

Privacy and the Past: Research, Law, Archives, Ethics

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Archival user studies typically conclude by saying more research needs to be done despite the difficulty in persuading researchers to spend time describing their experiences working in reading rooms. We simply do not have enough information on our clientele. We are fortunate, then, to have a detailed report from researcher Susan C. Lawrence, a professor of history at The Ohio State University, who has made extensive use of archival resources and has published several books and numerous articles on the history of medicine. Lawrence spent a number of years working on this book about archives and privacy, and she attended several annual meetings of the Society of American Archivists to gather detailed information on a subject that has long bedeviled both archivists and historians: the privacy rights, if any, of people who are no longer living. She looks at the subject from many angles: the actual laws and regulations, ethical considerations beyond legal requirements, user agreements, the use of institutional review boards, the working of the courts, the role of archivists, and the methods of historians. Not one to rely on hypothetical situations, Lawrence salts the entire text with a great number of thought-provoking case studies and interesting real-life examples. She has done her homework. Her bibliography includes 264 references, and her narrative is documented with twenty-nine pages of endnotes.

So, what exactly distracted Susan Lawrence from her chosen field of medical history and motivated this huge effort to come to terms with privacy and archives? She was angry. Lawrence is polite, soft-spoken, and calm and is used to working methodically and meticulously. She is not easily rattled. One of her graduate students was using what seemed to be open public documentation on indigent residents of a “poor farm” in the post-Civil War era. All the people named were long dead. It was a chance to recover the experience of people who are normally forgotten by history. While the student was at work, an irate stranger confronted her and abruptly ordered her to “cease and desist.” She was ordered to attend a meeting with the Health Insurance Portability and Accountability Act (HIPAA) compliance officer, the county board of supervisors, and the county attorney. The graduate student, who just thought she was working on routine mid-nineteenth-century history, was found in violation of the HIPAA Privacy Rule. It was a rude and unpleasant experience. As the student’s adviser, Lawrence was unamused. She assumed that the dead do not have privacy rights, but the wording of the Privacy Rule at that time, in 2006, was open

ended. The student and her adviser eventually found a work-around agreement. So as not to offend unknown surviving family members, they anonymized and masked names in a manner that could not be easily traced. Lawrence was able to overturn efforts to require prior approval of the final written report, and the student published her research in 2010. Lawrence was not entirely happy with this solution. Research should be replicable. Readers should be able to trace back through the footnotes to the original documents to verify the accuracy of the research. This basic research principle had to be violated to get the work through what felt like draconian obstacles. It felt like censorship, like a violation of the First Amendment.

Lawrence is aware that the Privacy Rule was revised in 2013 to provide an end date for restricting access to personal medical information, some fifty years after the death of the data subject. Fifty years still seems like an unnecessarily long interval to restrict use. She is also aware that archivists need to follow statutory requirements, especially regarding the use of medical information. Lawrence feels in general that archivists have a great deal of room for discretion in deciding what to restrict, and she sees a disturbing trend to obstruct use. She cites a case from 2008 when another historian and graduate student were prevented from using files on Civil War veterans. When the gatekeepers (i.e., archivists) could not prevent access, the state legislature passed special legislation to restrict the records. Lawrence is particularly concerned about this tendency to extend privacy rights to the dead. She is also worried that applying provisions for protecting human research subjects to ordinary oral history programs is stifling research on the living, and she feels these trends diminish the understanding of our common past.

At several points, she mentions the effect these trends and restrictive approaches have on access to digitized archives and online sources: "Well-meaning zeal to build regulatory bulwarks against unwarranted government surveillance, corporate data collection, and industrial-strength network hacking in order to safeguard personal privacy in the present must not be allowed to shape how we can understand the past" (p. 116). The more digital tools intrude on privacy, the more push back there is. This area is receiving increasing attention from historians such as Timothy Garton Ash, who has written extensively on the conflict between privacy and freedom of speech in the Internet age, specifically in his volume *Free Speech: Ten Principles for a Connected World*.¹ This conflict is no longer an esoteric subject restricted to discussion among information managers. In an era when huge search engines collect and market vast amounts of private information, often surreptitiously, legitimate research is being hampered in the name of privacy. We seem to be witnessing a historic shift that is creating confusion about the normal boundaries of propriety, community standards, and expectations for leading a private life. The more intrusions people

experience, the more they try to set up protective walls. Lawrence herself is willing to follow rules and respect protective walls up to a point. When she interviewed me for the book, she asked me to sign a formal release. She had secured advance approval from an institutional review board for her research on the book. But the subtext is that all this paperwork is counterproductive.

In her last chapter, Lawrence makes some far-reaching recommendations. First of all: "I cannot leave this book without calling for unqualified resistance to privacy protections for the dead" (p. 116). I think many archivists—not all, but many—would agree with this. It is difficult enough to safeguard the privacy of the living. Then she takes the argument further: "In the end, historians—just like anyone else—must follow their consciences. A historian may need to violate confidentiality agreements if the value of truth-telling or the demands of social justice outweigh privacy concerns, especially if such provisions are largely protecting the interest of powerful people who once engaged in wrongdoing" (p. 121).

The experience of seeing her graduate student's work obstructed in 2006 has led ten years later to a book that is a meditation on access, with some surprising conclusions. People who are refused access remember the experience vividly. It would probably be instructive for every reference archivist to have a project that required using archives in an unfamiliar repository and navigating the obstacles that can arise. In *Privacy and the Past*, we do not have a "user study" carefully designed by archivists to fit preconceived notions. It is a direct message from our clientele. While it is carefully documented, the conclusions may not fit into the paradigms we generally work with. Whether or not one agrees with every argument presented here, there are important lessons in this book that warrant serious attention.

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Archivist Emerita, Stanford University

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- ¹ Timothy Garton Ash, *Free Speech: Ten Principles for a Connected World* (New Haven: Yale University Press, 2016).