# CHAPTER 18

# Sharing (or Not Sharing) Sensitive Data

*Sara Mannheimer and Venice Bayrd*

## Introduction

Recent years have seen the rise of initiatives to share research data openly to facilitate research transparency and reproducibility and to advance and accelerate scientific discovery. However, not all research data should be made openly available. In this chapter, we examine sensitive data from the perspective of data curators. We provide an overview of sensitive data and discuss strategies that can enable sensitive data sharing or facilitate transparency when data cannot be shared. To illustrate the complexities of sensitive data, we provide an example of a form of data that may be less commonly recognized as sensitive—research data on water quality from private wells in Montana. We conclude the chapter with lessons learned and advocacy for an ethically centered, highly collaborative, interdisciplinary future for open data initiatives.

## Open Science and Open Research Data

Open research data is a key element of open science* and helps promote the open science goal of "making research products and processes available to all."[1] These research products can include scholarly publications, research data, and research workflows, such as the code used to generate and analyze data.[2] When we refer to open data and data sharing in this chapter, our intention is to refer to research data as well as other supporting documentation as applicable—e.g., field protocols, metadata, software, code, raw and intermediary data products, and so on.†

In her book *Big Data, Little Data, No Data*, Borgman suggests four key rationales for sharing research data: "...(1) to reproduce research, (2) to make public assets available to the public, (3) to leverage investments in research, and (4) to advance research and innovation."[3] Open research data produces additional transparency and reproducibility for open science by providing unrestricted and open access to the data that was analyzed to produce research results.[4] Open research data can also be reused for future research, thus advancing and accelerating

* The terms open scholarship and/or open research may also be used to more clearly include all disciplines, including humanities, arts, science, and social science. We use the term open science in this chapter, but our intention is to consider all disciplines in our discussion.

† For a fuller discussion of the complexities of defining data in different disciplines, see: Christine L. Borgman, *Big Data, Little Data, No Data: Scholarship in the Networked World* (Cambridge, MA: The MIT Press, 2015), https://doi.org/10.7551/mitpress/9963.001.

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science and potentially reducing financial and labor-related burdens on researchers and participants.[5] Disciplines that were early adopters of open data practices include: physics, which pioneered open access articles with arXiv[6] and has gone on to lead a generalist research data repository effort through Zenodo, a project from CERN;[7] ecology and environmental science, which produced The Joint Data Archiving Policy and launched the generalist Dryad Repository;[8] and genomics, which contributed to the open data movement with the Human Genome Project and Genbank[9] in the 1990s.[10] In social science, political science and psychology have been early adopters of data sharing practices, including scholarly conversations[11] and repository infrastructure for data sharing.[12]

In response to the potential benefits of open research data, policies to encourage data sharing began emerging in the early 2000s in the United States and worldwide.‡ Such policies have continued to grow since then. In 2013, the White House Office of Science and Technology Policy (OSTP) issued a memo regarding a national commitment to data sharing;[13] OSTP updated this guidance in 2022 to call for immediate, free access to federally funded research, including research data.[14] These United States policies have led to a requirement to include data management and sharing plans (DMSPs) in federal grant proposals. In Europe, the Horizon 2020 Programme open access pilot launched in 2014,[15] and the Open Data Directive was established in 2019.[16] Some private funders, such as Wellcome[17] and Bill & Melinda Gates Foundation,[18] require DMSPs. Academic societies and journals have also adopted data sharing guidelines and policies. These policies illustrate the widespread adoption of open data policies; however, most of these policies provide exceptions for various forms of sensitive data.

Many institutions have developed services and resources to facilitate research data management throughout the research lifecycle.[19] Help with data management planning, storage, curation, and sharing may be provided by university research offices, institutional review boards (IRBs), research cyberinfrastructure, academic libraries, and other university offices and services; collaborative partnerships between such entities are emerging to facilitate data-intensive research and research data management.[20] In academic libraries, the roles of data curator and data librarian are growing, providing guidance and training for researchers on data management planning, metadata, data use and reuse, repository selection, and data sharing considerations.[21]

Researchers have also responded to trends toward open data. A trio of articles by the DataONE Usability and Assessment group shows that researcher perspectives on open data have evolved over time—from limited understanding and acceptance of open data practices in 2011 to more widespread support for data management and sharing in 2020.[22] However, these studies found that, as of 2020, there is still "a discrepancy between positive attitudes and actual implementation of those principles by the scientific community."[23] These discrepancies stem from a variety of concerns from researchers, including the need to publish before sharing data, insufficient time or funding, lack of rights to make the data public, institutional support, and the potential risks of data sharing.[24]

# Sensitive Data

As noted above, despite prevailing rationales and trends, not all research data may be appropriate to share openly. This section begins by addressing some of the challenges specific to sharing sensitive data, including legal, cultural, ethical, and administrative concerns. The

‡ A note about the scope of this chapter: we come at this from a United States perspective because that is where we live and work. We cite some US-specific policies in this chapter, and we have also tried to include some international policy examples. Regardless of policies cited and examples provided, most of the ideas in this chapter will be transferable to many different contexts, including internationally. For more information on global open science efforts starting in the early 2000s, see the "Background Information" section of: OECD, "Recommendation of the Council concerning Access to Research Data from Public Funding," OECD/LEGAL/0347.

section closes with a discussion of several strategies that researchers and curators can employ to make data "as open as possible, as closed as necessary."[25]

## Challenges to Sharing Sensitive Data

The rise of data sharing has brought conversations about sensitive data to the fore. As open data becomes more common, it is all the more important to consider what makes data sensitive, including unexpected sensitivities that may arise. Responsible data sharing requires awareness of potential risks and potential harms to research stakeholders, and situations may arise in which the risks outweigh the rationales for sharing data openly.[26] Data sensitivity can arise in multiple scenarios. These situations may be related to legal constraints (e.g., proprietary data, intellectual property concerns), cultural considerations (e.g., Indigenous data sovereignty), human subjects considerations (e.g., privacy protections, consent, vulnerable behaviors or identities), and other types of confidential information. Sensitive data can arise in unexpected places as well, as illustrated in the subsequent "Water Quality Data from Private Wells" example.

Some examples of sensitive data include[27]

- human subjects data from research participants from vulnerable populations—e.g., children, people involved in illegal activities, political dissidents, religious minority communities, or respondents from marginalized and minoritized communities such as Black, Indigenous, LGBTQIA+, or disabled communities;
- human subjects data from research on sensitive topics—e.g., drug or alcohol use, details of sexual activity, relationship/domestic violence, criminal behavior, health and mental health-related questions;
- human subjects data relating to Indigenous cultures, communities, and knowledge;
- archaeological site information with geolocation data;§
- endangered species data;**
- patentable inventions or other proprietary data; and
- human subjects data that contains personally identifiable information that cannot be deidentified.

Internationally, various frameworks provide a spectrum of sensitive data guidance ranging from laws to non-binding recommendations to global initiatives that shape policy. The mismatch between international data privacy laws is one of the challenges to sharing sensitive data across borders,[28] adding an important layer of complexity to international research collaborations. In the United States, treatment of many categories of sensitive data is encompassed by technical implementations of Controlled Unclassified Information (CUI) protection in academic and other non-governmental systems.†† The Australian Privacy Act of 1988[29] and the Australian Research Data Commons provide legal guidance and resources, respectively, on sensitive data;[30] and the European General Data Protection Regulation (GDPR) and related directives[31] provide stringent protection of individual privacy rights. Global initiatives to address sensitive data and data privacy include the United Nations Global Pulse initiative,[32] the United Nations Declaration on the Rights of Indigenous Peoples,[33] and UN initiatives connecting big data and sustainable development goals.[34] The 2021 version of the Organisation for Economic Co-operation and Development (OECD) *Recommendation of the Council concerning Access to Research Data from Public Funding,*[35] also acknowledged that legal protections and cultural principles affect whether data may be openly shared.

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§ To explain further, keeping archaeological site geolocation data private protects the location of sensitive cultural heritage sites and prevents looting and vandalism.

** To explain further, keeping endangered species data private prevents poaching and species removal.

†† CUI standards in the US are addressed by Ron Ross and Victoria Pillitteri, "Protecting Controlled Unclassified Information in Nonfederal Systems and Organizations" (Gaithersburg, MD: National Institute of Standards and Technology, 2024).

The landscape of guidance addressing ethical sensitive data reuse is rapidly shifting. Sharing sensitive data has the potential to benefit science and society—as in the case of sharing clinical trial data to support global health.[36] But sharing sensitive data also has the potential to do harm to communities—as in the numerous documented instances of harms to Indigenous peoples as a result of data sharing.[37] Integrating culturally appropriate methods into curation practices is critical as open data initiatives advance. Methods can involve principles, including: findable, accessible, interoperable, reusable (FAIR)[38] and collective benefit, authority to control, responsibility, and ethics (CARE);[39] standards such as the draft IEEE P2890 Recommended Practice on Provenance of Indigenous Peoples' Data;[40] and distinctions-based approaches[41] early in the research process. Examples of operationalizing ethical practices to decolonize the curatorial process are emerging.[42] Thielen, et al. have begun to outline what a more thoughtful curatorial pace might resemble in practice.[43] Critical engagement with culturally appropriate practices will require relationship-building and time.

On the administrative side, challenges to handling, storing, and facilitating access to sensitive data can provide collaboration opportunities for librarians, information security staff, research IT professionals, and others.[44] Institution-level data governance policies may define various colloquial classes of sensitive data and suggest local storage guidance. However, the focus of such policies tends to be enterprise data (i.e., personnel, student, financial, and administrative data) rather than research data. As one example, at Montana State University, where we work, we have nuanced guidance for enterprise data, but less so for research data. Different types of enterprise data have known and predictable sensitivity/protection status, and therefore their treatment is defined within data governance policy. Research data, in contrast, are highly heterogeneous and unpredictable by nature, a fact that frequently (though certainly not always) renders sensitivity classification an ad hoc activity. Research data management is also often interwoven into IRB human subjects data decisions and/or informed consent agreements, and research compliance offices may be involved to provide guidance on research data protected by law. Determining storage solutions for sensitive data can thus become a collaborative, case-by-case process. This remains a topic to watch in the near future, as awareness of the enterprise versus research data governance gap is beginning to take shape in the library, information science, and IT communities (e.g., Nexus Day 2024 *Data Governance and Working with Data* workshop,[45] Research Data Alliance Sensitive Data Interest Group,[46] Sensitive Data Expert Group of the Digital Research Alliance of Canada).[47]

## Enabling Sensitive Data Sharing

As outlined above, sensitive data may not always be appropriate to share. However, there are strategies and considerations that can help enable responsible sharing of sensitive data. We suggest some of these strategies below.

### *Data Deidentification*

Data deidentification procedures aim to mask participant identities or other sensitive information by removing direct and indirect identifiers. Direct identifiers are pieces of information that can specifically identify an individual person or place, such as name, social security number, or address. Indirect identifiers are pieces of information that, on their own, do not identify a specific person but can be linked to other information to potentially reveal individual identities. Some examples of indirect identifiers are date of birth, zip code, gender, or geolocation.[48] However, deidentified data still holds a risk of deductive disclosure or re-identification,[49] and some data may be too sensitive to take on this risk.[50]

When sharing a dataset that includes deidentified data, data curators can help researchers include details about data status in the metadata, and they can work with researchers to help with deidentification. Some deidentification methods can introduce uncertainties or affect replicability and thus must be weighed carefully when evaluating data sharing options. If deidentification reduces the value of the shared data, sharing the data with access restrictions could be a better option.

## Restricted Access

If researchers wish to provide access to data that are too sensitive to be shared openly, some repositories provide resources and infrastructure to support various levels of restricted access to sensitive data,[51] including, in some cases, providing data enclaves in which data can only be accessed for data analysis, not download.[52]

## Data Licensing and Data Use Agreements

Regardless of how restricted or open sensitive data access may be, a license or public domain waiver can help make it clear to future users how data may be used and reused.[53] Data repositories can also provide data transfer and data use agreements that facilitate the responsible transfer and use of sensitive data.

## Informed Consent

Another important practice to enable sensitive data sharing is to appropriately obtain consent from research participants to share research data. Informed consent goes beyond simple consent to participation in research. To obtain informed consent, researchers must: 1) provide the necessary information for research participants to make an informed decision; 2) ensure that research participants fully understand this information; and 3) ensure that the decision to participate in the research is voluntary.[54] Informed consent practices have an impact on data sharing. In order to share data, even with restricted access, informed consent documents must include details about any potential future data sharing so that participants are aware of how data will be shared.[55] Researchers can also offer tiered consent.[‡‡] Tiered consent structures provide various consent options for participants—for example, opting into the study but opting out of data sharing, consenting to restricted data sharing, or allowing a subsection of data to be shared.[56] IRBs that oversee ethical practice in human subjects research,[57] funding agencies,[58] data curation professional groups,[59] and data repositories[60] may provide template language to facilitate participant consent to data sharing.

## Transparency Strategies When Sharing is Not Possible

For especially sensitive data that truly cannot be shared (or in the case that researchers have not obtained proper consent for data sharing), other strategies can support transparency. For example, sharing a subset of data or sharing aggregated data can mask participant identities and protect sensitive material while still providing some data access. Publishing a metadata record, sharing code books, or sharing an overview of the data can also enable discovery and enhance knowledge of the research without providing direct data access.

For sensitive data that cannot be shared, researchers may invoke exceptions to data sharing mandates from funding agencies. For example, in the United States, the National Institute of on Alcohol Abuse and Alcoholism provides guidance on exceptions,[61] the National Science Foundation (NSF) states that exceptions to its data-sharing requirements may be made "based on legal, privacy, ethical, intellectual property and national security considerations,"[62] and National Institutes of Health (NIH) includes "justifiable reasons for limiting sharing of data" in its Data Sharing FAQs.[63] Journal data sharing policies also allow researchers to explain any data sharing exceptions in the data availability statement.[§§] Sometimes data status may change during the course of a research project, as illustrated in the following "Water Quality Data from Private Wells" example. In the event of data status changes in grant-funded research,

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‡‡ Tiered consent may also be referred to as flexible consent, line-item consent, or multilayered consent.

§§ For example, see: "Reporting Standards and Availability of Data, Materials, Code and Protocols," Nature Editorial Policies, Nature, 2024; "Understanding Our Data Sharing Policies," Taylor & Francis, 2024, https://authorservices.taylorandfrancis.com/data-sharing-policies/; "Wiley's Data Sharing Policies," Wiley, 2024, https://authorservices.wiley.com/author-resources/Journal-Authors/open-access/data-sharing-citation/data-sharing-policy.html.

proactive DMSP changes made in consultation with funding agency program officers are both acceptable and expected. DMSPs are living documents—that is, DMSP updates are best seen as normative rather than exceptional or undesirable. Updating a DMSP may be necessary if the data status changes from shareable to non-shareable. For research that is not federally funded, DMSPs can be updated according to specific practices outlined by funders, research teams, or institutions.

## An Illustration of Sensitive Data

The strategies described in the previous section for facilitating sensitive data sharing can introduce uncertainties. For instance, masking or eliding spatial data fields is one option for geotagged data, but methods such as location offsets cannot be described in public metadata (due to potential for re-identification) and may affect replicability and reusability. The following illustration, drawn from our data curation work with researchers, is an example of geotagged data status shifting through the life of a project. This example illustrates the complexities of real-world sensitive data curation.

In addition to methodological uncertainties, this case study also demonstrates how multi-layered trust relationships within a research project can surface complex data management scenarios. We chose this example because it represents a less commonly considered situation relating to sensitive data and thus raises a variety of questions. We also chose it because we were engaged only at the end of the project, at which time we determined that the data could not responsibly be shared. Given the emergent and shifting nature of the issues described, we invite readers to consider, as we have done: what would have been a responsible course of curatorial action in this scenario had curators been involved in the project beginning in the research planning phase? There is no presumption here that data curators have all of the answers; rather, there is an earnest interest to examine the layers of complexity that can arise in the course of research, and to reflect on the resulting ramifications for our professional curatorial practice.

### *Water Quality Data from Private Wells*

Under the aegis of the Consortium for Research on Environmental Water Systems (CREWS) project (NSF-OIA award #1757351), researchers in Montana investigated water quality issues specific to intensive agriculture, hard rock mining, and energy extraction. As part of their investigations, CREWS researchers collected water quality data from wells on private farmland. One facet of privately held lands is economic: they are a real estate commodity. Well data that reveal the presence of contaminants can therefore become sensitive data because contaminant data could harm land valuation.

If sharing well data could jeopardize the researcher-partner relationship and/or permission to do the research on privately held land, researchers might choose to anonymize or exclude those data from a shared research dataset. For example, one CREWS researcher noted:

> *We did work to protect locations of some of our data collection on private land in [region] to protect the privacy of cooperating farmers. In my experience it is common that by the end of a project, farmers are fine with sharing data, but during the relationship building stage, it can be reassuring to them that we will not share the data with locations.*[64]

This scenario illustrates how sharing data from research conducted on private lands may depend upon the trust relationship built between researchers and private landowners. Research data resulting from a trust relationship may necessitate additional care to create a balanced approach to curation, considering trust relationships alongside privacy and research integrity protections and exemptions to sharing.

It can be difficult to foresee all potential data sensitivities ahead of time. Sometimes, as in this case, data curators are not consulted in advance, so whether approaches such as informed

consent are considered during the research planning phase becomes dependent on researchers' awareness of available strategies; this awareness, it bears mentioning, differs among disciplines. When data curators are involved early in the research lifecycle, it becomes possible to collaborate with researchers to continually reevaluate data stewardship responsibilities, especially prioritizing the relationship between the researchers and the research partners or research participants, and continually assessing the potential risks and harms that could be associated with sharing research data. As noted previously in the discussion of ethical data sharing, prioritizing ethical curation practices will require not only relationship-building but will also require taking the time to carefully consider data sharing from the outset of a project.

# Conclusion and Future Directions

It may not always be appropriate to openly share research data. In this chapter, we have discussed how data curators can facilitate sharing for sensitive research data, when appropriate. This chapter suggests that data curation professionals can assist with data deidentification, restricted access, data licensing and data use agreements, informed consent, and transparency strategies when sharing is not possible.

In an illustration of a real-world research scenario, we explored the complexities of handling sensitive data and the challenges of relationship-building among stakeholders when sharing sensitive data. In the course of our work as data curators, we have observed that trusted relationships between curators and researchers can make the difference between researchers either co-developing solutions for complex data sharing scenarios in collaboration with curators or not involving curators at all. As described by Farrell in 2023,[65] building collaborative partnerships between data curators and researchers is a critical pillar of future open data initiatives. As we have personally seen, building such trusted, collaborative partnerships is particularly important for projects involving sensitive data. Sensitive data sharing is context-specific and requires case-by-case consideration. With the proper relationship-building and collaborative structures, data curators can facilitate either sharing or not sharing sensitive data, depending on the specific context of each research project.

## *Notes*

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