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David Wright et Renée Saucier

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Résumé de l'article

Les historiens ont longtemps été contrariés par les défis que représente l'utilisation de dossiers médicaux comme sources historiques. Des questions éthiques concernant le statut et l'identité de patients décédés se profilent derrière de nombreuses questions méthodologiques et plusieurs problèmes d'interprétation. Quels droits ont les personnes décédées sur leur dossier médical? Quelles sont les obligations éthiques des chercheurs dans l'analyse de ces dossiers et, en particulier, leur devoir quant à la protection de l'anonymat des patients? Est-ce que les responsabilités des chercheurs diminuent à mesure qu'ils reculent dans le temps? Est-ce que les patients souffrant de troubles mentaux doivent être traités différemment par les chercheurs pour des raisons éthiques? Maintenant que les traitements offerts aux patients atteints de troubles mentaux à l'extérieur des asiles sont connus, est-ce qu'il y a une différence fondamentale entre le statut de ces patients et ceux qui sont institutionnalisés? Est-ce que la désignation de personnes comme étant « lunatiques » ou « idiotes » dans les certificats de décès ou les recensements demande une discrétion similaire? Est-ce que les préoccupations par rapport à la confidentialité sont en train de s'estomper face à l'importance de redonner aux personnes vulnérables leur individualité et de reconnaître leur agentivité? Cet article explore ces questions fondamentales pour les historiens de l'invalidité, de la médecine et de la société.

Madness in the Archives: Anonymity, Ethics, and Mental Health History Research*

DAVID WRIGHT AND RENÉE SAUCIER

Abstract

Historians have long been vexed by the challenges of using patient records as primary sources. Lurking behind the many methodological and interpretative challenges are ethical questions involving the status and identity of the dead patient. What rights do the deceased maintain over their medical records? What ethical obligations do researchers have in analyzing these historical records and, in particular, to preserving the anonymity of patients? Do professional duties diminish the further back one goes in time? Do patients suffering from mental distress differ from other "medical" patients in the ethical regard owed to them? Now that we know about the care of the mentally ill outside of formal institutions during the era of the asylum, is there something intrinsically different about the status of individuals once they entered formal institutions? Or do the designations of "lunacy" or "idiocy" on extramural death certificates or in census enumerators' schedules oblige a similar professional discretion? Is the concern over confidentiality giving way to a new emphasis on returning names (and agency) to vulnerable groups in the past? This paper explores these questions, ones that lie at the heart of what we do as historians of disability, medicine, and society.

Résumé

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Introduction

For the past three decades, the history of medicine has been dominated by the exploration of events, institutions, and clinical practices from the "patient's view," one that has often involved, amongst other things, the comprehensive examination of patient records in the past.[1] For practical reasons, many scholars have gravitated to institutional medical case files, using these sources to understand better the historical interplay between patients and practitioners.[2] There are now dozens upon dozens of *social* histories of medical institutions, with rich literatures in different English-speaking jurisdictions.[3] Quantitative and qualitative scholarship based on institutional medical records has been central to the emergence of the "social history of medicine" as a field of scholarship and the *raison d'être* of professional organizations such as the International Network for the History of Hospitals.[4]

This historiographical trend has been particularly pronounced in the history of *madness,* a topic of research whose popularity never

seems to diminish. The interest is understandable. Mental hospitals in the nineteenth century were extraordinary public institutions. By the end of the century they figured in the hundreds in the English- and French-speaking worlds; patients numbered in the hundreds of thousands. Lunatic asylums, as they were then commonly called, were by far the largest and most important welfare or quasi-medical institutions in the Western world by the dawn of the twentieth century. Moreover, the contested status of mental disorders and the dubious claim of expertise over their cure by nineteenth-century alienists have colluded to make the intersecting fields of the history of lunatic asylums, the history of psychiatry, and the history of madness irresistible to many researchers.[5]

The historiography of the lunatic asylum is large and contentious, and this paper does not seek to revisit complicated and long-standing debates about the social uses of the institution or the legitimacy of the psychiatric monopoly — if indeed there was a monopoly — over madness that emerged in the nineteenth century. Rather, it explores something altogether different — the duties and ethical obligations of the mental health historian, the implicit and often unspoken aspects of the art and practice of how scholars approach the historical medical record, particularly as it affects marginalized populations. How have medical historians understood their responsibilities to patient records and to wider communities? Are there inherent tensions, as Mitchinson and Iacovetta insightfully observed, between uncovering the "voices" of those "forgotten" by history and, simultaneously, masking their identity?[6] And are many of these debates shifting as archives cease to be physical places of research for élite scholars and become democratized and opened up through digitization and the Internet?

This paper explores the history of madness as an illuminating case study of larger debates over the practice and ethics of anonymizing historical medical records. First, it surveys the general practice of approaching records of "patients" in the English-speaking literature, including the principle of a universal closure period. Second, it analyzes the stated intentions of anonymity as historians have attempted to balance what some have characterized as the "right to research" with a "duty to protect." Third, the paper summarizes some aspects

of the naming (or pseudo-naming) of patients in the past. Special emphasis will be placed on how these tensions between scholarship and confidentiality are played out with respect to historians of the "Long Nineteenth Century," now that virtually all of the medical records for that century lie outside most legislated closure periods. We do not aspire to offer a single solution to these complicated questions, but rather hope that the issues raised in this paper spark more discussion and debate. We believe that mental health records have particular relevance for scholars examining other disempowered groups in the past, as traditional academic concerns over patient confidentiality become complicated by social movements seeking to empower themselves through the commemoration of their history and their re-claiming of an identity that was often suppressed or altered in the past.

100 Years of Solitude

The restriction of medical records in the English-speaking world has been informed for two generations by the convention of the "100 year closure period," part of a regime of closure regulations formulated in the wake of the Public Records Act of England and Wales (1958).[7] This convention was characterized by its simplicity, both in its previsions and underlying logic. *Medical* records generated by *public* institutions that were over 100 years old (at the time of access), were open to any member of the public who wished to view them. Any records younger than 100 years were technically closed, and required special research agreements with the archive and/or official depositor. Given the maximum human lifespan, it must have been deemed impossible for anyone still alive who could have known, or remembered, the person embodied in the open historical records. This simple rule thus ensured "confidentiality" during the maximum expected lifetime of the identified person, as well as the lifetime of anyone with any personal memory of that individual.[8] It also side-stepped the philosophical debate of whether individuals had a reasonable expectation of *posthumous* privacy, and, indeed, absolved historians of the challenging, if not impossible, task of having to determine whether or not a particular patient in an historical

record was actually alive (or not) at the time of scholarly research and publication.

Judging from major works in the history of mental hospitals, it appears that the model of the 100 year closure period influenced archival and access policies throughout the English-speaking world in the last decades of the twentieth century.[9] Scholarship reveals that the province of British Columbia closed medical records for 100 years, as did South Carolina and California in the United States, as well as New Zealand, for example. The province of Ontario restricted records for 100 years until recent legislation extended that closure period to 120 years for all medical records, or 50 years after the death of the individual.[10] This new variation of a closure period, augmented by a qualifying clause of a period after a person's death, is also evident in provincial legislation in New Brunswick and Newfoundland.[11] There are, of course, many variations in the English-speaking world: the State of Victoria (Australia), until recently, restricted access to all *children's* records for 100 years, but permitted access to those of adults after 75 years.[12] In Ireland, the National Archives (NAI) adopted the 100 year closure period as an *institutional* policy, in the absence of national legislation.[13]

Needless to say, despite the simplicity of a universal closure period, practical difficulties of access and debates over what constituted "public" institutions has led to some inconsistent application. For example, there has been some confusion over whether psychiatric facilities that were once run by charitable and/or religious organizations, but had subsequently been incorporated into postwar state health networks, were "public" institutions under legislation defining closure periods. For example, the historical records of some Quebec lunatic asylums, such as St. Jean de Dieu (now Louis H. Lafontaine hospital) in Montreal appear to be still under stewardship of the Catholic order of the Sisters of Providence despite the considerable public funds that were used to support patients over the decades.[14] And then there is the case of former (or current) private medical institutions that may or may not have received public funds over the course of the twentieth century. Charlotte MacKenzie, for example, in her book on the private Ticehurst Asylum in Sussex, England, acknowledged her gratitude to Nestor Medical Services Ltd., the

company that had inherited the management of Ticehurst, "for agreeing to follow the [British] Ministry of Health's directive on confidentiality of patient records," which followed the Public Records Act in recommending closure and anonymity for patient records within 100 years of their creation.[15] One could infer from this statement that they were not obliged to do so.

Despite ambiguities and uncertainties that have arisen from time to time, the practice of anonymizing patient records within a legislated, recommended, or informal closure period has been widespread for medical historians working on the early twentieth century, mental health historians included. Geoffrey Reaume, for example, anonymized all patients and relatives mentioned in post-1899 files of the Toronto Lunatic Asylum pursuant to the Ontario privacy legislation.[16] Peter McCandless, in his monograph entitled *Moonlight, Magnolias and Madness*, reminded readers that it is "unlawful to identify patients mentioned in them [South Carolina State Hospital records] by name" within the 100 year closure period.[17] Mark Jackson, in *The Borderland of Imbecility,* anonymized the institutionalized children discussed in his study of feeble-minded colonies in Edwardian England by use of initials for surnames.[18] Dennis Doyle created pseudonyms for patients, family members and some practitioners mentioned in patient files from the Lafargue Mental Hygiene Clinic in 1950s Harlem, New York.[19]

Anonymization — either through initials or pseudonyms — presumably protected the "confidentiality" of patients, a concept self-evidently drawn from the long-standing medical precept of *doctor-patient* confidentiality and reinforced in national privacy and ethics regulations, such as the first Canadian Tri-Council Policy on Research Involving Human Subjects (1998). In this guideline, the three Canadian national research councils spoke of a "general rule to protect privacy and confidentiality," recommending anonymization, and of course informed consent, at different stages of the research process.[20] The Tri-Council Policy, by default, became extended to research involving medical records within provincial closure periods (where applicable) and was silent on the issue of *posthumous* medical records. Clearly, however, the spirit was to err on the side of caution and ensure confidentiality unless otherwise indicated. Many of the

recommendations of the first Tri-Council Policy (1998) were formulated to address research protocols in the social sciences and, in particular, new approaches in qualitative research in such disciplines as sociology, anthropology, and social psychology that had medical or quasi-medical aspects to them. Historical research, and in particular oral history, were not principal concerns of these early protocols in Canada, leaving medical and social historians of the twentieth century caught up in the larger drag-net of ethical protocols and new privacy legislation.

The non-disclosure of nominal information in publications complicated one of the essential elements of historical scholarship — the need for authentication and interrogation of evidence. Pursuant to this general trend, and eager to fulfill their professional responsibilities of scholarship, many historians of health and medicine who have anonymized patients' names in the past three decades have also included a "neutral" identifier (such as a patient case number) which would then permit individuals, with the ability to access the archives, the opportunity to verify the primary historical research. Thus, James Moran replaced the names of patients admitted to asylums in the Canadian provinces of Ontario and Quebec with pseudonyms; he then alerted the reader that the information regarding each case could be gleaned from the references in the notes.[21] A similar practice was followed by Gayle Davis, in her study of sex, syphilis, and psychiatry in early twentieth-century Scotland.[22] Sally Swartz, in her examination of the Valkenberg Asylum in South Africa used first names and date of admission for patients confined to that mental hospital in the early twentieth century, a research practice which, she hoped, would preserve some degree of confidentiality, but also "identify records referred to in this paper, for those wishing to consult them."[23] Nancy Tomes adopted a similar approach in providing "keys" to the records of patients mentioned in her history of the Pennsylvania Mental Hospital.[24] In many of these cases, pseudonyms consistent with gender and even "ethnicity" were used to preserve the "human-ness" of the historical narrative.[25]

Others, however, expressed an implicit "duty to protect" (confidentiality) that was so important that it overrode even the scholarly imperative to verify the historical record. For example, Cheryl Warsh

opted to provide no "keys" to records cited in her study of patients at the Homewood Retreat in Guelph, Ontario.[26] In his research on the aged in the Rockwood Asylum (Kingston, Ontario), Edgar-André Montigny interpreted Ontario privacy legislation as requiring a similar act of non-disclosure.[27] Jacqueline Leckie, in her study of a colonial asylum in Fiji affirmed that, with respect to early twentieth century patients:

> Pseudonyms are used here. Unless referenced, primary citations in this paper are from doctors' and patients' records located at St Giles Hospital, Suva. To protect patient confidentiality, specific references are *not* given (emphasis added).[28]

Joel Braslow, in his exploration of sexual sterilization in a California mental hospital, explained, "In order to protect patient confidentiality, I have chosen not to footnote excerpts from the patient records with identifying data (such as medical record numbers)." a protocol that he preserved in his monograph, *Mental Ills and Bodily Cures*.[29]

In summary, many mental health historians have closely followed closure periods and the practice of anonymization, but clearly there were jurisdictions where there existed no explicit regulations. This problem seemed to be acute in the United States, where legislation and practice varied state by state. As a consequence, in the late 1980s, some leading historians of health and medicine encouraged colleagues to engage in a discussion to delineate professional codes of conduct. Guenter Risse and John Harley Warner, for example, urged colleagues to be as conservative as possible in their understanding of their professional duties. As they warned:

> …legal questions of authorship, ownership, and access to clinical charts threaten to complicate matters for future researchers. The burden of maintaining access to such documents rests squarely on the historians themselves, and much will depend on the manner in which scholars use such information and manage the issue of confidentiality.[30]

Risse and Warner may well have been influential in the establishment of a code of ethics for medical historians that was formally approved

by the American Association for the History of Medicine (AAHM) in 1991.[31] In a later piece, Warner articulated one of his principal concerns: "In the United States, the absence of uniform policies often leaves the management of confidentiality up [to] the individual historian in ways I find sometimes disturbing … and what worries me is that a single challenged instance of abuse by an insensitive historian might be enough to bring a backlash restricting access."[32] In a manner of speaking, Warner and others were attempting to encourage fellow historians to define and self-regulate, in a proactive manner, their professional behaviour concerning the use of medical records before one rogue researcher ruined the field for everyone.[33]

Posthumous privacy and ethical duties

Within this emerging discussion about the responsibilities of medical historians, it is fair to say that most researchers have argued, implicitly or explicitly, that they owe not just a *legal* but also an *ethical* duty to maintain the confidentiality of those mentioned in historical health records. So it is worth trying to unpack how that duty has been understood and expressed. In our review of the literature, we observed several things. First, it should be stated that the majority of authors working on the history of mental health included no reflective comments on the employment of anonymity in their published works, and if they did, merely referred to the legal constraints or research agreements that gave rise to the re-naming, or anonymization, of patients. This does not mean to imply that they never thought about the issue — but rather that it was not considered essential enough to be included in the publication itself. We also observed the relative paucity of reflective articles on this subject within the historical literature, despite an impression, by one of the authors having worked in the field for over 20 years, that it was something much talked about and debated informally amongst academics at scholarly meetings.

There have been a handful of articles, however, some of which touch directly or indirectly on the history of madness. Janet McCalman, in her reflection on the intersection of women's history

and medical history, articulated the need for a balance "between the need and right to know, examine and understand, and the individual's right to privacy and the protection of reputation."[34] Implicit in her analysis is that an ethical duty continues for an imprecise and perhaps indefinite posthumous duration — a parallel, one might infer, to the Common Law principle that "communications between lawyers and their clients should remain confidential in perpetuity."[35] Other historians have widened the ethical regard, placing as much, or even more, emphasis on the ethical duty towards *descendants* of patients. Yannick Ripa, whose work on women and madness in nineteenth-century France was a landmark in feminist scholarship, acknowledged that she had a duty to guarantee the anonymity of patients out of respect to their (living) *descendants*.[36] This concern finds an echo in the introductory comments by Jonathan Ablard in his history of madness in Argentina, when he informed the reader that he has "changed all of the names in order to respect the privacy of these individuals *and their families*."[37] (emphasis added) One senses in many of these brief discussions that the anxieties were less about the reputation of individuals who had been deceased for a generation or two or three, and more about the impact that nominal disclosure would have on their wider family. As Jonathan Sadowsky acknowledged: "I did not [therefore] pursue the families or descendants of inmates in cases where that might have been possible. This, I thought, might have brought attention to the families in inappropriate ways."[38] The Wellcome-funded research team at the University of Exeter (UK), who compiled a huge database of patients admitted to the county asylum up to the year 1914, also omitted last names in their study of the Devon county asylum "in order to avoid embarrassment of living relatives."[39] Clearly, there would have been no reasonable expectation that any patient in their analysis would have been living by the time of their scholarly publications in the late 1990s.

These considerations for the reputation and sensitivity of descendants appear to have informed a certain amount of scholarship on the Victorian period, particularly when it comes to "sensitive issues," pushing confidentiality and anonymity back into the nineteenth century and outside of standard formal closure periods.[40] As McCalman explained:

> I resolved not to use patient names. I have learned from past experience that Melbourne is still a very small town with a relatively stable population by international standards. While many immigrants come, once here, they mostly stay. Your potential readers always include direct descendants of patients and thousands of enthusiastic family historians who trawl every new publication for a mention of an ancestor. Quite rightly, they would not appreciate (and neither would their grandmothers), having intimate gynaecological problems linked to the real name of the patient in the public record, let alone their syphilis or septic abortions.[41]

Perhaps unsurprisingly, psychiatric records have sometimes been identified as being "sensitive" ones by some authors. Jacalyn Duffin, one of the few individuals to question the conservative admonitions of Risse and Warner (see below), and inclined to preserving the original names of the patients in her study of Dr. James Miles Langstaff, was required by research agreement to make an exception of those who were sent to the provincial lunatic asylum.[42] As Catharine Coleborne, an authority on mental hospital history in New Zealand and Australia, and whose research crosses the 100 year closure period, acknowledged in a recent article: "I endeavour to research and write in an ethical manner about these sensitive issues, including where they impinge on the histories of Maori and Aboriginal pasts."[43] Somewhat surprisingly, the AAHM declaration on professional guidelines in the use of medical records (1991) did not include "psychiatric" records as ones deserving particular caution, focusing instead on genetic disorders and sexually transmitted diseases. The concern over genetic disorders, in particular, may well have been a function of the sensitivities to private health insurance in the United States. As Alice R. Wexler observes, "Historical study of families associated with an autosomal dominant genetic disease such as Huntington's poses complex dilemmas relating to privacy and confidentiality for their descendants, particularly in a society in which health, life, and disability insurers routinely deny coverage to those with this illness in our families."[44] Archives too have become sensi-

tive to the use of medical records for purposes of determining or refusing medical insurance, adding greater complexity to the question of who has access to what records, and for what purposes.[45]

Pseudonyms and the social history of medicine

As some scholars sensed, there was something paradoxical about the rising tide of pseudonyms (and initials) amongst researchers of the history of medical institutions and practices. The social history of medicine was a movement that, amongst other things, intended to give a "voice" to patients in the past, a desire that reflected a larger historiographical trend of the "new" social history that sought to uncover those who had previously been "hidden" from history. This intellectual trend has had many manifestations in the last generation, from histories that attempt to give agency to African slaves in the pre-emancipation Americas; to the social history of learning disability in Britain, which incorporates oral history of those institutionalized; to the Truth and Reconciliation hearings, which attempt to remember and empower sufferers of Canada's residential schools for aboriginal children. Was it somewhat ironic, then, that medical historians were being encouraged to hide the identity of the very people they hoped to give agency to?[46] Canadian historians Wendy Mitchinson and Franca Iacovetta articulated this tension in a landmark collection of essays on the use of case records in social history:

> In uncovering their agency we face a paradox: our legal obligations as researchers to protect the privacy of individuals in the past can lead us to write the marginal into history by writing their names and faces out of it. But even this problem is not uniform across sources. Collections of records with varying provenance have different restrictions. The holders of some files place little if any restrictions on their use, others insist on name changes, while still others require anonymity to the point that a reader cannot trace the person through footnotes back to the original records.[47]

Critics of wholesale anonymization did question some of the assumptions of the emerging professional protocols. As the discussion

emerged in the late 1980s within the AAHM, Jacalyn Duffin questioned the assumption that researchers today could determine what diagnoses might be "sensitive" to individuals in the past:

> History is difficult enough without make-believe; imposing a double standard of identification, based on late-twentieth century determinations of confidentiality and of what diagnoses might be (or would have been?) "sensitive" to a mid-nineteenth century person, borders on hubris …. I believe these personal tales of fear, misery, injury, and death, now all more than one hundred years old, are not shameful — whatever the diagnosis may have been; they are an intrinsic part of the social history of Ontario, which deserves to be told fully.[48]

Amongst historians of madness, the South African historian of psychiatry, Julie Parle, recently adopted a similar position, suggesting whether anonymization actually perpetuated stigma associated with mental illness:

> To alter the names of the dozens of people to whom I refer would have been cumbersome, and to reduce them to initials would have further stripped down their identity, compounding that translation of the complex experiences of people into psychiatric "cases" that historians of medicine have sought to avoid. Arguably, if the "voice of history" is a sympathetic retelling of the suffering borne by such people, and their search for solace, it can contribute to a lessening of the marginalization of the mentally ill, both in the historical record, and in the present.[49]

Parle raises the profoundly interesting question of the extent to which anonymization runs counter to recent mental health initiatives to de-stigmatize mental illness through awareness-raising campaigns that emphasize disclosure and identification. Similarly, consumer-survivor groups around the world have been engaging in grass-roots initiatives to reclaim names and identities (see below).

Anonymization of medical records, of course, presupposes that the original medical case records are extant, or were created in

the first place. In certain colonial institutions, it is clear that more extensive records survive for white patients than for black African patients. The white patients, as observed by Jock McCulloch, who studied colonial psychiatry in Kenya, had the privilege of being remembered; black patients did not.[50] In her study of colonial Natal and Zululand, Parle observes, "In most instances, African and Indian patients are, in the sources, given only one name and their individual identities are thus already obscured."[51] Here, as in much literature on the history of slavery, the anonymizing impulse of research clashes with the desire to de-anonymize marginal groups, to rescue them from the indignity of having been re-named. The histories of slavery in the United States and the Americas are replete with historians attempting to rescue slaves from anonymity, in part by determining their real names. As expressed by Kátia de Queirós Mattoso, researchers hope to emancipate "these men and women from the anonymity in which they have been kept for so long."[52]

In response to growing concerns of humanists and social scientists to the one-size-fits-all approach, the 2010 iteration of the Canadian Tri-Council policy statement was more pluralistic and nuanced, recognizing the disparate research approaches in the Arts, and the tensions that might arise from comprehensive anonymity:

> The aims of qualitative research are very diverse, both within and across disciplines. The intended goals of qualitative projects may include "giving voice" to a particular population, engaging in research that is critical of settings and systems, or the power of those being studied, affecting change in a particular social environment, or exploring previously understudied phenomena to develop new theoretical approaches to research.[53]

For many working on colonial contexts, the process of naming (both historically and as scholars) remains a sensitive issue, one that invokes the renaming of enslaved or subjugated populations. Indeed, for some researchers examining the history of madness in Africa, renaming patients was largely beside the point, since many black patients had already been "re-named" by colonial physicians and

administrators. Little point in anonymizing individuals already stripped of the dignity of retaining their own names.[54]

The question of naming, being renamed, and being anonymized, strikes at the heart of some of the most important movements in public history and commemoration. Recent research has been exploring the way we remember the past and those actors within it. Within the history of madness, some of the most powerful projects have to do with commemorating hospital cemeteries, asylums (at least those that remain), or public history projects displaying artifacts of former patients.[55] These public acts of remembering are all about reclaiming individuals who have been stripped of their identities. How do historians respond to the desire of groups — the mentally ill, disability groups — eager to embrace their past through reclaiming their names and their collective histories?

Outside the Walls of the Asylum

The ongoing discussion over anonymization versus empowerment has been further complicated by the evolving state of research in the history of medicine in general, and madness in particular. To date, much of the debate over medical records in the past have focused on *institutional* medical records. This was reflective not only of the state of the research at the time — where hospital history was both popular and central to the history of medicine — but also due to the fact that many hospitals had excellent research collections. Clearly, this was the case in the history of madness where the rise (and fall) of the asylum was a central point of debate within the scholarship. However, as we know from the research of James Moran, Akihito Suzuki, and Catharine Coleborne,[56] madness did not confine itself to the Victorian lunatic asylum (or its successor institutions). It manifested itself in households, in courts of law, in public inquests, in community conflicts that were captured in a multitude of sources. Madness was subject to surveillance in decennial censuses (along with other basic medical questions) from the 1870s and to school surveys (for mental disability) from the 1890s. Lunacy commissioners, and their homologues in the British world, were obliged to investigate "single" lunatics in the community, in an unsuccessful

attempt to suppress the black market "trade in lunacy." Periodic exposés in Parliamentary Papers also discuss individual mad men and women. And many of the admission records associated with mental hospitals (such as certificates of insanity and reception orders) were, in fact, created in the community, and for administrative purposes ended up in the institution.[57] So, in reality, there exists a remarkable range of extramural historical sources that discuss the mental state and behaviour of the mentally ill in the past.

By contrast to the sensitivity of institutional records during the Victorian era, there seems to be relatively less concern about the anonymization of individual health (and mental health) records generated in the community. Take, for example, the digitization of nineteenth-century decennial census records. As many historical demographers are only too aware, there are dozens of projects that aim to digitize and render public, household enumerators' returns in English-speaking countries. These returns often included, from the mid-nineteenth century, a column on the "medical" status of the individual, including whether "blind, deaf and dumb," an "idiot," "lunatic," or "person of unsound mind." Indeed, the Mormons have completed the reconstruction of the entire 1881 Census for England and Wales. There are similar examples of mental incapacity — and non-psychiatric medical records — that are currently online in the digitized versions of court records, amongst others. Thus, is there something intrinsically or ethically *different* when madness manifests itself in a lunatic asylum rather than the community? How much does the context in which historical records are generated matter?

Conclusions

The anonymization of historical health records has been a pluralistic enterprise over the last generation, a mixture of legal restrictions, professional conventions, and unwritten ethical obligations that have been internalized and operationalized in a myriad of ways. This paper has attempted to survey the varied practices of medical historians — mental health historians in particular — regarding the presentation and re-presentation of patient records, capturing ethical duties to patients and their families. It has also attempted to high-

light some of the tensions in our approach to historical medical records more generally and the drift towards pluralism in practice.

Within the literature on the history of madness (and medicine more generally), it appears that the historians who have engaged with the question of patient confidentiality have done so on several levels — (1) what it means for the development of a professional code of ethics (the potential limitation of access to sources and public reaction to inadvertent disclosure); (2) how we strike a balance between their mission as social historians uncovering "hidden histories" that restore "agency" to vulnerable individuals of the past and their duties to protect confidentiality; (3) and how scholars extend ethical obligations beyond patients to descendants and communities. Despite the anxieties of senior members of the medical history community in the 1980s, there has been no predominant scandal that has altered dramatically the landscape of access or research in the discipline over the last quarter of a century.

When it comes to "mental health" records our concerns over privacy seem to be framed in particular ways that suggest our continued anxiety that psychiatric records — and by extension *mental illness* — is something deserving extra sensitivity. It is unclear whether this is a reflection of a history of treatment that occasions embarrassment (one thinks, for example, of the somatic therapies of the twentieth century), or a more implicit sense that mental illness is stigmatizing not only to those who were so labelled, but to generations yet unborn. Perhaps it is a sense of being extra cautious with populations that were vulnerable or marginalized in the past. This sensitivity manifests itself more strongly in our attitude to institutional records, which may reflect more our continued preoccupation with the *mental hospital* than a consistent attitude to historical medical records.

In the early stages of the evolution of the social history of medicine, caution tended to prevail. One can sense that many senior scholars sought self-regulation (and self-discipline) as a way of ensuring the growth and survival of the field. However, the early caution has given way to a greater openness and pluralism and a questioning as to whether anonymization is always called for or indeed appropriate. This flexibility has been fuelled by patient movements

themselves. The commemoration events at many former lunatic asylums seem to be about "recovering lost lives," as exemplified in the dozens of asylum cemetery projects and social media sites underway in North America and elsewhere. Quite the opposite of *concealing* the identity of now deceased mental patients, these events, often driven by patients' rights groups are all about *reclaiming* identity, of reversing anonymization, such as seen in the physical restoration of headstones in derelict asylum grounds.[58]

As we have mentioned briefly, there is reason to believe that these debates are becoming more, not less important, to medical and disability historians. In some jurisdictions, privacy legislation has made traditional studies of asylum (and other "sensitive") records all but impossible.[59] On the other hand, new projects in the Digital Humanities, combined with the renewed emphasis on public engagement, are providing hitherto untested waters in terms of access. We would venture to predict that the ability to make medical history records — including mental health records — readily available through digitization projects will renew the debate over anonymization and confidentiality in the years to come.

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DAVID WRIGHT is Professor of History, McGill University. His latest book is *DOWNS: The History of a Disability* (Oxford University Press, 2011).

RENÉE SAUCIER studied History and Women's Studies at McGill University. She is currently a researcher at the Hospital for Sick Children, Toronto.

DAVID WRIGHT est professeur d'histoire à l'Université McGill. Son dernier ouvrage s'intitule *DOWNS: The History of a Disability* (Oxford University Press, 2011).

RENÉE SAUCIER étudie l'histoire et les études féministes à l'Université McGill. Elle est présentement chercheure à l'hôpital pour enfants malades de Toronto.

Endnotes:

1 There is substantial literature on the historiography of health and medicine. For key papers outlining evolving approaches in the "social history of medicine" over the last four decades, see Jonathan Woodward and David Richards, "Towards a Social History of Medicine" in *Health Care and Popular Medicine in Nineteenth Century England*, eds. Jonathan Woodward and David Richards (London: Croom Helm, 1975), 15–55; Roy Porter, "The Patient's View: Doing Medical History from Below," *Theory and Society* 14, no. 2 (1985): 175–98; Judith Leavitt, "Medicine in Context: A Review Essay on the History of Medicine," *The American Historical Review* 95, no. 5 (1990): 1471–84; John Harley Warner, "The History of Science and the Sciences of Medicine," *Osiris* 10 (1995): 164–93; John Burnham, "A Brief History of Medical Practitioners and Professional Historians as Writers of Medical History," *Health and History* 1 (1999): 250–73; Frank Huisman and John Harley Warner, "Medical Histories" in *Locating Medical History: The Stories and Their Meanings*, eds. F. Huisman and J. Harley Warner (Baltimore and London: The Johns Hopkins University Press, 2004), 1–24; Flurin Condrau, "The Patient's View Meets the Clinical Gaze," *Social History of Medicine* 20 (2007): 525–40.

2 For an important exploration of this trend in Canadian historical scholarship, see Wendy Mitchinson and Franca Iacovetta, eds., *On the Case: Explorations in Social History* (Toronto: University of Toronto Press, 1998).

3 For an examination of the history of medical institutions, see Guenter Risse, "Hospital History: New Sources and Methods" in *Problems and Methods in the History of Medicine*, eds. Roy Porter and Andrew Wear (London: Croom, 1987), 175–204; and Jim Connor, "Hospital History in Canada and the United States," *Canadian Bulletin for Medical History* 7 (1990): 93–104. For an award-winning examination of the rise of hospitals in Canada, see David Gagan, *For Patients of Moderate Means: A Social History of the Voluntary Public General Hospital in Canada, 1890–1950* (Montréal and Kingston: McGill-Queen's University Press, 2002).

4 Dorothy Porter, "The Mission of Social History of Medicine: An Historical Overview," *Social History of Medicine* 8, no. 3 (1995): 345–60.

5 The history of the lunatic asylum, such as the social history of medicine, now constitutes a vast literature including dozens of monographs and well over 20 edited volumes in the last 30 years. For two edited collections examining the rise of the asylum in transnational perspective, see Joseph Melling and Bill Forsythe, eds., *Insanity, Institutions and Society: a social*

history of madness in comparative perspective (London: Routledge, 1999); and Roy Porter and David Wright, eds., *The Confinement of the Insane, 1800–1965: International Perspectives* (Cambridge, UK: Cambridge University Press, 2003). For a survey of the Canadian literature, see James Moran and David Wright, eds., *Mental Health and Canadian Society: Historical Perspectives* (Montréal and Kingston: McGill-Queen's University Press, 2006).

6 See Iacovetta and Mitchinson, Introduction, *On the Case*, 6. The dominant metaphor, particularly in the history of marginalized populations, is to refer to those "hidden" or "forgotten" by history. As an example in the history of disability, see Dorothy Atkinson, Mark Jackson, and Jan Walmsley, eds., *Forgotten Lives: Exploring the History of Learning Disability* (Kidderminster: BILD Publications, 1997): 6.

7 We suspect that different professional traditions exist in the English- and French-speaking worlds, which may be, in part, a reflection of the legacies of legal and ethical principles derived from the Common Law and the Civil Code, respectively. One obvious difference, for example, is the fact that the closure period in France is 150 years. Public Records Act (1958) Chapter 51; 6 and 7 Eliz 2. The Public Records Act was amended in 1967 and then substantially changed in light of the Freedom of Information Act (2000). Much of the legislation concerns when papers of government departments (in the United Kingdom) are made "public," what records will be selected for preservation, and what records will be destroyed. Latitude was given to extending the closure period of special "classes" of records of which "medical" ones were ultimately identified.

8 It is noteworthy that the debate over the permanent closure of the 1906 Canadian Census also involved debates over the 92 year closure period of census records. Many similar arguments — about the expected lifespan of individuals and the diminishment of the importance of privacy over time — also figured prominently in these discussions. See Expert Panel on Access to Historical Census Records, "Issues and Considerations," Statistics Canada, Archived Content at www.statcan.gc.ca/c1996-r1996/5214972-eng.htm, <viewed 6 February 2013>; James R. Robertson and Benjamin R. Dolin, "Legislative History of Bill S-13: *An Act to Amend the Statistics Act* (Census Records)," Law and Government Division, 20 February 2003; "Lobbying the Federal Government About the Census, Privacy, and Access to Information" Canadian Historical Association, "Advocacy" at www.cha-shc.ca/en/Advocacy_51/items/6.html, <viewed 6 February 2013>.

9 A truly global survey is beyond the scope of this paper. It should be noted, however, that many other (non-English-speaking) European countries, such as Norway, also adopted a 100 year closure period. Personal Communication with Dr Oyvind Thomassen, 30 April 2012.

10 This posthumous clause appears from time to time in legislation. British
     Columbia currently makes all records available 20 years after an individ-
     ual's death. Section 22 of [B.C.] Personal Information Protection Act
     [SBC 2003], Chapter 63, Current to 23 January 2013, Assented to 23
     October 2003. For Ontario, see Ontario Personal Health Information
     Privacy Act (2004), c. 3, Sched. A, s. 9 (1).
11 New Brunswick Personal Health Information Privacy and Access
     Act, Assented to 19 June 2009, Chapter P-7.05 at
     www.gnb.ca/0062/ PDF-acts/p-07-05.pdf, <viewed 7 February 2013>;
     Newfoundland & Labrador, Personal Health Information Act, SNL2008
     Chapter P-7.01: An Act to Provide for the Protection of Personal Health
     Information, Assented to 4 June 2008 at
     www.assembly.nl.ca/Legislation/sr/statutes/p07-01.htm, <viewed 7
     February 2013>.
12 Janet McCalman, "Writing the Women's Hospital History with Medical
     Records," *Health and History* 1, no. 2–3 (1999): 135. For a further dis-
     cussion on the recent changes in the Australian medical records, see below.
13 Outside of the NAI, individual research contracts are at the discretion of
     hospital managers. Indeed, in the absence of national legislation, and
     due to the fact that individual mental hospitals' archives are often uncat-
     alogued, this also permits a degree of latitude on the part of the
     researcher. Personal communication with Dr Oonagh Walsh, University
     College Cork, 11 May 2012.
14 See the interesting aside by Marie-Claude Thifault on the impact of the
     Duplessis Orphan scandal on the access of researchers to institutional
     records run by, or formerly run by, the Catholic Church in Quebec.
     Marie-Claude Thifault, "Citoyennes de St-Jean-De-Dieu. L'enfermement
     Asilaire des Femmes au Québec: 1873–1921" (thèse présentée à la Faculté
     des études supérieures et postdoctorales titre d'exigence partielle en vue de
     l'obtention du doctorat en histoire, Université d'Ottawa, 2002), 77.
15 Charlotte MacKenzie, *Psychiatry for the Rich: A History of Ticehurst
     Private Asylum* (London: Routledge, 1992), Acknowledgements, x.
16 Geoffrey Reaume, *Remembrance of Patients Past: Patient Life at the
     Toronto Hospital for the Insane, 1870–1940* (New York: Oxford
     University Press, 2000), 258.
17 Peter McCandless, *Moonlight, Magnolias & Madness: Insanity in South
     Carolina from the colonial period to the progressive era* (Chapel Hill:
     University of North Carolina Press, 1996), Preface, xiii–xiv.
18 Mark Jackson, *The Borderland of Imbecility: medicine, society, and the fab-
     rication of the feeble mind in late Victorian and Edwardian England*
     (Manchester: Manchester University Press, 2000), 15n12.
19 Dennis Doyle, "'A Fine New Child': The Lafargue Mental Hygiene
     Clinic and Harlem's African American Communities, 1946–1958,"

Journal of the History of Medicine and Allied Sciences 64, no. 2 (2008): 173 unnumbered note.

20 Medical Research Council (Canada), Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, and Tri-Council Working Group on Ethics, *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* (Ottawa: The Councils, 1998).

21 James Moran, *Committed to the State Asylum: insanity and society in nineteenth-century Quebec and Ontario* (Montréal and Kingston: McGill-Queen's University Press, 2000), Acknowledgements, x.

22 "Finally, while each patient was ascribed a unique identifying number within the database for ease of linkage between database tables and different asylum sources, this study will refer to individual patients by their name in order to make the study more 'human.' It should be stressed, however, that all patient names have been altered systematically and then abbreviated in order to protect the privacy of named individuals." Gayle Davis, *"The Cruel Madness of Love": Sex Syphilis and Psychiatry in Scotland, 1880–1930* (New York: Rodopi, 2008), 33.

23 This appears to be part of the research agreement that Swartz struck with the hospital management committee. See Sally Swartz, "The Black Insane in the Cape, 1891–1920," *Journal of Southern African Studies* 21, no. 3 (September 1995): 404–5n32.

24 Nancy Tomes, *A Generous Confidence: Thomas Story Kirkbride and the art of asylum keeping, 1840–1883* (New York: Cambridge University Press, 1984), 331.

25 In her study of gynecological treatment of women in early twentieth-century Canada, Wendy Mitchinson explains, "All the names of patients have been changed to protect their confidentiality. I have maintained the same initials and have substituted names suggestive of the same ethnicity." Wendy Mitchinson, "Problematic Bodies and Agency: Women Patients in Canada, 1900–1950" in *On the Case*, 283n6.

26 Cheryl Krasnick Warsh, *Moments of unreason — the practice of Canadian psychiatry and the Homewood retreat, 1883–1923* (Montréal and Kingston: McGill-Queen's University Press, 1989), 5.

27 Edgar-André Montigny, "'Foisted upon the Government': Institutions and the Impact of Public Policy upon the Aged. The Elderly Patients of Rockwood Asylum, 1866–1906," *Journal of Social History* 28, no. 4 (Summer 1995): 824. "All the people referred to in the following pages were patients or relatives of patients in the Rockwood Asylum. All information about them was obtained from the Asylum's patient case-files. Ontario's Freedom of Information Act prohibits mentioning the full names or case-file numbers of these patients. For this reason individual cases have not been footnoted."

28 Jacqueline Leckie, "Unsettled Minds: Gender and Settling Madness in Fiji" in *Psychiatry and Empire*, eds. Sloan Mahone and Megan Vaughan (New York: Palgrave Macmillan, 2007), 120n31.

29 Joel Braslow, "In the Name of Therapeutics: The Practice of Sterilization in a California State Hospital," *Journal of the History of Medicine and Allied Sciences* 51, no. 1 (1996): 37n25. "To protect patient privacy, all patient names and identifying characteristics have been changed. Further, all record numbers of patients have been altered. In all California state hospitals, patients were sequentially assigned numbers, starting with 1 for the first patient admitted. To preserve their relative order (which increased with each new admission), I have systematically changed the medical record numbers. In referring to a particular case, I will cite the hospital from which the record came, the recorded hospital number, date of citation, location of cited material in the record, and page number, if present. I have retained the original spelling and punctuation in all quotations from the medical record. Records from Patton State Hospital (in Patton, California) remain in the medical record department of that hospital. Records from Stockton State Hospital were at the Stockton Developmental Centre until its closing in February 1996. The records have been transferred to Napa State Hospital, located in Napa, California. With appropriate permission from the California Department of Mental Health, one can obtain actual patient record numbers from the author." Joel Braslow, *Mental Ills and Bodily Cures: Psychiatric Treatment in the First Half of the Twentieth Century* (Berkeley: University of California Press, 1997), 177.

30 Guenter B. Risse and John Harley Warner, "Reconstructing Clinical Activities: Patient Records in Medical History," *Social History of Medicine* 5, no. 2 (1992): 189.

31 Kenneth F. Kiple (Chair), Amalie M. Kass, Eric D. Kohler, and Samuel B. Thielman, "American Association for the History of Medicine. Report of the Committee on Ethical Codes: Ethical Codes Concerning Historical Research," *Bulletin of the History of Medicine* 65, no. 4 (Winter 1991): 565–70.

32 John Harley Warner, "The Uses of Patient Records by Historians — Patterns, Possibilities and Perplexities," *Health & History* 1, no. 2–3 (1999): 110.

33 A similar argument can be gleaned ten years earlier from a prescient article by a Canadian legal historian, though his clarion call to historians to engage in professional dialogue about best practices was broadly pitched and focused in particular on the use of information about living persons. See David H. Flaherty, "Privacy and Confidentiality: The Responsibilities of Historians," *Reviews in American History* 8, no. 3 (1980): 419–29, especially 421.

34 McCalman, 132–8. McCalman discusses the legal restrictions in the State of Victoria and asserts, "it will be many years before the descendants of those patients cease to care about such revelations and access to them will need to be tightly policed" (136).

35 Flaherty, 423.

36 Yannick Ripa, *Women and Madness: the incarceration of women in nineteenth-century France* (Cambridge, UK: Polity Press in association with Basil Blackwell, 1990), 162.

37 Jonathan D Ablard, *Madness In Buenos Aires: Patients, Psychiatrists and the Argentine State, 1880–1983* (Calgary, AB: University of Calgary Press 2008), 13.

38 Jonathan Sadowsky, *Imperial Bedlam: Institutions of Madness in Colonial Southwest Nigeria* (Berkeley: University of California Press, 1999), Preface, viii. Also see the similar remarks of Richard C. Keller, "When citing published case histories, I have used the names and abbreviations supplied by the author. In archival cases, I have concealed patients' identities to protect their and their descendants' privacy." Richard Keller, *Colonial Madness: Psychiatry in French North Africa* (Chicago: University of Chicago Press, 2007), 241n5.

39 Richard Adair, Bill Forsythe, and Joseph Melling, "A Danger to the Public? Disposing of Pauper Lunatics in late-Victorian and Edwardian England: Plympton St. Mary Union and the Devon County Asylum, 1867–1914," *Medical History* 42 (1998): 8n27.

40 It is worth noting that some non-English-speaking jurisdictions, such as France, have longer closure periods. In France, the closure period can extend as long as 150 years for some medical records, including psychiatric ones.

41 McCalman, 135–6.

42 "The real names of patients as written in Langstaff's documents have been used throughout this work, with the exception of names of patients sent to the Provincial Lunatic Asylum, as the archive of that institution stipulated patient anonymity prior to my examination of the material." Jacalyn Duffin, *Langstaff: A Nineteenth-Century Medical Life* (Toronto: University of Toronto Press, 1993), 258.

43 Catharine Coleborne, "Families, Insanity, and the Psychiatric Institution in Australia and New Zealand, 1860–1914," *Health & History* 11, no. 1 (2009): 82n2.

44 Alice R. Wexler, "Chorea and Community in a Nineteenth-Century Town," *Bulletin of the History of Medicine* 76, no. 3 (Fall 2002): 495–6, unnumbered note. Insurers in the United States are no longer permitted to deny individuals coverage due to pre-existing conditions.

45 Julie Parle, "The Voice of History?: Patients, Privacy and Archival Research Ethics in Histories of Insanity," *Journal of Natal and Zulu History* 24–25 (2006–2007): 185.

46 For an exploration of the patient's "voice" in the past, and its intersection with the convention of anonymizing patient records, see ibid., 164–87.

47 Iacovetta and Mitchinson, Introduction, *On the Case*, 6.

48 Duffin, 258-9.

49 Julie Parle, *States of Mind: searching for mental health in Natal and Zululand, 1868–1918* (Scottsville, South Africa: University of KwaZulu-Natal Press, 2007), 25–6.

50 At Mathari Mental Hospital, "Although eight out of ten of the patients were Africans, their stories have simply disappeared. There are no case-histories, and there is no correspondence from relatives or friends or from government officials inquiring as to their welfare. In contrast, the archive files are filled with the stories of insane Europeans and their relatives who were ruined by the loss of a husband or wife." Jock McCulloch, *Colonial Psychiatry and 'the African Mind'* (New York: Cambridge University Press, 1995), 28.

51 Parle, *States of Mind*, 25–6.

52 Kátia de Queirós Mattoso, *To be a slave in Brazil, 1550–1888*, trans. Arthur Goldhammer (New Brunswick, NJ: Rutgers University Press, 1986), 81. "I have tried to rescue from three centuries of anonymity and forced labor some three and a half million slaves, men and women who may now take their place not as mere agents of the will of their masters but as worthy and sentient beings in their own right, whose suffering and toil have fertilized the soil of Brazil." Ibid., 3.

53 Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2010, 137.

54 "The accuracy of names listed on African patients' files is often in doubt. This is because of numerous instances whereby authorities select a name for the person suspected of insanity because they do not trust the individual's ability to provide an accurate one." Lynette A. Jackson, *Surfacing Up: Psychiatry and social order in colonial Zimbabwe, 1908–1968* (Ithaca, NY: Cornell University Press, 2005), 197.

55 Catharine Coleborne and Dolly MacKinnon, eds., *Exhibiting Madness in Museums: Remembering Psychiatry Through Collections and Display* (New York: Routledge, 2011); and Nicole Baur, "On Site: Oral Testimonies in Mental Health History," *Social History of Medicine* 24, no. 2 (2011): 484–7.

56 James Moran, "Asylum in the Community: Managing the Insane in Antebellum America," *History of Psychiatry* 9, no. 34 (1998): 217–40; Akihito Suzuki, *Madness at Home : The Psychiatrist, the Patient, and the Family in England, 1820–1860* (Berkeley: University of California Press,

2006); Catharine Coleborne, *Madness in the Family: Insanity and Institutions in the Australasian Colonial World, 1860–1914* (New York: Palgrave MacMillan, 2009). For an early historiographical foray into this theme, see David Wright "Getting Out of the Asylum: Understanding the Confinement of the Insane in the Nineteenth Century," *Social History of Medicine* 9 (1997): 137–55.

57 David Wright, "The Certification of Insanity in Nineteenth-Century England," *History of Psychiatry* 9 (1998): 267–90.

58 David Wright and Nathan Flis, "Museums, Memory and the Lunatic Asylum" in *Exhibiting Madness in Museums*, 101–15.

59 McCalman, 135. "Unfortunately the law in the State of Victoria is less than helpful. When I began the project, the rule was open access to adults' records after seventy-five years, and to children's after one hundred. However, that rule now seems to have lapsed and access to records has become more ambiguous and difficult. Historians may seek dispensation from restrictions for projects of high scholarly value which are conducted under strict guidelines, just as medical researchers may; but access to patient and client records for both medical and social researchers is now clearly a matter for hospital and university ethics committees. Each case has to be considered on its scholarly merits and guidelines have to be policed. This may well mean submitting all written work from the research for scrutiny." Also see Catharine Coleborne and Dolly Mackinnon, "Introduction" in *'Madness' in Australia: histories, heritage and the asylum*, eds. Catharine Coleborne and Dolly Mackinnon (St. Lucia: University of Queensland Press, in Association with the API Network and Curtin University of Technology, 2003), 4–5.