

Report on historical mental health records seminar

Royal Irish Academy, 16 May 2019



The Royal Irish Academy, Ireland's leading body of experts in the sciences, humanities and social sciences, hosted a seminar on 16 May 2019 to discuss the current status of and access to historical mental health records in Ireland, and to consider alternative approaches in other countries towards such records which might serve as good practice models for Ireland to emulate.

The seminar marked the beginning of a partnership between the Royal Irish Academy, the Grangegorman Development Agency, the Health Service Executive, Technological University Dublin, Dublin City Council and the National Archives, Ireland. The partners have come together to develop of a 3-year project on the history of Grangegorman.

The organising committee for this event was Valeria Cavalli, Administrator and Marketing Executive, Royal Irish Academy, Catriona Crowe, MRIA, Ruth Hegarty, Managing Editor, Royal Irish Academy and Brendan Kelly, Professor of Psychiatry, Trinity College Dublin. The Rapporteur for the event was Patrick Nolan. This report has been written by Valeria Cavalli, Ruth Hegarty and Brendan Kelly.

Summary

- There is no standard protocol in Ireland for: the storage and management of archival materials from mental hospitals; historical research on these records; publication of materials or images from these records for the purposes of historical research.
- In Italy, all archives are regulated by the Cultural Heritage and Landscape Code (2004). With regard to mental hospital records, access and use are granted to all records older than 70 years. Moreover, researchers can request access to psychiatric records less than 70 years old. An ad hoc Commission, under the aegis of the Ministry of Home Affairs, decides on the admissibility of the request. If the Commission approves the request, those documents become accessible to all.
- In the United Kingdom, mental hospital records are owned by the nation and, as public records, they are held within archival repositories rather than hospitals. Access to information in public records is governed by the Freedom of Information Act of 2005, which instituted a general presumption in favour of public sector records being on open access, while also setting out a series of exemptions. Limitations on access are now based primarily on the nature of the information, rather than its age. A citizen right of access has in effect replaced the blanket 100-year closure period, although a general right of access is subject to the provisions of the Human Rights Act 2007.

On the basis of the above, and in line with international best practice, we make the following proposals for a national protocol governing access to, and publication of material from, mental hospital archives that are held or controlled by the Health Service Executive (HSE), for historical research purposes:

- Archival material over 100 years old should be freely available for historical researchers to consult without need for HSE approval and should also be fully publishable with no requirement for anonymity.
- Archival material that is over 50 but less than 100 years old should be available for historical researchers to consult following HSE approval and publication should be possible subject to HSE approval which would be granted subject to patients' names and precise addresses not being disclosed and photographs not being used.
- A national protocol governing access to and publication of historical mental health records should be developed by the HSE.

Format

The seminar was structured as two panel discussions, each followed by a Q&A session from the floor.

Panel 1, chaired by Catriona Crowe, MRIA, set the context in conversation with Brendan Kelly (Professor of Psychiatry, Trinity College Dublin) and Brian Donnelly (Senior Archivist, National Archives of Ireland). This discussion surveyed how historical mental health records are cared for in Ireland and considered the practical challenges encountered in granting access to and use of sensitive records. The particular archive which served as the focus for this discussion is the set of medical and associated records from St Brendan's Mental Hospital in Grangegorman, Dublin, and its constituent and predecessor institutions. These records are the property of the HSE but have been entrusted by the HSE to the National Archives on indefinite loan on the basis of a formal written agreement between the two bodies. The Grangegorman records are held under the National Archives reference number PRIV 1223.

The Panel 2 discussion, chaired by Ruth Hegarty (Managing Editor, Royal Irish Academy), considered international best practice in dealing with historical mental health records, with case studies presented respectively by Leonardo Musci (President, Memoria Servizi Archivistici, Rome, Italy) and Colin Gale (Director, Bethlem Museum of the Mind, London, UK).

The seminar was run under the Chatham House Rule, according to which, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed (<https://www.chathamhouse.org/chatham-house-rule>).

Opening

The seminar was formally opened by the Lord Mayor of Dublin, Nial Ring. He reflected on his own engagement with the Grangegorman History Project as part of the Consultative Group and Community Liaison Committee and noted that while the re-development of Grangegorman takes us into the future, it is always important to recognise and acknowledge where we have come from, even if that is sometimes a difficult process. He expressed his hope for positive outcomes from the seminar discussions, with a view to acknowledging persons who had spent time in our psychiatric hospitals and opening up access to the records of these people and their experiences. He concluded by welcoming the participation of experts from Ireland and beyond Ireland as offering models of how to strike the correct balance between individual privacy and the greater good in terms of access to the records.

Panel I

The first panel was chaired by Catriona Crowe. Catriona is former Head of Special Projects at the National Archives of Ireland. She is the author of *Dublin 1911* (Royal Irish Academy, 2011). She contributes regularly to the broadcast and print media on cultural and historical matters. She is a member of the Royal Irish Academy.

Introducing the Panel I discussion, Catriona observed that participants were gathered to try to educate themselves about Irish historical mental health records. She noted that the objective of the seminar was to help the HSE in their practice with regard to these valuable records, which as well as giving vital details about the treatment of mental illness from the mid-nineteenth century onwards, also comprise a social history of Ireland over 150 years.

The first two speakers were Brian Donnelly and Brendan Kelly, whom Catriona described as “two people who probably know more about mental health records than anyone else in the country”.

Brian Donnelly is Senior Archivist at the National Archives of Ireland. He is renowned and esteemed among archivists for his persistence and success in saving many valuable records from destruction.

Brendan Kelly is Professor of Psychiatry at Trinity College Dublin and Consultant Psychiatrist at Tallaght Hospital. He is the author of *Hearing voices: the history of psychiatry in Ireland* (Irish Academic Press, 2016), the first book to look in detail at the historical treatment of mental illness in Ireland. Thus, he combines the roles of eminent historian and practising mental health specialist.

I. Brian Donnelly: an overview of the development of mental health hospitals

Brian’s contribution focused on the records of mental health institutions with which he had dealt, what remains to be done, and current arrangements with the HSE for access to the Grangegorman records in the custody of the National Archives.

I.1 Mental hospital development in Ireland

St Patrick’s hospital in Dublin was founded by Royal Charter in 1746 and was the most notable example of the many philanthropic efforts to support mental health institutions in the eighteenth century. The Richmond Asylum, established by public subscription in 1814 and intended to cater for the whole country, was the first explicit use of the Grangegorman site for the treatment of mental illness. Later in the nineteenth century a countrywide system of district mental asylums was set up. By 1871 there were 22 district asylums in operation, a network of large institutions including Grangegorman. Subsequently, the Portrane Asylum was established as an auxiliary to Grangegorman. From 1930

onwards, the Irish Hospitals' Sweepstake yielded lottery money to support refurbishment and maintenance of the district asylums.

From the 1980s onwards many of these large mental hospitals closed as part of a decisive shift away from the in-patient treatment of people with mental illness. All of the district asylums had significant medical records but the care of and interest in these institutional archives varied. Usually the key to the maintenance of good records in good condition came down to the staff having a high degree of interest in the materials. Often records were consigned to basement or attics, the areas of the hospital where expenditure on maintenance was least. On closure of the large asylums the Health Board generally transferred the records to the local archives, but local archives only cover about half the country.

Some asylums had/have very rich material. For instance, the basement records of St Columba's in Sligo have incredibly disparate sources – unique casebooks for each female, books registering the private property of each patient. The Connacht asylum, St Brigid's in Ballinasloe, had a huge collection of records, with minutes going back to 1846. These are now transferred to the National Archives. Other asylums with good records include St Finan's in Killarney, whose records are in the Kerry County archives, Our Lady's in Ennis, St Joseph's in Limerick and St. Conal's in Letterkenny.

From Grangegorman the records of the Richmond Female Penitentiary are extant. This was the place from where female convicts were transported to Australia. From Dr Lalor's time in the mid-1800s Grangegorman became the preeminent asylum in Ireland. Grangegorman has a rich repository of photographs of staff and patients. From 1893 up to the 1950s a photograph of the patient was placed on the case notes file on admission. These photographs show a poignant insight into the human condition. From 1916 to 1919 the Richmond War Hospital within Grangegorman treated military men suffering from shell shock, whose records also survive.

1.2 Grangegorman records

The National Archives was not in a position to take in the Grangegorman records until the Wellcome Trust came to assistance with a funding grant. Meanwhile, the staff of the HSE and TU Dublin played a significant role in preserving records. Twenty-two tons of records were transferred to the National Archives and conservation work was carried out. Now, all surviving committal forms to Grangegorman have been entered in the database and ten sets of archives are available for research.

We should note, however, the legal protections applied to archives of hospitals and healthcare institutions. While these are not uniform around the country, they are generally strict. In the specific case of Grangegorman, an agreement between the National Archives and the HSE delineates the conditions of access to records as follows:

“It is agreed that requests for access shall be divided into Level One, Level Two and Level Three depending on the identity of the applicant and the purpose of the request for access.

Level One: clinical or other academic research access to records irrespective of the date on which created.

Level Two: genealogical or other access to records of an individual patient that are less than one hundred and twenty years old.

Level Three: general access to any and all types of records that are one hundred and twenty years or older.

It shall be the responsibility of the HSE to consider access requests and to determine the level of access to be granted in each case”.

Beyond Grangegorman, while some records remain in situ outside the National Archives, the National Archives knows what these hold on foot of a survey of hospital records in 2015 which can be accessed on the [National Archives website](#). This survey has six excellent recommendations for the care and management of the records.

2. Brendan Kelly: mental health records: stories and pictures

Brendan’s contribution focused on his work as a historian and on the challenges he encountered in accessing and using mental health records. His interest in researching the records of mental hospitals came about when he was serving as Registrar in the Central Mental Hospital (CMH) in Dundrum, Ireland’s only forensic mental hospital. Brendan wanted to explore the story of ‘Dora’, a patient at CMH who had killed her child in 1892. He applied to the HSE for permission to use the material but was told the records must maintain anonymity. This meant he could not link Dora’s trial record to her hospital record, thus making it impossible to write up a full picture of her health and circumstances. Years later, while working on his book *Hearing voices*, he noted the difficulty of obtaining permission to access photographs. Permission was eventually granted, but the patients’ faces had to be blocked out.

Brendan continued by emphasising the value of words and accompanying pictures to illustrate the past and the future. Asylums were very powerful institutions, huge centres of employment, and significant consumers of goods and services. For example, in the early 1900s the town of Ballinasloe had 5,600 inhabitants, of which 40% were patients in St Brigid’s, the Connacht Asylum. Researching asylum records can offer valuable information about the relationship between mental hospitals and their surrounding community, about patients’ socio-economic backgrounds and the ways in which people justified the incarceration of family members. Psychiatry has always reflected changes in society far more than any area of medicine or indeed any other area of social care. For this reason, he concluded,

there is clearly a need for a systematic protocol to cover access and publication of mental hospital records.

During the Q&A further emphasis was placed on the urge for a legislation to provide for the preservation of records of historic value, for transfer to archival custody after a designated period and for access to meet the information needs of individuals and for historical research. It was suggested that one way to implement the recommendation for primary legislation would be by extending the scope of the National Archives Act 2007 to cover health records of all hospitals.

Panel 2

The second panel was chaired by Ruth Hegarty. Ruth is Managing Editor of the Royal Irish Academy's publishing house. She established the Prism imprint of the RIA, which aims to produce beautiful books encouraging readers to return to the primary source, always accompanied by engaging scholarly commentary.

This panel discussion focused on international best practice in dealing with historical mental health records, with case studies from Italy and the United Kingdom. Introducing the topic and referencing the Grangegorman History Project, Ruth observed how evidence-based research, informed by the nuances of individual stories and context, could provide a commentary on the treatment of difference in Irish society. She then introduced the speakers, Leonardo Musci and Colin Gale, and invited them to present the current legislations covering psychiatric archival material in their respective countries.

Leonardo Musci is President of Memoria Servizi Archivistici and one of the founders of *Carte da legare*, Italy's online database of mental hospital records (<http://www.cartedalegare.san.beniculturali.it>).

Colin Gale is Director of Bethlem Museum of the Mind (<https://museumofthemind.org.uk/>) and co-author of *Presumed Curable: an illustrated casebook of Victorian psychiatric patients in Bethlem Hospital* (Wrightson Biomedical, 2003).

3. Leonardo Musci: access to archives in Italy

Leonardo began by setting out the big change in mental health care in Italy consequent to enactment of 'Law no. 180' in 1978 which repealed the 1904 law which had provided for forced admissions and worked within a concept of mental illness as a social risk. The new law amended the Italian Penal Code to restore the rights of mental patients and prohibited forcible psychiatric treatments. The law,

colloquially called the 'Basaglia law', after the psychiatrist who led the movement for reform, effectively ended the era of detention and repression for the mentally ill and led over the next 20 years to the closure of all in-patient mental hospitals in Italy. The law built on a significant movement within psychiatry to adopt a therapeutic approach in treating people with mental health issues.

In some cases (particularly in Venice, Naples, Rome, Reggio Emilia, Bologna and Volterra) management teams superintending the process of closure paid attention to the archives of the institutions. Still, some archives were lost in whole or in part due to negligence. While older mental health records were lodged with the relevant Provincial State Archive, most of the archives remained the responsibility of the Italian equivalent of the HSE. This led, in 1999, to the launch of the project *Carte da legare*, the title being an allusion to the practice of taking patients away in a straitjacket. As the mentally ill are now 'fit to be untied', their documents (*carte*) are to be tied (*da legare*), i.e. not scattered. Instead, the memory of their treatment is preserved.

Documents are not only to be tied and well-kept but available for research. The project was born for two purposes. Firstly: to organize and systematize psychiatric hospitals' archives to make these accessible. As a consequence, for the past 15 years historiography on Italian psychiatric hospitals has flourished, mainly driven by female scholars. The second objective of *Carte da legare* is to preserve the integrity of the records. *Carte da legare* promotes specific analytic filing of mental patients' records by means of a dedicated software, named *Arcanamente*, paid by State funds. The database now hosts about 139,000 patients' records (and 208,000 admissions records) from the end of the eighteenth century to the end of the twentieth century. An exact figure is not available for the number of people detained in psychiatric hospitals over that two-century period but it is estimated that about 1.5m Italians or people living in Italy have spent a period of their lives in a psychiatric hospital, with exact figures available from some provinces.

Italian archival law has always been liberal, based on the principle "all documents are accessible except". Access to mental health records is regulated by the Cultural Heritage and Landscape Code (2004), as all archives are treated as cultural heritage. According to the Code, psychiatric records that are 70 years old or older can be freely accessed and used. A researcher can request access to medical documents less than 70 years old. In that case, an ad hoc Commission, under the aegis of the Ministry of Home Affairs, shall decide on the admissibility of the request. If the Commission approves the request, those documents become accessible to all.

In theory, there is unrestricted access to and use of medical records older than 70 years. However, in practice, *Carte da legare* and other archives tend to block the publication/dissemination of names, places of birth etc., on the basis of the discretion of the archivist and having regard to peer pressure within the profession and to public opinion. Access is driven instead by a code of practice adopted in 1996. In practice then, safeguards, e.g. pseudonymisation, applying to documents less than 70 years old

are also likely to be applied to those over 70 years old. What happens usually is that the records over 70 years are released minus the surname and the place of origin of the patient (although given that the records are held on a provincial basis this narrows the place of origin somewhat).

A final point to note relates to deceased persons. Even though GDPR proper does not apply to deceased persons Italy, in its domestic law giving effect to GDPR the application of GDPR rights has extended to a deceased person in their own interest or to protect their family.

4. Colin Gale: access to archives in the United Kingdom

Colin Gale gave a presentation on the British perspective on medical records. He observed that archival practice in the UK is generally consistent with the archival principles propounded by Sir Hilary Jenkinson, Deputy Keeper of Public Records from 1947 to 1954, according to which records become archives upon the transfer of their custody away from those that created and maintained them, once the original purpose for which the records were kept has expired, to a professional class of archivists whose primary responsibility is the management of all the secondary purposes for which the archive might be required. Thus, in Britain, historic medical records tend to be held not within hospitals but within archival repositories: the Public Record Office of Northern Ireland in Northern Ireland; university archives in Scotland; and county record offices in England and Wales (rather than the National Archives, which tends to confine its record-keeping endeavours to the records of central government, excluding the National Health Service). Records belong in the public sector, including the records of all hospitals which are part of the National Health Service (NHS), regardless of the hospital's status, public or private, prior to the establishment of the NHS in 1948, and regardless of the actual age of the records.

In the UK, access to information in public records is now mainly governed by the Freedom of Information Act 2005. That Act provides a general right of access to information held by public authorities, subject to a number of exemptions, including: a data protection exemption, covering information about identifiable persons; a confidentiality exemption, covering information whose disclosure would give rise to an actionable breach of confidence; a health and safety exemption, covering information which would endanger someone's safety, or physical or mental health; and a catch-all exemption, covering information whose disclosure is prohibited by any other enactment. Therefore, limitations on access are now based primarily on the nature of the information, rather than its age, which means that a citizen's right to access in all cases where exemptions do not apply has superseded the blanket 100-year rule that used to apply.

Archivists have a duty to consider the ethics of the matter, as cultural differences are likely to play a part in shaping the way ethical judgements about access to medical records are made. But culture is

not always going to incline us only in the direction of keeping records closed for ever longer periods, or alternatively in the direction of record destruction. In different circumstances, culture could just as easily point us in the direction of greater openness.

The Q&A highlighted the current concern over the lack of a legislation, or even a rule of thumb, covering access to and use of psychiatric records in Ireland. Emerging material and stories of identified people can inform and change minds. However, the current situation poses challenges to both archivists and historians, and ultimately penalises society as a whole.

Conclusion

This seminar was organised with the intention of shedding light on the current status of and access to historical mental health records in Ireland and present alternative approaches in other countries as possible models to emulate. The points made during the exchanges of views will inform the development of policy and practice on access to psychiatric records.