



# Access to Archives

## Wellcome Library policy on personal data within archives

The Wellcome Library makes its collections freely accessible to the public in order to promote the understanding of medicine and its role in society, past and present. As part of its mission, the Library is committed to widening public access to its Archives and Manuscripts collections as far as possible, while at the same time handling personal information in the archives ethically, responsibly and lawfully.

The Library's *Access to Archives* Policy outlines the steps taken by the Library to balance the access needs of researchers with its duty of care to individuals mentioned in its archive collections. The Policy covers the following topics:

### [Legislative background](#)

A brief introduction to the Data Protection Act 1998, and an overview of the legal basis on which the Library makes personal data in its archives collections accessible for research.

### [Access categories](#)

The Library's procedure for judging which access category (i.e. open, restricted or closed) is appropriate for each set of personal data in its archives.

### [Online access to archives](#)

An overview of the basis on which the Library may make digital records available online, plus details of the Library's takedown policy and risk assessment procedure for identifying high-risk material prior to online publication.

### [Consulting the archives](#)

A guide to which categories of archive are suitable for consultation in the Library only, which are suitable for consultation online, and which may not be consulted at all, plus details of how researchers can register to consult the Library's archives.

### [Data subject access requests](#)

Guidance on how individuals may exercise their right under the Data Protection Act 1998 to obtain a copy of personal data held on them in the Library's archives collections.

### [Data subject requests to correct personal data held in archives](#)

Guidance on how individuals may exercise their right under the Data Protection Act 1998 to amend personal data held on them in the Library's archives collections.

### [Providing research copies of archive data](#)

An overview of the basis on which the Library may provide researchers with copies of personal data within its archives collections, plus a guide to which categories of archive may or may not be copied.

[Click here](#) to read the Wellcome Library's *Access to Archives* Policy in its entirety.



## **Access to Archives**

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# 1. Introduction

## 1.1 Aim of the Policy

The Wellcome Library makes its collections freely accessible to the public in order to promote the understanding of medicine and its role in society, past and present.

As part of its mission, the Library is committed to widening public access to its Archives and Manuscripts collections as far as possible, while at the same time handling personal information in the archives ethically, responsibly and lawfully. This Policy outlines the steps taken by the Library to balance the access needs of researchers with the Library's duty of care to individuals mentioned in its archive collections, in accordance with the high ethical standards espoused by the [Wellcome Trust](#).

This Policy was drawn up in consultation with the Information Commissioner's Office, and has been approved by the following Advisory Panel drawn from the Wellcome Trust and external bodies:

Richard Aspin, Head of Research and Scholarship, Wellcome Library (Chair)  
Sarah Clifford, Solicitor, Wellcome Trust  
Jenny Haynes, Archives and Manuscripts Manager, Wellcome Library  
Susan Healy, Information Policy Consultant and Data Protection Officer, The National Archives  
Christy Henshaw, Digitization Project Manager, Wellcome Library  
Robert Kiley, Head of Digital Services, Wellcome Library  
Susan Thomas, Digital Archivist, Bodleian Library  
Helen Wakely, Archivist, Wellcome Library  
Kath Webb, Archivist and Records Centre Manager, York Hospitals NHS Foundation Trust

This Policy was formally adopted by the Wellcome Library's Senior Management Team on 29 November 2010. The Library monitors data protection guidance and decision notices issued by the Information Commissioner's Office (the "ICO"), the UK data protection watchdog, as well as decisions issued by the Tribunal (Information Rights), and will review the Policy annually.

## 1.2 Legislative background

### 1.2.1 The Data Protection Act 1998 (DPA)

The Data Protection Act ("DPA") 1998 regulates how personal information relating to living individuals ("**personal data**") is processed (i.e. held, used and shared), to protect against the misuse of personal data and give rights to those who are the subject of such data ("**data subjects**"). The DPA is underpinned by eight data protection principles with which the Library must comply if material held within the Library's archives falls within the scope of the DPA, unless an exemption applies. These are discussed in paragraph 1.2.3 below.

A number of the Library's archive collections fall within the scope of the DPA as:

- (i) they contain *personal data*<sup>1</sup> i.e. they consist of:
  - information relating to living individuals who can be identified from that information or from that information and other information which is or is likely to come into the possession of the person using that information;
  - this information is held in a "**relevant filing system**" for the purposes of s.1(1) of the DPA (a manual filing system in which particular information about specific individuals can be readily retrieved), or is held electronically (i.e. in a database or a system with search capabilities which enables information about individuals to be identified and retrieved), or comprises 'accessible records' as defined in section 1(1)(d) and section 68 of the DPA (i.e. health records consisting of information relating to the physical or mental health or condition of an individual, which have been made by or on behalf of a health professional in connection with the care of that individual); and

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<sup>1</sup> See ICO Data Protection Technical Guidance Note '[Determining what is personal data](#)', 2007

- (ii) the Library is '**processing**' this personal data for the purposes of s.1(1) of the DPA, on the basis that the Library is *holding, using and may disclose* this information to third parties by making it available to Library users.

A significant proportion of the Library's archive collections fall outside the scope of the DPA since, whilst they may contain personal data, they are unstructured manual data that is not part of a 'relevant filing system'. However, in order to demonstrate the Library's commitment to the ethical handling of all personal information, the Library chooses to handle such unstructured manual data as if it were subject to the requirements of the DPA.

### **1.2.2 Processing for 'Research Purposes' under the DPA**

For the purpose of the Library's ICO notification, the Library processes personal data in accordance with the 'special purpose' approved by the ICO i.e. the data held comprises '*records selected for permanent preservation as archives, with a view to their use in historical or other research*' (see Society of Archivists et al, [Code of Practice for Archivists and Records Managers under Section 51\(4\) of the Data Protection Act 1998](#), 2007, paragraph 2.3.7).

The Library processes personal data for the purposes of archival preservation under the 'research exemption' set out in s.33 of the DPA. This provides an exemption from the fifth principle (*personal data shall not kept for longer than necessary*) as personal data processed for research purposes may be stored indefinitely as archives for research purposes provided that the following 'relevant conditions' are observed:

- The data is not processed to support measures or decisions relating to particular individuals; and
- The data is not processed in such a way that substantial damage or substantial distress is, or is likely to be, caused to any data subject.

Section 33 of the DPA also provides an exemption to the second data protection principle (*personal data shall be obtained only for one or more specified and lawful purposes and shall not be further processed in any manner incompatible with that purpose or those purposes*). Provided the personal data are used only for research purposes in compliance with the relevant conditions (above), this will be in accordance with the second data protection principle.

### **1.2.3 Compliance with the Data Protection Principles**

**1.2.3.1** While section 33 of the DPA provides the Library with exemptions from the second and fifth data protection principles as outlined in paragraph 1.2.2 above, it does not exempt the Library from complying with the remaining data protection principles, of which the most important is the first principle:

- First principle: Personal data shall be processed fairly and lawfully;
- Second principle: Personal data shall be obtained only for one or more specified and lawful purposes;
- Third principle: Personal data shall be adequate, relevant and not excessive in relation to the purpose(s) for which they are processed;
- Fourth principle: Personal data shall be accurate and where necessary kept up to date;
- Fifth principle: Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes;
- Sixth principle: Personal data shall be processed in accordance with the rights of the data subject under the DPA;
- Seventh principle: Personal data shall be kept secure; and
- Eighth principle: Personal data shall not be transferred to a country outside the EEA unless that country offers an adequate level of data protection.

**1.2.3.2** The first data protection principle requires data controllers to process personal data fairly and lawfully in accordance with one of the conditions in Schedule 2 or Schedule 3 of the DPA (paragraph 1.2.3.3 below outlines the condition on which the Library processes personal data). Data controllers must inform data subjects that their personal data is being held, the reason it is

being held and any other information necessary to make holding and using the data subject's personal data fair (Paragraph 2 of Part II of Schedule 1 of the DPA). This information is known as 'fair processing information'.

However, the Library can claim exemption from this requirement to provide fair processing information to data subjects whose personal data is contained in the Library's archives where to do so would involve 'disproportionate effort' on the Library's part to trace and inform all such data subjects<sup>2</sup> (see Paragraph 3(2)(a) of Part II of Schedule 1 of the DPA; and Society of Archivists et al, [Code of Practice for Archivists and Records Managers under Section 51\(4\) of the Data Protection Act 1998](#), 2007, paragraph 4.2.7).

**1.2.3.3** While the majority of the personal data held in the Library would not be considered to be sensitive material, the archives include records that are classed as "**sensitive personal data**" under s.2 of the DPA as they are personal data consisting of information as to individuals' physical or mental health, or sexual life. This sensitive personal data can take many forms, including patient case files, photographs, informal notes on patients in diaries, or correspondence by or about an individual.

The Library processes *personal* and *sensitive* personal data in accordance with the first data protection principle (fair and lawful processing), on the basis that such processing is '*necessary for the purposes of legitimate interests pursued by the data controller*<sup>3</sup> [*the Library*]' (Paragraph 5(1) of Schedule 2 of the DPA) and *sensitive* personal data is processed for 'research purposes' (see Statutory Instrument SI 2000 No.417 Data Protection (Processing of Sensitive Personal Data) Order 2000, Paragraph 9), as such processing:

- a. is in the substantial public interest;
- b. is necessary for research purposes (which expression shall have the same meaning as in s.33 of the DPA);
- c. does not support measures or decisions with respect to any particular data subject otherwise than with the explicit consent of that data subject;
- d. does not cause, nor is likely to cause, substantial damage or substantial distress to the data subject or any other person.

**1.2.3.4** Under Part IV of Schedule 8 of the DPA, it is possible to claim exemption from the second, third, fourth and fifth data protection principles for 'eligible manual data' which are processed only for the purpose of historical research. Such eligible data are defined at Schedule 8 paragraph 1(1) of the DPA as data that are subject to processing which was already under way immediately before 24th October 1998.

Immediately prior to 24 October 1998 the Library was processing for historical research purposes over 850 20th-century archive acquisitions, and in continuing to process these archives the Library can claim the exemptions outlined in Part IV of Schedule 8 of the DPA for the proportion that comprise manual personal data. This personal data largely takes the following forms:

- Structured medical case notes (e.g. heart disease case notes in the papers of Eldryd Parry; private patients' notes in the Grays (Essex) General Practice archive);
- Alphabetically arranged correspondence concerning individuals' sexual or medical histories (e.g. *Married Love* correspondence in the papers of Marie Stopes; letters on experiences of childbirth in the papers of Grantly Dick-Read); and
- Chemists' prescription registers (e.g. indexed registers in archive of Martindale and Co, Dispensing chemists; alphabetically arranged registers in archive of H C Croadsell, Chemist).

**1.2.3.5** The manner in which the Library will comply with the other data protection principles is discussed below.

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<sup>2</sup> This exemption does not apply to personal data obtained from the data subjects themselves.

<sup>3</sup> As long as this does not result in unwarranted prejudice to the rights, freedoms and interests of the data subject.

#### **1.2.4 *The Freedom of Information Act 2000 (FOIA)***

As a non-public body, the Library is not subject to the Freedom of Information Act 2000 (“FOIA”), nor does it acquire records that fall within the scope of FOIA. Nevertheless the Library recognises the broad impact that FOIA has had on access to the archives of deceased individuals both within and outside the public sector. Therefore, this Policy takes into account the Decision Notices issued by the ICO and the Tribunal (Information Rights) in response to applications under FOIA to consult the records of deceased individuals.

#### **1.2.5 *The Public Records Act 1958 (PRA)***

The Library is not a recognised ‘Place of Deposit’ under s.4(1) of the Public Records Act 1958 (“PRA”) and so does not acquire public records i.e. archives of bodies described or listed in Schedule 1 of the PRA. The provisions of the PRA are therefore not applicable to the Library’s Archives and Manuscripts collection.

## 2. Access categories

2.1 In order to protect the interests of individuals whose personal data appears in the archives, the Library's Archives and Manuscripts team assesses each set of personal data at the point of cataloguing and assigns access categories based on the content and type of record. Paragraphs 2.2 - 2.4 below explain how these access categories are decided upon.

The majority of the Library's archives are deemed *open* but a limited portion are classed as *closed* or *restricted*. The Library closes material which is highly sensitive and restricts access to material which is less sensitive but still needs some level of restriction:

Access category	Sensitivity <sup>4</sup> of material	Available to researchers?
Open	Non-sensitive	Generally accessible in the Library or online <sup>5</sup>
Closed	Highly sensitive	Not available for consultation <sup>6</sup>
Restricted	Less sensitive but still needs some protection	Available for consultation in Library only

### 2.2 Closure and restriction periods based on 100-year lifespan

Material deemed suitable for closure or restriction as outlined in paragraph 2.1 above is generally closed or restricted for a finite period based on an assumed lifespan for each individual of 100 years. In accordance with archival best practice in the United Kingdom, the Library's closure/restriction periods take into account the fact that the individual has already lived a certain number of years by the time the data on them is created (see [Society of Archivists Best Practice Guideline 8: After the Hundred Year Rule, 2004](#), paragraph 1).

When a record spans a number of years, or it is not possible or feasible to identify the date of birth of the individual(s) whose personal data is featured in a record, the Library applies the closure or restriction period to the last date in the record. The record becomes open on the January following the expiration of the closure or restriction period e.g. an infant's patient file for 1985-1988 would be closed for 100 years and become open on 1 January 2089.

With some exceptions (see paragraph 2.4 for further details), the Library's standard closure/restriction periods are as follows:

Does the material relate to adults, children or infants?	Closure/restriction period
Adults (16 years old or over)	84 years
Children (7-15 years old)	93 years
Infants (0-6 years old)	100 years
Material including a mixture of these categories	Whichever is the longer period applicable
Material where it is uncertain whether individuals are adults, children or infants	100 years

<sup>4</sup> 'Sensitive' is used here to mean sensitive in general terms, and not 'sensitive personal data' as defined in the DPA.

<sup>5</sup> There is one exception to this rule of thumb, and for detailed guidance readers are referred to paragraph 4.1 below.

<sup>6</sup> As above

### 2.3 Records requiring closure or restriction beyond data subject's lifespan

The DPA is only concerned with how the Library handles personal data relating to *living* individuals. However, the Library recognises that its data protection responsibilities do not end with the death of an individual.

As a non-public body, the Library is not subject to the Freedom of Information Act 2000 ("FOIA"), nor does it acquire records that fall within the scope of FOIA. However, a body of FOIA case law has established that the duty of confidence owed to an individual during their lifetime passes to their personal representative after their death for a duration yet to be established, as evidenced by the [Decision Notices](#) issued by the ICO in response to applications under FOIA to consult the records of deceased individuals. Therefore, confidential information originally obtained from the deceased (e.g. health records) may also need to be closed by the Library (s.41 of FOIA).<sup>7</sup>

In addition, archive records relating to deceased individuals may need to be closed or restricted by the Library if the record in question contains personal information about another identifiable living person as this would be classed as personal data under the DPA.

In light of this, for records whose closure or restriction period has expired, and for newly-catalogued records relating to a deceased individual, the Library's Archives and Manuscripts team reviews the material to check whether it is suitable to be classed as *open* material or is still sensitive enough to require closure or restriction.

Since there is currently no definitive legal guidance on the suitable *duration* of closure periods for the records of deceased individuals, the Library considers such records on a case by case basis in order to take into account the interests and expectations of data subjects. The Library uses the following criteria when reviewing the sensitivity of such records:

- Whether the information relates to the deceased's personal and private life;
- Whether the information was provided by the deceased;
- Whether the information was provided on the understanding that it would be kept confidential;
- Whether the information is already in the public domain;
- The potential damage or distress that the release of the data might have on any close family members of the deceased, or its impact on the private and family life of the deceased's family<sup>8</sup>; and
- Whether the data contains personal information about another identifiable living person.

### 2.4 Criteria for deciding the appropriate access category

**2.4.1** The Library is aware that judging the level of protection needed in relation to archive records may involve an element of subjectivity. In order to make its judgements as ethical, consistent and transparent as possible, the Library's Archives and Manuscripts team bases its decisions on a combination of record content/sensitivity and record structure.

As mentioned in paragraph 1.2.3, the Library's archives that are most likely to constitute *sensitive* personal data are those that relate to individuals' physical or mental health, or sexual life. Sensitive records organised in a standard, structured way (even if not arranged primarily by data subject name) are classed as *closed*. Informal, less structured records which incidentally contain isolated references to sensitive issues are classed as *restricted*.

**2.4.2** The Library generally aims to make archival material available for research when there are no sensitivity issues involved. Occasionally, however, for specific items that it would otherwise class as *open*, the Library may negotiate a period of closure/restriction in accordance with the wishes of the material's donor or depositor.

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<sup>7</sup> See ICO, [Practical Guidance: Information about the deceased](#), 31 July 2008

<sup>8</sup> Under Article 8 of the Human Rights Act 1998

**2.4.3** The most common types of record to be closed or restricted are:

Type of record	Closed or restricted?
Structured sensitive records e.g. medical case files, hospital daybooks	Closed  (84 / 93 / 100 years)
Personnel or grant application files containing confidential references or statements of opinion concerning individuals, where the file is part of a structured record series	Closed  (60 years <sup>9</sup> )
Unstructured records which contain incidental sensitive material  e.g. informal notes on individuals' health in a diary, correspondence touching on sexual life	Restricted  (84 / 93 / 100 years)
Confidential personnel or grant application references or statements of opinion concerning individuals, where the reference is held in unstructured records	Restricted  (60 years)
Grant application files containing purely administrative material  e.g. applicant contact details	Restricted  (30 years)
Membership records containing purely administrative material  e.g. field of research, publication lists, names of supporters and seconders, date of election etc.	Open  N.B. such records might warrant restriction/closure in cases where mere membership of a particular organisation was sensitive and otherwise untraceable
Records which fall outside the above categories, but which the donor/depositor feels merit some form of closure/restriction	The Library may negotiate a suitable period of closure/restriction with the donor/depositor
Records whose closure/restriction period has expired but which are deemed to require a further period of closure/restriction	Judged on case by case basis
Records whose data subject is deceased but which are deemed to require a further period of closure/restriction	Judged on case by case basis

<sup>9</sup> A 60 year closure is used on the basis that an individual is likely to be at least 20 years old when making a grant application, and thus will have completed their career by the time the closure period expires.

## 3. Online access to archives

### 3.1 Which categories of material may be consulted online?

The Library will only make material available online if it is classed as *open* and is over 10 year old (see paragraph 3.3.3 below). It does not place online any digital versions of records classed as *restricted* or *closed*. See paragraph 4.1 below for a table indicating which categories of archive are suitable for consultation in the Library only, which are suitable for consultation online, and which may not be consulted at all.

### 3.2 Transfers of personal data outside the European Economic Area

**3.2.1** The digitisation of analogue material, the acquisition of born-digital archives and facilitating online access to such material pose specific access challenges. Placing online digital versions of archives that contain personal data with the intention that such data be accessed globally constitutes a transfer of personal data outside the European Economic Area (**EEA**) for the purposes of the DPA's eighth data protection principle.<sup>10</sup>

**3.2.2** The eighth data protection principle states that personal data cannot be transferred to countries outside the EEA (including USA, Australia, New Zealand and African countries) unless there is an adequate level of data protection in place in that country. Transfers of personal data outside the EEA are permitted under Schedule 4 of the DPA if one of the conditions listed in this Schedule can be met. For example, the condition that the data subject has given consent to such transfer of their personal data outside the EEA, or the condition that the transfer is necessary for reasons of substantial public interest. However, the Library would not generally expect to be able to satisfy such Schedule 4 DPA conditions as it does not make personal data transfers on the basis of the scenarios set out in Schedule 4 DPA.

**3.2.3** The Library may, however, transfer personal data outside the EEA where the data is taken from records classed as *open* (with limited exceptions as outlined in paragraph 3.3 below). Since such records are lawfully made available for research purposes on an unconditional basis, the decision will already have been made that disclosure of such data will not adversely affect the relevant data subject. The Library as data controller may thus assess such transfers as adequate based on the nature of the personal data transferred and the the purposes for which the data are intended to be processed, in accordance with Paragraph 13 of Part II of Schedule 1 of the DPA.

The Library will only transfer such personal data in the form of online digital versions once it has undertaken a risk assessment to establish that no substantial damage or distress would be caused to data subjects by making the archives available in this way (see paragraphs 3.3 - 3.4 below).

Once the Library is ready to provide online access to digitised or born-digital archives, researchers will be permitted to download copies of online archives for their personal research (see paragraph 7.2 below).

**3.2.4** For records classed as *restricted* or *closed*, the Library does not place digital versions online in accordance with archival best practice (again, see Society of Archivists et al, [Code of Practice for Archivists and Records Managers under Section 51\(4\) of the Data Protection Act 1998](#), 2007, paragraph 4.13.1).

### 3.3 Currency of records

**3.3.1** While some records are judged non-sensitive and classed as *open* for consultation in the Library, they may acquire sensitivity if made available world-wide via online access. This particularly applies to very recently created material. The Library's Archives and Manuscripts collections include material that is very recent (i.e. created within the last decade), and most of the creators of (or individuals mentioned in) such material have had no say in the disposition of their personal information in this way and no reasonable expectation that it would be placed in the public domain within such a short period of time.

**3.3.2** The Library currently provides public access within its premises to recently created material classed as *open*, in order to provide researchers with information on recent biomedical, social and ethical trends. In facilitating the assessment of recent societal and historical impacts of biomedical

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<sup>10</sup> See ICO, [Data Protection Act 1998: The eighth data protection principle and international data transfers](#), 29 April 2010

research in this way, the Library provides essential support to the Wellcome Trust in its international [charitable mission](#) to support the brightest minds in biomedical research and the medical humanities.

As stated in paragraph 1.2.3, the Library provides such public research access on the basis of the Schedule 2 of the DPA condition that this is necessary for the purposes of legitimate interests pursued by the Library or by the third party or parties to whom the data are disclosed (as long as this does not result in unwarranted prejudice to the rights, freedoms and interests of the data subject). The Library is scrupulous in treating fairly all archives created within the last decade, and judges whether such records are suitable to be made available for research in accordance with the access assessment procedure outlined in paragraph 2 above even where the records fall outside the scope of the DPA.

**3.3.3** However, the Library is aware that online access to such recent material, otherwise of limited sensitivity, increases the risk that it may be processed in such a way that causes damage and distress to the data subjects concerned. This is particularly the case with born-digital records or those subjected to Optical Character Recognition (OCR) technology which are searchable by personal data elements e.g. name, address.

As a result, in order to protect data subjects' interests and to treat their personal data fairly and lawfully, the Library has decided not to make material classed as *open* available online until 10 years after the date of its creation. For material over 10 years old, the Library undertakes a risk assessment (see paragraph 3.4 below) prior to mounting digital versions online, and operates a takedown policy (see paragraph 3.5) where appropriate.

### 3.4 Assessing risk

**3.4.1** The Library aims as far as possible to identify high-risk material *prior* to online publication by risk-assessing all material due to be made available online. While it is not feasible to assess every piece of paper or born-digital document, the Library can mitigate risk by:

- Identifying which areas of each collection need the most detailed assessments (drawing on the Library's experience of the catalogues and collections);
- Assigning a risk category to each archive series based on the material's date and nature; and
- Examining a sample from each archive series appropriate to its risk category

Material that is classed as *restricted* or *closed* will not be made available online (see paragraph 4.1). Similarly, material under 10 years old will not be made available online (see paragraph 3.3.3).

**3.4.2** The risk assessment procedure comprises two stages as outlined in paragraphs 3.4.2.1 and 3.4.2.2. See Appendix 1 for a workflow diagram combining both stages.

**3.4.2.1** In stage 1 of the risk assessment, the Archives and Manuscripts team assesses each series of records against the following criteria in order to judge the appropriate risk category (the list of criteria is not necessarily exhaustive):

- Is the archive series *open*, *restricted* or *closed*? (if *restricted* or *closed*, assessment is not required as per paragraph 4.1)
- How comprehensive/detailed is the catalogue?
- Were the records created by a clinician?
- Do the files appear to be very mixed in content?
- How old are the records? (in general, sensitivity diminishes over time)
- Are individuals directly identifiable, or likely to be indirectly identifiable?
- Are identifiable individuals living or dead?
- Would the nature of the records cause individuals (or their close family members e.g. siblings, children) substantial damage or distress?
- Was the information provided on the understanding that it would be kept confidential?

- How is the information structured (e.g. is it arranged alphabetically by name; is the data capable of being searched?)

The Archives and Manuscripts team then assigns the archive series a risk category (A Low, B Medium or C High) and stipulates the size of the sample to be examined in detail, taking into account the size and other characteristics of the archive series in question. Appendix 1 contains current detailed procedural guidance for archivists and sensitivity reviewers. This may be modified to take into account the nature of the particular series under examination.

If 5% or more of an archive series turns out on assessment to contain sensitive data, the sensitivity reviewer will go on to examine additional material from the same series. Again, Appendix 1 contains current detailed procedural guidance on additional samples for archivists and sensitivity reviewers.

**3.4.2.2** In stage 2 of the risk assessment, the sensitivity reviewer examines in detail the stipulated sample of the archive series, checking documents against a checklist of sensitive personal data types and assessing the risk of substantial damage or distress that might be caused to the relevant data subject by placing the material online. See Appendix 2 for the sensitivity reviewer's workflow and checklist of sensitive personal data types.

The checklist of sensitive data types in Appendix 2 is not exhaustive, and can be added to as necessary during the assessment process. Nor must sensitive data in the categories listed automatically be suppressed from online access. Such data should only be withdrawn from access online if it would be unfair or unlawful to allow continued access, or if continued access would be likely to cause the data subject substantial damage or distress.

When considering the risk of causing substantial damage or distress, the sensitivity reviewer will take into account factors such as the age of the information, whether it relates to a living and identifiable individual, and whether the information is structured in such a way that it can easily be searched for data relating to particular individuals (as discussed in *Review Guidance: Re-review of open records containing personal information*, The National Archives, 2008).

When estimating whether an individual is living or not, the sensitivity reviewer will where practicable take into account whether the records relate to adults (over 16 years old or over), children (7-15 years old) or infants (0-6 years old), as outlined in paragraph 2.2. Where this is not feasible, the reviewer will err on the side of caution and assume that any individuals mentioned in records that are 100 years old or less are still living.

**3.4.3** The Library will suppress material identified as sensitive from online view, ideally by suppressing any sensitive documents in a file of material but leaving non-sensitive material in the same file viewable online. Where it is not practicable to suppress partial files in this way, the Library will suppress the entire file to ensure that any sensitive contents are not viewable online.

**3.4.4** The Library maintains a transparent audit trail of risk assessment judgements. In stage 1, the Archives and Manuscripts team records judgements over the appropriate risk category for each archive series. In stage 2, the sensitivity reviewer records judgements made on the sensitivity of documents examined in each sample.

### **3.5 Takedown policy**

Despite these safeguards it is possible that sensitive documents hidden in apparently non-sensitive files may occasionally be made available online. In order to minimise such risk, once the Library is ready to make digitised or born-digital archives available online for research, an online feedback facility will be provided for members of the public to alert the Library to potentially sensitive materials available online.

The material will immediately be taken down temporarily on receipt of such a request. The case will then be considered by a Panel composed of members of staff who provide relevant expertise. The Panel will aim to respond definitively within four weeks, but may need to ask for additional time to make a final decision if it is necessary to gather information or seek external opinions in order to take an informed view.

The Panel will approve continued withdrawal of the material only if one of the following criteria is met:

- The material is personal information about someone who is still alive and continued online access would be unlawful or unfair to him under the DPA or would breach his or his family's right to a private and family life under the Human Rights Act 1998;
- The material is personal information about a deceased individual that requires closure or restriction on the grounds outlined in paragraph 2.3;
- Making the material available online is an infringement of copyright<sup>11</sup>;
- The material is defamatory or obscene; or
- The material acquires sensitivity through being available online (as opposed to being available in paper or born-digital format solely in the Wellcome Library).

All takedowns will be signalled openly via the Library's website.

The information will be regarded as having been suppressed temporarily and will be restored at a date decided by the Archives and Manuscripts team once its sensitivity is deemed to have subsided.

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<sup>11</sup> The Library is currently drafting a policy document outlining its copyright methodology in relation to digitising Library materials. In the meantime, readers are referred to the [copyright statement](#) on the Library's website.

## 4. Consulting the archives

### 4.1 Can researchers consult all categories of material?

The table below indicates which categories of archive are suitable for consultation in the Library only, which are suitable for consultation online, and which may not be consulted at all.

Category of archive	Can consult in Wellcome Library?	Can consult online?
OPEN material created on or before 31 December 1999 <sup>12</sup>	Yes	Yes
OPEN material created on or after 1 January 2000 <sup>13</sup>	Yes	No
RESTRICTED material	Yes  (subject to approved application to consult restricted material – see paragraph 4.3 below)	No
CLOSED NHS hospital patient records disposed of by their creating body before 1958	Yes  (subject to permission from the appropriate Ethics Committee to consult related records retained by the hospital - see paragraph 4.4.2 below)	No
CLOSED material (other than the specific NHS category above)	No	No
UNCATALOGUED material	No	No

### 4.2 Registering to consult archives

#### 4.2.1 Current procedure

Researchers wishing to consult archives in person at the Library should follow the Library's [new reader application procedure](#). On their first visit to the Library, each researcher intending to consult archives must also complete a Reader's Undertaking (see Appendix 3).

In accordance with Statutory Instrument SI 2000 No.417 Data Protection (Processing of Sensitive Personal Data) Order 2000, the Reader's Undertaking requires researchers to undertake to abide by the following s.33 DPA conditions, namely that:

- data on living individuals is not processed to support measures or decisions with respect to particular individuals; and
- data on living individuals is not processed in such a way that substantial damage or distress is, or is likely to be, caused to any data subject.

<sup>12</sup> This date will be updated annually each January

<sup>13</sup> As above

#### **4.2.2 Future procedure**

Once the Library is ready to make digitised and/or born-digital archives available online for research purposes, the Library will update its registration and e-registration procedures to incorporate the data protection clauses from the current Reader's Undertaking in Appendix 3.

At this point, researchers registering in person at the Library will be able to consult materials classed as *open*, either in analogue form or via digitised/born digital versions online. In-person researchers will be able to consult *open* material under 10 years old (either in analogue form or via stand-alone PCs for born-digital material).

Researchers wishing solely to consult *open* archives over 10 years old remotely via online versions will be able to do so once they have completed the Library's e-registration procedure (again, the procedure will be updated to incorporate the data protection clauses from the current Reader's Undertaking in Appendix 3).

#### **4.3 Consulting restricted archives**

Registered researchers in the Library wishing to consult archives classed as *restricted* should submit an Application for Access to Restricted Material (see Appendix 4). Application forms are available in the Library's Rare Materials Room and applications are usually processed by Library staff within two hours of submission.

The application form requires the researcher to specify the nature and subject of their research, the specific restricted records to be consulted, and how they intend to use the data in their research (e.g. compile statistical analysis, extract medical symptoms from case notes). Applications will only be approved if the researcher undertakes:

- not to use the information obtained from the records for any purpose other than the specific research described in their application for access;
- not to use the information obtained from the research in any way which might allow the identification of individuals<sup>14</sup>;
- not to divulge to a third party information contained in restricted records; and
- to respect the confidentiality of any documents or information not connected with their research but which may be seen in the course of it.

#### **4.4 Consulting records created by public authorities**

The Library is not a recognised Place of Deposit under s.4(1) of the PRA and so does not acquire public records i.e. archives of bodies described or listed in Schedule 1 of the PRA. However, the Library's Archives and Manuscripts collections include a limited number of records which emanate from public authorities.

##### **4.4.1 Public records presented under the PRA**

The Library holds a small number of public records presented with the cognisance of The National Archives (formerly Public Record Office) under s.3(6) of the PRA, for example, the archive of the Association of Community Health Councils for England and Wales (reference SA/CHC).

On presentation to the Library, such records cease to be public records and are no longer covered by FOIA, and so are made available to researchers for access on the same basis as privately created records.

##### **4.4.2 NHS hospital records within personal papers**

A limited number of the Library's archive collections include stray National Health Service (NHS) records that became intermingled with an individual clinician's personal papers during their career and were subsequently deposited in the Library as part of a personal archive.

For example, the personal papers of William Walters Sargant include some patient files from Sutton Emergency Hospital (the Second World War evacuation site of the Maudsley Hospital), the main

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<sup>14</sup> Readers are asked to use code letters that do not reflect the names of individuals, and to anonymise data during the initial note-taking process, to prevent accidental access by third parties to notes including names or other identifying details.

body of which are held by the Bethlem Royal Hospital Archives and Museum as part of the South London and Maudsley NHS Trust.

Since NHS organisations were not covered by the PRA until 1958 and could legally dispose of their records in any way they wished before that date, any NHS records that were removed from an NHS organisation before 1958 and intermingled with personal papers are not public records and are not covered by FOIA.

Accordingly, the Library's Archives and Manuscripts team judges whether or not such records are suitable to be made available to researchers on the same basis as the privately created records in the Library's collections.

However, in order to maintain a fair and consistent approach to requests for research access, if a researcher has been granted formal permission by a hospital's Ethics Committee to consult NHS hospital patient records, the Library will make any stray related pre-1958 patient files accessible to the researcher under the same terms.

According to the Hospital Records Database run by the Wellcome Library and The National Archives (searchable online at <http://www.nationalarchives.gov.uk/hospitalrecords>), the Library does not hold any post-1958 stray NHS hospital records. However, the Archives and Manuscripts team intends to conduct a survey of the Library's archive holdings within the next 6 months to confirm that this assumption is correct. If any stray post-1958 NHS records are identified in its collections, the Library will take advice from The National Archives on the appropriate course of action.

#### **4.4.3 General practitioner records**

The Library's Archives and Manuscripts holdings include a number of 20th century general practitioner archives. While many of these archives relate to solely private practices, some relate to National Health Service (NHS) practices or to private practices which transferred to the NHS in 1948. The records include administrative records such as articles of partnership, financial records, practice meeting minutes etc., and also deceased patient records, visits registers etc.

NHS general practitioners are independent contractors, and as such their records are not covered by the PRA (i.e. they are not referred to in schedule 1 of the PRA). As a result, the practice of the Archives and Manuscripts team has been to handle general practitioner archives according to the access assessment procedure outlined in paragraph 2 above.

However, NHS general practitioners currently have a statutory contractual obligation to transfer the records of deceased patients to the relevant Primary Care Trust<sup>15</sup> (and before that the relevant Family Health Service Authority<sup>16</sup>), and must handle research requests to consult deceased patient records in accordance with FOIA.

Consequently, the Archives and Manuscripts team intends to survey its general practitioner archives within the next 6 months to clarify the terms on which such archives were transferred to the Library. Once the Library has done so, it will take advice from The National Archives on the appropriate course of action regarding access to each collection.

#### **4.5 Closed archives**

Researchers may not consult *closed* material without the express permission of the data subject whose personal data is contained in the material.

#### **4.6 Uncatalogued archives**

As a general rule, researchers may not consult material until it has been catalogued and thus assessed in terms of sensitivity by the Archives and Manuscripts team.

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<sup>15</sup> Statutory Instrument 2004 No. 291 The National Health Service (General Medical Services Contracts) Regulations 2004, Schedule 6, Part 5 (N.B. NHS White Paper 'Equity and excellence: Liberating the NHS', 12 July 2010 recommends that PCTs are phased out in 2013)

<sup>16</sup> Statutory Instrument 1992 No. 635 The National Health Service (General Medical Services) Regulations 1992, Schedule 2, Paragraph 36

#### **4.7 Breaches of confidentiality**

Researchers should note that they will be banned from access to any of the Library's collections, services or facilities either in the Library or online if they breach the confidentiality conditions outlined in the Library's registration form or Application for Access to Restricted Material form.

Researchers who breach the Library's code of ethics in this way may also be disbarred from receiving Wellcome Trust funding for research.

## 5. Data subject access requests

**5.1** The sixth data protection principle requires the Library to process personal data held in its archives in accordance with the rights of the relevant data subjects. Data subjects are entitled, under s.7 of the DPA, to obtain a copy of their personal data held in the Library's archives and to be informed by the Library as to how this data is used and accessed. The Library reserves the right to refuse to process subject access requests that relate to archival records outside the scope of the DPA, i.e. records containing personal data that are not held in a 'relevant filing system'.

**5.2** If the data subject wishes to view their personal data held within the Library's archive collections, they must make a written subject access request<sup>17</sup> to the [Wellcome Trust's Data Protection Compliance Officer](#).

The Data Protection Compliance Officer will liaise with the Archives and Manuscripts team over arrangements for making the data available. This will include putting in place any measures required to prevent disclosure of personal data relating to third parties that might appear in such archive holdings (for example, redacting references to such third parties before disclosing the material).

When a data subject makes a formal subject access request to the Wellcome Trust's Data Protection Compliance Officer, the following shall apply:

- The Wellcome Trust will charge the data subject a fee in accordance with the prescribed maximum fee under the DPA for responding to such request;
- Requests will be processed promptly and at most within 40 calendar days from the date that the Wellcome Trust has received a duly completed subject access request form, proof of the data subject's identity and the requisite fee; and
- The copy of personal data provided in response to the subject access request will be in permanent form (i.e. a paper or electronic copy), unless providing the data in such form would involve a *disproportionate effort* on the part of the Wellcome Trust or the data subject agrees otherwise.

**5.3** Alternatively, if the data subject wishes to view their personal data within archive holdings which are classed as *open* or *restricted*, they may register as a new Library reader (see paragraph 4.2 above). They may then consult the relevant material in the Library (or online if available).

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<sup>17</sup> Preferably using the subject access request form obtainable from the Data Protection Compliance Officer.

## 6. Data subject requests to correct personal data held in archives

**6.1** As stated in paragraph 5 above, the sixth data protection principle requires the Library to process personal data held in the archives in accordance with the rights of the data subject. Data subjects are entitled under s.14 DPA to request an amendment to their personal data held by the Library if the data subject considers it to be inaccurate, or to request the blocking, erasure or destruction of their personal data.

However, in the case of personal data kept solely as a historical record, the ICO does not require the Library to regularly update such data as this would defeat the purpose of maintaining the historical record. Nor would the ICO expect to support a case aimed at the destruction of personal data selected for permanent preservation as archives (see Society of Archivists et al, [Code of Practice for Archivists and Records Managers under Section 51\(4\) of the Data Protection Act 1998](#), 2007, paragraph 4.7). In such cases the Library would use supplementary statements as outlined in paragraph 6.2 to make rectifications to the personal data without damaging archival integrity.

**6.2** If a data subject wishes to make an amendment to their personal data held in the Library's Archives and Manuscripts collection, they should:

- Contact the [Archives and Manuscripts](#) team to request a data amendment request form (Appendix 5);
- Return the completed form and proof of their identity to the [Archives and Manuscripts](#) team.

The Library will place a copy of any supplementary statement on the relevant archive's accession file, and make the supplementary statement available to researchers as appropriate (for example, as a note in the relevant catalogue record, a reference in the metadata for a born-digital archive, a copy on acid free paper in the relevant hardcopy archive file, or a digital version in the online version of the archive).

## 7. Providing research copies of archive data

**7.1** Under the DPA, providing copies of records containing personal data in response to enquiries from researchers based outside the EEA is considered a transfer of such personal data outside the EEA. As stated in paragraph 3.2, the eighth data protection principle states that personal data cannot be transferred to countries outside the EEA without an adequate level of data protection.

**7.2** As stated in paragraph 3.2 above, the Library only makes personal data in archive records available to researchers located outside the EEA where such data can be transferred in accordance with the eighth data protection principle, i.e. the data is taken from records classed as *open* (with limited exceptions as outlined in paragraph 3.3), on the basis that disclosure of such data will not adversely affect the relevant data subject, and that such transfers are adequate based on the nature of the personal data transferred and the purposes for which the data are intended to be processed (in accordance with Paragraph 13 of Part II of Schedule 1 of the DPA).

Accordingly, the Library provides researchers on request with copies of personal data from archives classed as *open* in the form of image files (hardcopy or electronic).

Once the Library is ready to provide online access to digitised or born-digital archives, researchers will be permitted to download copies of online archives for their personal research (please note that the Library will only make material available online if it is classed as *open*, and will not place online any records classed as *restricted* or *closed*, as outlined in paragraph 3.1 above).

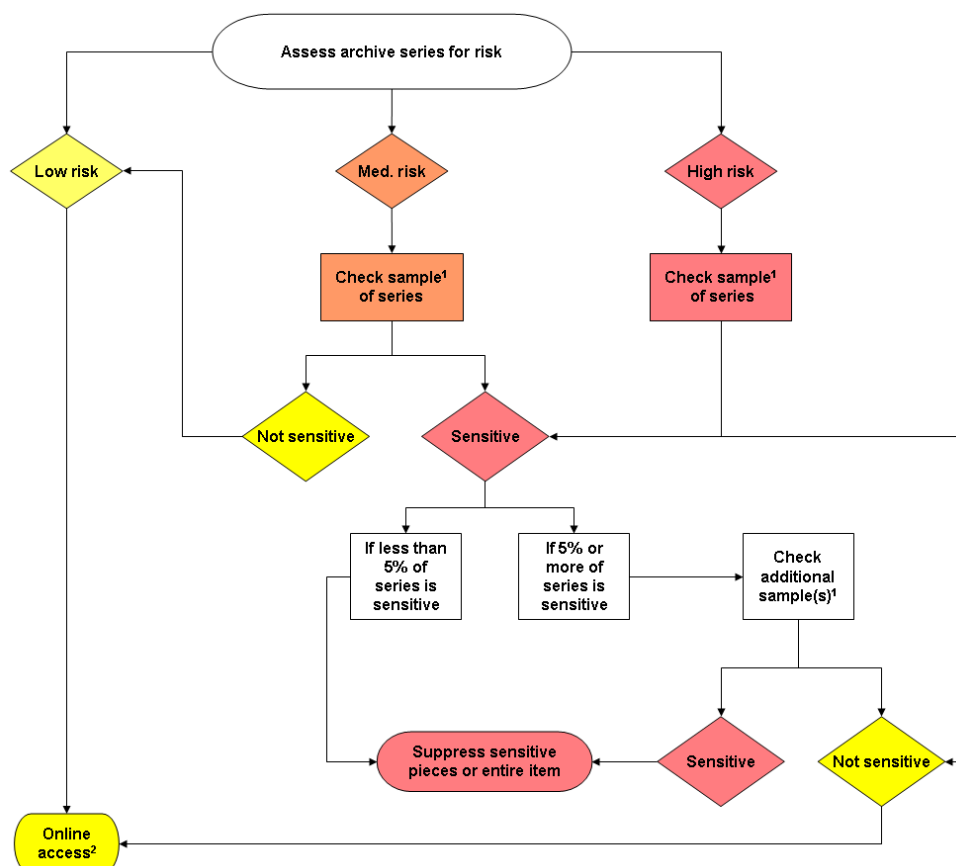
**7.3** The Library does not provide copies of records classed as *restricted* or *closed* except in response to a subject access request made by the relevant data subject, as outlined in paragraphs 5.1 – 5.2 above. In this way, the Library protects against the disclosure of third party personal data contained in *restricted* or *closed* records, in accordance with the requirements of the DPA.

Please note that the Library can provide copies from the small number of archive collections that are restricted at the request of the depositor (e.g. Eugenics Society archive), as long as the researcher has obtained the necessary permission to consult the archive from the depositor and no personal data is disclosed by making such copies available to the researcher without the consent of the relevant data subject(s).

**7.4** Researchers are not allowed to use personal digital cameras to make copies from any Archives and Manuscripts collections (or indeed from any other Special Collections consulted in the Library's Rare Materials Room).

## Appendix 1

# Risk assessment workflow for material to be made available online



### <sup>1</sup>Risk assessment sampling procedure

The Archives and Manuscripts team assesses each series of records against the criteria laid out in paragraph 3.4.2.1, assigns the archive series the appropriate risk category (A Low, B Medium or C High), and stipulates the size of the sample to be examined in detail. As the table below indicates, the size of the sample for risk categories B and C is flexible to take into account the size and nature of the archive series in question.

For example, it may be necessary to check 100% of a category B series which comprises 2 files and is ambiguously described in the catalogue. On the other hand, it may be necessary to check only 75% of a category C series which comprises 20 files and is catalogued in comprehensive detail.

Risk category	Level of risk	General nature of records	Sample to examine
A	Low	<ul style="list-style-type: none"> <li>Records are 100 years old or more</li> <li>No living individuals</li> <li>No risk of damage or distress to close family members of individuals mentioned</li> </ul>	0%
B	Medium	<ul style="list-style-type: none"> <li>Records are 50-100 years old</li> <li>Some living individuals</li> <li>Little risk of damage or distress to individuals or their close family members</li> </ul>	Up to 100% depending on the nature and extent of the specific record series
C	High	<ul style="list-style-type: none"> <li>Records are less than 50 years old</li> <li>Some living individuals</li> <li>Potential damage or distress to individuals or their close family members</li> </ul>	50-100% depending on the nature and extent of the specific record series

Cont.

## Appendix 1

### Risk assessment workflow for material to be made available online (cont.)

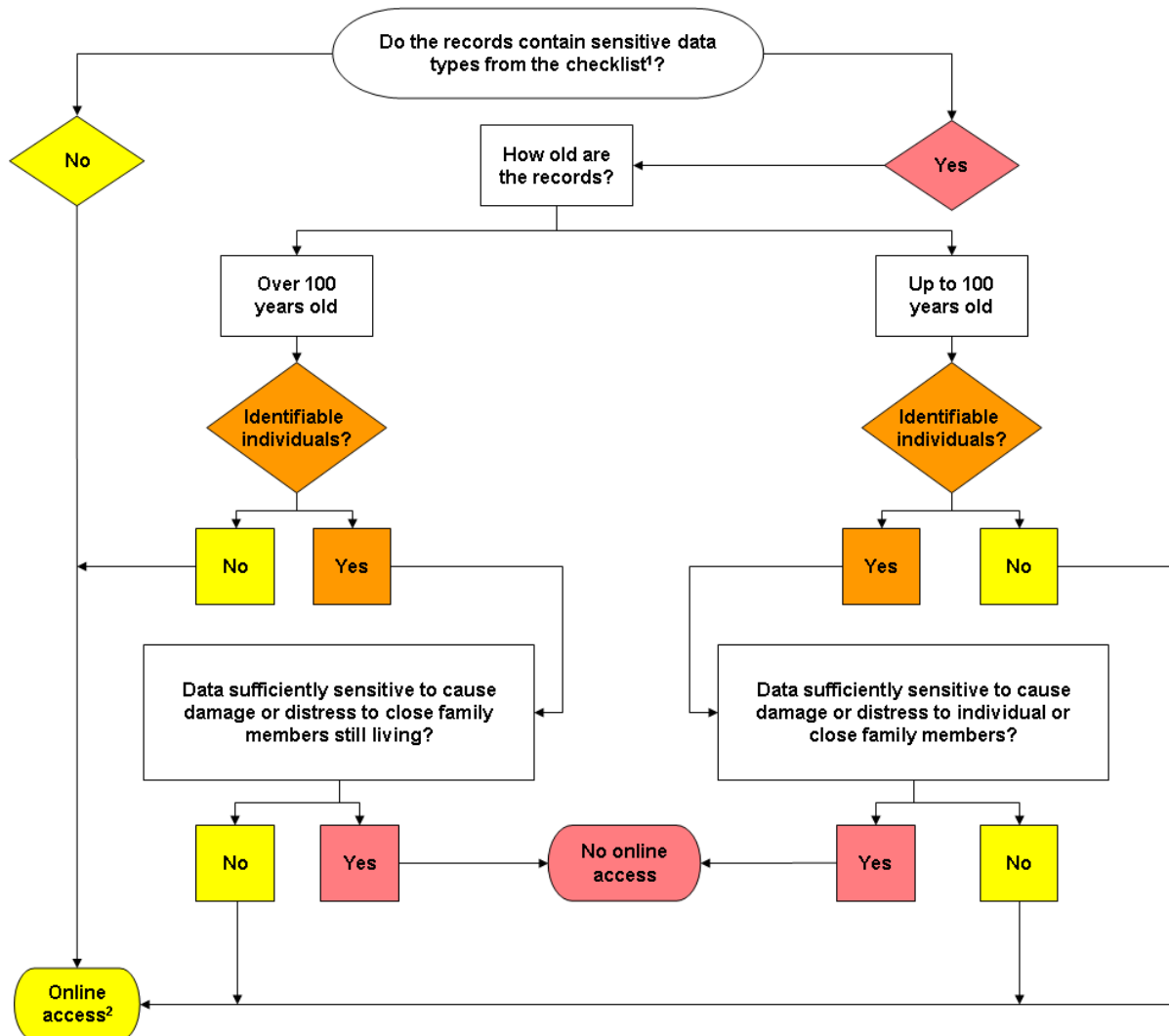
If 5% or more of an archive series turns out on assessment to contain sensitive data, the sensitivity reviewer will go on to examine additional samples from the same series i.e. an additional 25% or more for category B material, and the remainder of the series for category C material:

Risk category	Initial sample size	Additional sample(s) to examine
B	Up to 50%	(1) Additional 25%* of series (2) If the additional 25% sample also contains sensitive material, examine remainder of series  *If it is not feasible to separate out an additional 25% sample because the series contains too few files, the sensitivity reviewer will simply examine the remainder of the series
B	50% or more	Remainder of series
C	50% or more	Remainder of series

<sup>2</sup>Copyright permitting

## Appendix 2

# Sensitivity reviewer's workflow



### <sup>1</sup>Checklist of sensitive personal data types

The sensitivity reviewer will examine the sample records for sensitive personal data types as listed in section 2 of the DPA:

- Racial or ethnic origin
- Political opinions
- Religious or similar beliefs
- Membership of a trade union
- Physical or mental health or condition
- Sexual life
- Alleged or actual commission of any offence
- Court proceedings for any (alleged) offence and disposal of proceedings

In addition, the sensitivity reviewer will examine the sample records for other types of data that are considered sensitive in general terms (even if not sensitive personal data as defined by section 2 of the DPA):

- Peer review comments for honours or awards
- Personnel or grant application files containing confidential references or statements of opinion
- Job or grant application files containing purely administrative material under 30 years old
- Bank, financial or credit card details
- National Insurance numbers
- Tax, benefit or pension records
- Fingerprints

<sup>2</sup>Copyright permitting

## Appendix 3



# Wellcome Library Archives and Manuscripts Reader's Undertaking

<b>Reader no.:</b> .....	<b>Title:</b> .....	<b>Last Name:</b> .....
<b>Forename:</b> .....	<b>Institution / company etc:</b> .....	
<b>Nature of research (please circle): book / article / thesis / dissertation / media / family / other (please specify)</b> .....		
<b>Subject of research:</b> .....		

### Conditions of access

- Under s.33 of the Data Protection Act 1998, personal data on living persons may only be accessed for research purposes on condition that:
  - the data are not processed to support measures or decisions with respect to particular individuals
  - the data are not processed in such a way that substantial damage or distress is, or is likely to be, caused to any data subject
- Some collections contain medical information or material of a private and sensitive nature relating to individuals. Normally such material less than 100 years old will not be made available to readers, but access may in certain cases be allowed on condition that:
  - the reader will not use the information obtained from the records for any purpose other than the specific research described in their application for access.
  - the reader will not use the information obtained from the research in any way which might allow the identification of named individuals.
  - the reader will not divulge to a third party information contained in restricted records.
  - the reader will respect the confidentiality of any documents or information not connected with their research but which may be seen in the course of it.
- For some collections permission of the donor/depositor is required for access and it is the reader's responsibility to obtain this.
- Readers are reminded that the onus for satisfying the legal requirements of the Copyright Acts rests with them. Should the reader wish to publish extracts from the documents s/he is responsible for ascertaining the ownership of copyright and obtaining the necessary permission from the copyright holder and in some cases the permission of the owner of the collection.
- Acknowledgement may be made in any published work to the Wellcome Library, 183 Euston Road, London NW1 2BE, quoting the identifying references of the documents and the name of the collection.

### How your personal information will be used

- The Library will keep your Reader's Undertaking indefinitely as a record that you have accepted our conditions of access to Archives and Manuscripts material;
- We will use the information on your research project and institution to monitor the types of research for which our collections are used;
- We will not share your personal information with any third parties.

**I hereby acknowledge that I have read and understood the conditions above, and have received a duplicate copy of this undertaking.**

Signed: ..... Date: .....

Copy handed/sent to reader by: ..... Date: .....

**Staff use only** Collections suggested to reader: .....

Donor/depositor permissions necessary? Y  N  Specify collection/s: .....

Receipt of permission noted by: ..... on: .....

## Appendix 4



### Wellcome Library

### Application for Access to Restricted Archival Material

Reader no.: .....	Title: .....	Last Name: .....
Forename: .....	Institution / company etc: .....	
Nature of research ( <i>please circle</i> ): book / article / thesis / dissertation / media / family / other ( <i>please specify</i> ) .....		
Subject of research: .....		
.....		

Which restricted records do you wish to see? (specify full reference for each item e.g. SA/BGU/E.14/2)

.....

.....

.....

How do you intend to use data from the specified files in your research? (e.g. compile statistical analysis, extract medical symptoms from case notes)

.....

.....

.....

#### How your personal information will be used

- The Library will keep your form indefinitely as a record that you have accepted our conditions of access to the restricted material specified on the form;
- We may share information on your research use of the specified material with:
  - (a) the data subject(s) of the material if they ask for this information in accordance with their right under s.7 of the Data Protection Act 1998, or
  - (b) the donor or depositor of the material;
- We will not share your information with any other third parties.

I hereby acknowledge that I have signed an Archives and Manuscripts Reader's Undertaking, and agree to abide by its access conditions if I am granted access to the material specified above. I also undertake to provide the Archivist with draft text in advance of publication should I wish to publish data from restricted access material.

Signed: ..... Date: .....

#### Staff use only

Donor/depositor permissions necessary? Y  N  Donor/depositor permission received? Y  N

Reader's application approved? Y  N

Reason for refusal of application: .....

.....

Copy handed/sent to reader by: ..... Date: .....

## Appendix 5



### Wellcome Library

#### Data subject request to amend personal data held in archives

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##### 1. Details of person requesting the amendment

Title: ..... Last name: .....

Forename: ..... Address: .....

.....

Tel. no.: ..... Fax: ..... Email: .....

##### 2. Are you the data subject?

**YES** Please supply evidence (original or copy) of your identity (e.g. driving licence, passport, national identity card, photo-pass) and address (e.g. recent bank statement or letter/bill from a utility company). Please include a stamped addressed envelope for returning the documents (*please go to section 5*)

**NO** You must enclose the written authority of the data subject that you are acting on their behalf, together with evidence of their identity and address as above (*please complete sections 3 and 4*)

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##### 3. Details of the data subject (if different from person named in section 1)

Title: ..... Last name: .....

Forename: ..... Address: .....

.....

Tel. no.: ..... Fax: ..... Email: .....

##### 4. Please describe your relationship with the data subject that leads you to make this amendment request on their behalf

---

##### 5. The data to be amended

- What are the data?  
(Please give collection and item references)

*Please turn over*

