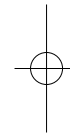
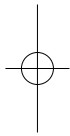

Best Practice Guideline 8

After the hundred year rule

Guidance for archivists and records managers
on access to medical records under the
Freedom of Information Act



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on behalf of the Health Archives Group
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Acknowledgements and disclaimer

The guidance that follows has been written on behalf of the Health Archives Group to help archivists and records managers in England and Wales make disclosure decisions in response to requests to see (or obtain information from) NHS medical records. Both in-house archivists and records managers holding the medical records of their own Trusts, and local authority archivists holding historic medical records that have been deposited with them, are likely to see the numbers of such requests increase once individual access rights under the Freedom of Information Act come into force on 1 January 2005.

It is not intended as guidance on disclosure decisions in general, and certainly not as guidance on the procedures that must be followed in response to requests made under the Freedom of Information Act.¹ It should not be construed as constituting legal advice, or as representing the views of the authors' respective employers.

References in this document to "the Lord Chancellor's one hundred year closure period on medical records" (or "the Lord Chancellor's hundred year rule") and "place/s of deposit approved by the Lord Chancellor for the permanent preservation of public records" may require clarification in the light of the proposed eventual abolition of the post of Lord Chancellor. From 2003, both the hundred year closure period on medical records (until 2005) and approved places of deposit have been administered by the Secretary of State for Constitutional Affairs, acting in the capacity of Lord Chancellor until the role is abolished.

A draft of this document has been seen by Phil Boyd of the Office of the Information Commissioner and comments received were taken into account when producing the final text. Susan Healy, Alistair Tough, Bruce Jackson,

Katherine Webb, Nicholas Baldwin, and others also read this document in draft and made comments and contributions that resulted in its improvement. Further comments on the usefulness or otherwise of this guidance should be either submitted directly to the authors, or to the Secretary of the Health Archives Group.

The authors are also grateful to the London Archives Regional Council for enabling the purchase of a copy of John MacDonald and Clive Jones' *The Law of Freedom of Information* (Oxford University Press, 2003) under its small grants scheme. This volume is perhaps the most comprehensive statement of the law on the subject; for an admirably succinct statement of the impact of the Act, see Rosemary Pattenden's *The Law of Professional-Client Confidentiality: Regulating the Disclosure of Confidential Personal Information* (Oxford University Press, 2003).²

The photographs on pages 3, 4, 20 and 23 appear by permission of Bethlem Royal Hospital Archives and Museum. All website addresses mentioned in footnotes were checked and found to be correct in November 2003.

¹ Guidance that is more generally applicable may be found in *The Law of Freedom of Information*, edited by John MacDonald and Clive Jones (Oxford University Press, 2003), chapter 5, pp. 99-148. Procedures for responding to Freedom of Information requests are set out in the "Lord Chancellor's Code of Practice on the discharge of public authorities' functions under Part 1 of the Freedom of Information Act 2000, issued under section 45 of the Act", available online at <http://www.dca.gov.uk/foi/codepafunc.htm>.
² paras. 18.51-18.60, pages 635-640.

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2. Introduction

Medical records managers and archivists have been dealing with requests for access to medical records for years. Most records managers will be used to giving data subject and data subject representative access to medical records under the Data Protection Act 1998 and giving legal representative and claimant access to medical records of deceased data subjects under the Access to Health Records Act 1990 (as amended). Most archivists will be used to applying the hundred year closure period on general access to them authorised by Lord Chancellor's Instrument for third party access. Some may even have begun to provide third party access to medical records in accordance with section 33 of the Data Protection Act, or regulations made under section 60 of the Health and Social Care Act 2001.

But the law on third party access to public sector medical records (in fact access to all NHS records, clinical and non-clinical⁶) is about to be revolutionised, and all who hold these records need to be aware of the new legislative framework that will soon govern access to them.

From 1 January 2005, there will be a statutory



Photograph pasted into an early twentieth century medical record. Patient identifiable material may sometimes be found in other records, such as photographs, letters, admission, discharge and other registers.

right of access to information held by public authorities under the Freedom of Information Act 2000. This general right is in addition to (and does not replace) the existing limited rights of access to medical records under the Access to Health Records Act, the Data Protection Act and regulations made under section 60 of the Health and Social Care Act. However, the new general right to access is qualified by a series of exemptions, which are listed and defined in the Act. If an exemption applies to the information requested, then it may be withheld, although with some exemptions there is a further requirement to consider whether the public interest in releasing the exempt information is greater than the public interest in withholding it. If no exemption applies, the information must be released.

Which exemptions are most likely to apply to medical records will be discussed later: First it is worth asking why, for how long, how and where should medical records be retained in the first place. As access rights under the Freedom of Information Act are in addition to, rather than in replacement of, existing statutory access rights, and are primarily aimed at people other than the subjects of the information, it will also be useful to review the existing framework for access before looking at the Freedom of Information Act exemptions in detail, and providing rules of thumb for archivists and records managers to use when responding to access requests.

⁶ This includes the clinical and non-clinical records of NHS predecessors. It should be noted that patient-identifiable material may sometimes be found in other records, such as photographs, letters, admission, discharge and other registers, complaints files and even meeting minutes and papers. Where such material contains clinical detail, access to these records should be restricted along the same lines as access to medical records.

3. Retention of medical records

3.1 Why retain medical records?

Medical records should be made and retained

- primarily, to provide a medical history that can be relied upon to support the ongoing clinical care of the people who are the subjects of the records, and in case of any legal action, and
- secondarily, to support medical, epidemiological, historical and other research.

The primary rationale for making and keeping medical records requires little explanation here.⁷ The secondary group of reasons, however, are worth further consideration.

The Data Protection Act 1998 (which governs the collection and use of data concerning living persons) requires that personal data shall only be obtained for one or more specified and lawful purposes and shall not be further processed in a manner which is incompatible with such purpose/s. Section 33 of the Act provides that processing of data only for research purposes will be deemed compatible with the purpose/s for which the data were collected, as long as such processing is in compliance with the following conditions:

- that the data are not processed to support decisions about individuals being made on the basis of the processing, and
- that substantial damage or substantial distress is not likely to be caused to any data subject by the processing of the data.

In effect, section 33 permits (and regulates) the permanent retention of medical records in a place of deposit approved by the Lord Chancellor for the preservation of public records, or comparable archival institution.⁸ It

also provides for their use in research, as outlined in para. 4.1 below.

The destruction of medical records not only prevents their use in medical and other research that might otherwise have been carried out. It also reduces the value of any research that has already been carried out using these records, by making it impossible to verify its accuracy.

3.2 How long should medical records be kept?

The law does not specify exactly how long medical records need be kept. Nor does it actually require their destruction at any particular point in time. The Data Protection Act does require that personal data shall not be kept for longer than is necessary for the purpose/s for which it was collected, or any compatible purpose/s. But clinical necessity

⁷ It is worth pointing out, however, that records that are being held to support ongoing clinical care should be kept separately from those that are being kept for medico-legal reasons only, as a means of ensuring purpose limitation as required by the Data Protection Act.

⁸ According to the Information Commissioner ("Use and Disclosure of Health Data: Guidance on the Application of the Data Protection Act 1998", May 2002, chapter 3, available online at: <http://www.dataprotection.gov.uk>), section 33 cannot be used to justify the retention of records for longer than would normally be the case simply on the strength of a supposition that the records might be used for research in the future. However, the Commissioner has approved a special purpose notification to cover the archival processing of records. (See subsection 2.3.7 of the Code of Practice for Archivists and Records Managers under section 51(4) of the Data Protection Act prepared by the National Archives (formerly Public Record Office), the Society of Archivists and the Records Management Society (available online in draft only in pdf and Microsoft Word format at <http://www.archives.org.uk/thesociety/soacodeconsult.pdf> and <http://www.archives.org.uk/thesociety/soacodeconsult.doc> respectively). It is not necessary, in other words, to justify the continued retention of records in places of deposit for public records by reference to their actual or intended use in research.

(one of the purposes for which data were collected) may well dictate that medical records are kept for the lifetime of their subjects. And the requirements of research (a compatible purpose⁹) may dictate that medical records are kept well beyond the lifetime of their subjects - to all intents and purposes, permanently. It is worth remembering in the context of research that in any case the Data Protection Act has no force with respect to the records of the dead.

The Department of Health has issued guidance on good practice concerning the retention of all NHS records, clinical and non-clinical, in the circular entitled "For the Record" (HSC 1999/053). Appended to the circular is a retention and disposal schedule that identifies minimum retention periods for identified record classes, including medical records.

Records should not face automatic destruction at the end of the applicable retention period. Rather, they should then be reviewed to determine whether they are suitable for destruction, selection for permanent preservation or some other form of retention. Some of the considerations that should play a part in the review of medical records are listed in "For the Record"'s "Notes on preservation of patient records for historical purposes".¹⁰

Different minimum retention periods are assigned to different types of medical record in the "For the Record" schedule. The clock usually starts ticking "after the conclusion of treatment", but not always. The medical records of mentally disordered persons, for instance, should be kept for a specified minimum period "after no further treatment is considered necessary" - a clinical judgement which, in the case of some mentally disordered persons, may not be able to be made during the lifetime of that person.

3.3 How can medical records be retained?

Whereas the destruction of records is an irreversible act, their retention can be costly. Although outline guidance on how to identify and preserve records worthy of permanent preservation is given in the "For the Record" schedule, selection and retention strategies for medical records are more fully discussed in the Health Archives Group's booklet entitled *Hospital Patient Case Records: a guide to their retention and disposal*, which has been recently revised.¹¹ The second edition of a booklet by Hamish Maxwell-Stewart and Alistair Tough entitled *Selecting Clinical Records for Long-Term Preservation: Problems and Procedures* (Wellcome Unit for the History of Medicine, University of Glasgow 1999) is also worth consulting.

An accurate log of the destruction of any medical records should be kept, along with documentation of the policies which authorised destruction. These will need to be consulted in response to access requests made under the Freedom of Information Act.

⁹As long as processing is in compliance with the conditions mentioned in para. 3.1 above.

¹⁰Page 10 of HSC 1999/053, Appendix B: NHS Retention & Disposal Schedule, available online at: <http://www.doh.gov.uk/nhsexec/manrec.htm>.

¹¹Available online at: <http://www.pro.gov.uk/archives/standards/hospitalrecords.htm>.

3.4 Where should medical records be retained?

Of course, all decisions about which medical records to retain beg the question "where should they be kept?" The main options are set out in *Hospital Patient Case Records: a guide to their retention and disposal* as follows:

- Suitable accommodation may be available on the hospital site.
- Another record store may be built, purchased or leased by the hospital.
- A commercial storage facility may be used.
- A local authority or other publicly funded record office may be persuaded to take the records.¹²

A relatively small number of NHS Trusts maintain an in-house place of deposit approved by the Lord Chancellor for public records, in which medical records over thirty years old may be kept. The majority that do not should make arrangements for the transfer of any historic medical records that merit permanent preservation (and are no longer required for clinical purposes) to an appropriate local record office.¹³

The guidance given in the remainder of this document concerning access to medical records has been written for the use of both in-house archivists and records managers holding the medical records of their own Trusts, and local authority archivists holding historic medical records that have been deposited with them.

Chancellor for public records may be found in Appendix B3 of HSC 1999/053, Appendix B: NHS Retention & Disposal Schedule, available online at: <http://www.doh.gov.uk/nhsexec/manrec.htm>.

¹² Health Archives Group, *Hospital Patient Case Records: a guide to their retention and disposal*, s. 4.01, available online at: <http://www.pro.gov.uk/archives/standards/hospitalrecords.htm>.

¹³ A list of places of deposit approved by the Lord

4. The existing legal framework for access to medical records

There is no common law right of access to medical records. Such rights and permissions as do currently exist are defined in the Data Protection Act 1998 (for data subject, data subject representative and third party access), the Access to Health Records Act 1990 as amended (for legal representative and claimant access) and regulations made under section 60 of the Health and Social Care Act 2001 (for third party access). The Public Records Act 1958 provides for general release of medical records over one hundred years old.

4.1 Data Protection Act

The Data Protection Act 1998 confers upon data subjects a general right of access to their own personal data. This includes personal data that consists of information as to the physical or mental health or condition of the data subject.

However, the right to access this type of information has been modified by the Data Protection (Subject Access Modification) (Health) Order 2000. Personal data that is likely, in the opinion of the clinician who last treated the data subject, to cause serious harm to the physical health or condition of the data subject or any other person if accessed is exempted by Article 5 of the Order from the Act's general access provisions. Of course, it will only be possible to make use of this order in cases where the data controller has a ready means of communication with that clinician.

Procedures for access requests to which the provisions of the Data Protection Act apply are already functioning in most NHS Trusts. Further information is available online.¹⁴ A useful draft "Code of Practice for records managers and archivists under 51(4) of the Data Protection Act 1998" has also been produced, by the Society of Archivists.¹⁵ It is not intended to

review these procedures here. For present purposes it is enough to note that, under the Act, applicants' rights of access are ordinarily limited to their own records, and there is no general right of access to the medical records of the dead.

The only exception to this is laid out in section 33 of the Data Protection Act, which provides that processing of data for research purposes will be deemed compatible with the purpose/s for which the data were collected, as long as such processing is in compliance with the following conditions:

- that the data are not processed to support decisions about individuals being made on the basis of the processing, and
- that substantial damage or substantial distress is not likely to be caused to any data subject by the processing of the data.

Section 33 does not confer upon researchers a right of access to medical records; rather it permits and regulates the granting of research access by data controllers. It should be noted that data controllers proposing to grant research access to medical records under section 33 would clearly have to be satisfied that there was no possibility of the disclosure of patient-identifiable information for any non-research purpose.

¹⁴ In pdf format at <http://www.doh.gov.uk/ipu/ahr/dpa1998.pdf> and in Microsoft Word format at <http://www.doh.gov.uk/ipu/ahr/dpa1998.doc>.

¹⁵ See footnote 8 above.

4.2 Access to Health Records Act

The Access to Health Records Act 1990 was substantially amended by the Data Protection Act 1998. In its amended form, it enables an application for access to the medical records of the dead to be made, either by the personal legal representative of the deceased subject or by any person who may have a claim arising out of the subject's death. To be accessed under the provisions of this Act, the medical records in question must have been created on or after 1 November 1991.¹⁶

Once again, procedures for access requests under this Act as amended are well established in most NHS Trusts, and will not be the subject of further attention here.¹⁷

4.3 Health and Social Care Act

Section 60 of the Health and Social Care Act 2001 gives the Secretary of State for Health power to make regulations to provide for the use by third parties of patient identifiable information needed to support essential NHS activity without the consent of patients. The power can only be used to support medical purposes, including research, that are in the interests of patients or the wider public, where obtaining consent is not practicable and where anonymised information will not suffice.

The Act does not confer any right of access to medical records; it simply permits access to be granted. Research proposals that involve access to patient identifiable information for these purposes must be submitted to a Patient Information Advisory Group, set up under the Act in December 2001 to advise the Secretary of State for Health. The Secretary of State

recently issued Health Service (Control of Patient Information) Regulations 2002 under the Act, which includes class regulations that allow cancer and communicable disease registries to be maintained without separate application to the Patient Information Advisory Group. It is anticipated that class regulations will be made to cover the most common forms of activity that require access to patient identifiable information, and that the Group will only deal individually with proposals that are not covered by the class regulations.

Information on procedures for access requests made in accordance with regulations made under section 60 of the Health and Social Care Act, and general information about the workings of the Act and the activities of the Patient Information Advisory Group is available online.¹⁸

¹⁶ Or be necessary to make intelligible any part of a record which was created on or after 1 November 1991, and to which access is required under the Act.

¹⁷ The Access to Health Records Act 1990 is available online at: http://www.hms.gov.uk/acts/acts1990/Ukpga_19900023_en_1.htm. There is an NHS Executive Letter EL(97)11: "Charging Under the Access to Health Records Act 1990" which is available online at: [http://www.info.doh.gov.uk/doh/coin4.nsf/page/EL-\(97\)11?OpenDocument](http://www.info.doh.gov.uk/doh/coin4.nsf/page/EL-(97)11?OpenDocument).

¹⁸ Information on procedures for access requests can be found in pdf format at <http://www.doh.gov.uk/ipu/confiden/genguide.pdf> and in Microsoft Word format at <http://www.doh.gov.uk/ipu/confiden/genguide.doc>. General information about the Act and the Patient Information Advisory Group can be found at <http://www.doh.gov.uk/ipu/confiden/index1.htm>.

4.4 Lord Chancellor's Instrument on closure of medical records - the "hundred year rule"

The Public Records Act 1958 as amended gave the Lord Chancellor power to issue instruments to vary the standard thirty year closure period for public records. By an Instrument dated 9 December 1991 (LCI 92), a general closure period of one hundred years is prescribed for "National Health Service records which consist of information relating to the physical or mental health of identifiable individual patients".¹⁹

At present, access to medical records under one hundred years old (calculated from the last date on the record) can only be granted

- if the request can be made under the provisions of the Data Protection Act, Access to Health Records Act, or regulations made under section 60 of the Health and Social Care Act, or
- under the Public Records Act, by special permission of the health authority that created or inherited the records.

Health authorities can permit "privileged access" by third parties to medical records under one hundred years old at their discretion under s.5(4) of the Public Records Act. This power has been most fully stated in Health Circular 61/73 (which has since been superseded by "For the Record") as follows:

"The [Public Records] Act provides that documents closed to the public in general may nevertheless be made available to the holder of special permission to see them obtained by the department or body concerned. 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."

It is important to remember that access under this provision is by permission, not by right. In particular, trusts may be reluctant to grant requests made by biographers, genealogists and others with research interests in particular individuals, since these are rarely in a position to provide a credible undertaking not to identify any data subject by name in any work that may result from their research. In any event, requests for "privileged access" to medical records under one hundred years old should be referred to the Caldicott Guardian and/or Research Ethics Committee appointed by the NHS Trust concerned.²⁰ Archives staff have no unilateral discretion to permit "privileged access" to these records, regardless of whether the archive concerned is a local record office which holds the records on deposit, or an in-house place of deposit.

¹⁹ It is worth noting that the medical records of hospitals and services that never became part of the National Health Service are not subject to this Instrument, nor indeed to the Public Records Act, Access to Health Records Act or regulations made under section 60 of the Health and Social Care Act. However, access to these records is governed by the Data Protection Act. In cases where non-NHS medical records are held by local (or other public) record offices, access to them will be governed by the Freedom of Information Act as of 1 January 2005, unless these are held on loan (see footnote 50 below).

The power to issue instruments prescribing closure periods for public records under the Public Records Act as amended will end on 1 January 2005. From that date on, there will be a general right of access to information held by public authorities under the Freedom of Information Act. According to National Archives advice, existing instruments (including the instrument prescribing a one hundred year closure for NHS medical records) will also lose their force on 1 January 2005, because the part of the Public Records Act under which they were made has been repealed by the Freedom of Information Act. Accordingly, it will not be possible to cite the "hundred year rule" in order to claim that medical records contain information that is exempt from disclosure under the Freedom of Information Act by virtue of the fact that disclosure is prohibited under an enactment.²¹

²⁰ Either directly on a case-by-case basis, or indirectly by establishing protocols for responding to such requests. The one exception to this is where the last date in the record is within the last one hundred years, but the information requested is over one hundred years old (such as might well be the case in long-running registers). Places of deposit holding such information may grant access to it without reference to the Caldicott Guardian and/or Research Ethics Committee of the Trust concerned, as long as it can be done in such a way as to protect information less than one hundred years old from view. For further details, see <http://www.pro.gov.uk/archives/standards/NHSregisters.rtf>.

²¹ In other words, an exemption on the ground of the "hundred year rule" cannot be claimed under section 44 (1) (a) of the Freedom of Information Act.

5. Exemptions to access rights under the Freedom of Information Act

Once Freedom of Information third party access rights come into force in 1 January 2005, it will no longer be necessary for requests for access to medical records to fall within Data Protection, Access to Health Records or Health and Social Care Act section 60 regulation criteria in order for them to be granted.²² Nor will the Lord Chancellor's hundred year rule apply to these requests, as already explained - so the concept of "privileged access" to records under one hundred years old will be obsolete.

In effect, a new avenue to third party access to medical records will be opened up by the Freedom of Information Act. However, it is worth noting in passing that the Freedom of Information Act is unlikely to provide an alternative route of access to medical records for those whose research projects are anticipated under the permissive provisions of section 33 of the Data Protection Act or regulations laid down under section 60 of the Health and Social Care Act (concerning which see 4.1 and 4.3 above).²³

Third party access under the Freedom of Information Act will be governed by a series of exemptions laid out in the Act. If an exemption applies to the information requested, then it may be withheld. If no exemption applies, the information must be released.

In principle, any one or more of the twenty-four exemptions specified in the Act may apply to information that has (or could) become the subject of a request by a third party. In practice, however, some of these exemptions - such as sections 29 (the economy), 32 (court records) and 34 (parliamentary privilege) - could not possibly apply to medical records, while many others - such as sections 24 (national security), 30 (investigations and proceedings conducted by public authorities)

and 31 (law enforcement) - are unlikely to apply in the overwhelming majority of cases. Only the exemptions most likely to apply to medical records are reviewed here.²⁴

If a request for information is refused, it must be made clear to the applicant why - in other words, it must be made clear which exemptions apply. If more than one exemption applies, it would be best practice to name them all when communicating the decision to refuse access to the applicant.

²² However, if requests do fall into one or other of these criteria, they should continue to be processed in accordance with the relevant established procedures - regardless of whether applicants know, or cite, the correct statute under which they are applying for access. Those applications that meet Data Protection Act criteria must be processed according to procedures established under that Act, as the information requested is exempt from disclosure under the Freedom of Information Act (see subsection 40(1)). Those applications that meet Access to Health Records or Health and Social Care Act criteria must be processed according to procedures established under these statutes, as the information requested is exempt from disclosure under the Freedom of Information Act on the ground of its being otherwise "reasonably accessible to the applicant" (see section 21, discussed at para. 5.2 below). Only requests which are not eligible to be processed under the Data Protection, Access to Health Records or Health and Social Care Acts should be processed under the provisions of the Freedom of Information Act.

²³ This is because the Freedom of Information Act's exemptions on disclosure of information will restrict access to medical records far more than the provisions of section 33 of the Data Protection Act and regulations laid down under section 60 of the Health and Social Care Act.

²⁴ For guidance on the application of other Freedom of Information exemptions, see *The Law of Freedom of Information*, edited by MacDonald and Jones, chapter 6, pp. 149-205, or the document entitled 'Walking Through the Exemptions? Freedom of Information Act: Exemption Questionnaire to Map your Pathway' written by Tessa Shellens, a consultant in healthcare and public sector law at Morgan Cole, available online at: http://www.foi.nhs.uk/downloads/025_Walking_through_the_exemptions_Morgon_Cole.doc.

Before communicating with applicants concerning requests for information, the authority should consider the separate question of whether it is under a duty to confirm or deny that it holds the information. The Freedom of Information Act confers a general duty to confirm or deny as well as a general right of access, but some of its exemptions apply not only to the content of the information requested, but also to the fact that the information is held. For instance, there is no duty to confirm or deny that the information requested is held if confirmation or denial would constitute an actionable breach of confidence, or is prohibited by any enactment.²⁵ The authority will have to look at the terms of each exemption to establish whether the duty is set aside in any particular case. It should take particular care not to inadvertently confirm its possession of information that is exempt from the duty. For example, if the authority refused to confirm or deny in all cases where such information is held, but issued denials in all cases where it is not, the refusal to confirm or deny would amount to confirmation of possession of the information.²⁶

5.1 Fees regulations (section 12)

Information contained in medical records will be exempt from disclosure under the Freedom of Information Act if the costs of complying with the request for information would exceed the "appropriate limit", which will be prescribed by regulations on costs to be made from time to time under the Act. However, according to section 13 of the Act, where the cost of compliance exceeds the "appropriate limit", the information may still (but does not have to) be provided at a fee to be calculated in accordance with these regulations.

Fees regulations have yet to be finalised, and will in any case be subject to review from time to time. However, draft regulations were circulated for comment in 2002.²⁷ These suggest an "appropriate limit" of £550, and also specify how costs might be calculated. According to the draft, the following may be included in calculating costs: costs incurred

²⁵ Freedom of Information Act, subsections 41(2), 44(2). Cases in which the mere confirmation that information is held might constitute an actionable breach of confidence can easily be imagined. Identifying information relating to particular classes of patient (for example, the subjects of fertility treatment, termination of pregnancy, sexually transmitted diseases or rape) is protected by statute: the Human Fertilization and Embryology Act 1990 s. 33, the Abortion Act 1967 s. 2, the NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000 article 2 and the Sexual Offences (Amendment) Act 1976 ss. 4(1) as amended by s. 158 of the Criminal Justice Act 1988 respectively. As such it is exempt from disclosure, and the duty to confirm or deny, under section 44 of the Freedom of Information Act (as well as under section 41). The duty to confirm or deny the existence of particular records within classes that are not protected by statute may still be set aside by subsection 41(2) where the disclosure of the mere fact that an individual was in receipt of treatment is considered to amount to an actionable breach of confidentiality (perhaps because the treatment is thought to carry social stigma). However, it is unlikely to do so where the information requested is contained in medical records that are over thirty years old. It is worth noting in this connection that registers of patients admitted to psychiatric institutions in England and Wales, which are on open access at the National Archives, effectively provide confirmation of treatment received by individual patients up to 1960.

²⁶ This should be borne in mind when using the decision tree for responding to Freedom of Information requests for information from medical records at the end of this document (see para. 9.1 below). The assumption is made for the purposes of the decision tree that the authority holds records containing the information requested, and that the information is subject to the Freedom of Information Act. (As outlined in footnote 50 below, the only records that are exempt from the Act are those of non-NHS or non-NHS predecessor records which are not owned by the record-holding authority, but held on loan.) But if any section of the Freedom of Information Act exempts the authority from the duty to confirm or deny that the information requested is held, the authority must refuse to confirm or deny in exactly the same terms whether or not the records are held.

²⁷ Available as Appendix J to *The Law of Freedom of Information*, edited by MacDonald and Jones, pp. 1030-1032.

in determining whether information as described in the request is held, locating and retrieving it, and giving effect to any preference expressed by the applicant as to the means by which it should be communicated, including the cost of staff time in doing so (other than time spent in determining whether there is an obligation to comply with the request). The costs of informing the applicant whether it holds the information requested and of communicating any such information must not be included.

Costs involved in making information from medical records available might include the cost of conservation to damaged or vulnerable records, the cost of anonymising or otherwise editing information so as to avoid contravention of the data protection principles or breach of confidentiality, the cost of media transfer where that is necessary to make the records accessible, and so on.

The fees regulations in force at the time of any application for information from medical records must be consulted before reliance is placed on section 12 to refuse to disclose information because the cost of doing so exceeds the "appropriate limit", or on section 13 to calculate disclosure fees. At the time of writing, only draft regulations were available, and naturally these are subject to change.

5.2 "Accessible by other means" exemption (section 21)

Information contained in medical records will be exempt from disclosure under the Freedom of Information Act if it is already "reasonably accessible to the applicant". Clearly, it is not going to be necessary to lodge a Freedom of Information request to gain access to

information that is already available by other means.

The section 21 exemption will cover all third party applications for information in medical records which meet Data Protection, Access to Health Records or Health and Social Care Act criteria. These applications should be processed in accordance with procedures established under these respective statutes.

The exemption would also be used for third party applications to see historic medical records which fall outside the Data Protection, Access to Health Records and Health and Social Care Act section 60 regulation access regime as long as these records can be demonstrated to be otherwise already "reasonably accessible". If records have been transferred to a place of deposit for public records approved by the Lord Chancellor; the responsibility for demonstrating that they are "reasonably accessible" falls upon the authority that maintains the place of deposit (which may, or may not be, the health authority itself). The inclusion of an "archives class" in the publication scheme of the responsible authority would provide support for a claim that records on general access at a place of deposit were "reasonably accessible".²⁸

It is likely that access to records transferred to places of deposit will be limited to those records catalogued in the public-interface finding aids of the place of deposit (other than

²⁸ It may be that a forthcoming "National Standard on Access to Archives" (draft available online at: <http://www.pro.gov.uk/archives/bsqg/access.htm>) will be used to evaluate whether records held in a place of deposit are "reasonably accessible".

those noted in the said finding aids as unavailable for general access). If so, a section 21 exemption could not be claimed for uncatalogued or 'unavailable' records.

Though places of deposit will not be able to rely upon the "hundred year rule" to deny any access to records less than one hundred years old, for practical purposes they will have to continue to rely upon a set period of time as a rule of thumb to determine which records may be designated as "open information" (made available for general access, rather than in response to particular applications), and which may not. This is discussed further in paras. 6.1 and 6.2 below.

5.3 "Personal information" exemption (section 40)

Information contained in medical records will be exempt from disclosure under the Freedom of Information Act if, and to the extent that

- it constitutes data of which the applicant is the data subject, or
- it constitutes data of which the applicant is not the data subject, but disclosure would contravene any of the Data Protection Act's data protection principles, or section 10 of that Act (which confers a right to prevent processing likely to cause substantial damage or distress).

In the case of third party access (where applicants are not the data subjects of the records), section 40 does not offer blanket exemption against disclosure. Exemption is limited to those cases where disclosure would contravene one of the data protection principles, or section 10 of the Data Protection Act. However, the Freedom of Information Act's section 41 exemption is wider in its scope than that of section 40, and a section 41

exemption will apply to most if not all of the third party access cases to which a section 40 exemption will apply.

In all cases, the section 40 exemption only applies to personal data. Personal data is defined by the Data Protection Act as data that relate to a living individual which can be identified from those data. It is important to note that section 40 *cannot be used to exempt from disclosure the medical records of (or any information about) the dead*. This is the case regardless of the age of the record, or the length of time that has elapsed since the death of its subject.

In considering whether section 40 exempts from disclosure information from any particular medical record, it should be borne in mind that it may not always be possible to verify whether the subject of the record has in fact died. This will most likely be the case where no proper documentary evidence of the death of the subject can be produced, or where the medical record does not provide enough information to establish that its subject is also the subject of the evidence of death that is supplied. In cases such as these, death may be reasonably assumed to have taken place, according to National Archives practice, on the subject's one hundredth birthday, as calculated from their age, or year of birth, as supplied in their medical record. (Where it is not possible to determine the age of the data subject from the records, an adult's age may be assumed to be sixteen, a child's age may be assumed to be seven, and an infant's age may be assumed to be zero, for the purposes of this calculation.²⁹) Unless it is possible to verify the death of the subject of a medical record, subjects born (or assumed to be born) less than one hundred years ago must be assumed to be living, and the information contained in their records possibly subject to exemption under section 40 of the Freedom of Information Act.

5.4 "Actionable breach of confidence" exemption (section 41)

In view of the limited applicability of section 40 to the records of the living, it is easy to imagine circumstances in which it (and sections 21 and 38) afford no protection to the sort of information that is contained in medical records. For example, what "if a doctor who treated a celebrity suffering from AIDS during his final illness were subsequently to sell to a newspaper intimate details which had been revealed to him by his former patient in confidence, and in the expectation that the doctor would continue to respect that confidence after the patient's death...?"³⁰ One of the exemptions which might be relied upon to withhold disclosure of such information under the Freedom of Information Act is detailed in section 41 of the Act.³¹

Under section 41, information will be exempt from disclosure if it was obtained by the public authority "from any other person" and disclosure "would constitute a breach of confidence actionable by that or any other person". Information contained in medical records is always obtained from another person, either directly (e.g. consultation notes) or indirectly (e.g. x-rays or test results), insofar as that person is the subject of the record. The reach of the section 41 exemption with respect to medical records depends upon how long the common law duty of confidentiality lasts after the patient has died.

In its most recent advice to doctors on confidentiality, the General Medical Council (GMC) states:

"You still have an obligation to keep personal information confidential after a patient dies. The

extent to which confidential information may be disclosed after a patient's death will depend on the circumstances. These include the nature of the information, whether that information is already public knowledge or can be anonymised, and the intended use to which the information will be put. You should also consider whether the disclosure of information may cause distress to, or be of benefit to, the patient's partner or family."³²

This advice assumes a general obligation to keep personal information (of the type that is contained in medical records) confidential for the duration of the subject's life as a baseline.³³ Although, in general, English courts are reluctant to protect very old information from disclosure, the duration of the duty of confidentiality is likely to vary according to the nature of the information to which it relates.³⁴ It is likely that the courts would support the

²⁹ In February 2003, the Advisory Council on Public Records ruled that the age of adults of indeterminate age may be assumed to be sixteen, and the age of children of indeterminate age may be assumed to be seven, for the purpose of calculating the putative anniversary of the birth of data subjects in a particular class of records (minuted under item 3.6.3). Depending upon how particular classes of medical records are structured, it may be that similar assumptions could be applied to their subjects.

³⁰ R.G. Toulson and C.M. Phipps, *Confidentiality* (London, Sweet and Maxwell 1996), para. 6-04, page 72.

³¹ At present, information on AIDS patients (and certain other classes of patient) would be exempt under section 44 ("prohibited by or under any enactment") in perpetuity. However, HM Government has announced its intention to place time limits on all disclosure prohibitions in primary and secondary legislation, and it is reasonable to suppose that no longer period than the lifetime (or assumed lifetime) of the data subject will be used for this purpose. See para 5.5 below for further details.

³² Section 5, para. 40 of guidance entitled "Confidentiality" (September 2000), available online at <http://www.gmc-uk.org/standards/default.htm>. This advice is repeated in the GMC's "Blue Book" on standards of professional conduct and medical ethics (*Professional Conduct and Discipline: Fitness to Practice* (December 1993), para. 91), and in the Declaration of Geneva.

GMC's view that, with respect to a medical record, the duty of confidentiality lasts at least as long as the lifetime of its subject.³⁵ Whether they would support any action for breach of confidentiality brought by a third party after the subject's death has not yet been tested. Since section 41 explicitly limits the exemption to cases in which disclosure would constitute an *actionable* breach of confidence, the reach of the exemption must remain uncertain to the extent that case law is inconclusive. With particular respect to the question as to whether a third party action for breach of confidence could be brought after the death of the subject of the breach, it has been argued that in particular circumstances (such as the situation of the celebrity and his doctor outlined above) it could be considered unconscionable, and therefore inequitable, to divulge confidential information after the death of the person to whom the confidence is owed. In these circumstances, it is argued, the deceased's estate would have standing to sue.³⁶ This line of argument appears to have been accepted in the *Russo v Nugent Care Society* judgement, but it could not yet be said to be fully supported by case law.³⁷

What are archivists, records managers and health authorities to do in the face of this uncertainty? As of 1 January 2005, they may have to make judgements concerning the duration of the duty of confidentiality in order to make disclosure decisions.³⁸ They may not have the luxury of waiting until case law is clearer, and they cannot be expected to second-guess the likelihood of any legal action being brought, let alone the outcome of any possible action, in order to make disclosure decisions. In all probability, the best approach is one of caution. The section 41 exemption should not be applied only to cases in which a successful action for breach of confidentiality is considered *likely* to follow disclosure; it should

be applied to any case in which an action for breach of confidentiality following disclosure is considered *within the bounds of possibility*.

Of course, access applications that are refused on the grounds of the section 41 exemption can be taken by the applicant to the Information Commissioner on appeal. In cases where the Information Commissioner rules in favour of disclosure, the health authority has the right to appeal to the Information Tribunal against this decision, and it has a further right to appeal to the courts on any point of law (including potential breach of confidence) arising out of an adverse Tribunal ruling. If there

³³ Elsewhere in its advice on confidentiality, the GMC recognises that there are exceptions to this general obligation. Many of these relate to situations in which requests for information are made by persons who are properly authorised to act on behalf of the data subject.

³⁴ Charles Foster and Nicholas Peacock, *Clinical Confidentiality* (London, Monitor Press, 2000), para. 2.5.7, page 5; Toulson and Phipps, *Confidentiality*, para 4-13, page 63.

³⁵ Foster and Peacock, *Clinical Confidentiality*, para. 2.10, pages 14-16.

³⁶ Foster and Peacock, *Clinical Confidentiality*, para. 2.3.2, page 3; cf. Toulson and Phipps, *Confidentiality*, para. 13-17, pages 155-156. Of course, there may be considerable evidential problems in pursuing such a case arising from the fact that the confider of the information is no longer alive.

³⁷ Rosemary Pattenden, *The Law of Professional-Client Confidentiality: Regulating the Disclosure of Confidential Personal Information* (Oxford University Press, 2003), paras. 5.46 - 5.54 and 18.59, pages 153-158 and 639. In his *Russo* judgement, Scott Baker J argued that the duty of confidentiality may in certain circumstances extend beyond the death of the confider, though it cannot be considered in law to last indefinitely. "The duration of... such duty will vary according to the nature of the information and the nature of the relationship. Nor does the death of the confider necessarily bring the confidentiality to an end, for example where a patient has confided confidential information to a doctor and then dies. ... In principle a duty of confidentiality should cease if the information loses the quality of confidence, whether through the passage of time, loss of secrecy or other change of circumstances..." (*ibid.* para. 5.49, page 155).

³⁸ They should note, however, that "it was suggested during the Committee stage of the Bill in the House of Lords that a breach of confidence would only be actionable if the person bringing the claim for breach of confidence against the public authority would be successful in their claim" (*The Law of Freedom of Information*, edited by MacDonald and Jones, para. 6.67, p. 167).

are cases in which authorities retain strong misgivings about disclosing information which (in their view) may give rise to actions for breach of confidentiality, they may decide to exercise these rights rather than acquiesce with the Information Commissioner and/or Tribunal against their better judgement. It may be that a significant proportion of requests to access medical records which could not otherwise be refused (for example, because they are not already reasonably accessible to the applicant, because disclosure is not likely to endanger anyone's health or safety, and/or because they are the records of the dead) are likely to be refused by virtue of section 41 (in tandem with section 44, on the grounds that disclosure is prohibited by the Human Rights Act 1998³⁹). Applied to "third party" access to the medical records of the living, these exemptions provide a clearer and more comprehensive disclosure exemption than does section 40. Unlike section 40, they may also apply to the records of the dead. They are therefore likely to be often cited in support of decisions to refuse Freedom of Information access applications.

5.5 "Prohibited by or under any enactment" exemption (section 44)

As has already been noted,⁴⁰ information contained in medical records will be exempt from disclosure under the Freedom of Information Act if disclosure is prohibited by or under any enactment, incompatible with any European Community obligation, or would constitute or be punishable as a contempt of court.

Enactments that prohibit the disclosure of particular classes of information include

- the Human Fertilization and Embryology Act

- 1990 (section 33 prohibits the release of information that would identify anyone who undergoes fertility treatment),
- the Abortion Act 1967 (section 2 prohibits the release of information that would identify anyone who undergoes termination of pregnancy),
- the NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000 (article 2 prohibits the release of information that would identify anyone who has contracted a sexually transmitted disease), and
- the Sexual Offences (Amendment) Act 1976 (subsection 4(1) as amended by section 158 of the Criminal Justice Act 1988 prohibits the release of information that would identify any rape victim).

When the clause of the Freedom of Information Bill which became section 44 of the Act was being debated at Committee stage (in October 2000), the Minister of State at the Cabinet Office estimated the number of such enactments to be about 400.⁴¹ The prohibitions in these enactments are all targeted at specific (sometimes highly specific) categories of information, and only a tiny minority of prohibitions will apply to the information contained in medical records. Where they do apply, however, the information is exempt from disclosure. How long information that is the subject of one of these enactments remains exempt under section 44 depends entirely upon the terms of the relevant enactment. To take an example from those abovementioned, section 4 of the Sexual Offences (Amendment) Act 1976 (as amended by section 158 of the Criminal Justice Act 1988) prohibits disclosure of information that would identify a rape victim for the lifetime of the victim. However, the

³⁹ See para. 5.5 below.
⁴⁰ See footnote 25 above.

effect of many other enactments, including the Human Fertilization and Embryology Act 1990, the Abortion Act 1967 and the NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000, is to prohibit disclosure of information in perpetuity. In November 2002, the Lord Chancellor's Department indicated that HM Government did "not consider this to be desirable and will seek to introduce time limits" into prohibitions on disclosure of information in primary and secondary legislation.⁴²

In addition to enactments that prohibit the disclosure of particular classes of information, the Human Rights Act 1998 (which enshrines the European Convention on Human Rights) may impose a more far-reaching limitation on access to medical records. Article 8 of the Convention states "Everyone has the right to respect for his private and family life, his home and his correspondence". In *R (on the application of Addinell) v Sheffield City Council (2000)*, the father of a 17 year old who committed suicide was refused access to his son's social services records by the Divisional Court, partly on the ground that Article 8 of the Convention protected the son's privacy, even after his death.⁴³ If this judgement establishes a precedent for the application of the Human Rights Act 1998 to cases involving access to information from medical records, it would tend to protect such information from disclosure, even in cases where the Data Protection Act does not apply because the subject of the records has died.⁴⁴

No mention is made in the *R v Sheffield City Council* judgement of any time limit on the withholding of records containing private information about an individual who has since died. This is unsurprising, considering that the case was heard little over a year after the death of the subject of the records that were the subject of the access application. It is

unlikely that *R v Sheffield City Council* establishes a precedent for the protection of private information in perpetuity. A practical and defensible approach would be to consider that information from all the medical records of the living is protected from disclosure under section 44 (relying upon article 8 of the European Convention on Human Rights enshrined in the Human Rights Act 1998), and that information from the medical records of the dead is also protected from disclosure under section 44 (relying upon article 8) insofar as it is also protected from disclosure under section 41, the "information supplied in confidence" exemption.⁴⁵

5.6 "Health and safety" exemption (section 38)

Information contained in medical records will be exempt from disclosure under the Freedom of Information Act if disclosure would, or would be likely to, endanger the safety, or the physical or mental health, of any individual.

⁴¹ See *The Law of Freedom of Information*, edited by MacDonald and Jones, para. 6.85, p. 172. As part of a review done for the purpose of identifying how many of these enactments could be repealed or amended, a full list of enactments, which was correct as at November 2002, has been made available online at: <http://www.dca.gov.uk/foi/foidoirpt2.htm>.

⁴² See <http://www.dca.gov.uk/foi/foidoirpt2.htm>.

⁴³ Mr Justice Sullivan's judgement, as approved by the Court, concludes "...considering questions of privacy and family life under article 8, the balance would come down firmly in favour of social service records remaining confidential to the deceased". See Pattenden, *Law of Professional-Client Confidentiality*, para. 19.91, pages 679-680.

⁴⁴ If the records in question in *R v Sheffield City Council* were medical records, Mr Addinell would in all probability have had a right to access to them under the Access to Health Records Act as amended. The case nevertheless establishes in principle that the European Convention on Human Rights may be considered to offer protection to the deceased as well as the living. Applied to a different set of facts (specifically a set of facts in which no right of access exists in statute), this principle may well protect information in the medical records of the dead from disclosure.

Although it might be imagined that this exemption would apply to a fair proportion of the information contained in medical records, in practice it is unlikely to be solely relied upon to deny requests for third party access to the information in them. In most if not all cases in which a section 38 exemption will apply, a section 40 (personal information) and/or section 41 (information provided in confidence)⁴⁶ exemption will also apply. These latter exemptions are wider in their scope than that of section 38. Further, unlike the exemptions in sections 21 (accessible by other means), 40 (personal information), 41 (information provided in confidence) and 44 (prohibited by or under an enactment), a section 38 exemption is not absolute. Before relying on non-absolute exemptions such as that in section 38, the public interest in maintaining the exemption must be weighed against and considered greater than the public interest in disclosure. Before refusing an access application on the sole basis of this "public interest" test

- places of deposit to which medical records have been transferred must consult the authority (probably via its Caldicott Guardian and/or Research Ethics Committee) that maintained the records prior to transfer, and the authority must in turn consult the Secretary of State for Constitutional Affairs, and
- authorities that retain their own medical records must consult the Secretary of State for Constitutional Affairs (with respect to applications for access to records over thirty years old).

Lastly, and perhaps most importantly, the exemption is framed narrowly to apply only to those cases in which disclosure would put at risk someone's health or safety. It is designed to prevent *actual damage*, not mere distress.

While the law does not prevent the release of information that may cause distress to the applicant, archivists and records managers may recognise a moral responsibility to concern themselves with the manner in which such

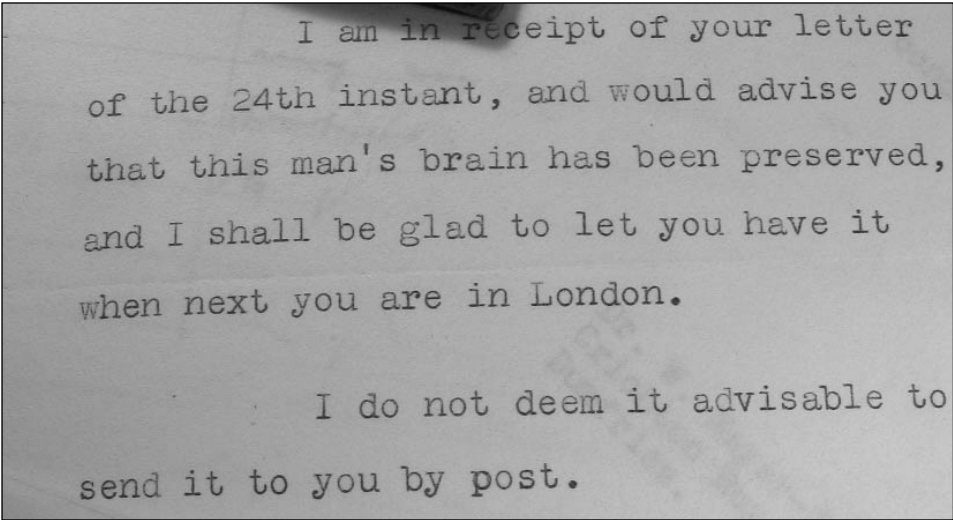
information is released.⁴⁷ Medical records rarely make jolly reading, either for the subject of the records (who may apply for access to them under the Data Protection Act) or relatives, descendants and other third parties. Descriptions of symptoms, treatments and (in the case of deceased patients) autopsies may be upsetting for the general reader even if they are clinically unremarkable. Further, previous generations of note-takers sometimes used language in that would today be regarded as inconsiderate, even offensive, in the belief that their reports would never be publicly released. One is entitled to wonder, for instance, about the bedside manner (if not the objectivity) of the doctor who in the 1890s described a 42-year old patient as "a fat man who looks his age".⁴⁸ Archivists and records managers would do well to consider how best to release potentially upsetting information in response to a request to access medical records. They cannot refuse to release it on the grounds of anticipated distress, nor need they feel obliged to defend or apologise for it. But they may be in a position to prepare the applicant for access to the information, for example by explaining its nature, its phraseology or the way it is structured with reference to its historical context.

⁴⁵ See para. 5.4 above.

⁴⁶ With respect to section 41, it should be noted that, although the exemption is technically absolute, in practice it carries with it a built-in public interest test, in that there is a public interest defence to a claim for breach of confidentiality (see *The Law of Freedom of Information*, edited by MacDonald and Jones, paras 6.73-6.77, pp. 169-170).

⁴⁷ This could be understood as an aspect of the duty to "provide advice and assistance" imposed by section 16 of the Freedom of Information Act.

⁴⁸ It should not be thought that such an approach to note-taking is confined to the Victorian era. See <http://news.bbc.co.uk/1/hi/health/3159813.stm> for some modern examples.



I am in receipt of your letter
of the 24th instant, and would advise you
that this man's brain has been preserved,
and I shall be glad to let you have it
when next you are in London.

I do not deem it advisable to
send it to you by post.

Text of a letter dated 1940 concerning the use of human organs in research. Previous generations of note-takers sometimes used language that would today be regarded as inconsiderate.

6. New rules of thumb for those who hold medical records

In the light of the regime on access soon to be ushered in by the Freedom of Information Act, which will supersede the Lord Chancellor's one hundred year closure period on medical records, archivists and records managers holding medical records stand in urgent need of guidance. The "hundred year rule" will only continue in force (qualified as it is by the access provisions of the Data Protection, Access to Health Records and regulations made under section 60 of the Health and Social Care Acts, and the non-statutory provisions for third party "privileged access") until 1 January 2005.

Under the Freedom of Information Act, access decisions will have to be made by the record-holding authority rather than the record-creating authority (unless the records are held on loan). In some cases this will be one and the same, but in cases where medical records have been transferred to a local (or other public) authority record office, that record office will have responsibility for managing the decision-making process.⁴⁹ Moreover, all decisions about access to medical records (other than records that are held on loan) that are made by public authorities (including record offices) will have to be taken in the light of the Freedom of Information Act, regardless of whether those records are NHS (or NHS predecessor) records.⁵⁰

The principles behind the rules of thumb set out below have been used to construct decision trees for responding to requests to access medical records, and for setting general access periods on medical records. These may be found at the end of this document (see paras. 9.1 and 9.2).

6.1 Rules of thumb for responding to requests to access medical records

It is clear that under the new regime each access request must be considered individually to determine whether the information requested is subject to any exemption. However, it is likely that one or other of the Freedom of Information Act's provisions is likely to exempt most, if not all, medical records under thirty years old from disclosure.⁵¹ Further, it is likely that section 21 will exempt most, if not all, medical records over one hundred years old from disclosure under the Freedom of Information Act.⁵² In practice, requests to access medical records between thirty and one hundred years of age will require the greatest amount of individual attention, because while none of the exemptions is universally applicable to records of this age, any of them (but especially any of those in sections 12, 21, 38, 40, 41 and 44) may apply in particular cases.

⁴⁹ It is acknowledged that in certain circumstances (for instance, before relying solely on a conditional exemption to refuse an access request) it may need to consult the record-creating authority as part of that process.

⁵⁰ Except in the case of non-NHS or non-NHS predecessor records which are not owned by the record-holding authority, but held on loan. These are not subject to the Freedom of Information Act.

⁵¹ This is because, in most cases where none of sections 21, 38, 40 or 44 apply to records under thirty years old, section 41 may be cited. Cf. Pattenden, *Law of Professional-Client Confidentiality*, para. 18.54, page 637: "Clients should not worry unduly about records that are less than 30 years old; public authorities can rely on a large number of exemptions to refuse information." For further details, see para. 5.4 above.

⁵² The reason for this is that information contained in medical records over one hundred years old is likely to be exempt because it is already "reasonably accessible to the applicant", either under the provisions of the Health and Social Care Act or under the authority's publication scheme (as long as the scheme gives details of the place of deposit in which the records are held, and records over one hundred years old are catalogued and on open access at the place of deposit). See para. 5.2 above for further details.



A row of medical casebooks. Historic medical records are often structured sequentially in bound volume format.

If the medical records of adults, children and infants are clearly distinguished from one another (for example, by separation into separate classes), then the medical records of adults (considered as a class) may be put on general access once the records are eighty-four years old, and the medical records of children (considered as a class) may put on general access once the records are ninety-three years old. In this case, section 21 will exempt from disclosure under the Freedom of Information Act both the medical records of adults (once the records are eighty-four years old) and the medical records of children (once the records are over ninety-three years old).

Therefore, in cases where the medical records of adults, children and infants are not distinguished from one another, rules of thumb for responding to requests to access medical records are as follows:

6.1.1 Information contained in medical records requested by the data subject is exempt from disclosure under section 40, and the request must be handled as a subject access request under the Data Protection Act (as amended by the Freedom of Information Act);

6.1.2 Information contained in medical records less than thirty years old is likely to be exempt from disclosure to third parties under section 41 and 44, if not under sections 12, 21, 38 and 40;

6.1.3 Information contained in medical records between thirty and one hundred years old may or may not be exempt from disclosure to third parties under sections 12, 21, 38, 40, 41 and 44, and;

6.1.4 Requests relating to information contained in medical records over one hundred years old are likely to benefit from the exemption at section 21 (information already reasonably accessible).

In cases where the medical records of adults, children and infants are distinguished from one another, rules of thumb for responding to requests to access medical records are as follows:

6.1.5 Information contained in medical records requested by the data subject is exempt from disclosure under section 40, and the request must be handled as a subject access request under the Data Protection Act (as amended by the Freedom of Information Act);

6.1.6 Information contained in medical records less than thirty years old is likely to be exempt from disclosure under section 41 and 44, if not under sections 12, 21, 38 and 40;

6.1.7 Information contained in medical records between thirty and eighty-four years old (in the case of records of adults), ninety-three years old (in the case of records of

children) and one hundred years old (in the case of records of infants) may or may not be exempt from disclosure under sections 12, 21, 38, 40, 41 or 44, and;

- 6.1.8 Requests relating to information contained in medical records over eighty-four years old (in the case of records of adults), ninety-three years old (in the case of records of children) and one hundred years old (in the case of records of infants) are likely to benefit from the exemption at section 21 (information already reasonably accessible).

The guiding assumptions behind these rules of thumb are that there is a strong possibility that medical records will be exempt from disclosure under the Freedom of Information Act until the hundredth anniversary of the birth of the subject of the records concerned, and that medical records will be "reasonably accessible" past this anniversary. The rules of thumb are an attempt to apply the assumptions to responding with requests to access medical records. Individual authorities and/or places of deposit may find means of applying these assumptions to their responses to access requests that better suit the way their records are structured.⁵³

In any case, it should be remembered that neither the assumptions and the rules of thumb can be relied upon to refuse access requests. Instead, they are intended to highlight which requests are likely to require most by way of individual consideration to determine whether any of the exemptions detailed in the Freedom of Information Act may be used to refuse access. The decision tree for responding to requests for information in medical records

at the end of this document is provided as guidance for this individual consideration of requests (see para. 9.1 below).

When using these rules of thumb to determine how to respond to access requests, it should be remembered that historic medical records are often structured in such a way as to contain the records of more than one individual in close proximity, usually sequentially in bound volume format. Archivists and records managers should take care in allowing access to information contained in such volumes. In particular cases, it may be decided that no exemption applies to the information that is the subject of the access request, but it does not follow from this that the entire contents of the volume in which it is contained may be freely consulted. Archivists and records managers should take whatever measures are necessary to limit access to the information that has been requested, for example by providing access to photocopies or other surrogate copy of the information that has been requested, or otherwise extracting the information from the volume in which it is contained.⁵⁴

⁵³ For example, in cases where it is possible to identify a class of records solely relating to geriatric patients, it may be possible to apply an amended form of the rules of thumb numbered 6.1.5 - 6.1.8 to access to these records, substituting the upper end dates in 6.1.7 and 6.1.8 for a shorter period (forty years, say, if it is known that patients under the age of sixty were never admitted).

⁵⁴ This is in parallel to the situation that obtains at present under the "hundred year rule" with respect to medical records over one hundred years old contained in volumes which also contain more recent data. See footnote 20 for further details.

6.2 Rules of thumb for setting general access periods on medical records

How to respond to individual third party requests to access medical records is one thing. Which medical records to put on general access at a place of deposit or elsewhere as a matter of course is quite another. After 1 January 2005, the "hundred year rule" will no longer apply, but as a practical matter a period of time will have to be fixed as a rule of thumb to determine which records may be designated as "open information" (made available for general access, rather than in response to particular applications), and which may not. The most important considerations in doing so relate to the likely impact of Freedom of Information Act's exemptions.

First, records that are available for general access at a place of deposit or elsewhere are likely to benefit from the Freedom of Information Act's section 21 exemption on the ground of being already "reasonably accessible to the applicant", especially if the publication scheme of the authority that holds the records contains mention of them. However, medical records which are uncatalogued, or marked as 'unavailable for general access' in the catalogue, will not be exempt under section 21, and on receipt of requests for information from them, the authority will need to make individual disclosure decisions. It is in the interest of both the authority and the place of deposit to catalogue and make available for general access as many records as possible, so that they are "reasonably accessible to the applicant" and therefore benefit from the section 21 exemption.

However (and this is the second consideration), authorities will not wish to

make available for general access a class of records which contain an appreciable number of records to which exemptions (other than the section 21 exemption) are likely to apply. The most relevant exemptions to consider in this connection are those in sections 40 (which protects "personal information"), 41 (which protects "actionable confidential information") and 44 (which protects information whose disclosure is "prohibited by any other enactment").⁵⁵

In particular cases, section 40 may exempt information contained in the medical records of the living (and those that cannot be proved or reasonably assumed to be dead⁵⁶) from disclosure, and sections 41 and 44 (the latter insofar as reliance is put upon the Human Rights Act 1998) may exempt information contained in the medical records of both the living and the dead from disclosure. Certainly it is inconceivable that any of these sections would exempt information from medical records over one hundred years old from disclosure. This is because the subject of a medical record with an end date over one hundred years old may be assumed to have died, and because the contents of a medical record with an end date over one hundred years old may be assumed to be no longer private or confidential, regardless of the period that has elapsed since the person's death. But

⁵⁵ The section 38 (health and safety) exemption is not relevant in this context because in most if not all cases in which it will apply, a section 40 (personal information), section 41 (confidential information) and/or section 44 (prohibited by any other enactment) exemption will also apply.

⁵⁶ See comments in para. 5.3 above.

it cannot be assumed that all medical records under one hundred years old would not be exempt under sections 40, 41 or 44. Considered as a class, for instance, the medical records of infants cannot be assumed to relate entirely to subjects that have since died until the records are one hundred years old. Nor can the medical records of the dead be assumed to be no longer private and/or confidential as a matter of course. Whether the records of any particular deceased person continue to be considered confidential would depend, according to the General Medical Council, upon circumstances such as "the nature of the information disclosed, the extent to which it has already appeared in published material and the period which has elapsed since the person's death".⁵⁷ Whether they continue to be considered private for the purposes of applying article 8 of the European Convention on Human Rights will depend upon how the courts apply the precedent of *R v Sheffield City Council*.⁵⁸ A sensible approach, as outlined in 5.5 above, would be to regard the records of a deceased person as "private" and therefore protected from disclosure under section 44 of the Freedom of Information Act for as long as (and no longer than) they can be regarded as "confidential" and therefore protected from disclosure under section 41 of the Act.

If the medical records of adults, children and infants are clearly distinguished from one another (for example, by separation into separate classes), then the medical records of adults (considered as a class) may be assumed to relate to subjects that have since died once the records are eighty-four years, and the medical records of children (considered as a class) may be assumed to relate to subjects that have since died once the records are ninety-three years old. Further, when the medical records of adults are eighty-four years

old, and the medical records of children are ninety-three years old, they may safely be assumed to be no longer private or confidential.

Therefore, in cases where the medical records of adults, children and infants are not distinguished from one another, rules of thumb for deciding which medical records may be made available for general access (rather than in response to particular applications), and which may not, are as follows:

6.2.1 Medical records under one hundred years old should be unavailable for general access as a matter of course, and (where they have been transferred to a place of deposit) marked as such in the place of deposit's public-interface finding aids, if they appear at all, and;

6.2.2 Medical records over one hundred years old should be catalogued and appear in the place of deposit's public-interface finding aids as being available for general access as a matter of course.

In cases where the medical records of adults, children and infants are distinguished from one another, rules of thumb for deciding which medical records may be made available for general access (rather than in response to particular applications), and which may not, are as follows:

6.2.3 Medical records of adults should be unavailable for general access as a matter of course, and (where they have been

⁵⁷General Medical Council, *Professional Conduct and Discipline: Fitness to Practice* (December 1993), para. 91. For more details, see para 5.4 above.

⁵⁸For more details, see para. 5.5 above.

transferred to a place of deposit) marked as such in the place of deposit's public-interface finding aids, if they appear at all, until the records are eighty-four years old;

6.2.4 Medical records of children should be unavailable for general access as a matter of course, and (where they have been transferred to a place of deposit) marked as such in the place of deposit's public-interface finding aids, if they appear at all, until the records are ninety-three years old;

6.2.5 Medical records of infants should be unavailable for general access as a matter of course, and (where they have been transferred to a place of deposit) marked as such in the place of deposit's public-interface finding aids, if they appear at all, until the records are one hundred years old, and;

6.2.6 Medical records of adults (where these records are over eighty-four years old), children (where these records are over ninety-three years old) and infants (where these records are over one hundred years old) should be catalogued and appear in the place of deposit's public-interface finding aids as being available for general access as a matter of course.

The guiding assumptions behind these rules of thumb (as with those detailed in 6.1 above) are that there is a strong possibility that medical records will be exempt from disclosure under the Freedom of Information Act until the hundredth anniversary of the birth of the subject of the records concerned, and that medical records will be "reasonably accessible" past this anniversary. These rules of

thumb are an attempt to apply the assumptions in order to determine which records may be designated as "open information" (made available for general access, rather than in response to particular applications), and which may not. Individual authorities and/or places of deposit may find means of applying these assumptions to their decisions on general access periods that better suit the way their records are structured.

Again, it should be remembered that historic medical records are sometimes structured in such a way as to contain the records of more than one individual in close proximity, usually sequentially in bound volume format. In using these rules of thumb to inform a decision about which medical records to put on general access as a matter of course, archivists and records managers should take into account the contents of the entire volume.

In any case, it should be remembered that the decision of an authority and/or place of deposit to make medical records 'unavailable for general access' for any set period will not in itself exempt the information in those records from disclosure under the Freedom of Information Act in response to any particular application. It is simply an expedient adopted to protect the large proportion of records dated within the set period which will be exempt under the Act.

7. Conclusion

The end of the Lord Chancellor's prescribed closure period on medical records need not be feared by archivists and records managers. January 2005 will not herald 'open season' on access to medical records. The sections of the Freedom of Information Act which specify the classes of information to be exempt from disclosure provide adequate protection for confidential information and the like. But nor can NHS (and NHS predecessor) medical records remain closed to public access 'forever', either under the current access regime or under the new legislation. The major change is the replacement of the blanket "hundred year rule" with a series of more focussed exemptions. These should enable continued protection for those medical records that need it, and greater access to those medical records that don't.

Guidance on making disclosure decisions in response to requests for information from NHS medical records is offered in the hope that archivists and records managers holding such records can follow an approach that is considered and consistent, and therefore both easier to administer and less liable to challenge.

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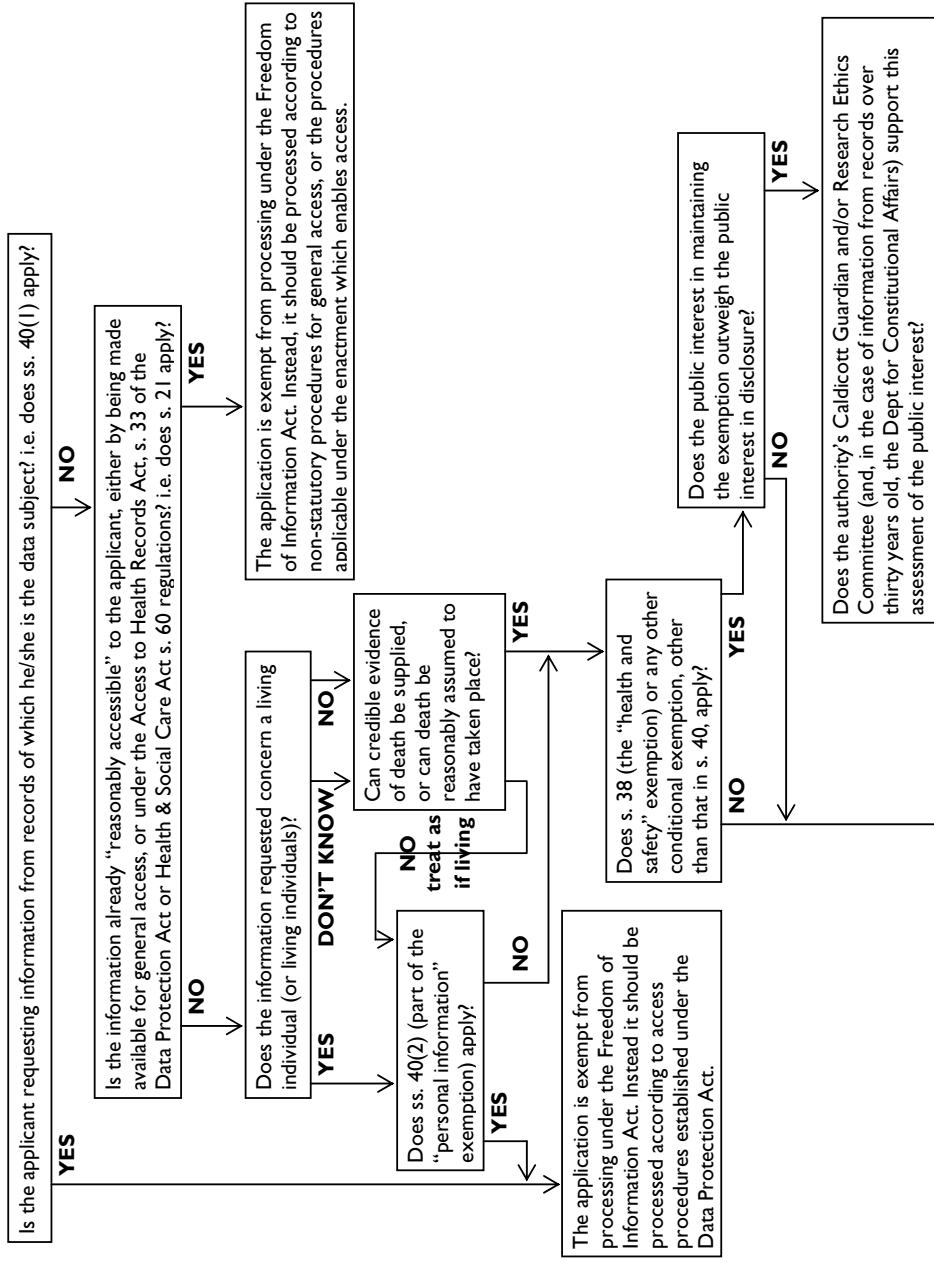
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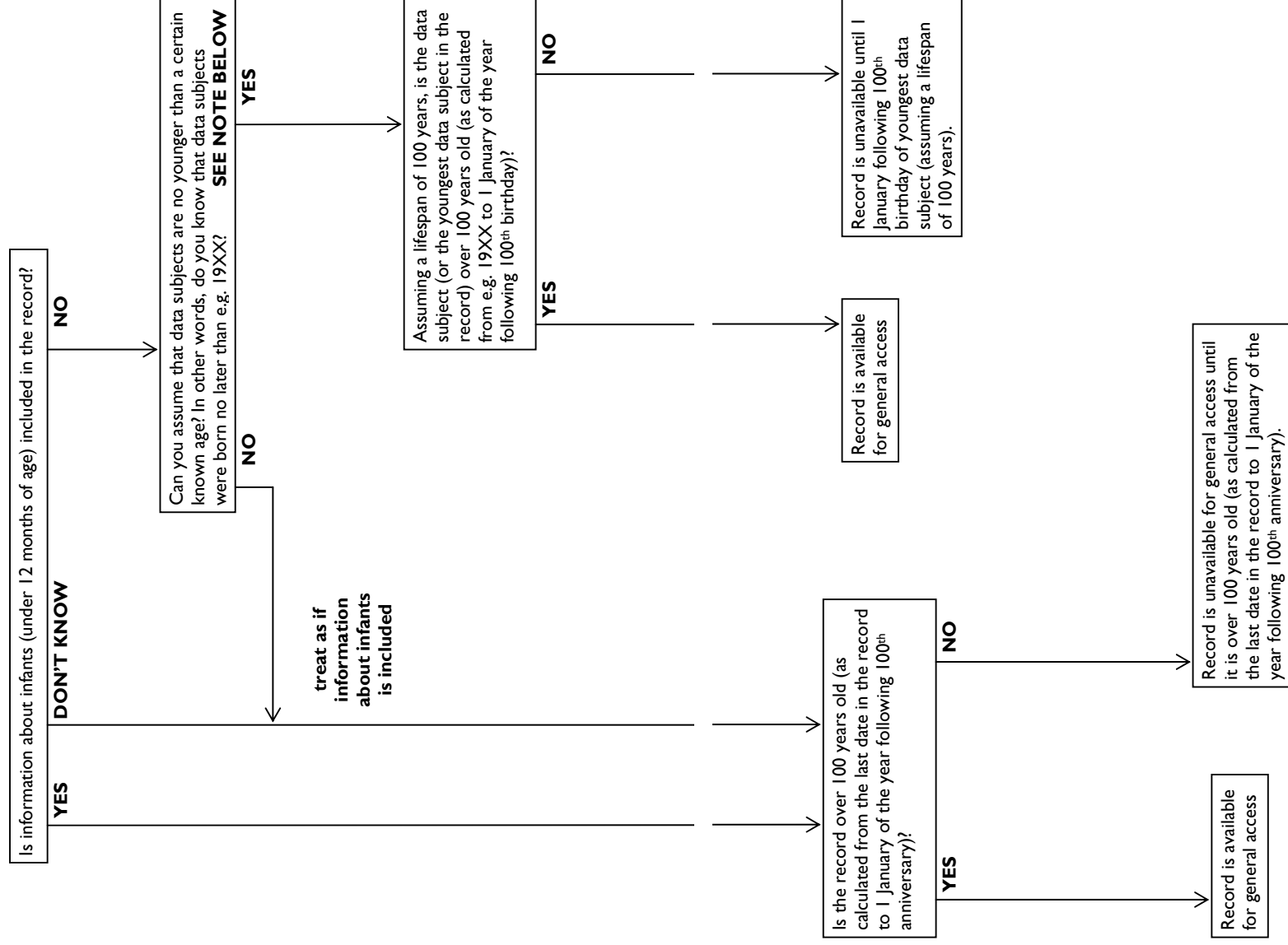
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9. Decision trees 9.1 Decision tree on responding to individual Freedom of information requests for information from medical records



NOTE: Where the duty to confirm or deny whether information is held is set aside, authorities must take care that they do not inadvertently confirm their possession of the information requested. Refusing to confirm or deny only in cases where the information is held, and issuing denials are issued in cases where the information is not held, would amount to confirmation that the information is held in the former cases. In all cases where the Freedom of Information Act sets aside the duty to confirm or deny possession of information, authorities should communicate their refusal to confirm or deny in exactly the same terms whether or not they actually hold the information requested (whether or not, in fact, this decision tree has been used to determine whether access can be given). In the case of the duty to confirm or deny being set aside by s. 44 (the "prohibited by any other enactment" exemption), the particular enactment which prohibits disclosure should not be specified, because doing so may indicate the specific nature (and therefore existence) of the information. For instance, if a refusal to confirm or deny was made on the basis of s. 46, and it was stated that, if the information was held, it would be exempt under s. 46 because it is prohibited from release by the Abortion Act, it is likely that information which should remain exempt would be compromised.

9.2 Decision tree on setting general access periods on medical records



NOTE:

If the age of the youngest data subject is unknown, but it is known that the records only contain information about adults (rather than children and infants), the youngest data subject may be assumed to be sixteen years old.

If the age of the youngest data subject is unknown, but it is known that the records contain information about adults and children (but not infants) the youngest data subject may be assumed to be seven years old.

