data sharing, a topic of paramount importance in our exploration of barriers to data sharing and their impact on data sharing platforms. As researchers grapple with the increasing need for collaboration and data reuse, understanding the legal and ethical landscape, particularly regarding sensitive personal data, becomes paramount. This analysis will explore the multifaceted challenges researchers face in complying with regulations like GDPR, ensuring informed consent aligns with data sharing practices, and managing the intricacies of international data transfer.

Subtheme 1.1: GDPR and its Impact on Data Sharing Practices

The implementation of the General Data Protection Regulation (GDPR) marked a significant shift in data protection practices across Europe, profoundly impacting how researchers collect, store, and share data. While the principles of data protection enshrined in GDPR are widely supported, researchers express concerns regarding the complexities of its practical application, particularly in the context of international data sharing.

One of the key challenges emerging from the analysis is the difficulty of navigating varying interpretations of GDPR across institutions and national authorities. Researchers find themselves caught between conflicting interpretations, even within the same geographic location, which creates significant bureaucratic hurdles and slows down research endeavors. For instance, one researcher [1:2.1] described facing significant debate and conflicting interpretations of GDPR within their own university and hospital, highlighting how discrepancies in understanding the regulation can hinder collaboration even at a local level. Another researcher [1:2.17] recounted their experience of encountering roadblocks due to differing interpretations of data access regulations between a university and regional authorities within the same city, hindering their ability to conduct research using existing datasets.

Furthermore, the practical implications of GDPR on international data sharing, particularly with collaborators outside the EU, raise concerns about the perceived lack of clarity and flexibility in applying GDPR principles. The requirement for informed consent, while crucial for protecting individual privacy, poses challenges in international collaborations where obtaining consent for future, unspecified research purposes may not align with initial consent agreements or cultural norms. One researcher [3:2.5] noted that while GDPR contains provisions favorable to research (specifically mentioning Article 89), these are often deemed inapplicable in international collaborations, necessitating informed consent procedures that may not always be practical in cross-border research.

This perceived conflict between the principles of open science and the data protection requirements of GDPR is another critical aspect highlighted by the analysis. While open science encourages data sharing and reuse to accelerate scientific progress, the stringent requirements for purpose limitation and data minimization under GDPR, particularly when dealing with sensitive personal data, present challenges for researchers seeking to share data broadly. A researcher [6:2.12] highlighted this tension, explaining that the open access to data for any purpose is simply "out of the question" due to GDPR restrictions, especially when dealing with sensitive personal data requiring specific purpose justification for access. This tension underscores the need for a nuanced approach that balances the benefits of open science with the imperative of individual privacy.

In conclusion, while GDPR represents a crucial step towards harmonizing data protection practices across Europe, its implementation has created practical challenges for researchers engaged in data sharing, particularly in international collaborations. Addressing these concerns requires ongoing dialogue between policymakers, legal experts, and the research community to develop more flexible and context-specific interpretations of GDPR that facilitate responsible data sharing without compromising individual privacy rights.

Subtheme 1.2: The Use of Privacy as a Barrier to Data Sharing

While safeguarding privacy is a fundamental ethical principle in data sharing, our analysis reveals instances where privacy concerns may be used instrumentally as a convenient justification to resist data sharing, particularly when researchers are reluctant to relinquish control over their data or aim to maintain a competitive edge. This finding underscores the importance of distinguishing

genuine privacy concerns from situations where privacy is invoked as a barrier to collaboration and data reuse.

Researchers perceive a reluctance to engage in data sharing, often disguised by emphasizing potential privacy risks, even when data could be shared securely and ethically. This suggests that data ownership and the desire to retain control over potential publications and recognition within the research community might supersede the benefits of collaborative research. One researcher [4:2.8] explicitly stated their belief that the invocation of GDPR and privacy concerns is often a smokescreen for unwillingness to share data, stemming from a sense of data ownership rather than legitimate privacy concerns. This sentiment was echoed by another researcher [4:2.9], who argued that the "privacy argument" against data sharing is frequently a guise for researchers who want to maintain control over their data and potential research outputs, hindering the progress that could be achieved through collaboration.

This perceived misuse of privacy concerns as a barrier to data sharing emphasizes the need for more transparency in data governance models and the promotion of open science principles. Encouraging a culture of data sharing requires addressing the underlying motivations for data hoarding, such as concerns about data ownership, recognition, and potential misuse.

In conclusion, while respecting and protecting individual privacy is paramount in data sharing practices, it is crucial to recognize that privacy concerns can be misused to impede collaborative research. Fostering a culture of open science necessitates a balanced approach that addresses legitimate privacy concerns while encouraging data sharing practices that promote scientific progress for the benefit of all.

Subtheme 1.3: Challenges with Informed Consent and Evolving Data Sharing Practices

The evolving landscape of data sharing practices, particularly in the context of long-term cohort studies, presents significant challenges regarding informed consent. Our analysis highlights the limitations of consent obtained in the past, which might not adequately cover the breadth of data sharing practices common today, especially for older cohorts where initial consent procedures may predate contemporary data sharing technologies and ethical considerations.

Researchers express concerns about sharing individual-level data due to limitations in the original informed consent agreements. Participants may have consented to data storage and use for specific research purposes outlined at the time of data collection, but these purposes might not encompass the broader data sharing practices prevalent today. One researcher [1:2.14] expressed the view that while sharing anonymized datasets would be ideal, the reality of obtaining informed consent for specific, often narrowly defined, research purposes creates limitations. They highlighted that participants primarily consent to data storage and use within the bounds of the original study, potentially limiting broader data sharing initiatives. The same researcher [1:2.14] emphasized the importance of understanding the local context and rationale behind data collection, suggesting that sharing data without this nuanced understanding could lead to misinterpretations.

These findings highlight the ethical dilemma faced by researchers who are eager to share data for broader scientific benefit but are constrained by the limitations of past consent practices. Addressing this challenge requires a multi-pronged approach. Open communication with study participants about evolving data sharing practices and the implications for their data is crucial. Implementing mechanisms for dynamic consent, allowing participants to revisit and modify their consent preferences over time as data sharing practices evolve, can empower individuals and enhance trust in research.

In conclusion, reconciling evolving data sharing practices with informed consent obtained in the past, especially for older cohorts, presents a significant ethical challenge. Developing robust and flexible consent procedures that anticipate future data sharing needs while ensuring individual autonomy and trust will be crucial for maximizing the utility of valuable cohort data for scientific progress.

Subtheme 1.4: Managing the Complexities of International Data Transfer and Varying Regulations

International data sharing, while crucial for addressing global health challenges and advancing scientific knowledge, introduces significant complexities related to data transfer agreements, compliance with diverse data protection regulations across borders, and managing varying interpretations of legal and ethical frameworks. Our analysis reveals that navigating these complexities is a considerable source of concern for researchers, particularly when collaborating with countries outside the European Union, where data protection frameworks may differ considerably from GDPR.

Researchers highlighted the bureaucratic and legal obstacles encountered when negotiating data sharing agreements across international borders. The lack of harmonized data protection regulations globally, coupled with varying interpretations of ethical guidelines, can lead to uncertainty and delays in research projects. One researcher [1:2.17] described difficulties in accessing data even within the same city due to conflicting interpretations of data governance between different authorities, highlighting the challenges of navigating bureaucratic hurdles. Another researcher [2:2.3] pointed out restrictions on data transfer depending on the specific country involved, suggesting that international data sharing requires careful consideration of local regulations and potential limitations.

Experiences shared by researchers suggest that collaborating with countries outside the EU can be particularly challenging due to differences in data protection frameworks. One researcher [3:2.6] recalled facing difficulties when American colleagues, accustomed to less stringent data protection regulations, encountered obstacles accessing data stored under the auspices of GDPR after returning to the US. This experience underscores the need for clear communication and understanding of varying legal frameworks among international collaborators. Another researcher [3:2.7] noted that while GDPR applies across the EU, differing interpretations and levels of restrictiveness in implementing the regulation across member states create ambiguity and necessitate careful navigation.

These findings highlight the need for standardized guidelines and streamlined procedures for international data sharing. One researcher [3:2.10] observed that researchers in the US often struggle to grasp the complexities and requirements of GDPR, suggesting a need for greater awareness and understanding of international data protection frameworks. Developing internationally recognized data sharing agreements and ethical guidelines could help mitigate legal uncertainties and foster greater trust among collaborating institutions.

In conclusion, managing the complexities of international data transfer and navigating the patchwork of data protection regulations globally remains a significant barrier to data sharing. Harmonizing legal frameworks, fostering international cooperation, and developing clear, standardized guidelines for cross-border data sharing will be crucial for facilitating responsible and ethical data exchange on a global scale.

Subtheme 1.5: The Need for Clear Guidance and Support in Navigating Legal and Ethical Frameworks

The complexities of navigating legal and ethical frameworks related to data sharing underscore the pressing need for clear, accessible guidance and support for researchers. Our analysis reveals a strong desire among researchers for practical advice on interpreting data protection regulations like GDPR, navigating data transfer agreements, and addressing uncertainties surrounding the permissible scope of data use.

Researchers expressed frustration with the lack of clear, actionable advice from legal experts and data protection officers within their institutions. The perceived ambiguity surrounding GDPR interpretation and implementation creates uncertainty and hesitancy among researchers, hindering data sharing initiatives. One researcher [2:2.2] expressed frustration that while data protection officers are consulted for guidance on GDPR compliance, the responses received are often vague and lack specific instructions, leaving researchers unsure about the proper course of action. Another researcher [2:2.2] highlighted the reliance on individual interpretations of GDPR, noting that even within the same institution, different individuals may interpret the regulations differently, leading to inconsistent data sharing practices.

This lack of clear guidance is exacerbated by limited resources and support within institutions, particularly regarding GDPR compliance in data sharing. Researchers often find themselves navigating complex legal frameworks independently, relying on their own interpretations or seeking external advice, which can be time-consuming and costly. One researcher [7:2.15] described the limited staffing and expertise available within their institution to provide support for data sharing initiatives. This lack of dedicated support can be a significant barrier, particularly for researchers who are not well-versed in data protection law and require expert guidance to ensure compliance.

Furthermore, the challenges of international data sharing are compounded by varying interpretations and understanding of GDPR requirements across borders, particularly with collaborators outside the EU. This highlights the need for clear, standardized guidelines and resources that can be easily understood and implemented by researchers from diverse legal backgrounds. One researcher [3:2.10] pointed out that researchers in the US often struggle to grasp the intricacies of GDPR, suggesting a need for educational resources and cross-cultural training to bridge the knowledge gap and facilitate international collaboration.

In conclusion, empowering researchers to share data responsibly and ethically requires providing them with the necessary tools and support. This includes developing clear, practical guidelines for interpreting and implementing data protection regulations, establishing dedicated support services within institutions to provide expert advice on data sharing procedures, and fostering international collaborations to harmonize legal frameworks and promote a global culture of ethical data exchange.

Overall Conclusion

Navigating legal and ethical considerations is not a mere hurdle in data sharing but a foundational pillar upon which responsible and sustainable data sharing practices must be built. This theme, with its intricate subthemes, demonstrates that researchers are not merely seeking technical solutions for data sharing but also grappling with the profound implications of data sharing for individual privacy and the responsible use of sensitive information. The analysis reveals that while regulations like GDPR are essential for establishing a framework for data protection, their implementation can create unanticipated challenges for researchers, particularly in international collaborations where varying interpretations and a lack of clear guidance can impede data sharing initiatives.

The findings underscore that addressing these challenges requires a multi-pronged approach. Policymakers must prioritize developing clear, standardized guidelines for data sharing, particularly concerning international data transfer and the interpretation of complex data protection regulations. Institutions must invest in resources and support services to equip researchers with the knowledge and tools needed to navigate legal and ethical considerations effectively. Moreover, fostering a culture of open science requires addressing the underlying motivational factors that contribute to data hoarding, promoting transparency in data governance models, and incentivizing responsible data sharing practices that prioritize both scientific progress and individual privacy.

By addressing these multifaceted challenges, the research community can create a more robust and ethical data sharing ecosystem that unlocks the full potential of valuable data resources while safeguarding individual rights and fostering global scientific collaboration.