

MAXIMISING ACCESS TO HISTORIC MEDICAL RECORDS

BY COLIN GALE AND KATHERINE WEBB¹

Law

On 8 November 2007 the following letter was written to the editor of *The Times*:

Dear Sir, On Wednesday [7 November] Times 2 reported that in the 1940s and 1950s James Gambell wrote a series of letters to his county council asking for the release of his daughter Jean from hospital detention under the Mental Deficiency Act. In the event, Jean did not return home until this year, shortly before her death. The correspondence is still in existence, according to the report, but in the absence of a court order the council have refused Jean's family access to it.

The letter continues:

Isn't this an extension of the secretive paternalism that has caused the Gambell family so many years of heartache? Perhaps an appeal to the Information Commissioner should be considered. Disclosure of this correspondence could not conceivably result in an actionable breach of confidence. The letter-writer died fifty years ago, the subject of the letters has also died and presumably her only personal representatives are the family members who have requested access.

Then the letter-writer concludes:

Maybe the correspondence would show council bureaucracy of the 1940s and 1950s in a bad light. Maybe it wouldn't. Either way, we live in an age of freedom of information and (to paraphrase George Santayana) the society that cannot remember the past is condemned to repeat it.

This letter, written by one of the authors of this paper, was never actually published by *The Times*, but its inclusion here has nothing to do with the writer's wounded pride! It simply serves as a prompt to think about how in England we came to the situation in which a letter like this could be written.

Time was when life was simple for archivists in England when they received third-party requests to access historic medical records. Lord Chancellor's Instrument number 92 made the records of National Health Service (NHS) and NHS predecessor bodies which consisted of information relating to the physical or mental health of identifiable individual patients unavailable for public inspection for a period of a

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hundred years after the last date on the record. The Public Records Act gave power to the Lord Chancellor to issue such instruments and the only part archivists had to play was to locate the last date on the record and do their sums. If the record was older than a hundred years, then archivists could permit third-party access; if it wasn't, they couldn't. The only authority that could permit privileged access to more recent records was the health authority responsible for the creation of the record. This was a system of discretionary privileged access, governed by Health Memorandum guidance dating from 1961 that read in part:

Hospital authorities should exercise the greatest discretion in granting such permission in the case of medical records and other documents containing information about patients. It is advised that they should require from persons seeking such permission a signed undertaking not to identify any individual patient's case by name in any work resulting from such research.²

This route of access predated and was never entirely superseded by, the research access provisions of section 60 of the Health and Social Care Act 2001.

But the Freedom of Information Act repealed the part of the Public Records Act which gave the Lord Chancellor power to issue such instruments and consequently all the instruments and guidance that had been issued lost their legal force overnight. Since the start of 2005 the people of England have been in a brave new world. The hundred-year rule is dead and third-party access to NHS and NHS predecessor medical records is now governed by the Freedom of Information Act and its various exemptions. Moreover, responsibility for deciding how to respond to access requests now falls clearly on the shoulders of the record-holder rather than the record-creator. It is important that these things are stated, we believe, in light of the assumption that is currently widespread among archive professionals and archive users alike that the hundred year closure period on medical records is still in place, along with the provisions for applying for privileged access to the record-creating health authority. In a recent issue of the *Journal of the Society of Archivists*, for example, the authors of a report on access restrictions in force across Europe state that 'in the UK, the [maximum] closure period for medical records [is] 100 years from the time of the creation of the document and this remains unchanged by the new Freedom of Information Act'.³ To be fair, the authors are Estonian archivists who have in good faith relied upon information provided to them and the article demonstrates a degree of knowledge about access to medical records in Estonia and the rest of the European Union that we can only envy. However, they are mistaken about the present state of affairs in post-Freedom of Information Act England.

Does this change in access regime represent a challenge to archivists in the UK public sector? It certainly does – they must become intimately acquainted with the Freedom of Information Act. They must learn to love it, so to speak. And they must reconcile themselves to making decisions in response to access provisions on a case-by-case basis without the reassurance of a blanket hundred-year rule, or a refer-it-to-someone-else-for-them-to-make-the-decision rule. Does the change represent a threat to the confidentiality of information which by rights ought to remain private? Not in our view – the exemption provisions of the Freedom of Information Act provide

² Health Memorandum 61(73), paragraph 17.

³ Jaak Valge and Birgit Kibal, 'Restrictions on Access to Archives and Records in Europe: A History and the Current Situation', *Journal of the Society of Archivists*, vol. xxviii, no. 2 (Oct 2007), page 208.

ample protection for such information. Does the change represent an opportunity to maximise access to historic medical records within the parameters of freedom of information and data protection legislation in England? Yes it most certainly does. A blow-by-blow account of these parameters, entitled *After the Hundred Year Rule*, was written for the Society of Archivists by Colin Gale and Catherine Redfern in 2004.⁴ It is a work of reference with respect to the exemption provisions of the UK Freedom of Information Act and proposes rules of thumb to follow with respect to managing third-party access to medical records.

The rules of thumb proposed in *After the Hundred Year Rule* are based on the fact that the medical records of the living are protected by the Freedom of Information Act's data protection exemption. Now it may interest you to know, if you don't already, that the UK National Archives routinely make a working assumption about the human life-span for the purpose of deciding which records to put on open access. That working assumption is that most everyone dies on or before their hundredth birthday. A second working assumption is made in *After the Hundred Year Rule*: that if in historic medical records, there is a clear division maintained between the medical records of adults and those of children, it should be safe to assume that anyone admitted to hospital as an adult was aged at least sixteen on the day they arrived. On this basis, data protection will not exempt the historic medical records of adults from disclosure under the Freedom of Information Act once these records are eighty-four years old. Archivists still need to do their sums!

So, does this mean that, under the UK Freedom of Information Act regime, the medical records of adults, considered as a class, can and should be proactively reviewed with the intention of opening to public access after eighty-four years? We think that it does. The reason for this is that no other exemption in the Freedom of Information Act can tenably be held to protect information about adults that is over eighty-four years old. There has been a lot of discussion as to whether the Act's actionable breach of confidence exemption, or its health and safety exemption, or its any other enactment exemption, protects information concerning deceased patients. In certain limited circumstances, one or other of these exemptions might provide protection and in other circumstances they might not. Case law is our only reliable guide as to what constitutes an actionable breach of confidentiality and case law is our only reliable guide as to how enactments such as the Human Rights Act may have a bearing on disclosures. Unsurprisingly, this area of law has yet to be fully mapped out. The rules of thumb in *After the Hundred Year Rule* are based on the reasonable judgement that none of these exemptions would protect information about adult patients that was recorded over eighty-four years ago.

Now it may be that those in the know concerning records of the deceased might think to themselves 'That's not what the UK Information Commissioner has said in the guidance issued in March 2007'.⁵ The guidance makes the following points:

1. that information concerning a deceased person might in some cases be presented together with information about a living person and might therefore be protected by the Freedom of Information Act's data protection exemption (section 40);

⁴ Colin Gale and Catherine Redfern, *After the Hundred Year Rule: guidance for archivists and records managers on access to medical records under the Freedom of Information Act* (Taunton: Society of Archivists, 2004), available online at <<http://www.archives.org.uk/download.asp?id=188>> and <http://www.healtharchives.org/docs/After_100_year_rule.pdf> (accessed on 20 Dec 2007).

⁵ Available online at <www.ico.gov.uk/upload/documents/library/freedom_of_information/detailed_specialist_guides/access_to_information_about_deceased_220307_v1.1.pdf> (accessed on 20 Dec 2007).

2. that the private and family life of living people, which is protected by the Human Rights Act, might be adversely affected by release of information about a deceased relative and that such information might therefore be protected by the Act's 'any other enactment' exemption (section 44);
3. that there might be circumstances in which a duty of confidentiality owed to a person could be actionable after their death by their personal representative and that confidential information might therefore be protected by the Act's actionable breach of confidence exemption (section 41).

These points are all well made and each of them is canvassed in chapter 5 of *After the Hundred Year Rule*. (With respect to the third point, it is worth mentioning that the Information Tribunal has recently upheld a decision by the Information Commissioner to refuse third-party access to medical records in precisely these circumstances. The records in question were nine years old and the personal representative of the deceased subject was opposed to their disclosure.)⁶ None of these points invalidate the rules of thumb set out in *After the Hundred Year Rule* with respect to third-party access to medical records. Archivists need reliable rules of thumb to govern closure periods and the likelihood of any of these points applying to records over eighty-four years old, considered as a class, is so small as to be negligible, except in a few identifiable and tightly defined sets of circumstances (a few of which will be considered later in this paper).

One might then say, 'But what about the Information Commissioner's remarks in his decision notice on the 1911 census?' Last year the Information Commissioner, acting on a particular set of circumstances that surrounded an appeal that was brought to him, required the UK National Archives to disclose information from the 1911 census to a family historian. At the time, he was careful to stress that this did not amount to a decision that the 1911 census should be immediately disclosed in its entirety. The Commissioner gave a number of examples of the type of personal information contained in the census that might enjoy the ongoing protection of the Freedom of Information Act's actionable breach of confidence exemption. These examples included

1. details of infirmity or other health-related information;
2. information about family relationships which would usually have been kept secret, for example: information that a child who was being raised as the child of the head of the household was in fact the offspring (perhaps illegitimate) of another family member;
3. information relating to very young children who were born in prison and whose birthplace is not recorded on their birth certificate.

The same type of information, in other words, that might easily appear in a medical record. As it happens, none of this type of information was contained in the particular census return that had been requested. The Commissioner expressed the view that if it had, it could have been withheld under the confidence exemption, even though it was ninety-five years old at the time the decision was taken.⁷ Where, it may be asked,

⁶ cf. Information Tribunal decision of 17 Sept 2007 re: Epsom and St Helier University NHS Trust available at <[www.informationtribunal.gov.uk/Documents/decisions/mrspbluckvinformationcommissioner\(17sept2007\).pdf](http://www.informationtribunal.gov.uk/Documents/decisions/mrspbluckvinformationcommissioner(17sept2007).pdf)> (accessed on 20 Dec 2007).

⁷ cf. Information Commissioner's decision notice of 11 Dec 2006 available at <www.ico.gov.uk/upload/documents/decisionnotices/2006/101391_dn_rt_changes.pdf> (accessed on 20 Dec 2007).

does this leave the eighty-four year rule of thumb as laid out in *After the Hundred Year Rule*? Our answer is that it leaves it completely intact. Remember that the rule of thumb applies to information about *adult* patients recorded over eighty-four years ago. A different calculation would have to be made concerning the medical records of a maternity or a children's hospital. In such a case, we could only be confident that none of the data subjects were still living after the passage of one hundred years, engaging the UK National Archives' working assumption about maximum human life-span. To understand the Commissioner's decision about the 1911 census, we need to remember that by its very nature it contains information about everyone who was then living in England and Wales, from the oldest to the very youngest. Because of this it must potentially be considered to contain information about living individuals, protected from disclosure by the Freedom of Information Act's data protection exemption, until 1 January 2012.

In our view, the Commissioner's decision on the 1911 census would have been more elegant had it taken as its starting point the Freedom of Information Act's information-intended-for-future-publication exemption and then engaged the public interest test to decide what to do in the particular circumstances of the case before it. In view of the settled determination of the UK National Archives to publish the 1911 census on 1 January 2012, it might easily have taken this course. Doing so would have avoided giving the very regrettable impression that the 1911 census could, as far as the Information Commissioner is concerned, stay closed forever. Remember that the data protection exemption contains a time limitation within itself, in that it protects information concerning living persons only. Similarly the actionable breach of confidence exemption is implicitly time limited, in that case law presently gives no support to the notion that a court action for breach of confidence, brought by someone who was not party to that confidence, could succeed eighty-five or more years after the event.

The UK's Data Protection Act affects the regime on access to both English and Scottish health records, but Scotland has its own Freedom of Information Act, which came into effect on 1 January 2005, the same date as the access provisions of its UK cousin were implemented. Prior to the Scottish Act, the closure period on Scottish medical records, as set out in 1993, was 100 years after date of last entry (for the records of infants) and 75 years after date of last entry (for the records of adults). The UK and Scottish Freedom of Information Acts are broadly comparable and both have a data protection exemption that covers the records of the living – Section 40 in the UK Act, Section 38 in the Scottish. However, Section 38 of the Scottish Act contains a clause specifically exempting the health records of deceased patients from disclosure under the Act for one hundred years after the date of last entry. There is no parallel clause in the UK legislation. One might say that the hundred year rule is alive and well north of the border and that what Estonian colleagues have written about the UK holds good at least for Scotland. But that would not be the most precise way of describing the effect of this clause. While the clause releases authorities from any obligation to provide access to information from the health records of the deceased, it does not actually prevent them from providing such access, always assuming that such provision is otherwise legal. In the final analysis, therefore, the situation with respect to access to medical records in Scotland is not altogether different from that in England. Although *After the Hundred Year Rule* was written for an English audience, there is no reason why Scottish archivists cannot adapt the rules of thumb outlined in it for their own use.

To return to the point about information intended for future publication: everything held in an archive, if it is not already on open access, is information intended for future

publication. It is entirely right that archivists pay close attention to the legislative constraints upon access with a view to ensuring compliance and in this respect the Freedom of Information Acts have been a professional challenge to archivists in both England and Scotland for the past few years. But it is also right for archivists to be committed to maximising access to information within the relevant constraints, rather than to multiplying the obstacles to access that stand in people's way and in this respect Freedom of Information legislation and the culture change that is beginning to be associated with it, represents a major opportunity for archivists to facilitate expanded access to the information within their professional care.

Colin Gale

Practice

The Freedom of Information Act has had a enormous impact not just on access, but also on the culture of archivists working within the public domain. Those of us working for the NHS (as I do), or in local authority record offices, have had to re-think how to respond to requests to see health records. We cannot rely on our well-worn, tried and tested responses and procedures, using those familiar stock phrases, such as: 'you need to have permission from the local NHS Trust', or 'these records are closed for a hundred years'.

You could say that it's all been much more of a burden since the access provisions of the Freedom of Information Act came into force (the requests I deal with annually have more than trebled since 1 January 2005), but it has also been more of an opportunity and, to me at least, rather a relief. An end to protests such as: 'but my great grandmother would be aged over 150 now, if she was still alive – she was in the asylum in 1910 – why on earth can't I see her records?' Before Freedom of Information, my Trust insisted that nothing younger than a hundred years in date could be released.

But it is true that life is now not so simple. We are the ones who must make the final decisions and this is a big responsibility. We certainly need some well understood procedures in place which aim for consistency, both with the Act, with other places of archive deposit and even amongst staff within the same archive office. We must widen access, yet at the same time achieve a balance, so we avoid letting out information inappropriately, with all the associated risk.

Perhaps the easiest decision in re-thinking access after Freedom of Information has been to determine what is on open access (and here again, a cultural change is symbolised by the terminology – we now talk about 'open access', not 'closure periods'). What does 'open access' mean? This refers to the records which can be consulted freely by anyone, without vetting or prior permission. But has making a decision on what is on open access really been so simple? Gale and Redfern's *After the Hundred Year Rule* suggests that the medical records of adults, as a class, can and should be opened to public access after eighty-four years. While supporting this in theory, from a practical perspective I am not convinced that eighty-four years is always satisfactory. To begin with, medical records (especially psychiatric records) can contain third-party information – usually about other family members. If records are on open access at eighty-four years, third parties who were very small children at the time might well still be alive. Does this matter? Well, it might. To take one example, in one case a son requested access to the psychiatric records of his deceased mother. The records were duly checked. I found however that mention was made of the applicant's brother – both were very young children at the time. The brother had been stealing and had been up before the juvenile magistrates' court. The brother who requested

the information might have known about this – or maybe not. In any case, since the brother could still be alive (and in fact I knew he was), I redacted the information. But what if these had been eighty-four year old records on open access, with both brothers alive and well and aged in their nineties? If a hundred years is taken as the open access point, it does significantly minimise such difficulties.

For such reasons I still work on a basis of an across-the-board one hundred years from the end date in the records for open access. In many ways this is less confusing – with the same access rule for records of children and of adults. But it isn't done as a matter of convenience. Indeed it would be more convenient to have open access at eighty-four years for adults. But I remain unconvinced that you can safely separate information about adults from information about children. In maternity records there is clearly no separation, so these must have a hundred-year open access rule in any case. And I also note that if I were operating in Scotland rather than in England, one hundred years would be the cut off point, under the Scottish Freedom of Information Act, between what is on open access to all and what might be accessible with permission. But I must stress that in practice, it does not mean a barrier to access – it is merely the point after which records need to be vetted first.

From an archivist's point of view, vetting the medical records of deceased patients requested under the Freedom of Information Act is time consuming and not always easy. But it can be rewarding. In practice, my experience shows that nearly all requests to access health records are from relatives. Sometimes the requests come from people researching their family tree, who find evidence from a death certificate that an ancestor died in the asylum (this might not be a very distant relative either; it might be a grandmother, for instance). But other access requests are more urgent and more poignant, from relatives seeking information which will resolve unanswered questions and fulfil a real emotional need. The following are a few examples of the many requests I have dealt with during the past two-and-a-half years. An elderly woman visited to access her deceased mother's maternity records in order to try and piece together details of her mother. She was born illegitimate, but although she lost contact with her mother she was not an adoptee. She also wanted to trace her father (she had an idea who he might be) and any other living relatives she had. The result of her application was that she was able to access most of these records, but some third-party information was caught by section 40 of FOI (data protection) and was redacted. A woman contacted me to access maternity records because she suspected that the woman she had been brought up to believe was her mother (who was still alive) was not her biological parent. She was not able to access the records, which were all exempt under FOI section 40 and the Data Protection Act, but I spent some considerable time talking to her about her suspicions and advising her what avenues she could try next. Despite her disappointment, the discussions proved helpful. Several cases have involved sons or daughters of psychiatric hospital patients, who were children when their parents were admitted; in the 1950s or 1960s children were often told very little of what went on – and this complete lack of knowledge and understanding has troubled them all their adult lives.

In considering such requests, remember that responses to Freedom of Information requests are meant to be purpose-blind. Once the information is out there, in public, it doesn't matter that it is for a relative in the first instance. So it is useful to ask yourself: is this information which should be out there for anyone to know? If you think not, then you can be certain that you'll be able to cite one of the Freedom of Information Act exemptions. *After the Hundred Year Rule* very usefully summarises how and why these apply – every archivist should read this and understand it. And then you will find

that in practice it always boils down to the fact that some information is sensitive and confidential, but confidentiality lessens with the passage of time; while information about the living is covered and protected by the Data Protection Act.

The case records I hold mostly have a cut-off date of 1960 for admissions. Generally, then, access to these will be less of a contentious issue than it might be for those of more recent date. On the other hand, records of long stay psychiatric patients might have end dates in the 1980s or 1990s, with all sorts of details of kin within them. It's true to say that most of the information I redact from records is third-party information which is actually or potentially covered by the Data Protection Act (so covered by Freedom of Information Act section 40). This is where it gets tricky. Freedom of Information responses are to be purpose-blind – but it is usually a relative who is asking. Sometimes it can be useful to enter a dialogue with the requestor, as information is often given which makes a difference as to whether information is redacted or not. In fact, in practice, I always ask for as much information from requestors as possible. So, for example, when the daughters of a deceased psychiatric patient wanted to access their mother's case notes, they told me that their father was still alive – and it wasn't so much that he would oppose their request, rather that they didn't want to involve him and bother him, possibly stirring up memories. But since they were children at the time (they were all middle-aged now) they felt they wanted to understand more about the circumstances of their mother's committal. The notes were actually rather old in age; but because their father, as the next of kin, was still alive (with potentially much information about him in the records too), I decided that access should not be granted, sections 40, 41 and 44 of the Freedom of Information Act being applicable. However, I talked this over with the applicants so that, in the end, it became a mutual decision. They felt they might make their request again, later on, once more time had passed and once their father had died. I was able to assure them that the records would still be here.

I think the best advice I can give to anyone vetting records under the Freedom of Information Act is that you must use common sense and imagination. Experience in dealing with requests suggests that the Freedom of Information Act backs your instincts up. And do make sure the deceased person really is dead, with the proof of a death certificate (although you might waive this if you feel a 150 year-old person would clearly be dead). The more you deal with Freedom of Information enquiries, the more confident you will feel. But it is also true to say that every single case will be different, so you will always need to think hard about what you do. 'Case-by-case basis' means just that; there is not a magic 'one-size-fits-all' solution.

Here is some more advice. Always try and provide as much access (safely) as possible, redacting what is necessary. If you cannot provide access, requestors always appreciate a full explanation of your reasons – put in plain language, not hiding behind the legislation and just citing the paragraph numbers of Freedom of Information Act exemptions. This is also likely to gain the trust of applicants who, with greater understanding, are less likely to appeal against any access decisions which disappoint them. When people have accessed the information, you might need to talk through the wider context of health care or attitudes of the time, to explain what happened or why. Admissions to mental hospitals, for example, often weren't talked about and were occasionally covered up. On the other hand, psychiatric hospitals did sometimes genuinely lose contact with the families of long-stay patients, as the immediate next of kin died with the passage of time. One man who accessed case notes was so shocked and moved that a great-aunt had been apparently forgotten about – she was a patient in a local mental hospital for forty years – that he vowed that to erect a family memorial

for her. I have had several applicants clearly moved by what they have found out and needing to talk about it, to discuss the wider context, to help them understand. A woman recently came here to see if there were surviving maternity records for her deceased mother in order to find out more about her twin, who died a few hours after birth: we were able to provide details, including information about where the twin would be buried. The applicant was extremely grateful – she hadn't even known she had a twin for the early years of her life, as her (now deceased) parents wouldn't talk about it. So operating Freedom of Information can involve much more than the simple provision of information – it is not too much to say that you can make a real difference to some people's lives. These are examples drawn from my experience – but they must be familiar to anyone who provides access to deceased persons' records.

If this sounds as though archivists have become, in some respects, counsellors, (whether we like it or not), then this should give us pause for thought, as we digest the implications. Space, privacy and advice on where to go next, are all services we should be ready to provide where necessary. It is not satisfactory to address sensitive medical questions about psychiatric treatments, for example, or discuss an applicant's sometimes painful personal experiences in searching for a mother or a father, in the middle of a busy search room, within the full hearing of other staff and researchers. Private spaces need to be found. In my experience this move to a private space may simply involve moving to the quiet landing outside our search room, or, for more prolonged discussion, to my own office upstairs.⁸ The exact location is immaterial: the important thing is to have a demarcated space available in such circumstances.

As well as providing space, one should also think through the sort of advice one can reasonably give. For seventeen years I have been a dedicated health archivist and to some specialist questions I can certainly provide answers which draw on my own knowledge and experience. Often this is enough. On the other hand, the important thing is to know your limits and know what other helpful services can be drawn upon by the applicant either before or after they have accessed the records. Adoptees seeking birth parents should always contact a social worker in the first instance, so their application is mediated through social services. Where applicants are not adoptees it can also be helpful to point them in the direction of the adoption support services both local and general (there is much advice and information available on the web). This might help them understand some of the context of what they find. As a general rule, you might have a procedure whereby applicants are encouraged to take copies of puzzling or distressing records to their general practitioner or other health professional: some will, some won't, but some might follow this advice who would not otherwise have thought of doing this. This is probably a particularly useful procedure to adopt if requests to access medical records are likely to be dealt with by any one of a number of general archivists who might have varying degrees of expertise and experience. Whatever the situation in the record office, the important thing is to know how much you can reasonably deal with and to know and be ready to give information about other agencies which might provide advice and information on the issues raised.

Moving from the particulars of dealing with Freedom of Information access requests on a case-by-case basis to an overview of the procedures involved in doing so, it is important to have a clearly worked out access policy and procedure. This is so that

⁸ The need for privacy was taken into account in the design of the new Borthwick building (opened 2005). There are several archive collections which involve archivists having to deal with confidential material and sensitive enquiries. The staff area was consequently designed as a central open space surrounded by individual, soundproofed, offices.

everyone involved – whether staff or applicants – knows what the process involves. This should also cover all types of requests for access. Not all requests to access health records are requests under Freedom of Information. A subject access request (SAR), where a person wants to access his or her own records, is covered by the Data Protection Act and the local NHS Trust will have an agreed procedure for dealing with SARs. Your policy and procedure, worked out in liaison with the Trust, should be clear what the procedure is when the records are held in the archive repository. An access request from a researcher wanting to work on a cache of material, which is not on open access, for the purposes of a research project is yet another different case. The Data Protection Act contains specific research clauses for this situation,⁹ and the NHS has a tightly controlled system of research approval – there will be a local NHS contact point to give advice on this, so that this too should be something clearly laid down in the access policy.

Since the access provisions of the Freedom of Information Act came into force, I, with the other archivists at the Borthwick Institute, where I am based, have firmed up our access procedures and documentation. We have drawn up a written access protocol for the York NHS archives under the Data Protection Act 1998 and the Freedom of Information Act 2000. We have also drawn up a very similar protocol for the archive of the independent Retreat Hospital, which is also held at the Borthwick. We have appended to these policies our researcher application form for access to closed sensitive and confidential personal data, in compliance with the Data Protection Act 1998 (see diagram 1). This is a document which we drew up a few years back, which is modelled on a form drawn up long ago by the (then) Health Authority Archives Group and similar to, though more elaborate than, the form appearing as an appendix to the recently issued data protection code of practice for archivists and records managers.¹⁰ This form is used in-house for access to all kinds of records, not just health records. It summarises the main undertakings and responsibilities in relation to the Act which the researcher agrees to sign up to. We also provide the researcher, alongside this form, with a handout reproducing the research clauses in the Act. Any researcher still needs prior permission from the Retreat, or the NHS, to work on their archives, if they are not already on open access. But this form is useful as the archive repository's evidence of permission for access. Finally, we have recently drawn up for staff a flowchart of how we deal with applications to access medical records: this is in effect a diagrammatic summary of the access protocols (see diagram 2).

So far the discussion and perspective has been based on my own experience: I am an English NHS archivist, though based within a large general, university-run, record office. I work for a public authority, within the environment of a public authority, so the records I look after are covered by the Freedom of Information Act. But what if I didn't work in the public sector? If I had records not covered by FOI? How would the Freedom of Information Act impact on my duties? Would it have altered how I deal with access requests?

The first point to make is that the situation isn't necessarily straightforward even in the context of a public authority record office. For example, as already mentioned, the Borthwick holds both a large NHS archive (obviously covered by Freedom of

⁹ Data Protection Act 1998. Part IV. Exemptions. Section 33. Research, history and statistics, Schedule 8 Transitional Relief Part IV. Exemptions after 23 Oct 2001 for Historical Research.

¹⁰ The National Archives, Society of Archivists, Records Management Society and National Association of Information Management, *Code of practice for archivists and records managers under Section 51(4) of the Data Protection Act 1998* (Aug 2007), available online at <<http://www.nationalarchives.gov.uk/documents/dp-code-of-practice.pdf>> (accessed on 20 Dec 2007).

Information) and the archive of the Retreat – an independent psychiatric hospital. The National Archives has issued guidance on assessing whether deposited private archive collections are covered by the Freedom of Information Act. This document notes that

. . . as a general rule, the more involvement there has been by a public body in creation of the private archive collection, the more public funding there has been for its preservation, the less control the owner has retained over access and use of the collection and the more constrained is his right to withdraw it from the authority, the more it is likely that the collection falls within the Freedom of Information Act.¹¹

The Retreat archive has been accommodated at the Borthwick for more than thirty years, during which time staff have provided storage, administered access and undertaken cataloguing and conservation. In recent years the office has received grants under the Wellcome Trust's Research Resources in Medical History Scheme for cataloguing and conservation of the archive: such grants assume that the archive will have maximum possible access by the public. But the Retreat has in any case always been keen to promote its archive for research use. So it has been decided in the wake of Freedom of Information legislation to treat it in exactly the same way as the NHS archive. This is, of course, operationally convenient, but it also offers the maximum amount of access balanced with confidentiality and controls. The arrangement is now documented in the access protocol to Retreat health records and also in a separate document, agreed with the Retreat, which sets out the exact relationship between us and the Retreat in relation to the storage of and access to, the archive.

Nor is the situation straightforward within non-public archive offices.¹² Independent health bodies or charities may have semi-public functions or have contracts with public authorities such as the NHS, the Department of Health or the higher education sector. Any records relating to such activities including all communications may be caught by the Freedom of Information Act. In addition, the records of non-public bodies are, just like those of public authorities, subject to the Data Protection Act, which has to be taken into account in any granting of access to researchers to material which may be governed by that Act. Controls and documentation, such as a researcher access agreement form, need to be put into place.

But both in theory and in practice, an archive created and held by a non-public body which has no public aspect or any link with a public authority can have an access regime which is entirely determined by that non-public body. It is a matter, then, for individual decision. Bodies might operate a positive access regime, encouraging access within the necessary confidentiality controls, or, at the furthest extreme, bodies might have a regime which positively discourages even reasonable, non-risk, access. And a variety of factors might determine what the access regime might be. Such factors might come down to resources and the internal culture and governance of the non-public body and perhaps also how far it has existing contacts with the public sector. In practice, then, there may be a wide variety of access regimes. Even where 'closures' are administered for certain types of records, there might be special arrangements made

¹¹ The National Archives, Guidance on assessing whether deposited private archive collections are covered by the Freedom of Information Act 2000 (FOI) (Kew, The National Archives, July 2005), available online at <http://www.nationalarchives.gov.uk/documents/guidance_private_archives.pdf> (accessed on 20 Dec 2007).

¹² We are grateful to Dr. Jennifer Haynes, Archivist at the Royal College of Obstetricians and Gynaecologists, for advice on this part of the paper.

for *bona fide* researchers on request – or there might simply be blanket closures made in all circumstances.

But the Freedom of Information cultural change, the move towards greater access and transparency means that, as time goes on, the maintenance of a rigidly closed archive, or one which has an access regime which is very much at odds with the provisions of the Freedom of Information Act, will become harder to defend against changed public expectations. Public pressure may force bodies, otherwise reluctant to embrace change, to adopt a more open culture. Other factors may also work towards this, for example where outside funding is sought and access is a condition of a grant award. Whatever access arrangements are put in place, it is important to agree and to document the procedures involved and maintain the balance between confidentiality controls and access provisions.

In conclusion, the Freedom of Information Act has been a good thing for health archives. It has undoubtedly opened up information which it was unreasonable to keep closed. By allowing requests for more recent material to be assessed on a case-by-case basis it provides an appropriate level of access for every application. This might be more work for us; but it also allows us as professional archivists, who know the records well, to take control in access requests and to make decisions based on our skills and knowledge. And in the final analysis, the greater culture of openness is both healthy and desirable.

Katherine Webb

Appendix 1

Researcher Application

**for access to closed sensitive and confidential personal data,
in compliance with the Data Protection Act 1998**

I (name)

of (address)

request permission to consult (details of records)

for the following research purposes

**I understand that I shall become responsible for compliance with
the Data Protection Act 1998 in relation to any processing by me of
personal data obtained from the above records.**

Please read the conditions listed overleaf and sign the Research Agreement

Appendix 1 (back)

Researcher Agreement

**for access to closed sensitive and confidential personal data,
in compliance with the Data Protection Act 1998**

- (1) My research will not be used to support measures or decisions with respect to particular individuals.**
- (2) My research will not cause or be likely to cause substantial damage or substantial distress to any person who is the subject of those data while he or she is alive or likely to be alive (assuming a life span of 100 years).**
- (3) I shall not make the results of my research available in a form which identifies any data subject without the consent in writing of the data subject and the data controller.**
- (4) I understand that the processing of any personal data disclosed to me, including copying, realignment, transmission abroad and publication, is subject to the Data Protection Act and is my responsibility.**
- (5) I have received information about the Data Protection Act and the relevant conditions within it which relate to research access to data.**

Signed

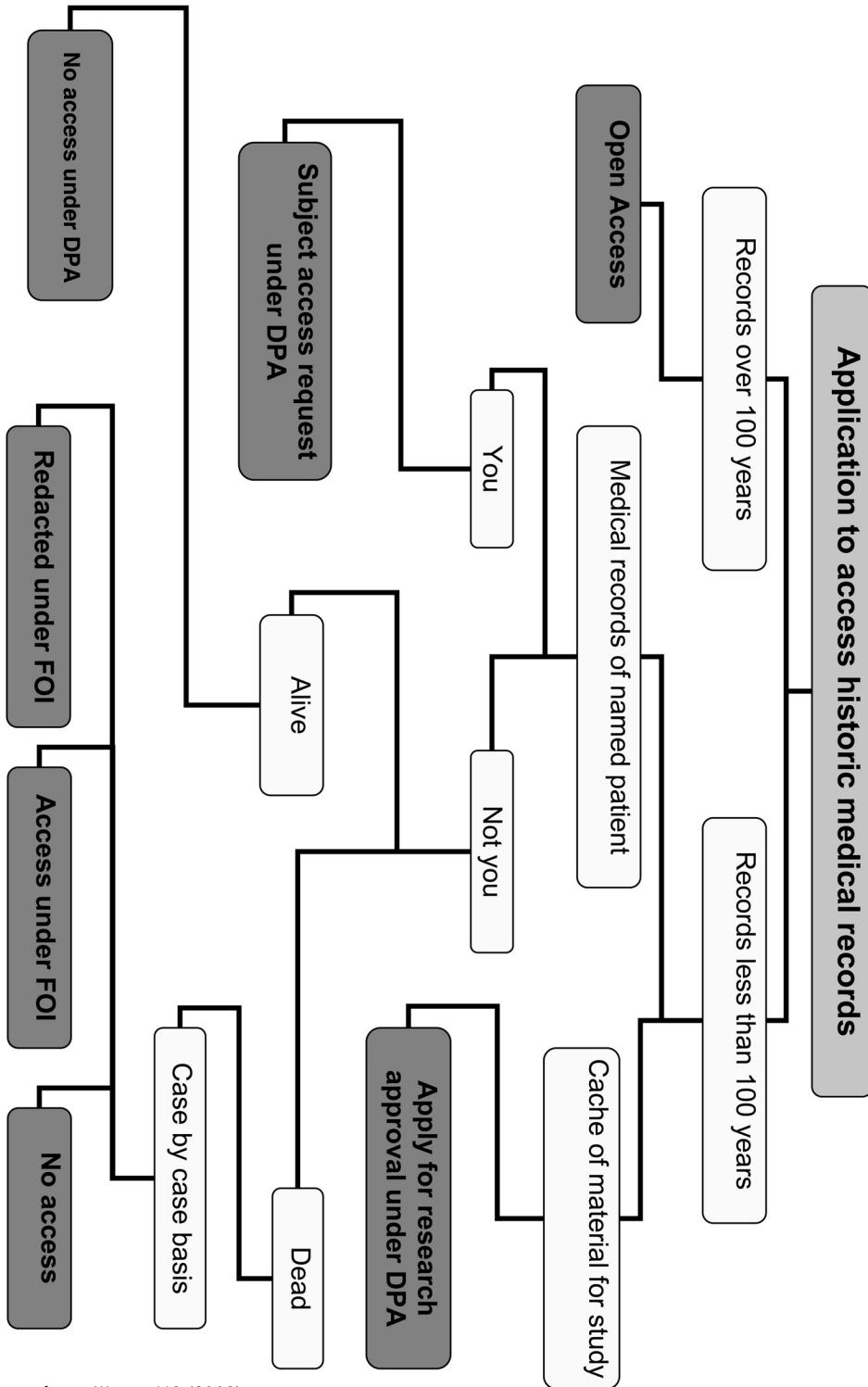
(Researcher)

Date

Signed

(for the Borthwick Institute)

Date



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