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Patient Experiences of Access to Mental Health Records

A thesis submitted in partial satisfaction of the
requirements for the degree

Master of Library and Information Science

by

Noah Geraci

2016

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2016

ABSTRACT OF THE THESIS

Patient Experiences of Access to Mental Health Records

by

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Master of Library and Information Science

University of California, Los Angeles 2016

Professor Anne J. Gilliland-Swetland, Chair

This thesis seeks to shift the discussion of mental health records in archives and records management literature by foregrounding the autonomy and experiences of records subjects, drawing from the scholarship surrounding archival activism, human rights and disability studies. Using qualitative content analysis of in-depth interviews with five people who have accessed their own records in California, this exploratory study shows evidence that mental health records serve significant practical and affective functions for the people whose experiences they document and that there are multiple barriers to accessing these records. Though contemporary mental health records are typically not stewarded in archival repositories, their associated challenges present a rich opportunity and argument for the value of nonaligned archival advocacy, and for professional archives and records communities to engage with immediate records needs in communities at large.

The thesis of Noah Geraci is approved.

Michelle L. Caswell

Jonathan Furner

Anne J. Gilliland-Swetland, Committee Chair

University of California, Los Angeles

2016

Dedicated to Erica Botz and Horacio Roque Ramírez

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Chapter 1: Introduction

“The archivists handed me a manila folder. On the front of it were the words ‘DULLY, Howard.’ The great mystery of my life was inside.”

Howard Dully and Charles Fleming, *My Lobotomy* (New York: Three Rivers Press, 2008).

“Every individual is a key stakeholder in access to records, potentially if not always in practice— not simply the ‘users we prefer’, already trained and skilled in using our descriptive methods to enable retrieval.”

Barbara Reed, “Reinventing Access,” *Archives and Manuscripts* 42, no. 2 (May 4, 2014): 123.

Existing research on medical records within archival studies has been relatively limited, often taking legal and privacy issues as its primary focus.¹ Surrounding mental health records in particular, the research has not generally incorporated the perspectives of records subjects, often minimizing their agency and ability to comprehend or make decisions around their own records.² Within the field, the Health Insurance Portability and Accountability Act (HIPAA) is largely understood as privacy legislation, though it also contains the important “right of access” clause, codifying the right to access one’s own records.³

Within archival studies, there is an increasing interest in affect, ethics of care, and the emotional impacts of records on users.⁴ For example, in Australia, this has been explored

1. See, for example: S. C. Lawrence, “Access Anxiety: HIPAA and Historical Research,” *Journal of the History of Medicine and Allied Sciences* 62, no. 4 (January 4, 2007): 422–60, doi:10.1093/jhmas/jrl048; Judith A Wiener and Anne T Gilliland, “Balancing between Two Goods: Health Insurance Portability and Accountability Act and Ethical Compliancy Considerations for Privacy-Sensitive Materials in Health Sciences Archival and Historical Special Collections,” *Journal of the Medical Library Association : JMLA* 99, no. 1 (January 2011): 15–22.

2. Lorraine Dong, “Taking the Long View of Medical Records Preservation and Archives,” *Journal of Documentation* 71, no. 2 (2015): 387–400.

3. “The HIPAA Privacy Rule’s Right of Access and Health Information Technology” (Office for Civil Rights, U.S. Department of Health & Human Services, n.d.).

4. See Marika Cifor, “Affecting Relations: Introducing Affect Theory to Archival Discourse,” *Archival Science* 16, no. 1 (March 2016): 7–31, doi:10.1007/s10502-015-9261-5; Michelle Caswell and Marika Cifor, “From Human Rights to Feminist Ethics: Radical Empathy

particularly in regard to individuals who have been in institutional care as children,⁵ and in Canada there has been some exploratory work regarding the records of residential schools for indigenous children and the related Truth and Reconciliation Committee.⁶ Less engagement with these topics has been seen by archivists in United States perhaps because of the U.S. reluctance to adopt a records continuum approach that more willingly engages with records at all stages in their lifecycle and with records that are not in archival repositories.

On either a U.S. or international scale, there has still been little work specifically surrounding records created in mental healthcare systems. Yet this work clearly aligns with goals of archival autonomy⁷ and meta-archival advocacy⁸ articulated by prominent scholars as being critical elements of societal grand challenges and the future of archival and recordkeeping professions.

Despite a lack of existing scholarly research on the topic, the significance of mental health records to the people whom they have been created about is illustrated by texts such as Howard Dully's autobiography *My Lobotomy*, which details his emotionally charged experiences

in the Archives," *Archivaria* 81, 2016,
<http://journals.sfu.ca/archivar/index.php/archivaria/article/view/13557/14916>.

5. Jacqueline Z. Wilson and Frank Golding, "Latent Scrutiny: Personal Archives as Perpetual Mementos of the Official Gaze," *Archival Science* 16, no. 1 (2015): 93–109, doi:10.1007/s10502-015-9255-3.

6. Lisa P. Nathan, Elizabeth Shaffer, and Maggie Castor, "Stewarding Collections of Trauma: Plurality, Responsibility, and Questions of Action," *Archivaria* 80 (2015), <http://journals.sfu.ca/archivar/index.php/archivaria/article/view/13545>.

7. Joanne Evans et al., "Self-Determination and Archival Autonomy: Advocating Activism," *Archival Science* 15, no. 4 (December 2015): 337–68, doi:10.1007/s10502-015-9244-6.

8. Anne J. Gilliland, "Permeable Binaries, Societal Grand Challenges, and the Roles of the Twenty-First-Century Archival and Recordkeeping Profession," *Archifacts*, 2015.

as an adult retracing and recovering information through records about the lobotomy forced upon him at twelve.⁹

Formerly institutionalized artist, writer and activist Dorothy Dundas’s collage poster *Behind Locked Doors*, created using recontextualized pieces of her records, engages themes of records, identity, power and control and demonstrates the power of possessing and re-shaping one’s own record. About the collage, Dundas has written, “When people look at my poster, their most frequent response is, “Wow! How can I get my own records? I have always wanted to have mine!” I tell them, “Just do it! And be persistent. Even if the contents turn out to be upsetting, I doubt you will ever be sorry.”¹⁰

Within clinical research and practice in the United States, the OpenNotes project has advocated for healthcare providers to make current visit notes, including mental health notes¹¹, available to patients, and has reported positive outcomes for patient care.¹² The research presented in this thesis aims to complement from a humanities-inflected archival perspective the work of OpenNotes and other medical transparency advocacy: bringing a temporally longer view of access and preservation, and centering ex/patient experiences through open-ended qualitative methods rooted in disability studies and feminist frameworks. The ultimate goal is to improve awareness among information professionals around the experiences of individuals accessing their

9. Dully and Fleming, *My Lobotomy*.

10. Dorothy Dundas, “Behind Locked Doors: How I Got My Hospital Records, and What I Did With Them,” *Mad In America*, May 13, 2014, <http://www.madinamerica.com/2014/05/behind-locked-doors/>.

11. Michael W. Kahn et al., “Let’s Show Patients Their Mental Health Records,” *JAMA* 311, no. 13 (April 2, 2014): 1291–92, doi:10.1001/jama.2014.1824.

12. Tom Delbanco et al., “Inviting Patients to Read Their Doctors’ Notes: A Quasi-Experimental Study and a Look Ahead,” *Annals of Internal Medicine* 157, no. 7 (2012): 461–70.

own records, to encourage critical reflection around archives and records access and description practices to improve service and accountability to this user population on both individual and systemic scales.

Research questions

Why do people access mental health records created about themselves, and what do they do with them? What are the practical and affective experiences of people accessing such records? How and why should archives and recordkeeping professionals incorporate an understanding of these experiences to meet the needs of this population?

Key terms and concepts

Mental health record

There is no existing scholarship which explicitly engages with creating a definition of a mental health record. In the design of this research, a mental health record is being understood loosely as any record reflecting an encounter with a mental healthcare provider or entity or mobilized for purposes related to mental health. This includes, but is not limited to, mental health-related records created by hospitals, clinics, schools, social service agencies, private practitioners and treatment facilities, group homes, jails, prisons or courts of law. Ultimately, “mental health record” will be defined by each interview participant according to their own experience and interpretation.

This research takes the perspective that neither “mental health” nor “record” are categories with hard borders. While a project with a broader or more theoretical scope might rightly seek to highlight other potential kinds of mental health records beyond the clinical record, such as patient diaries and artwork, or records of patients’ rights groups, this study’s focus on

issues surrounding access to “official” records necessitates the use of a more conservative definition.

Access

The Society of American Archivists’ *Glossary of Archival and Records Terminology* defines access as both the ability to locate relevant information, and the permission to locate and retrieve the information.¹³ Both of these facets of access are central to mental health records access and thus make this a generally useful working definition. The only necessary modification is to call into question “information” as the sole object of access. While many seeking access to their mental health records may be in search of the information contained in these records, another factor may be the experience of encountering the record’s physical form. Other users may need to obtain a copy of a record to submit elsewhere to fulfill a specific legal or bureaucratic requirement, with little regard for the information contained within.

Greater clarity will be provided here by the results of this research, which seeks to begin from a perspective that makes no assumptions about records seeker desires, goals or motivations. Barbara Reed’s “Reinventing Access,” which articulates a commitment to serving all kinds of users and critically examines questions of infrastructure design and professional priorities in relation to access, is a central text for the way access is being approached here.

Affect

Affect is both like and not-quite emotion. Feminist theorist Patricia Clough articulates the

13. Richard Pearce-Moses, *A Glossary of Archival and Records Terminology*, Archival Fundamentals Series (Chicago: Society of American Archivists, 2005): 2.

subtle difference by naming affect as an immediate internal, embodied response (philosopher Brian Massumi calls it a “prepersonal intensity”)¹⁴ that is distinct from the social meaning-making processes that shape affect into emotion.¹⁵ Feminist theorist Sara Ahmed has conceptualized affect as “sticky”: “Affect is what sticks, or what sustains or preserves the connection between ideas, values, and objects.”¹⁶ Affect has been a prominent concern in critical theory, cultural studies, feminist and queer theory over the past two decades, and has recently gained increased traction in the archival sphere.¹⁷

When applied in the realm of qualitative social science research, it may be impossible to wholly preserve the theoretical integrity of affect as distinct from emotion. The boundaries become blurry: there is no way to empirically observe or record internal, presocial affect, particularly of a person other than one’s self. Instead, this research will rely on affect as self-reported by participants, and as it can be externally observed by the researcher: perhaps an impure affect from the point of view of an affect theorist, but an attempt to grasp at something a bit more complex and nebulous than emotion, and inclusive of bodily reactions as well as those more immediately articulated as emotions.

14. Brian Massumi, “Introduction,” in *A Thousand Plateaus: Capitalism and Schizophrenia*, by Gilles Deleuze and Felix Guattari, 1 edition (Minneapolis: University of Minnesota Press, 1987), xvi.

15. Patricia Ticineto Clough, “Introduction,” in *The Affective Turn: Theorizing the Social*, ed. Patricia T. Clough and Jean Malley, 1st edition (Durham: Duke University Press Books, 2007), 2.

16. Sara Ahmed, “Happy Objects,” in *The Affect Theory Reader* (Durham, NC: Duke University Press Books, 2010), 29.

17. UCLA’s Department of Information Studies hosted a symposium dedicated to affect in archival studies in 2014 (see *Affect and the Archive*, accessed November 12, 2015, <https://affectandthearchive.wordpress.com/>), and affect is the focus of a special 2016 issue of *Archival Science*, edited by Anne Gilliland and Marika Cifor.

Chapter 2: Literature review

Patient access to records in clinical research and medical informatics

In a clinical context in the United States, patient access to medical records was first advocated in print in 1973 by Budd Shenkin and David Warner, arguing in an opinion piece that

easier patient access to records could increase patient satisfaction with healthcare and improve patient autonomy in decision-making. They advocated for legislation to be passed that would entitle all patients to receive copies of unexpurgated inpatient and outpatient medical records.¹⁸

Over twenty years later, this legislation came to pass in the form of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Though HIPAA is colloquially known as privacy legislation, it serves a number of functions beyond regulating privacy and confidentiality through the establishment of the category of “Protected Health Information,” including codifying a patient’s right to access their own record in most cases. Notably, records classed as “psychotherapy notes” are excluded here, but this does not bear on access to psychiatry or other mental health-related records.¹⁹

The OpenNotes project, initiated in 2010 by physician-researchers at Harvard Medical School, promotes healthcare transparency from a provider perspective by advocating and providing a platform for patient online access to provider visit notes. In a year-long quasi-experimental trial of the OpenNotes platform with primary care doctors and patients at three sites, researchers assessed the effects of the program on doctors and patients through collecting data on portal use and administering surveys to participants regarding behaviors and views regarding the program. Results showed an overwhelmingly positive response from patients, with 77% to 87% of patient respondents across sites reporting that access to the notes helped them feel more in control of their care, and doctors reporting minimal effects on their work lives.²⁰

18. Budd N. Shenkin and David C. Warner, “Giving the Patient His Medical Record: A Proposal to Improve the System,” *New England Journal of Medicine* 289, no. 13 (September 27, 1973): 688–92.

19. 45 CFR 164.524 - *Access of Individuals to Protected Health Information.*, accessed October 29, 2015, <https://www.law.cornell.edu/cfr/text/45/164.524>.

20. Delbanco et al., “Inviting Patients to Read Their Doctors’ Notes.”

While a limited geographic scope and the possibility that respondents who completed the surveys were those with more positive perspectives on the project limit the generalizability of the findings, it points in interesting directions for records access, and the results are echoed by research on notes access within the Veterans Administration health system, which includes “behavioral health” records created by psychologists, psychiatrists and social workers.²¹

In a finding particularly relevant to the current research project, Delbanco et al. report that 59% to 62% of patient respondents desired the ability to add commentary to their provider’s notes, which might be understood in an archival context as “talking back to the record.”²² Also significant is that, while OpenNotes research thus far has been carried out in the context of primary care medical records, project leaders published a 2014 opinion piece, simply and aptly titled “Let’s Show Patients Their Mental Health Records,” in the *Journal of the American Medicine Association*. This piece explicitly advocates for mental health records transparency and addresses concerns from a provider perspective, arguing that records regarded as “behavioral health” should not be restricted differently than other medical records.²³ The authors cite a particularly poignant reflection from a psychologist colleague who initially had reservations

21. See Kim M. Nazi et al., “VA OpenNotes: Exploring the Experiences of Early Patient Adopters with Access to Clinical Notes,” *Journal of the American Medical Informatics Association* 22, no. 2 (March 1, 2015): 380–89. Susan S. Woods et al., “Patient Experiences With Full Electronic Access to Health Records and Clinical Notes Through the My HealtheVet Personal Health Record Pilot: Qualitative Study,” *Journal of Medical Internet Research* 15, no. 3 (2013).

22. See Kathy Carbone, “Artists in the Archive: An Exploratory Study of the Artist-in-Residence Program at the City of Portland Archives & Records Center,” *Archivaria* 79 (Spring 2015): 27–52 for an in-depth exploration of the concept of “talking back to records” and records annotation in the context of art pieces created using police surveillance records.

23. Kahn et al., “Let’s Show Patients Their Mental Health Records.”

about sharing patient notes but eventually came to express a nuanced view on language and recordkeeping:

When we think [and write] about our patients in a kind of language that *we* deem inappropriate or potentially offensive to the uninitiated, who is to say that our own attitudes toward our patients are not affected by that language? Wouldn't we be closer to our patients' experience if we got into the habit of thinking about them in language they would find meaningful and useful?²⁴

The primary limitation of applicability here for records access research conducted by healthcare providers is that participating providers are willingly making their notes and other records available as they are creating them. Provider-researchers and participants in OpenNotes research are working at institutions with an organizational commitment to improved transparency, and are creating records with knowledge of the patient as reader. Thus, while their findings are significant for records creation and management practices going forward, indicating the benefits and significance of patient access to records, there remains a gap in study of patient/user experiences navigating systems not designed to promote patient access to records, or accessing records not created with them in mind as readers. There is also a lack of conversation in both directions between the clinical informatics literature and more humanities-influenced archival studies scholarship.

Medical and mental health records in archival studies

The archival studies literature regarding mental health records, and medical records more broadly has historically been slow to grapple with the complex issues brought up by these

24. Cassandra Cook, PhD, e-mail communication, cited in Kahn et al.

records. One early *American Archivist* article on the topic details, from a purely practical standpoint, the implementation of a records management program for medical records in Ohio state mental hospitals. Gill and Mitchell outline records retention practices that were determined to be most functional and economical from the point of view of the hospitals, which were struggling in terms of space and staff time to manage an increasing volume of records. This included retaining only a limited set of records permanently, including admission, diagnostic, and death certificates, and destroying records such as treatment records, case histories, and correspondence after one to three years. While there is some consideration given to future research value of records, there is no mention of patient access to records or consideration of why some records might hold personal value for patients.²⁵

Little more was published surrounding medical records in archives until the 1980s, when a literature engaging privacy and confidentiality issues began to emerge. This growing concern might be read as influenced by U.S. deinstitutionalization policies of the 1970s, which set into motion the closure of many large residential psychiatric institutions²⁶, leaving a large body of records that brought up legal uncertainties for archivists seeking to accession them. Roland Baumann cites one such case, the transfer of Ionia State Hospital records to the Michigan State Archives²⁷, in his argument for state legislatures to pass laws clarifying accession and access

25. James Gill and Thornton Mitchell, "Ohio—Disposition of Medical Records in State Mental Hospitals," *The American Archivist* 26, no. 3 (1963): 371–78.

26. See Duane Stroman, *The Disability Rights Movement: From Deinstitutionalization to Self-Determination* (Lanham, MD: University Press of America, 2002).

27. Notably, this body of records later formed a major source for Jonathan Metzl's critical analysis of race and diagnostic categories in *The Protest Psychosis: How Schizophrenia Became a Black Disease* (Beacon Press, 2011).

restrictions for records containing confidential information in state archives, with the goal of maximizing preservation and access wherever possible within these bounds.²⁸ Irene Kearsey, on the other hand, emphasized the problems of public archives acquiring such records both in regard to confidentiality concerns and volume of records.²⁹

Research surrounding privacy and confidentiality of medical records in archives as it relates to historical research has continued intermittently to the present.³⁰ The work of Anne T. Gilliland and Judith Wiener is particularly salient in not only identifying legal and ethical challenges through a historical survey of legal and professional ethics literature³¹, but also in providing recommendations for archivists to address these challenges, arguing that “with thoughtful planning, it is possible to balance the integrity of and access to the historical record of sensitive documents, while supporting the privacy protections of HIPAA and professional ethical standards.”³² Such considerations have been translated into a set of specific access recommendations for archival repositories by medical archivists Phoebe Evans Letocha and Emily Novak Gustainis, who created these recommendations as part of a Council for Library and

28. Roland M. Baumann, “The Administration of Access to Confidential Records in State Archives: Common Practices and the Need for a Model Law,” *The American Archivist* 49, no. 4 (October 1, 1986): 349–69.

29. Irene Kearsey, “Some Problems in Placing Modern Medical Records in Public Archives,” *Archives and Manuscripts* 17, no. 2 (1989).

30. See Lawrence, “Access Anxiety”; John Petrilo, “Legal and Ethical Issues in Protection of the Privacy of Behavioral Health Care Information,” in *Privacy and Confidentiality in Mental Health Care*, ed. John J. Gates and Bernard S. Arons, (Baltimore, Md: Health Professions Press, 1999), 91–125.

31. Judith A. Wiener and Anne T. Gilliland, “Digitizing and Providing Access to Privacy-Sensitive Historical Medical Resources: A Legal and Ethical Overview,” *Journal of Electronic Resources in Medical Libraries* 8, no. 4 (2011): 382–403. Note that author Anne T. Gilliland of the University of North Carolina should not be confused with Anne J. Gilliland of UCLA, who is the chair of this thesis committee and also cited throughout.

32. Gilliland and Wiener, “Balancing between Two Goods.”

Information Resources (CLIR) grant project with a focus on ethically maximizing access to health-related collections.³³

Lorraine Dong's work currently provides the most thorough engaged questions around mental health records, and her argument for historical mental health records as cultural heritage documents significantly advances the conversation beyond a focus on privacy and confidentiality, while still relying on the notion of the historical record as invoked by Wiener and Gilliland. Using Actor-Network Theory, a material-semiotic approach drawn from science and technology studies that frames nonhuman entities as active participants in systems and relationships, Dong conceptualizes mental health records as actants that serve a multitude of functions over time in the classification and treatment of patients and in the development of psychiatry and psychiatric hospitals as institutions: important documents for scholarship in the history of medicine.

While Dong briefly mentions the potential for mental health records to support "liberation historiography," or the writing of new historical narratives by members of marginalized communities, records subjects' perspectives are not centered in Dong's work, which places the record as central actant, giving more attention to the agency of the record itself than to the life it documents. In other words, her argument for the records' value centers around broad concepts of cultural heritage and historical value, rather than affective or practical value for records subjects.

Anna Sexton's work creating participatory digital archives of mental health recovery

33. Phoebe Evans Letocha and Emily R. Novak Gustainis. "Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information about Individuals," February 1, 2015, <http://www.medicalheritage.org/2015/02/12/now-available-recommended-practices-for-enabling-access-to-manuscript-and-archival-collections-containing-health-information-about-individuals/>.

stories bears mention here as a project recognizing the agency of people with mental illnesses, centering people rather than the record itself or the broader historical record.³⁴ This worthwhile project in the tradition of documentation strategy works to collaboratively preserve underrepresented perspectives and pose questions about authority and autonomy by creating new records.

While not specific to medical records or people with mental illnesses, Sara White's "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description" makes an important disability studies intervention in archival scholarship that is highly relevant here, as this project conceives of mental illness as situated loosely within the category of disability. White argues that disability studies scholar Tobin Siebers' theory of complex embodiment, situated in the interplay of social and medical models of disability, can provide a framework for archivists to make nuanced considerations of disability in appraisal, arrangement and description.³⁵ While there is a small body of literature addressing physical disability access issues in archival practice³⁶, White is the first archival scholar to take a broader

34. Anna Sexton, "About," *Archive of Mental Health Recovery Stories*, accessed January 31, 2015, <http://mentalhealthrecovery.omeka.net/about>.

35. Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description," *American Archivist* 75, no. 1 (2012): 109–24.

36. See Lance L. Fischer, "The Deaf and Archival Research: Some Problems and Solutions," *American Archivist* 42, no. 4 (1979): 463–64; Brenda Beasley Kepley, "Archives: Accessibility for the Disabled," *American Archivist* 46, no. 1 (1983): 42–51; Ronald L. Gilardi, "The Archival Setting and People with Disabilities: A Legal Analysis," *American Archivist* 56, no. 4 (1993): 704–13; Frank H. Serene, "Making Archives Accessible for People with Disabilities" (National Archives and Records Administration), accessed February 14, 2015, <http://www.archives.gov/publications/misc/making-archives-accessible.pdf>; Lora J. Davis, "Providing Virtual Services to All: A Mixed-Method Analysis of the Website Accessibility of Philadelphia Area Consortium of Special Collections Libraries (PACSCL) Member Repositories," *American Archivist* 75, no. 1 (2012): 35–55; Kristina L. Southwell and Jacquelyn Slater, "An Evaluation of Finding Aid Accessibility for Screen Readers," *Information Technology*

theoretical approach to disability in archives, categorically considering people with disabilities as a group marginalized in archival collections as well as access, and drawing from the rich body of disability studies scholarship to address these issues.

Archives and power: human rights, community, affect and trauma

There are a number of strands in contemporary archival studies scholarship that engage in critical inquiry regarding the power relationships surrounding archives and records and to which the current project is indebted. Michelle Caswell's articulation of a survivor-centered approach to human rights records is particularly relevant here, applying principles from community archives to human rights archives, which have often not regarded survivors of human rights abuses as a primary user group,³⁷ just as medical archives have not traditionally centered ex/patients as users. Arguing for principles of participation, shared stewardship, multiplicity, archival activism, and reflexivity, Caswell's thinking here runs parallel to the disability rights slogan "Nothing about us, without us," arguing that records subjects must be centered not only as users but as decision-makers in archives that contain records of their experiences. This line of thinking in regard to human rights records is extended in Wood et al.'s work in regard to use of archival description to support human rights uses of records and collections.³⁸

Caswell's work with Marika Cifor on radical empathy and feminist ethics in archives

and Libraries 32, no. 3 (2013): 34–46.

37. Michelle Caswell, "Toward a Survivor-Centered Approach to Records Documenting Human Rights Abuse: Lessons from Community Archives," *Archival Science* 14, no. 3–4 (October 1, 2014): 307–22.

38. Stacy Wood et al., "Mobilizing Records: Re-Framing Archival Description to Support Human Rights," *Archival Science* 14, no. 3–4 (October 2014): 397–419.

pushes the conversation around social justice and archival ethics beyond rights-based frameworks to a more fluid centering of empathy and affect that may be more relevant for exploring many of the questions and experiences brought up by emotionally charged collections.³⁹

In Australia, Canada, the United Kingdom and Ireland, emerging discourses bridge human rights and affect concerns in regard to records of people who have been in institutional out-of-home care as children. Notably, the research of Frank Golding and Jacqueline Wilson is openly informed by their own experiences in care, and engages the complex affective ramifications of accessing these records as adults, which they characterize as inherently paradoxical:

The experience of reading such scurrilous descriptions and accounts of one's self can be shocking, infuriating, and immensely distressing; yet it may be necessary, if only to verify that events occurred as one has said they occurred, and/ or simply to make sense of the behaviour of former carers.⁴⁰

Golding and Wilson go on to argue for the importance of records subject agency, and that research conducted in these records should directly involve the people represented in the records as “insider researchers” in order to honor personal dignity as well as maintain integrity in the research.⁴¹

The research of Joanne Evans et al. surrounding self-determination and archival autonomy also emerges from this Australian context, with a particular focus on the role that failures of recordkeeping have played in enabling abuse in out-of-home “care,” and how the profession can now engage in activism and advocacy to serve the unmet needs of survivors.

39. Caswell and Cifor, “From Human Rights to Feminist Ethics.”

40. Wilson and Golding, “Latent Scrutiny”:6.

41. Ibid., 15.

Archival autonomy, identified as a societal grand challenge intrinsically linked to community self-determination, is defined here as “the ability for individuals and communities to participate in societal memory, with their own voice, and to become participatory agents in recordkeeping and archiving for identity, memory and accountability purposes.”⁴²

In a Canadian context, in scholarship based in the development of an archives for materials related to Canada’s ongoing Truth and Reconciliation Commission surrounding abuse of indigenous children in residential schools, Lisa Nathan et. al use the terms “traumatic collections” and “collections of trauma” interchangeably to discuss “purposeful gatherings of materials that seek to include the records of disruptive, violent histories; efforts to document (e.g. via testimonials) these events; and/or the subsequent activities that engage truth telling, justice, and/or reconciliation.”⁴³

The concept of trauma is invoked by Nathan et. al without being unpacked or interrogated: there is a large volume of trauma studies scholarship in humanities and social sciences that could provide context. Particularly salient here are critiques that the category of trauma has frequently been deployed in ways that are ethnocentric, prescriptive, and individualistic.⁴⁴ This does not make the concept of trauma unusable, but means that its use should acknowledge its limitations and be critically evaluated for appropriateness to a given context.

Anne Gilliland’s VIA framework for community archives– named for its central priorities of voice, identity, and activism in marginalized communities– is a framework for approaching

42. Evans et al., “Self-Determination and Archival Autonomy.”

43. Nathan, Shaffer, and Castor, “Stewarding Collections of Trauma.”

44. See, as one example of this critique, Stef Craps, *Postcolonial Witnessing: Trauma Out of Bounds* (New York: Palgrave Macmillan, 2012).

archives and recordkeeping that explicitly makes central the interests, needs and well-being of a community. Notably, Gilliland specifically names mental health patients as a VIA-relevant community⁴⁵, suggesting an opening for research such as the current project.

Mad studies

The choice to approach mental health records issues by focusing on the experiences and perspectives of current and former patients places this research in relationship to mad studies and disability studies more broadly. Mad studies is a field of study, most strongly developed in Canada, that takes a social, relational, identity-based, and anti-oppression approach to the historical and current study of mental and behavioral difference, and explicitly places “Mad people and Mad culture” at its core. It takes a strong social constructionist view of madness and traces its lineage to patients’ rights and antipsychiatry activism that first gained traction in the 1960s.⁴⁶

The current research is indebted to the work of mad studies scholars such as historian Geoffrey Reaume, who have carved out space for mad perspectives in academia despite facing significant obstacles⁴⁷: Reaume recounts expressing an interest in studying the history of psychiatry from a patient perspective early in his graduate studies, and being told by a senior historian of psychiatry that the patient writings he was interested in were meaningless, no more

45. Anne J. Gilliland, *Conceptualizing 21st-Century Archives* (Chicago: Society for American Archivists, 2014): 20-21.

46. Brenda A. LeFrançois, Robert Menzies, and Geoffrey Reaume, *Mad Matters: A Critical Reader in Canadian Mad Studies* (Canadian Scholars’ Press, 2013): 12-13.

47. See Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor: University of Michigan Press, 2011).

than signs of pathology.⁴⁸ The prioritization of physician perspectives and dismissal of patient perspectives that Reaume has sought to rectify in the history of medicine is intertwined with the prioritization of physician and institutional records and devaluation of patient records that has too often been common in medical archival collections. Conversely, being able to demonstrate that historians such as Reaume are invested in patient perspectives and in using patient writings and records in their research can help archives and records professionals, particularly in academic settings, make a stronger argument for taking preservation of and access to these materials more seriously.

Yet despite a shared interest in patient autonomy, the current research does not fit neatly into the field of mad studies. Although mad studies refuses to claim a disciplinary or methodological allegiance, most existing research in the field takes a historical or cultural studies approach: there is little precedent for doing empirical social science research under the banner of mad studies. Additionally, this research does not take up the strong social constructionist position that characterizes mad studies; rather, it seeks to retain an openness to individual conceptions of experience. Within disability studies at large, there has been greater engagement with and scholarly conversation surrounding social science methodologies and empirical research, and with conceptions of disability that do not fit neatly into a strong medical or strong social model.

Chapter 3: Methods

Methodological frameworks

This research is situated within a disability studies framework in order to continue the work of Sara White's much-needed disability intervention in archival studies and position itself

48. Geoffrey Reaume, "Mad People's History," *Radical History Review* 94 (2006): 172.

within a tradition of critical social thought grounded in the experiences of marginalized people. Yet there is not a unified methodological framework in disability studies: methodology has been the subject of intense debate within the field, with tension between histories of abusive and exploitative research involving people with disabilities, development of participatory activist research frameworks that promote a strong social model of disability, and more recent critical evaluation of those frameworks and proposal of a critical realist approach. The current research aligns itself most closely with the nuance and pragmatic grounding of critical realism, while honoring the histories that produced a desire for emancipatory research.

In the early 1990s, U.K. disability studies scholar Mike Oliver called for the development of a new emancipatory paradigm for disability research, influenced by feminist and ethnic studies epistemologies. Oliver makes the bold argument that existing research on disability had made no positive contribution to the lives of people with disabilities, and that the social relations of research needed to be fundamentally altered to challenge oppression.⁴⁹ The emancipatory approach was taken up by many in disability studies, and was further explicated by Stone and Priestly in their work on the role of nondisabled researchers in disability research. Stone and Priestly identified six frequently-cited core principles of emancipatory research, beginning with “the adoption of a social model of disablement as the epistemological basis for research production.”⁵⁰

Yet the contradiction and assumptions inherent in beginning a participatory research endeavor with the *a priori* acceptance of a specific model have not gone unnoticed by other

49. Mike Oliver, “Changing the Social Relations of Research Production?,” *Disability, Handicap & Society* 7, no. 2 (June 1992): 101–14.

50. Emma Stone and Mark Priestley, “Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers,” *British Journal of Sociology*, 1996, 699–716.

scholars. Danieli and Woodham argue that the imperative to begin any emancipatory research project with the social model of disability runs counter to other emancipatory principles of listening to and validating marginalized voices: the social model, which conceives of disability as purely socially constructed, is not universally accepted among people with disabilities.⁵¹ Beginning with insistence on one particular understanding of disability, rather than being open to a range of opinions and lived experiences, could alienate or further marginalize prospective research participants. Danieli and Woodham also call for a deeper engagement by disability scholars with the evolving conversations surrounding methodology in feminist and ethnic studies.⁵²

Based on these and other critiques⁵³ scholars, including Nick Watson and Tom Shakespeare, have begun to propose a critical realist approach to disability research, influenced by the work of philosopher Roy Bhaskar. Critical realism, in essence, argues that phenomena do exist independently of our knowledge: that it is not reality itself that is socially constructed, but

51. Work surrounding chronic illness has particularly challenged the assumptions of the strong social model: see Simon J. Williams, "Is Anybody There? Critical Realism, Chronic Illness and the Disability Debate," *Sociology of Health & Illness* 21, no. 6 (November 1, 1999): 797–819, doi:10.1111/1467-9566.00184.

52. Ardha Danieli and Carol Woodhams, "Emancipatory Research Methodology and Disability: A Critique," *International Journal of Social Research Methodology* 8, no. 4 (October 2005): 281–96, doi:10.1080/1364557042000232853.

53. Another major critique and contradiction of emancipatory research particularly relevant to the current project is that it is based around a paradigm in which people with disabilities are regarded, often by nondisabled people, as having special problems or needing special assistance: othering as it attempts to "include." See Nick Watson, "Researching Disablement," in *Routledge Handbook of Disability Studies*, Reprint edition (Routledge, 2014), 102; Michael P. Kelly, "Some Problems in Health Promotion Research," *Health Promotion International* 4, no. 4 (1989): 317–30.

rather our ways of understanding and exploring it.⁵⁴ Proponents in disability studies argue that a critical realist approach allows for more careful attention to embodiment and material conditions, and opens up a wider range of research questions about lived experience that are foreclosed by a strict emancipatory research approach.^{55 56}

This line of thought dovetails with Sandra Harding’s work on strong objectivity and feminist epistemology, which has also been influenced by Bhaskar. Harding argues that the problem with a conventional conception of objectivity is not that it is too rigorous or “objectifying,” but that it is not rigorous or thorough enough to accomplish either the goals it claims or goals of social transformation: that a genuine, strong objectivity can be achieved only through prioritizing marginalized perspectives and understanding knowledges as situated.⁵⁷

The current research takes up Donna Haraway’s claim, cited by Harding, that it is possible “to have simultaneously an account of radical historical contingency for all knowledge claims and knowing subjects, a critical practice for recognizing our own ‘semiotic technologies’ for making meanings, and a no-nonsense commitment to faithful accounts of a ‘real’ world.”⁵⁸

54. Watson, “Researching Disablement,” 102.

55. Watson, “Researching Disablement,” 102; Tom Shakespeare, “Critical Realist Approaches to Disability,” in *Disability Rights and Wrongs Revisited*, 2 edition (London ; New York: Routledge, 2013), 72–91.

56. These methodological debates have taken place primarily among disability scholars in the U.K. In the U.S., disability studies has primarily found a home in English and cultural studies programs, and thus has largely not waded into the waters of empirical research.

57. Sandra Harding, “Rethinking Standpoint Epistemology: What Is ‘Strong Objectivity?’,” *Centennial Review*, 1992, 437–70.

58. Donna Haraway, “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective,” *Feminist Studies* 14, no. 3 (1988): 575, doi:10.2307/3178066.

Positionality and notes on “community”

As a user of mental health services, I identify as part of the community in which I will be conducting research. The perspective I bring to this project is shaped by personal experience; existing relationships and commitments to other people with mental illnesses or mental healthcare experiences, as well as other disabilities; and past work experience in community-based disability support and mental health services.

The decision not to name this project explicitly as community-based, participatory, or similar, despite my existing ties and strong concern for community interests, is an intentional one based on several factors. First, while there are a variety of communities that specifically coalesce around mental health experiences, this research understands mental illness and patienthood primarily as an elastic social category⁵⁹ that cuts across a multiplicity of broader communities and experiences (economic, geographic, social, ethnic, dis/ability, sexuality). There is no specific existing community whose interests and experiences could stand in for mental health records subjects as a whole. While collaboration with a specific existing community might be fruitful and appropriate in a project focused on issues or needs pertaining to that community (for example, former patients of a particular institution, or members of a particular online forum), the broad, exploratory scope of this project would make such an approach reductive.

Second, the context and limited resources of this project create labor concerns regarding the time and effort required on the part of community members to co-create a truly inclusive or participatory research study. There is no funding with which community members could be compensated fairly for the extensive time and labor they would be asked to contribute in such a

59. See Tobin Anthony Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008).

paradigm. Within a thesis project that must be single-authored, community members could also not be appropriately credited with authorship for their contributions (and academic authorship does not carry the same currency for someone operating outside of an academic context). While the hope is that this research will ultimately have positive effects on the lives of mental health records subjects, there is no concrete immediate benefit that would create an ethical situation for placing significant demands on participants' time and labor.

That said, some choices that might be deemed radically participatory in a traditional academic context simply seemed ethically and socially appropriate here: in particular, keeping in contact with interview participants throughout the project's lifecycle to update them on its progress, offering the opportunity to read and comment on drafts, and to choose the pseudonyms by which they would be referred to within the thesis.

Additionally, my life, friendships and research are very much intertwined. I have tried to use my acknowledgments page graciously and generously, to credit all those in my life whose insights, in conversations both casual and heavy, works-in-progress, private blog posts and ephemeral artworks, have shaped my thought around mental illness, disability, records, trauma, identity and memory. Ultimately, while this thesis is an individual academic work with a fairly traditional architecture, the broader projects and currents that it is a part of are not at all individual.

Limitations

This research seeks to address an area that has been little-studied, and is being undertaken by an individual researcher at the masters' level. Despite its broad intentions of addressing

mental health records access, its scope is inherently limited, and it can be regarded as an exploratory step. It is not intended to produce generalizable results, but rather to welcome into the professional and scholarly discourse voices that have been frequently elided. Approaching the research from a qualitative, humanities-inflected framework also runs the risk of alienating or being seen as unserious by strict post-positivists. Yet this research seeks to address a dearth of humanistic perspectives in medical records literature. Its approach, aiming for flexibility and nuance, and its focus of study, complex and emotionally charged personal experiences, are intertwined.

As mental health experiences in general are sometimes seen as highly sensitive in U.S. culture, participants' comfort level in speaking candidly on the topics of this study might be limited. Effort to mitigate this is made by focusing the interview questions entirely on records, at no point inquiring about specific diagnoses or healthcare experiences unrelated to records, and by allowing participants to choose a location for the interview where they feel most comfortable.

Specific limitations affecting the pool of potential research participants are further elaborated under "Participant selection."

Participant selection

An estimated 43.8 million adults, or 18.5% of the adult population, in the United States had a diagnosable mental illness in 2013, according to the National Survey on Drug Use and Health (NSDUH).⁶⁰ The number of currently living adults who have been subjects of mental health records can thus be estimated to be even higher, as it would include people who are not

60. "Any Mental Illness (AMI) Among Adults," *National Institute of Mental Health*, accessed October 9, 2015, <http://www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-ami-among-adults.shtml>.

currently categorized as having mental illnesses, but have come in contact with mental healthcare systems as patients at some point in their lives.

Given the size of this population, and the limited scope and resources of this project, it would not be feasible to attempt to study a statistically representative sample. Instead, given that these perspectives have been starkly underrepresented and underexplored in scholarly and professional conversations on mental health records, the aim is exploratory: to capture, amplify and analyze a small selection of personal narratives and perspectives that will complicate these conversations and suggest avenues for future research. With this in mind, the projected sample size was four to six interviewees, and ultimately, five interviews were conducted.

Participants were recruited via announcements on social media sites Facebook, Tumblr and Twitter, as well as through posting paper fliers at independent living centers— community centers born out of deinstitutionalization and disability rights movements—in the greater Los Angeles area. Both the digital and physical sites of outreach were chosen due to their community-oriented, autonomous nature: the social media sites listed, while for-profit and corporate-owned, have become important avenues for the formation of communities particularly for young people with mental illnesses or histories of trauma, while outreach at independent living centers was intended to provide opportunity to reach older participants and those who are not active on the Internet.

While outreach through medical or social service organizations might appear to be a natural fit to reach potential participants, these sites were purposely excluded, in part to make clear to potential participants that this research is coming from a non-medical perspective and is not affiliated with any service provider, and in part to avoid recruiting participants who are currently in acutely vulnerable states and thus potentially unable to give meaningful consent to

participate in academic research. It was anticipated that people who are already involved with either online or offline communities of advocacy or support will be more comfortable sharing their experiences than those who are not, and may already be “out” to people in their lives about their mental health experiences and thus face decreased risk if data security were ever to be compromised.

While I stand by my outreach strategy, it also begs the question of how one might accurately delineate between medical, social service, and community spaces. The lines are not as bright as the methods assumed, and truly non-medical, non-social welfare spaces for people with mental illnesses and disabilities to come together outside of these supervised matrices of authority and control are extremely few. This is why the online social media spaces in which outreach was also conducted are of such importance. But of course, there are multiple barriers to access these spaces, both technologically specific and general to social participation and visibility.

Both the histories and present work of independent living centers are incredibly important. Spatially, however, many of them are situated in large office buildings or complexes filled with mainstream social service and medical offices. For example, one center visited in the research process in Alhambra, California is located in a disorienting 11-building, 1,000,000-square foot business park that also contains county social service offices, and related programs of USC Keck School of Medicine and the for-profit Alliant International University. Even though independent living centers are philosophically outside of these systems, they do not always “feel” that way physically or atmospherically.

The decision not to flier at the Los Angeles LGBT Center was also a fraught one. Though it is a community center in name, in my experience of time spent there it largely functions as and

feels like a medical and social services center. I feared that the independent orientation of the project might not be visible when promoted in that context, but am unsure if this was the correct decision.

In the end, I am unsure if the recruitment methods were successful. Some responses came through the ILC fliers, but the majority of interviews came about through social media, with people whom I had existing direct or indirect connections. Would taking a less purist approach to choosing spaces for outreach have allowed more interviews with people who have limited social connections and/or internet access, and whose lives are more wholly subsumed by medical and social service systems? While the answer is probably yes, I felt too morally squeamish in this initial exploratory research to venture beyond strict community-based recruitment approaches, even among a population where access or inclusion in any sort of community is not to be taken for granted.

A pre-screening instrument was used to ensure that the sample included a diverse set of identities and experiences, particularly age and racial diversity. In order to accommodate a range of communication abilities and preferences, potential participants were offered the option of completing the screening through an online survey instrument created with LimeSurvey, or by phone, though all participants opted to use the online survey.

The research sample was limited by a number of factors: as a researcher who is only fluent in English, I was only be able to interview English-speaking individuals, and was only able to conduct research in California due to financial and time limitations. Additionally, legal, policy, and ethical concerns precluded seeking interviews with people who are currently incarcerated, otherwise institutionalized, or under conservatorship. Thus, perspectives of some of the most severely marginalized individuals who have had contact with mental healthcare systems

are not included. This is no small issue, and poses a serious limitation: the people who are excluded from the current research hold valuable perspectives that are among the most worthy of being heard. However, the hope is that exploring records challenges faced even by people who are less severely marginalized will begin to open this area for further study, including the ability to conduct more inclusive research.

Data collection

To address the lack of records subject perspectives in the current research in this area, this study utilized semi-structured, in-depth qualitative interviews. This method was chosen because of its strengths in capturing a level of detail in responses that can rarely be captured by other methods⁶¹, a characteristic that is particularly appropriate for research concerning affect and complex experiences. The goal was to allow interviewees to articulate their experiences and perspectives on their own terms to the extent possible in this context. The nature of affect would make it difficult to record well using quantitative methods, and the semi-structured interview allows both for more participant-directed responses and for the creation of a supportive space to share personal narratives that could not be established through a survey. While the results are not broadly generalizable, they are not intended to be so: in this case, the intent is to illustrate, document and amplify voices that have largely been absent from the scholarly conversation surrounding mental health records, and to bring them into this conversation.

Interviews took place in person at participant-chosen sites throughout California, and lasted between 30 minutes and one hour. While it was anticipated that participants would choose

61. Steinar Kvale, *Interviews: An Introduction to Qualitative Research Interviewing* (London: SAGE, 2008).

to be interviewed at home or in other spaces familiar to them, most opted for alternate spaces arranged by the researcher, such as private study rooms at university libraries. Interviews were recorded using a digital audio recording device. While video recording was initially suggested as a method more effective for capturing embodied affect, it was ultimately decided that this would be too intrusive to facilitate a comfortable space for interviewees, and would also create additional challenges for confidentiality and data management.

Additionally, while it was initially planned to take detailed research notes on factors such as body language and general impressions not captured by audio recording, this plan was abandoned within the first interview, when it became evident that this would closely mimic practices of mental health recordkeeping perceived negatively by participants, and associated with surveillance and misunderstanding. Through the course of the project, multiple interviewees discussed frustration with the emphasis their records placed on observation and assumptions surrounding their appearance and perceived affect, rather than the content of their concerns. Thus, as a corrective, the decision was made to primarily understand affect here as explicitly described by the participants, rather than to make assumptions based on external observation. The written notes that were kept surrounding interviews primarily documented date, time, and location, as well as any fleeting analytical thoughts and ideas on the part of the researcher.

Data analysis

Data analysis for this project took the form of qualitative content analysis.⁶² Interviews were transcribed by the researcher using Wreally Transcribe, a low-cost, browser-based

62. Philipp Mayring, "Qualitative Content Analysis," *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 1, no. 2 (June 30, 2000), <http://www.qualitative-research.net/index.php/fqs/article/view/1089>.

transcription software.⁶³ This decision was made due to the small number of interviews and the lack of budget to pay a fair wage to a transcriptionist. Interviews and were then printed and initially annotated and coded for themes by hand, then by using Microsoft Word comments, iteratively developing a semi-standardized list of codes. Again, these methods were determined both by the small scale of the project, which made time-intensive methods possible, as well as by lack of funding for licensing qualitative data analysis software such as NVivo.

Content analysis has historically been more closely associated with disciplines such as communication, media studies and nursing than with “critical” social justice-oriented research. A method like critical discourse analysis, with its built-in inclinations toward an analytic of power and the creation of a better world, might be highly productive if approaching mental health records or patienthood by studying the official texts and discourses that create them: for example, a critical reading of healthcare provider documentation manuals or retention schedules.

Yet for the purposes of the current project, the simplicity offered by content analysis is most appropriate. The goal is not to critique the texts at hand, or to regard them as disembodied texts, but to listen to and take seriously people’s accounts and understandings of their own experiences, and to fairly interpret these experiences to wider scholarly and professional communities. Working within a category of people who have frequently had narratives mangled or misinterpreted in official records, a straightforward process of careful listening and faithful representation might be the most radical way to begin.

63. Though the software is browser-based and on the software-as-a-service model, all data is stored locally. Care was taken to ensure that no participant data was transmitted to non-local storage. See “Frequently Asked Questions,” *Transcribe*, accessed May 25, 2016, <https://transcribe.wreally.com/faq>.

Participant makeup

Five interviews were conducted between December 2015 and March 2016 in Southern, Central and Northern California, ranging in length from 30 minutes to one hour. The makeup of the participants, as expressed in the initial screening, was as follows:

Table 1: Participant makeup

| Racial or ethnic identities⁶⁴ | Number of participants⁶⁵ |
|---|--|
| Latina | 2 |
| Mixed | 2 |
| White, Caucasian | 2 |
| Black | 1 |
| Korean | 1 |
| South Asian | 1 |

| Gender⁶⁶ | Number of participants |
|----------------------------|-------------------------------|
| Female, girl, woman | 4 |
| [Gender field blank] | 1 |

| Age range | Number of participants |
|------------------|-------------------------------|
| 18-24 | 1 |
| 25-34 | 2 |
| 35-44 | 1 |
| 45-54 | 1 |

64. The terms used here are those indicated, verbatim, by participants in a free-text form field in the initial screening.

65. These numbers add up to more than the total number of participants because of the participants who identified as mixed-race and indicated multiple identities here.

66. The terms used here are those indicated, verbatim, by participants in a free-text form field in the initial screening.

Four of the participants learned about the study through social media, while one made contact after seeing a paper flier. No potential participants needed to be screened out, though one participant who completed the online screening did not respond to follow-up contact.

Four participants identified their gender as female, girl, or woman; while one did not indicate a gender identity. No participant identified as male or as a man. There are several reasons that this might be: though I am a man, my own social circles tend to skew toward feminist LGBTQ spaces, thus perhaps skewing the pool of participants who were recruited through social media posts. It also may reflect gendered differences in mental health and healthcare experiences.⁶⁷

For future, larger-scale studies it may be necessary to actively seek out men to participate in order to include a fuller range of voices, and to begin to understand how mental health records experiences may differ by gender. Yet in the case of this small, exploratory study, the focus on not-men, however unintentional, has provided particularly rich sources for considering marginalized subjectivities and recordkeeping.

Chapter 4: Findings

Motivations for requesting records

Table 2: Reasons reported for requesting records

67. See Joan Busfield, “Sexism and Psychiatry,” *Sociology* 23, no. 3 (1989): 343–64.

| | | |
|-------------------|---------------------------------------|---|
| Logistical | <i>Academic</i> | <ul style="list-style-type: none"> • Application for registration with college/university student disability services; academic accommodations. • College/university academic and financial aid appeals (i.e. petitioning to maintain regular student status after health-related academic challenges). |
| | <i>Healthcare and social services</i> | <ul style="list-style-type: none"> • Moving, changing healthcare providers, or seeking new provider after lapse in treatment. • Initial application for Social Security disability benefits (SSI/SSDI). |
| | <i>Legal</i> | <ul style="list-style-type: none"> • SSI/SSDI appeals. • Proof of emotional distress in court cases. |
| Personal | | <ul style="list-style-type: none"> • Curiosity. • Personal archiving. • Memory. • Ownership. |

Four participants had requested records for a combination of the logistical and personal reasons detailed in Table 2— a specific impetus in one of the logistical categories serving as the immediate motivation, augmented by a personal interest. One participant described accessing records for a logistical (legal) reason only and not attaching strong personal interest or value to them.

Process

“Frustrating” was the word most frequently used by interviewees to describe their experiences requesting and receiving their records, with the time between initial request and records receipt ranging from several weeks to approximately six months. For the four interviewees who initiated the process themselves, the first step was seeking information on the process and requirements for requesting records. This was accomplished through combinations of online search engine queries, searching and reading healthcare provider websites to locate pages for records departments, making phone calls, or inquiring in person at the office from

which they wished to request records. This step often resulted in confusion and conflicting information, and there is no reliable, centralized source of information to turn to. Multiple interviewees reported doing extensive online research at this stage, but came away with quite different understandings and impressions from one another, particularly around legal issues and one's own rights surrounding records.

The next step was to fill and sign a release of information authorization. This form was made available in some cases on provider websites, and in others available only upon request and in paper form. Even participants who were able to obtain forms online reported not being able to fill or submit them electronically, but rather needing to print forms, fill by hand, and return by mail, fax, or in person.

For some participants, this step was relatively straightforward, but for others less so. Lydia⁶⁸ described waiting two months after initially faxing her release form to a large hospital group, only to receive a response by mail stating that her authorization was incomplete. It was unclear to her what was missing, so she re-faxed her form after reviewing it for completion and making a minor correction. After waiting a month longer, she received another response by mail again indicating that the authorization was “invalid or incomplete,” and that her signature was required in a section of the form that did not appear to exist, in order to authorize the release of “highly confidential” information. During this process, she attempted to reach the medical records department by phone for clarification and her calls were not returned. Finally, she returned the form by fax a third time after adding multiple signatures in various sections, and her

68. All names of interview participants have been changed to protect privacy. As an effort to honor participant agency in this act of renaming, interview participants were invited to choose their own pseudonyms. For more on this practice, see Ruth E. S. Allen and Janine Wiles, “A Rose by Any Other Name: Participants Choosing Research Pseudonyms,” *Qualitative Research in Psychology* 13, no. 2 (December 18, 2015): 149–65.

request was approved.

For those who were required to make requests in person, experiences varied widely. Christine, who made her request at a university student health center, reported a quick, positive experience with a helpful employee, while Eleanor, a member of a large managed care organization, described the release of information office she visited as being “like the DMV,” spending a significant amount of time waiting in a crowded office with long lines and few employees, whom she described as being polite but visibly overworked.

The step following the authorization is, of course, waiting. Interviewees reported this period of waiting to take between approximately three weeks and six months, and for longer wait times to be characterized by frustration, anxiety and doubt. Efforts to self-advocate and follow up on the status of requests were generally not met with meaningful information, but external advocates seemed to have more efficacy.

This was most pointedly demonstrated by the experiences of Eleanor, who had a close family member employed by the same managed care organization from which she requested records. The family member, who did not work in the records department but worked in another department as in the same building, was able to advocate for her and “go bug them on breaks.” Through her family member, Eleanor was able to learn that some of her older paper records were in off-site storage and would take longer to retrieve. Yet despite her familial connection to the organization, her overall request process still took several months, and she reported being unsure if she would have received the records at all if not for her family member’s advocacy on her behalf.

Several interviewees also described experiencing confusion or lack of clarity at this stage about what they were entitled to request or what they would be receiving: what constituted the

full or complete record? For example, Eleanor described initially being offered a USB drive which only contained very basic information, such as a list of medications prescribed to her, and having to inquire further to receive a more thorough record. She did not re-attempt to request the full record for several years following this, due to being discouraged in her first request and told she would be charged a fee per page.

Nina, who in one instance attempted to request records from therapy she received at a domestic violence shelter, also described initially being told that she could not request her full records and could only be provided with a very general, brief report synthesized from the records. She had conversations with multiple employees attempting to clarify records policies, as she felt it personally important to receive a complete record. In another instance, when Nina requested records from a hospital stay, she was also initially given a very brief record which she was told was her records in their entirety. After Nina's self-advocating to receive a more complete record, the employee she spoke with needed to receive authorization from a supervisor in order to release the full record, which was several hundred pages longer than the initial record she was given.

Records were received in a variety of formats and delivery methods, with no one format or method predominating among the group interviewed. These included paper records by mail or in person, digital records delivered on physical media (CD-Rs or USB drives) by mail or in person, and, in only one case, digital records access delivered via online portal. As Eleanor, Nina, and Lydia's experiences illustrate, the process of requesting, advocacy, and receiving are iterative, sometimes requiring several repetitions before securing a thorough record (or, in Lydia's case, any record). In at least two instances described by two different interviewees, records requested were never received at all.

Renee, the participant whose experiences were most dissimilar to the others interviewed, described a much smoother process primarily because she did not initiate or manage her own request—her records were requested by her attorney specifically for use in a legal case, and were made available to her by the attorney at the conclusion of the case. While she did not experience the frustrations described by the other participants, her experience likewise demonstrates the significance of strong external advocacy in the records request process.

For all participants, the final stage of a records request was their use of the records. This includes activating the records for the legal, healthcare, social service and academic uses outlined in Table 2, as well as personal use: reading, reflecting, preserving, and, as Eleanor in particular described, creative repurposing in writing and art. Significantly, two participants reported that only upon reviewing their records did they become aware of particular diagnoses that had been assigned to them.

Mismanagement

Though no participant described their records experiences as wholly negative, the interviews revealed an array of dysfunctional and irresponsible practices in the creation and management of mental health records. For example, Eleanor described finding pages of another patient’s mental health record, containing “highly personal” information, interspersed with her own record, which was missing substantial portions. Concerned, she filed a HIPAA complaint through the Department of Health and Human Services Office for Civil Rights website, but over one year later has not received any confirmation or update on the status of her complaint. Additionally, because of the records’ formatting as a single PDF file, there is no straightforward way for her to excise the stranger’s records from her own.

Christine, who attempted as a teenager to start therapy at a major research university's training clinic because she saw it as the most accessible and affordable option available to her, was not informed that all sessions would be video recorded until she arrived at her first appointment and was asked to sign a consent form to be recorded for training purposes. She described feeling taken aback and overwhelmed by this, but was unsure how to back out, and so stayed for the first session and was recorded despite not having the opportunity to consider this decision or give meaningful consent. At present, the website for this clinic still does not make their recording practices clear, mentioning recording only at the bottom of their "Frequently Asked Questions" page under the question, "What does it mean that [clinic] is a training clinic?"

Nina is currently involved in a legal case surrounding an auto accident in which she was injured. In the aftermath of this accident, she began seeing a therapist in private practice who accepted her case on a lien basis, agreeing to receive payment once the legal case was resolved. Yet she reports that the therapist's inappropriate records practices have resulted in significant delays and challenges to the resolution of an otherwise straightforward lawsuit. When Nina's lawyer requested records from the therapist to prove emotional distress as a result of the accident, the therapist furnished extensive notes that focused on personal information from Nina's childhood and mental health challenges prior to the accident, rather than on the traumatic effects of the accident itself. This damaged Nina's credibility in the view of the opposing counsel, and revealed information she could have reasonably expected to remain private.

Additionally, the therapist revealed to Nina that her notes had been made available to a third party for transcription and editing services, something to which Nina had not consented to or been made aware of at the outset of her treatment. According to Nina, the therapist defended this decision as being HIPAA-compliant because Nina's name was not attached to the notes that

the transcriptionist worked with. However, under HIPAA, there are 18 categories of personally identifying protected health information (PHI), which include name as well as geographic identifiers and dates.⁶⁹

Records content

Participants reported feeling surprise and dissatisfaction regarding the content of their records. One of the most recurring complaints was feeling that there was an excessive focus on describing and assessing physical appearance, and a lack of focus on the content of the words, ideas and issues they remembered expressing to their healthcare providers.

For example, Lydia described her records as vague and unhelpful: “I guess the weird thing about these records, which I guess is normal, is how they tend to focus on how you ‘present.’ Do you look agitated in their opinion? Do you look as though your grooming is not good? What’s your living situation? What’s your family situation? Just going down the list.” The people of color who were interviewed seemed in particular to report records content that focused strongly on their appearance, ethnic background, and family relationships.

Even when some words and ideas were recorded, there was often a sense that the records represented a mismatch of priorities between patient and provider. As Nina described, “Sometimes they would pick on a small detail that to me was completely unimportant, but they would skip something that was huge to me, that I spent a lot of time talking about.” This was compounded by the fact that it was often apparent that important records were missing. For example,

69. “HIPAA PHI: List of 18 Identifiers and Definition of PHI,” *UC Berkeley Committee for Protection of Human Subjects*, accessed May 25, 2016, <http://cphs.berkeley.edu/hipaa/hipaa18.html>.

Lydia reported, “I remember being given some kind of a test in the hospital similar to an IQ test— there was no record of that. It doesn’t show it. I wanted to know what was the test, why did they give it to me, and what was the result.” Eleanor described having seen a particular psychiatrist for several years, and despite receiving records for before and after this time period, she received no records from this particular provider.

Interviewees with records from multiple providers also reported questions and confusion around the vast differences in the recordkeeping styles of individual practitioners, such as some who would write verbose, detailed description and others who seemed to copy and paste vague single sentences repeatedly, such as “Patient discussed anxiety.” In general, interviewees experienced their records as highly subjective documents that seemed to represent their healthcare providers’ personalities, ideas and opinions much more so than their own.

While there seemed to sometimes be a correlation between satisfactory records and positive relationships with providers (and inversely, with “bad” records and bad providers), this was not always the case. Lydia in particular described having had a close, positive rapport with a previous therapist, and being surprised to encounter very vague, impersonal records of this experience. In this case, she wondered if perhaps the vagueness was intentionally chosen by the therapist to protect her privacy or avert surveillance in some way.

Affect

The affective response most frequently described by interviewees surrounding the request process was frustration and overwhelm, the reasons for which should be evident based on the preceding subsections. Several interviewees also described experiencing fear of having their interest in their records pathologized as a symptom of mental illness, such as to be seen as

paranoia.

The responses most frequently described surrounding the records themselves were surprise or shock at the records' content—at what information was included or not included, at use of language, and at veracity or lack thereof. Other responses described around contact with the records included feelings of upset, sadness, anxiety, confusion, betrayal, violation, a sense of guilt at reading something perceived as not intended for oneself, and a sense of strangeness at seeing one's own self and experiences reflected back in this official format—yet frequently feeling interested and compelled to continue reading despite this constellation of uncomfortable reactions.

“Funny” was a word used by multiple participants to describe both the sense of strangeness described above, as well as finding humor in the records, such as in clinical turns of phrase or in the choices of what had been recorded. For example, Christine was particularly interested in the phrase “flattened affect” that had been used to describe her, and one of Eleanor's favorite parts of her records was the line “Patient states it would be easier to stay in bed and eat waffles.”

Memory and identity

Lydia and Eleanor in particular discussed memory at length in regard to their records, and records as tools that can both support and obscure memory. “As women we're taught not to trust our own memory,” Eleanor reflected, particularly in regard to experiences of trauma and abuse. She described finding comfort and validation in a portion of her records that referred to a particular injury she had received from an abusive ex-partner and the associated emergency room visit and mental health follow-up; seeing this as proof that the incident really did happen as she

remembered it.

Lydia described experiencing challenges and gaps in her own memory related both to her mental illness and to her medication regimen. She would like her records to be able to assist more with keeping track of her experiences with mental healthcare by providing accurate description of, for example, kinds of treatment approaches she had tried and goals she had set in the past with providers. She described having a former friend who often accompanied her to appointments, and how this person became over time a sort of record and a place where knowledge and memory was stored. With this person no longer in her life, she wishes to be able to rely more on her written records to fill in memory gaps, but did not find the records she received to be useful for this purpose.

Eleanor also spoke about engaging creatively with her records in a spirit of transformation of memory and identity. As a teenager, for example, she recalls creating collages with her many psychiatric prescription labels, and described finding a sense of power in taking these slips of paper printed with her name and the names of doctors and medications, and forming them into something else. More recently, she has followed a similar impulse by posting cut-up and annotated excerpts from her records on a personal blog:

As a teenager and also as an adult, I so often had no control over what happened to me. Especially around medication: like, just take this, oh it's not working, taper down, take something else. So it's the process of taking [a document] that's about you that's out of your control, and putting in through these processes to make it something else. The image in my mind is like the old drive-through bank tubes, where information gets sucked up and propelled through space. It's words that I said that were then written down by a clinician and turned into this official document, but then I can receive them and turn them into something else.

Reshaping records and processes

What would a better kind of record look like? Better recordkeeping and request processes? Interview participants gave a variety of thoughtful answers to these questions, but among the most recurring themes was transparency: first, transparency that records are being kept at all. No participant reported being clearly informed at the outset of treatment about what kinds of records were being kept, how and where they were kept, and if and how one might access them. Several said that they planned in the future to ask more questions about records and recordkeeping to new providers, and that they would recommend other patients do the same. While this is a valuable, strategic way to approach self-advocacy, in an ideal system this burden should clearly not be placed on patients, and provider attitudes and cultures would shift to create records transparency throughout processes of treatment.

Christine, who was alarmed by the attention paid in her records to her physical appearance and clothing, articulated a desire for a more objective, standardized record that would leave less room for such commentaries, and would allow her to have a consistent idea or expectation of what was being recorded.

Lydia, who requested her records in hopes that they would be useful for continuing therapy in a new city, described a more useful therapy or counseling record for her as one that would functionally reflect the content of the sessions: “things that we were working on, or, things that were issues. What steps we took, like, what plans we made, what things didn’t work. What things I was able to do, what things I wasn’t able to do.” She hopes that a record like this would help her remember past treatment experiences and make future treatment more effective. Yet she reported finding little of this in the records she received, and greater focus on demographic and family information, as well as, like Christine, attention to appearance.

In terms of request processes, participants again articulated a desire for greater transparency and easier access to information surrounding the process, including how to make requests, what to expect, and guides on interpreting information such as clinical abbreviations or poor handwriting. Some also suggested it would be useful to have a designated “point person” or advocate who could answer questions and assist with requests and interpretation. Christine, who accessed her records for the purpose of receiving academic support in a university setting, was one of those who voiced this suggestion and felt it would be particularly helpful to have more guidance in terms of precisely what records students needed to provide to access such services. She described feeling a sense of regret after submitting her complete records as part of an academic appeal, as she felt this probably wasn’t necessary and was concerned about privacy risks, but due to vague instructions had been unsure what she needed to provide.

Several participants also discussed issues with language use in their records and expressed desire for a medical glossary that would help translate abbreviations or medical terminology into plain language. Participants also reported difficulty interpreting provider handwriting.

Chapter 5: Discussion

Role of archivists

Though this research was initiated in the disciplinary context of archival studies, there is a conspicuous lack of archivists or archival repositories in participants' experiences. Many of the records being accessed are relatively recent and thus still being maintained as active records by the creating bodies. Even when older, nonactive records are moved into other regimes of management and storage, such as the off-site vaults mentioned to some participants, they do not appear to fall under the purview of archivists trained and/or titled as such.

It is difficult to draw precise conclusions here in a country where healthcare is predominantly provided by corporate entities, and corporate archives exist purely to serve business goals.⁷⁰ For example, nationwide managed care organization Kaiser Permanente, with over 170,000 total employees, appears to employ a single individual in the role of "Heritage Resources Archivist," with a focus on overall corporate history and legacy.⁷¹

Though identifying the precise patient records lifecycle within large healthcare entities and their corporate archives would require further research, it is likely that those making decisions that impact records access are in roles such as records managers, records analysts, and release of information officers; and those working directly with records are in roles such as medical records transcriptionists and coding technicians, records clerks, and general records center staff, the latter two roles in many cases employed by information management vendors such as Iron Mountain.

70. See Becky Haglund Tousey and Elizabeth W. Adkins, "Access to Business Archives: U.S. Access Philosophies" (Japan-U.S. Archives Seminar, University of Tokyo: Society of American Archivists, 2007).

71. According to Kaiser archivist Lincoln Cushing's public LinkedIn account, "I am the only archivist/historian on staff for the entire national organization." Lincoln Cushing, "Lincoln Cushing," *LinkedIn*, accessed May 11, 2016, <https://www.linkedin.com/in/lincoln-cushing-a832b9a>.

Archival repositories are occasionally a site for people to access their own records, as Howard Dully describes in *My Lobotomy*. With the assistance of National Public Radio researchers and George Washington University archivists, Dully accessed records of his 1960 lobotomy in the Walter Freeman and James Watts Papers at the GWU University Archives⁷². The repository holds Dully's records because his lobotomy was performed by prominent psychosurgeon Walter Freeman, who was affiliated with GWU, and patient records and correspondence are included in the papers acquired from Freeman and his associate James Watts.⁷³ In general, patient-related records appear more likely to be retained in academic archival repositories when associated with the papers of a prominent university-affiliated physician.⁷⁴

Archivists working with such collections or at institutions that hold them can benefit their potential users by being attuned to attitudes and experiences of ex/patients toward records such as the ones described by interview participants, and consider what metadata and outreach practices might increase transparency and improve access by living patients to their own records.

But what of the records of the vast majority of patients who have not been seen by prominent doctors with papers in university archives? While the issues and needs at hand are highly relevant to the skills, commitments and perspectives of archivists, in the U.S. in particular

72. Dully and Fleming, *My Lobotomy*: 219.

73. "Guide to the Walter Freeman and James Watts Papers, 1918-1988," MS0803.UA, Special Collections Research Center, Gelman Library, The George Washington University, accessed April 27, 2016, <https://library.gwu.edu/ead/ms0803.xml>.

74. As another example, UCLA Special Collections holds a collection of the papers of Ralph R. Greenson, a former UCLA faculty member best known as the psychiatrist to Marilyn Monroe and a prolific author on psychoanalytic topics. Patient notes are amongst the collection with an overall focus on Greenson's career. See Simon Elliott et al., "Finding Aid for the Ralph R. Greenson Papers, 1934-1979 (Collection 1497)," UCLA Library Special Collections, 2009, <http://www.oac.cdlib.org/findaid/ark:/13030/kt6w1024rs/>.

where a records continuum approach has not been broadly adopted, there is not a strong history of archivists engaging in records advocacy beyond the scope of their individual institutions or collections. Yet that is precisely the kind of intervention that is needed: the meta-archival, non-aligned archival advocacy that Gilliland calls for as one of the major functions of the profession in the twenty-first century.⁷⁵ This might include, among a variety of tactics, policy advocacy, engagement in official inquiries to recommend changes to recordkeeping practices, and aggregation of information or creation of centralized resource guides for ex/patients seeking their records.

The desires for assistance with accessing and interpreting records that were articulated by participants are very similar to reference and other public service work performed by many archivists. Yet because these records are already frequently deprioritized by their creating entities and not accessioned by archives, it is unlikely that these roles for archivists would naturally emerge or be funded within existing systems. Additionally, nonaligned advocates could serve a watchdog function and would not be pressured to ultimately serve the business interests of large healthcare organizations over the needs and interests of people accessing their own records.

Despite the focus of this study on access, it is also critical to prioritize the safety, preservation and stewardship of these important records. When “access” has been invoked throughout this thesis it is purely in relation to people seeking access to records that have been created about themselves, not to these records being made broadly publicly accessible, which is not what is desired by any of the interviewees and would present grave problems with

75. Gilliland, “Permeable Binaries, Societal Grand Challenges, and the Roles of the Twenty-First-Century Archival and Recordkeeping Profession.”

surveillance and privacy.⁷⁶

“Community,” archives and disability

This research began from a perspective critical of simplistic notions of community and grounded in the complex relationships and power dynamics that make up marginalized, identity-based communities. Yet it still also began with an implicit ethical commitment to “community” as the other of academia and institutions. Throughout the research process, it became more evident that “community” and access to community are highly fraught within contexts of mental illness and disability, and that rather than conceiving of a commitment to community for research in this arena, articulating the ethical commitment as one to marginalized people is sounder and more inclusive.

This first began to emerge while conducting outreach to potential participants, as detailed in Chapter 2 (Methods), and wondering if conducting outreach strictly in online and physical spaces viewed as “community-based” rather than medical, social welfare, or otherwise authoritarian or institutional, was excluding marginalized people who may be isolated from social interaction and community spaces, and have most of their time and energy consumed by moving through these systems.

It is worth noting that in a disability services context, “the community” is frequently used by social service providers as a generic term to refer to the world at large, or not-institutions. For example, people who live in their own apartments, as opposed to in a hospital or nursing home, are said to be living “in the community.” This definition mirrors the way “community” is

76. Ibid.

typically used in archives and academic settings—also to mean not-institutions, but in reference to very different kinds of institutions. Thus, while the structures of the definitions mirror each other, the referents are quite different.

While “community” invoked in an academic setting in the U.S. generally has significant populist implications, seen as much more accessible than universities and other large organizations; in a disability and mental illness context, living and being included in “the community” is something that many people do not have the opportunity to do, something that often requires significant resources and support, and something that cannot be taken for granted. If there is to be fruitful collaboration between people with mental illnesses and other disabilities, medical and social service providers, archivists and scholars, more precise use of language may be necessary.

Chapter 6: Conclusion

The results of this study, though small in scale, demonstrate several important points for future research and advocacy. First, despite being created primarily to fulfill business functions of healthcare-providing entities, mental health records can hold significant value, both affective and practical, for the people whose experiences they document. These users activate their records for purposes related to memory and selfhood, as well as a range of legal, medical, social service and academic functions. Second, because these records are not generally created or managed with the records' subjects considered as a primary user group, there are significant barriers to access characterized by a lack of transparency and consistency, as well as records content that does not always serve the needs of this user group well.

Third, contemporary mental health records in the U.S. are generally not being stewarded in archival repositories but rather are retained and disposed of under corporate records management programs. While some U.S. archivists might take this to mean that these records and their users are thus outside the scope of our work, I argue that it is within the social and ethical responsibilities of our field to address the pressing records justice issues here and engage throughout the records lifecycle. This engagement continues a precedent set by the records continuum model and engagement with human rights recordkeeping, memory, accountability, and growing engagement with affect. Because preservation of and user access to these records may at times run counter to the goals of the creating bodies, it is an area in which non-aligned archival advocacy has potential to make substantial difference.

One fundamental challenge faced by individuals accessing their own records is difficulty in finding information surrounding the process: about what records exist, about what their rights are, about how to initiate the request process with various entities, about what to expect from the

request process and from records content. As interviewees in this study frequently reported beginning their search for information through Google, creation of an online portal that would gather this information at one site, including clear and trustworthy legal and policy resources and links to release of information offices for major U.S. healthcare providers, would be of significant assistance. Making print and alternate format resources available as well as conducting in-person workshops could also help reach people with a variety of abilities, learning preferences, and degrees of Internet non/access.

As the scope of this study was so general and exploratory, there are many more avenues in which more specific research and targeted resources would be worthy of pursuit: for example, records access experiences of people who have or are labeled as having intellectual and developmental disabilities; experiences of currently and formerly incarcerated people; experiences related to foster care and group home systems; experiences of non-English speakers (including users of signed languages); experiences with access to mental health records across national borders; experiences accessing records of now-closed or downsized institutions; experiences of survivors of the private “troubled teen” industry.

It will also be important to pay attention to emerging records and data management practices with the current popularity of behavioral therapy methodologies such as Applied Behavior Analysis and Cognitive Behavior Therapy that involve collection of large quantities of data in the course of treatments; as well as the vast quantities of data and metadata generated by emerging telehealth and “quantified self” practices. What happens to this data? Where does it live? Who has access to it? What are the surveillance implications? Particularly unsettling are mobile applications such as StudentLife, developed at Dartmouth College in 2014 to monitor students’ mental health through automatically collecting and analyzing data on communication,

sleep, physical activity, and location.⁷⁷ While these practices are not yet widespread, they are a signal of what may be to come.⁷⁸

As more data is collected and more and more kinds of records surrounding mental health are created, the landscape of records access and attempts to gain thorough knowledge or control over one's own records will become even more complex, and only heighten the need for dedicated, ethical records advocates. There is a wide range of rich and badly needed work in this area, the scope of which for the time being is primarily limited by lack of resources.

77. Rui Wang et al., "StudentLife: Assessing Mental Health, Academic Performance and Behavioral Trends of College Students Using Smartphones" (ACM Press, 2014), 3–14, doi:10.1145/2632048.2632054.

78. It is worth noting, for example, that the ankle monitor, now commonly part of house arrest sentences in the U.S., was initially invented by Harvard graduate students in behavioral psychology in the 1960s and was intended as a tool for positive reinforcement rather than for carceral uses. Its uses in corrections gained popularity in the 1980s, and its inventors have vocally disapproved of the device's trajectory and current use: inventor Kirk Gable was quoted by *Wired* magazine referring to it as an "evil mutant." See Gary Wolf, "The Twin Inventors of Electronic Monitoring Still Have Regrets," *Wired*, October 23, 2007, <http://www.wired.com/2007/10/ps-ankle/>; J. Robert Lilly and Richard A. Ball, "A Brief History of House Arrest and Electronic Monitoring," *Northern Kentucky Law Review* 13 (1987): 343.

Appendix: Interview Protocol

Have you ever had the chance to look at your own mental health records?

If yes:

- How? What were the circumstances in which you got to see them?
- Did you have to make an effort to get them? What was the process like? Did you have help?
- Were the records in paper or electronic form?
- If through a website, was the website easy or hard to use?
- If you had to interact with anyone in person or over the phone to get the records, what was that like? How did they treat you? Do you know what their job was?
- How did the process make you feel?

- Why did you access the records? Did you have a specific reason or goal in mind?
- What was it like to see the records? What did it feel like?
- Did you find what you expected to find? Were there any surprises?
- Did you understand everything that was written in the records? Were there things you didn't understand?

- If you could re-write or add to your records, what would you say? What would an accurate record look like to you? What would it feel like? What words, materials, etc would be used?

If no:

- Have you tried to look at your records? What happened when you tried?
- Why did you try to access the records? Did you have a specific reason or goal in mind?
- What was the process like? Did you have help?
- Were the records in paper or electronic form?
- If through a website, was the website easy or hard to use?
- If you had to interact with anyone in person or over the phone to get the records, what was that like? How did they treat you? Do you know what their job was?
- How did the process make you feel?
- How did it feel to not be able to see your records?

For all:

- What do you think someone should know if they are just starting the process of accessing their records? Is there any advice or information you wish you'd had at the beginning?
- What kind of help would be/have been useful to you?
- Do you have ideas about how processes for accessing records could work differently or how people involved could do things differently?

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