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More important for my immediate purposes is that, as you will recall, one of the underlying reasons for the non-disclosure of the public records relating to the mentally ill relates not to a protection of their privacy - for the people I have written about are long dead - but the protection of their descendants in the hypothetical case that they should be embarrassed or troubled by the madness of their ancestors. But unto which generation should such protection be extended?<sup>18</sup> To what extent, as I suggested earlier, does such withholding of the names of those most afflicted contribute to further discrimination against the living?

We might also ask what difference it makes to point out that medical records themselves have a history. The rise of psychiatric record-keeping accompanied the rise of asylum medicine in the 1800s. The format of these notes varied considerably, becoming more regular only after mid-century. Moreover, the

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<sup>17</sup> In the history of psychiatric institutions, there was a shift from the Case-Book format to loose leaf folders, a little before WW1. While many Case-Books have been preserved, individuals' folders have more usually been destroyed. For an exploration of case notes as a source, see J. Andrews, 'Case notes, case histories, and the patient's experience of insanity at Gartnavel Royal Asylum, Glasgow, in the nineteenth century', *Social History of Medicine*, 11, 2, 1998, pp. 255-81. Andrews makes use of the full names of the patients he discusses.

<sup>18</sup> The records of criminal lunatics held at Britain's famous Broadmoor prison, for example, are closed, probably in perpetuity. According to John Heritage, 'The problem of access to patient information is ... complex and unresolved. Medical records seem likely to remain closed for ever except to bona fide medical researchers. Exceptionally, and subject to medical counselling, such information may be interpreted to genuine next-of-kin. As a policy, the hospital will not engage in any discussion of named patients with anybody on a routine basis. The hospital has an indefinitely long duty of care to its patients and their families, which it takes very seriously. There is a body of opinion which considers that criminal lunatic non-medical records are so sensitive that whereas lunatic or criminal records are opened after three generations this is not sufficiently long to protect the descendants of Broadmoor patients. Four generations (125 years) has been proposed informally as a minimum closure period but no formal consideration has yet taken place.'<http://www.berksfhs.org.uk/journal/Jun2002/jun2002BroadmoorHospitalArchives.htm> Accessed on 3 November 2005 at 14:05.

notion of patient confidentiality is itself a relatively recent one, emerging in the late nineteenth century as a by-product of the corporate ownership of hospital records, and not as a consequence of concern for patient rights.<sup>19</sup> Not only were physicians and clinicians now denied the right to retain what had hitherto been their private property, patients continued to be denied access to their own records.

The bureaucratization of medical record-keeping, not surprisingly, soon brought with it problems of storage, and, it soon became common practice for such records to be destroyed after a stipulated storage period. In South Africa in 1929, the Director of Archives instructed that records of mental institutions were to be destroyed after seven years. Where any have survived has been because of the neglect of hospital authorities to comply with this instruction, or the occasional act of preservation by administrators interested in institutional history. This means that these patients (and later their descendants) were denied access to the very records that inscribed their insanity, and which were presented as justification for their confinement in a psychiatric facility. The preservation of the Reception Orders, however, provides something of a counter-balance and their availability as public documents means that, for those with a will to pursue family history, some records remain.

In the last decade, in South Africa, as elsewhere, there have been important changes in the ways in which medical records are kept and there has been renewed debate about access and privacy, with requirements simultaneously for greater control over patient records *and* greater access to them by those who have appropriate authorization. The Patients' Rights Charter, for instance, unequivocally states that 'Everyone has the right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and the costs involved, for one to make a decision that

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<sup>19</sup> B.L. Craig, 'The Role of Records and of Record-Keeping in the Development of the Modern Hospital in London, England, and Ontario, Canada, c.1890-1940', *Bulletin of the History of Medicine*, 65, 1991, pp.39-393.

affects any one of these elements.' It also has an Informed Consent clause which states that 'Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or an order of the court.'<sup>20</sup>

Confidentiality has, of course, become an issue of even more burning concern - legally as well as ethically - in the context of HIV/AIDS. On the matter of the preservation of records, digitization and other electronic forms of inscription are advocated as being the answer to storage issues. One argument in favour of the long-term retention of such records after the death of a patient would presumably lie in the great interest of descendants who may wish to examine their genetic inheritance for *bone fide* health reasons. Nor are family members the only ones with access to such records. States and medical insurance companies have begun to lay their claims to them too.

The ethics of patient record-keeping, then, are not fixed in time or meaning. Nor, it is to be hoped, are the objects of social shame. The twentieth century saw, for instance, a lessening - in some parts of the world at least - of some forms of social discrimination, against those who had cancer, or who were gay or lesbian, or of the physically disabled. The writing of the histories of such previously marginalized and often discriminated against people was, in part, aided by the telling of their histories. But, this brings us to a set of somewhat different ethical questions about the purpose of history-writing and the role of academics. To quote from a recent text on the history of medicine, 'history is not able to supply any easy lessons for present-day issues, but medical history can make a subtle

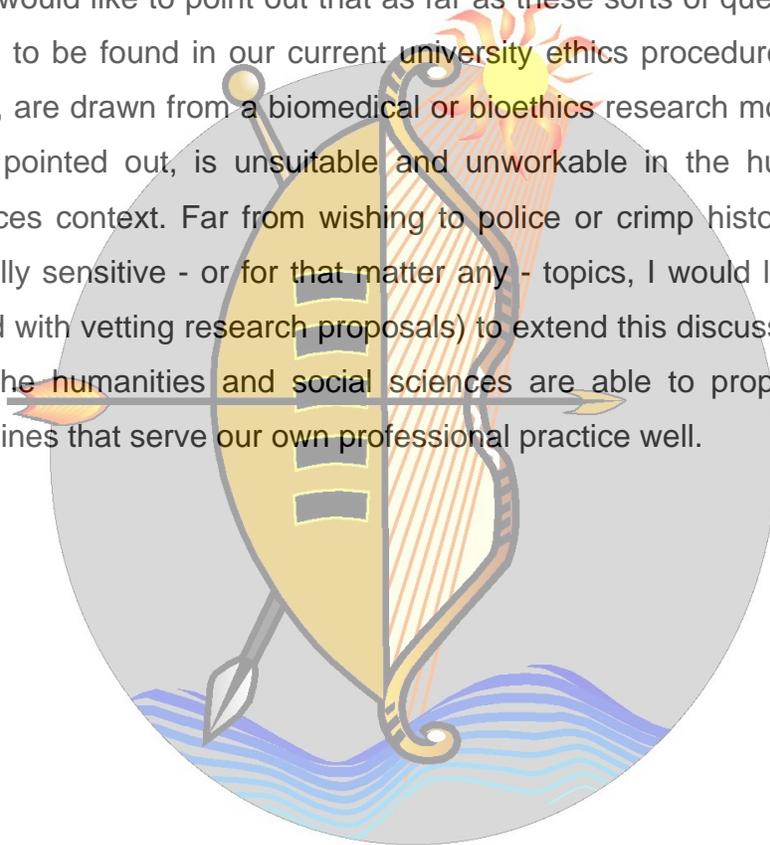
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<sup>20</sup> Found at <http://www.doh.gov.za/docs/legislation/patientsright/chartere.html>. Accessed 5 November 2005 at 12:30. I have not been able to establish the period for the retention of patient records. Interestingly, the Promotion of Access to Information Act (2000) appears to exempt the privacy clause for a person who has been dead for longer than 20 years.

and powerful difference in people's lives... Relevance and responsibility go hand in hand.'<sup>21</sup>

My larger question, then, relates both to the tug between the oft-made injunction to historians to let documents and subalterns 'speak' and to the rights to privacy, confidentiality and - perhaps - ignorance, of their descendants; and to other questions about silences, closure and stigma.

In closing, I would like to point out that as far as these sorts of questions go, few answers are to be found in our current university ethics procedures which, in a further irony, are drawn from a biomedical or bioethics research model which, as many have pointed out, is unsuitable and unworkable in the humanities and social sciences context. Far from wishing to police or crimp historical research into potentially sensitive - or for that matter any - topics, I would like (as one of those tasked with vetting research proposals) to extend this discussion further so that we in the humanities and social sciences are able to propose workable ethics guidelines that serve our own professional practice well.



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<sup>21</sup> F. Huisman and J. Harley Warner, 'Medical Histories' in F. Huisman and J. Harley Warner (eds) *Locating Medical History: The Stories and Their Meanings* (Baltimore and London: The Johns Hopkins University Press, 2004), pp. 23 and 24. In this edited collection, two articles in particular address the role of 'cultural historian as social activist'. They are A.D. Dreger, 'Cultural History and Social Activism: Scholarship, Identities, and the Intersex Rights Movement'; and A. M. Brandt, 'From Analysis to Advocacy: Crossing Boundaries as a Historian of Health Policy'.