Access to personal data within our research collections
May 2018

Wellcome Collection is currently reviewing and extending these guidelines to include data which may be sensitive, but is not personal data. At the same time we are updating our procedures on access to personal data in our collections as new data protection regulations come into effect in the European Union.

We are confident that our current procedures are already compliant with the new legislation, but we are taking the opportunity to make improvements to make them easier to understand. These revised procedures will be published by the end of 2018.

Meanwhile, our new Access Policy sets out Wellcome Collection’s commitment to maximising access to our museum and library, and to identifying the ways in which we achieve this across the organisation. The policy relates to all collections held by Wellcome Collection as well as our services, activities, facilities, content and programmes onsite, off-site and online.
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1.0 Introduction

Scope of the policy
The Wellcome Library makes its collections accessible to the public in order to promote the understanding of medicine and its role in society, past and present. As part of our mission, we are committed to widening public access to our archive, image and sound collections as far as possible, while at the same time handling personal and sensitive information in these research collections lawfully, ethically and responsibly.

This policy sets out the process we follow to assess and categorise the materials within our research collections, and the basis on which we make the following materials available:

- Still images or artworks
- Moving images
- Audio recordings
- Text-based material

Legal and ethical framework

Data Protection Act 1998
A number of the materials within our collections fall within the scope of the Data Protection Act 1998 ("DPA") as they contain personal data i.e. information relating to living individuals who can be identified from that information or from that information and any other available information, which is:

(i) held in a relevant filing system, that is a filing system in which particular information about specific individuals can be readily retrieved, including information held electronically); or

(ii) an accessible record under s.68 DPA, for example an accessible health record.

Due to the nature of much of the material in our collections, broadly relating to the medical humanities, we also have sensitive personal data in our collections as we hold information relating to the physical or mental health and sexual life of individuals.
We hold, use and make available personal data and sensitive personal data, on the following bases under the DPA, as discussed in more detail in the Appendix 4.1:

(i) For research purposes: under the specific research exemption in the DPA; and

(ii) For non-research purposes: we hold and make available personal data for a variety of purposes in pursuit of our legitimate interest of promoting the understanding of medicine and its role in society, past and present. Where the material contains sensitive personal data which has not been made public as a result of steps deliberately taken by the subject of that data, we only make this material available with the explicit consent of that person.

A significant proportion of our collections fall outside the scope of the DPA since, whilst they may contain personal data or sensitive personal data, they are unstructured manual data that is not part of a relevant filing system or they are the personal data of a deceased person. However, in order to demonstrate our commitment to the ethical handling of all personal data, we choose to handle such unstructured manual data as if it were subject to the requirements of the DPA. In particular, we recognise that our data protection responsibilities do not end with the death of an individual where making available a deceased person’s personal data could impact on close family members connected to the deceased person or referred to in the material.

**Freedom of Information Act 2000**

As a non-public body, we are not subject to the Freedom of Information Act 2000 (FOIA), nor do we acquire materials that fall within the scope of FOIA. In exceptional circumstances we might consider acquiring material from a public authority subject to FOIA, but only where (a) The National Archives approves the acquisition, and (b) the public authority retains legal responsibility for handling FOIA access requests, or the material is exempt from access requests under the s.21FOIA exemption for material that is already ‘reasonably accessible’.

**Public Records Act 1958**

We are not a recognised ‘Place of Deposit’ under s.4(1) of the Public Records Act 1958 (PRA) and so do 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 our research collections.

We do hold a limited number of records which were created by public authorities, but we hold these on the same basis as privately-created records on approval from The National Archives (see Appendix 4.1).
2.0 How do we decide whether material is suitable for access?

We assess all material within our research collections to determine whether material is suitable for access (and if so, the type of access). We base our assessments on the following considerations:

1. whether the material contains personal data or sensitive personal data;

2. whether we have the relevant individual’s explicit consent to a particular use of their personal or sensitive personal data; we take steps prior to acquiring material within our research collections to verify that where consent has not been obtained, this is not due to the relevant individual’s refusal to consent;

3. whether the material has already been made public as a result of steps deliberately taken by the individual whose personal data or sensitive personal data is featured in the material;

4. whether the material contains other information of a sensitive nature (i.e. where the material is not personal data or sensitive personal data under the DPA, but nevertheless might cause substantial damage or distress to the close family of a deceased individual, or contains material such as sexually explicit images or disturbing images of diseased body parts);

5. where applicable, what permissions we have from the copyright holder of the material to make the material available.

The assessment takes place in several phases. This staged approach allows us to take into account the nature of the specific material being assessed and how we plan to make the material available:

- Phase 1: Initial assessment
- Phase 2: Detailed assessment
- Phase 3: Assessment prior to online publication

These three assessment phases are outlined below.
2.1

Phase 1: Initial assessment

We apply this initial assessment to all types of research material either when we acquire it or when we catalogue it, in order to establish how sensitive the material is and under what conditions we can make it available to researchers.

The initial assessment is outlined below (fig. 1).
**Fig. 1 Phase 1: Initial assessment**

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- **Is the material personal data as defined by DPA?**
  - *(i.e., identifies a living individual AND in relevant filing system as defined by DPA)*
  - **Yes**
  - **No**

  **Choose option**
  - **Personal data as defined by DPA**
  - **Sensitive personal data as defined by DPA**

- **Do we have the individual's permission to make available?**
  - **Yes**
  - **No**

  **Open access within library**
  - **Yes**
  - **No**

  - **Already made public as a result of steps deliberately taken by the individual?**
    - **Yes**
    - **No**

  - **Assign access categories according to nature of material**
    - **See fig. 2 or fig. 3**

- **Is the material sensitive in general sense?**
  - *(e.g., could research access cause substantial damage or distress to the close family of a deceased individual?)*
  - **Yes**
  - **No**

  **Assign access categories according to ethical considerations beyond DPA requirements**
  - **See fig. 2 or fig. 3**

- **Allow access according to the consent terms**
  - **See Phase 2: With permissions**

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Subject to any applicable copyright or other restrictions (e.g., taste and decency)

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1 We take steps prior to acquiring material within our research collections to verify that where consent has not been obtained, this is not due to the relevant individual's refusal to consent.
2.2
Phase 2: Detailed assessment

Once the initial assessment is completed, we then choose the appropriate procedure for more detailed assessment of the specific research materials:

- **Material with permissions** from the individual whose *personal or sensitive personal data* features in the material
- **Material without permissions** from the individual whose *personal or sensitive personal data* features in the material

These assessment procedures are outlined below.
Phase 2:  
Material with permissions (for research access within the library only)

At this stage we are assessing the suitability of the material for research access within the library only. The material’s suitability for online access is assessed separately in Phase 3.

Sometimes the individual whose personal or sensitive personal data features in material gives us permission to make that material available for research or other activities. The permission level varies depending on the specific material, but common permissions allow us to make the material available for one or more of the following options:

- Healthcare professional research/teaching use
- Academic research/teaching use
- General research use
- All uses including media publication

Examples of material with permissions include our Wellcome Images Biomedical Collection of contemporary clinical and biomedical images selected from teaching hospitals and research institutions in the UK and beyond. The clinical images within this collection are photographs taken of patients by professional medical photographers, and illustrate signs or symptoms of disease or injury, general healthcare, and sciences from genetics to neuroscience. In order to safeguard the confidentiality of individual patients, we only acquire such clinical images from medical photographers who can provide us with satisfactory assurances that they have already obtained permission from patients to make their images available for research, teaching or publication purposes. Furthermore, we only use such clinical images in a way which would be within the reasonable expectation of the individual patient and consistent with the terms of the permission granted.
Phase 2:
Material without permissions (for research access within library only)

At this stage we are assessing the suitability of the material for research access within the library only. The material’s suitability for online access is assessed separately in Phase 3.

For material without permission from the individual who is the subject of the material, we choose one of the two assessment procedures below depending on the nature of the material being assessed:

- **Risk assessment** (fig.2)
  
  We use this approach where it is not possible to assess the material item by item due to the size or mixed nature of the specific collection (e.g. archive collections, large groups of images)

- **Granular assessment** (fig.3)
  
  We use this approach where it is not feasible properly to assess material via spot checks, or where it is feasible or necessary to assess the level of sensitivity item by item (e.g. film and audio recordings, individual images).

  This approach is particularly suitable for assessing moving image and sound recordings: we need to watch or listen to such recordings in their entirety in order to catalogue them, and it is especially difficult to gauge the sensitivity of a sound recording from spot checks at random points in the recording.

These two assessment workflows are outlined below.

For details of the periods for which material may be closed or restricted, see Appendix 4.5.
| Fig. 2 Phase 2: Risk assessment for material without permissions (for research access within library only) |
Sensitive personal data in a relevant filing system
(e.g. medical case files, hospital daybooks, albums of clinical photographs)

Personal data in a relevant filing system
(e.g. personnel files containing confidential references or statements of opinion concerning individuals, or grant application files containing administrative information on individuals)

The material is sensitive in general sense (but not personal data or sensitive personal data as defined by DPA)

The image/artwork is sensitive in content or theme but the individual is not identifiable

The subject of the data is deceased but research access could cause substantial damage or distress to their close family?

Made public as a result of steps deliberately taken by the individual AND the public version of the information matches the material exactly?

Has the material already been made public? (e.g. reproduced in a medical journal, or discussed in an online forum)

Made public as a result of steps deliberately taken by the individual AND the public version of the information matches the material exactly?

Is making the material available for research access in library fair? i.e.
(i) this use of the material is within the individual's reasonable expectation; AND
(ii) it won’t prejudice the rights and freedoms or legitimate interests of the individual.

Restrict
Allow open access
Close or restrict on case by case basis

Allow open access
Close or restrict on case by case basis

The material is personal data or sensitive personal data as defined by DPA

No
Yes

Yes
No

No
Yes

No
Fig. 3 Phase 2: Granular assessment for material without permissions (for research access within library only)
The material is personal data or sensitive personal data as defined by DPA

Sensitive personal data in a relevant filing system (e.g. digital moving image recording of patients receiving treatment)

Made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for public distribution)

Yes

No

Does the material include content on the checklist of high-sensitivity themes?²

Yes

No

Personal data in a relevant filing system (e.g. a photograph of laboratory staff at work)

Can material be made available for research access in library without causing damage or distress to individual?

Yes

No

The material is sensitive in content or theme but the individual is not identifiable?

Allow open access

Close/restrict on case by case basis

The material is unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

For what audience was the material created or distributed?³

General public audience

Specific audience

No

Yes

Is the individual deceased but public access could cause substantial damage or distress to their close family?

Close or restrict on case by case basis

Restrict

Can material be made available for research access in library without causing damage or distress to individual?

Yes

No

The material is sensitive in general sense (but not ‘personal data’ or ‘sensitive personal data’ as defined by DPA)

Is the material unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

Close or restrict on case by case basis

Restrict

For what audience was the material created or distributed?³

General public audience

Specific audience

Yes

Restrict/open on case by case basis

Restrict

The material is personal data or sensitive personal data as defined by DPA

Is the material sensitive in content or theme but the individual is not identifiable?

Allow open access

Close/restrict on case by case basis

The material is unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

Close or restrict on case by case basis

Restrict

For what audience was the material created or distributed?³

General public audience

Specific audience

Yes

Restrict/open on case by case basis

Restrict

Made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for public distribution)

Yes

No

Does the material include content on the checklist of high-sensitivity themes?²

Yes

No

The material is sensitive in general sense (but not ‘personal data’ or ‘sensitive personal data’ as defined by DPA)

Is the material unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

Close or restrict on case by case basis

Restrict

For what audience was the material created or distributed?³

General public audience

Specific audience

Yes

Restrict/open on case by case basis

Restrict

Is the material sensitive in content or theme but the individual is not identifiable?

Allow open access

Close/restrict on case by case basis

The material is personal data or sensitive personal data as defined by DPA

Is the material unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

Close or restrict on case by case basis

Restrict

For what audience was the material created or distributed?³

General public audience

Specific audience

Yes

Restrict/open on case by case basis

Restrict

Is the individual deceased but public access could cause substantial damage or distress to their close family?

Close or restrict on case by case basis

Restrict

Can material be made available for research access in library without causing damage or distress to individual?

Yes

No

The material is sensitive in general sense (but not ‘personal data’ or ‘sensitive personal data’ as defined by DPA)

Is the material unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

Close or restrict on case by case basis

Restrict

For what audience was the material created or distributed?³

General public audience

Specific audience

Yes

Restrict/open on case by case basis

Restrict

Is the material sensitive in content or theme but the individual is not identifiable?

Allow open access

Close/restrict on case by case basis

The material is personal data or sensitive personal data as defined by DPA

Is the material unstructured but contains sensitive material on potentially living and identifiable individuals? (e.g. analogue audio recording detailing an individual’s medical experiences)

Has the material been made public as a result of steps deliberately taken by the individual?₁ (e.g. by participating in a film intended for distribution)

Yes

No

Close or restrict on case by case basis

Restrict

For what audience was the material created or distributed?³

General public audience

Specific audience

Yes

Restrict/open on case by case basis

Restrict

Is the individual deceased but public access could cause substantial damage or distress to their close family?

Close or restrict on case by case basis

Restrict

Can material be made available for research access in library without causing damage or distress to individual?

Yes

No
Notes to fig.3
Phase 2: Granular assessment for material without permissions (for research access within library only)

1 Has the material been made public as a result of steps deliberately taken by the individual?

We begin our granular assessment procedure with this question as it determines whether or not we can make sensitive personal data accessible for research. In the absence of documented permission from the individual whose personal or sensitive personal data features in the material, we use our best judgement to decide on a case by case basis whether the individual has participated deliberately in making their data public, the circumstances around this and therefore whether the information can be made available by us. When considering this, we take into account the extent to which the information has previously been made public (i.e. how widely available the information has previously been made) and whether circumstances have changed since the information was previously made public, which might suggest that subsequent disclosure of the material could have a detrimental effect on the individual. Examples of material assessed in this way might include:

- An identifiable individual’s medical case file, 1980-1990. Given to the library as part of a series of case files in the archive of an organisation campaigning on behalf of patients. The individual has previously obtained a photocopy of their case file and published it in its entirety via their personal website. In this case we would close the main series of case files but allow research access to the specific individual’s case file (as long as access would not infringe the data protection rights of third parties mentioned in the material).
- A series of film recordings of vulnerable patients with brain conditions receiving treatment, 1940s. The films are systematically arranged by name and depict anaesthetised subjects receiving brain stimulation. Some patients are captured pre- and post-operatively. In this case we would close the material as the patients are highly unlikely to have expected the recordings to be distributed beyond the clinical care setting, or even to have been aware of the recordings.
- Post-operative photograph of a 14-year old heart transplant recipient at Harefield Hospital, with his parents, 1984. Photographed and interviewed by press photographers for publicity material on the procedure. In this case we would make the material open as the patient clearly expects his image and comments to be published in the press.

2 Checklist of highly sensitive themes. We decide whether to open or restrict the material by considering its contents against the following checklist:

- Genito-urinary
- Gynaecology
- Nude children
- Obstetrics
- Paediatrics
- Pathology
- Psychiatries
- Recognisable dead individuals
- Unusual or graphic surgical operations
- Vulnerable patients (e.g. with disabilities or psychiatric disorders)

3 For what audience was the material created or distributed? Was the material intended for or distributed to a wide general audience (e.g. a public information film designed to encourage public uptake of TB testing), or was it created for a specific, limited audience (e.g. a recording of an operation made as a surgical training aid)?
Phase 3: Assessment prior to online publication

2.3

The basis on which we are allowed to transfer personal data outside the European Economic Area by making it accessible online is explained in Appendix 4.2.

We aim as far as possible to identify high-risk material prior to online publication by assessing all material due to be made available online. We will only make material available online to a general research audience if it is classed as open.

In addition, we will only make open material under 10 years old available online to a general research audience where it is accompanied by permission from the individual whose personal data features in the material, or it has been made public as a result of steps deliberately taken by the individual.

We do this on the grounds that material classed as open for consultation in the library may acquire sensitivity if made available world-wide via online access, especially very recently created material. Our collections, especially our archive collections, include material that is very recent (i.e. created within the last decade). Most of the creators of (or individuals mentioned in) such material have had no say in the placing of their personal information in the library in this way and no reasonable expectation that it would be placed in the public domain within such a short period of time.

We are aware that online access to such recent open material increases the risk that it may be processed in such a way that causes damage and/or distress to the individuals concerned. This is particularly the case with born-digital materials or those subjected to Optical Character Recognition (OCR) technology that are searchable by personal data elements e.g. name, address.

Our assessment procedure prior to online publication depends on whether or not the material is accompanied by permission from the individual whose personal or sensitive personal data features in the material:

- **Where we do have permission** from the individual, we make the material accessible online as specified by the permission (see Phase 3: Material with permissions (for online access) below).

- **Where we don’t have permission** from the individual, we follow the most appropriate of the two assessment workflows outlined below (figs. 4-6)

Our pre-online assessment procedure is supplemented by a takedown policy (see Appendix 4.4).
Phase 3
Material with permissions (for online access)

Sometimes the individual whose personal or sensitive personal data features in material gives us permission to make that material available both for research and other activities such as online publication (see Phase 2 assessment above).

We will only make material accessible online in accordance with the specific permission level for the material in question.

We may occasionally suppress material online for reasons other than the permission level (e.g. taste and decency considerations).
Phase 3
Material without permissions (for online access)

For material without permission from the individual who is the subject of the material, we choose one of the two assessment procedures below depending on the nature of the material being assessed:

- **Risk assessment** (figs.4-5)
  
  We use this approach where it is not possible to assess the material item by item due to the size or mixed nature of the specific collection (e.g. archive collections, large groups of images).
  
  We assess only material that has been classed as open for research access within the library (see fig.2). We do not consider providing general online access to material that has been closed or restricted.
  
  While it is not feasible to assess every piece of paper, image or born-digital document, we mitigate risk by:
  
  - Identifying which areas of each collection need the most detailed assessments (drawing on our experience of the catalogues and collections);
  - Assigning a risk category to material based on its date and nature; and
  - Examining a sample from the material appropriate to its risk category.

- **Granular assessment** (fig.6)
  
  We use this approach only where we have already assessed material item by item for research access in the library (see fig.3), and are able to judge its suitability for online access without additional detailed review:
  
  These two approaches are outlined below.
Overview of risk assessment procedure

Assess material for risk²

Low risk → Med. risk → Check sample² → Not sensitive

High risk → Check sample² → Sensitive¹ → If less than 5% of series is sensitive → Suppress sensitive pieces or entire item

Sensitive¹ → If 5% or more of series is sensitive → Check additional sample(s)³

Sensitive → Not sensitive

Online access⁴
Notes to Fig 4
Phase 3: Risk assessment for material without permissions (for online access)

1 Assessing risk. We assess material against the following criteria in order to judge the appropriate risk category (A Low, B Medium or C High):
   - Is the material open, restricted or closed?
   - 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 is the material? (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 material 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?)

2 Size of the sample to be examined. The size of the sample for risk categories B and C is flexible to take into account the size and nature of the specific material e.g. we check 100% of category B material which comprises 2 files and is ambiguously catalogued, but may check only 75% of a category C series which comprises 20 files and is catalogued in detail.

<table>
<thead>
<tr>
<th>Risk category</th>
<th>General nature of records</th>
<th>Sample to examine</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (Low)</td>
<td>Material is 100 years old or more</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>- No living individuals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- No risk of damage or distress to close family members of individuals mentioned</td>
<td></td>
</tr>
<tr>
<td>B (Medium)</td>
<td>Material is 50-100 years old</td>
<td>Up to 100% depending on the nature and extent of the specific material</td>
</tr>
<tr>
<td></td>
<td>- Some living individuals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Little risk of damage or distress to individuals or their close family members</td>
<td></td>
</tr>
<tr>
<td>C (High)</td>
<td>Material is less than 50 years old</td>
<td>50-100% depending on the nature and extent of the specific material</td>
</tr>
<tr>
<td></td>
<td>- Some living individuals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Potential damage or distress to individuals or their close family members</td>
<td></td>
</tr>
</tbody>
</table>
3 **Additional samples.** If 5% or more of the material turns contains sensitive data, we will check additional samples from the same material:

<table>
<thead>
<tr>
<th>Risk category</th>
<th>Initial sample size</th>
<th>Additional sample(s) to examine</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Up to 50%</td>
<td>(1) Additional 25%* of material</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2) If the additional 25% sample also contains sensitive material, examine remainder of material</td>
</tr>
<tr>
<td></td>
<td></td>
<td>*If it is not feasible to separate out an additional 25% sample because the material contains too few files, we will simply check the remainder of the material</td>
</tr>
<tr>
<td>B</td>
<td>50% or more</td>
<td>Remainder of material</td>
</tr>
<tr>
<td>C</td>
<td>50% or more</td>
<td>Remainder of material</td>
</tr>
</tbody>
</table>

4 **Meaning of term ‘sensitive’.** We use the term ‘sensitive’ here to mean both sensitive under the terms of the DPA, and sensitive in a general sense.

5 **Considerations beyond sensitivity.** We provide online access subject to any applicable copyright or other considerations (e.g. taste and decency).
Fig. 5 Phase 3: Risk assessment for material without permissions (for online access)

Risk assessment stage 2: Sensitivity review

1 Checking the sample

(a) We check the sample to assess whether it contains any of the following categories of sensitive personal data:
   - 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

(b) We also check the sample material for other types of data that are sensitive in general terms:
   - 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

2 Considerations beyond sensitivity. We provide online access subject to any applicable copyright or other considerations (e.g. taste and decency). Before deciding whether to make information available online we consider whether publication would be fair to the individual (see paragraph 2.3 above).
Fig. 6 Phase 3: Granular assessment for material without permissions (for online access)

- **Item is classed OPEN for research in library (see fig.3)**
  - Consider general online access

- **Item is classed RESTRICTED for research in library (see fig.3)**
  - Is the item suitable for a specific audience, and already made public as a result of steps deliberately taken by the individual?
    - Yes
      - Consider restricted online access to authenticated users
    - No
      - Is it possible to redact any information that could identify the individual?
        - Yes
          - Consider general online access
        - No
          - No online access

- **Item is classed CLOSED for research in library (see fig.3)**
  - No online access
Accessing and copying materials

3.0

Access and copying conditions vary depending on the type of material. For details of which materials can be accessed or copied in the library or online, see the table and notes below (fig.7).

To find out more about individuals’ rights under the DPA regarding their personal data in our research collections, see Appendix 4.3 covering:

- Access requests
- Requests to amend data in research collections
- Requests to prevent processing data

For information on our takedown policy see Appendix 4.4.
<table>
<thead>
<tr>
<th>Type of material</th>
<th>Access in library?</th>
<th>Access online?</th>
<th>Can copy or download?</th>
</tr>
</thead>
<tbody>
<tr>
<td>OPEN</td>
<td>Yes¹</td>
<td>Yes² (except certain materials under 10 years old³)</td>
<td>Yes</td>
</tr>
<tr>
<td>RESTRICTED</td>
<td>We don't have permission to make available from the individual who is the subject of the material</td>
<td>Yes (subject to approved Restricted Access application⁴)</td>
<td>No⁵</td>
</tr>
<tr>
<td></td>
<td>The material is judged suitable for a specific audience</td>
<td>Yes (for authenticated users)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>We do have permission to make available from the individual who is the subject of the material</td>
<td>Yes (subject to the conditions outlined in the permission level⁶)</td>
<td></td>
</tr>
<tr>
<td>CLOSED</td>
<td>NHS general practitioner clinical records of non-deceased patients</td>
<td>Yes (with permission from the applicable NHS Research Ethics Committee⁷)</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Research project papers containing NHS patient case records</td>
<td>Yes (with permission from the applicable NHS Research Ethics Committee⁷)</td>
<td>Yes (with permission from the applicable NHS Research Ethics Committee⁷)</td>
</tr>
<tr>
<td></td>
<td>NHS hospital patient records disposed of by their creating body before 1958</td>
<td>Yes (with permission from the appropriate hospital ethics committee⁷)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Private hospital patient records</td>
<td>Yes (with permission from the appropriate hospital ethics committee⁷)</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>All other CLOSED material</td>
<td>No</td>
<td>Yes (with permission from the appropriate hospital ethics committee⁷)</td>
</tr>
</tbody>
</table>

¹ Access may be subject to conditions.
² Access may be subject to conditions.
³ Certain materials under 10 years old may require additional permission.
⁴ Restricted Access application may be required.
⁵ Permission to copy may be subject to additional conditions.
⁶ Conditions outlined in the permission level.
⁷ Permissions from the appropriate ethics committee may apply.
<table>
<thead>
<tr>
<th>UNCATALOGUED material</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>(We cannot provide access until material has been assessed for sensitivity via cataloguing)</td>
<td></td>
</tr>
</tbody>
</table>
Notes to fig.7
Access and copying conditions

1 Consulting material at the library. Researchers must register on their first visit. Our registration form requires researchers to acknowledge their data protection responsibilities to individuals mentioned in our research collections by signing the statement ‘I will use personal data on living persons for research purposes only. I will not use personal data to support decisions about the person who is the subject of the data, or in a way that causes substantial damage or distress to them.’

2 Consulting material online. Researchers don’t need to register. However, a specific access condition applies to personal data under 100 years old where the material is not accompanied by permission from the individual whose personal data features in the material, or has not been made public as a result of steps deliberately taken by the individual. Researchers must accept the following statement the first time in each new browsing session that they seek to view such material: ‘By viewing this and any subsequent archive material under 100 years old, I agree that I will use personal data on living persons for research purposes only. I will not use personal data to support decisions about the person who is the subject of the data, or in a way that causes substantial damage or distress to them.’

3 Open material under 10 years old. We only make such material available online to a general research audience where it is accompanied by permission from the individual whose personal data features in the material, or it has been made public as a result of steps deliberately taken by the individual.

4 Consulting restricted material. Researchers must register and then submit a Restricted Access application. Application forms are automatically issued to researchers in the Rare Materials Room if they order up restricted material, and applications are usually processed by Library staff within two hours of submission. Researchers must give details of their research, the specific restricted materials to be consulted, and how they intend to use the data (e.g. compile statistical analysis, extract medical symptoms from case notes). They must also agree not to make copies of restricted material and to anonymise personal details when taking notes.

5 Preventing copying of restricted material in library. Restricted material is made available to readers in distinctive marked containers to allow us to monitor its proper use by researchers.

6 Consulting materials accompanied by permission from the individual to make available. This category of research material largely consists of our Biomedical Collection of clinical images. Access to these is generally restricted to healthcare professionals. Healthcare professionals wishing to use these clinical images must register their request with Wellcome Images online, and will be contacted by Wellcome Images staff to discuss their application. Healthcare professionals whose applications for access are approved may view the clinical images online. Depending on the permission level, we may grant researchers who are not healthcare professionals in-person access to these clinical images under staff supervision in the library. Such researchers should in the first instance email Wellcome Images to discuss their application.

We hold a small range of other materials accompanied by permissions from the individual, and access to these is governed by the specific permission level for each material.

7 Consulting closed materials accessible with NHS or private hospital ethics committee permission. The Wellcome Trust does not convene its own independent ethics review body, so if a researcher cannot obtain external ethics committee permission, we cannot make available the relevant closed material. The Wellcome Trust assumes that such permission will only be granted if both the requirements of the DPA and the common law of confidentiality can be satisfied.

8 Breaches of confidentiality conditions. We will ban researchers from access to any of our collections, services or facilities if they breach the confidentiality conditions outlined in our registration form or Restricted Access application form. Researchers who breach our confidentiality conditions in this way may also be disbarred from receiving Wellcome Trust funding for research.
4.0 Appendices

Appendix 4.1 Legal framework
Appendix 4.2 Transfers of personal data outside the European Economic Area
Appendix 4.3 Individuals’ rights regarding their personal data
  - Subject access requests
  - Requests to correct personal data held in research collections
  - Requests to use of personal data likely to cause damage or distress
Appendix 4.4 Takedown policy
Appendix 4.5 Closure and restriction periods
Appendix 4.6 Useful resources
Legislative background - The Data Protection Act 1998 (DPA)
The Data Protection Act 1998 ("DPA") regulates how personal data is acquired, held, used and shared, to protect against the misuse of personal data and give rights to those who are the subject of that data. Under the DPA, the library is classed as a data controller in respect of this information as it determines the way in which the information is held and used. The DPA is underpinned by eight data protection principles with which we must comply if material held within our research collections falls within the scope of the DPA, unless an exemption applies. These are discussed below.

What is personal data?
A number of our research collections fall within the scope of the DPA as:

(i) they contain personal data 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 (that is, 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 68 of the DPA (as it contains 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

(ii) we are processing this personal data for the purposes of s.1(1) of the DPA, on the basis that we are acquiring, holding, using and may disclose this information to third parties by making it available for both research and non-research purposes.
The basis on which we store and use personal data under the DPA

(i) Use for ‘Research Purposes’

We store and make available personal data in accordance with the ‘special purpose’ approved by the Information Commissioner’s Office (“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).

We store and make available 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 DPA principle (personal data shall not be kept for longer than necessary) as personal data stored and made available for research purposes may be stored indefinitely as archives for research purposes provided that the following ‘relevant conditions’ (as defined in s.33(1) DPA) are observed:

• The data is not processed to support measures or decisions relating to the individual concerned; and
• The data is not processed in such a way that substantial damage or substantial distress is, or is likely to be, caused to the individual.

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.

While section 33 of the DPA exempts us from complying with the second and fifth data protection principles, it does not exempt us from complying with the remaining data protection principles:

First principle: Personal data shall be processed fairly and lawfully;
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;
Sixth principle: Personal data shall be processed in accordance with the rights of the individual concerned, under the DPA;
Seventh principle: Personal data shall be kept secure against unauthorized handling and accidental loss or destruction; 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.
Appendix 4.1
Legal framework (cont.)

The first data protection principle requires us to process personal data fairly and lawfully in accordance with one of the conditions in Schedule 2 of the DPA and, where sensitive personal data is being processed (as defined below), one of the conditions in Schedule 3 of the DPA must also be satisfied (see below for the basis on which the library processes personal data, for the purposes of Schedules 2 and 3 of the DPA). Data controllers must inform individuals that their personal data is being held, the reason it is being held and any other information necessary to make holding and using the individual’s personal data fair (Paragraph 2 of Part II of Schedule 1 of the DPA). This information is known as ‘fair processing information’.

However, we can claim exemption from the requirement to provide fair processing information to individuals whose personal data is contained in our collections where to do so would involve ‘disproportionate effort’ on our part to trace and inform all such individuals (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).

While the majority of the personal data held in the library would not be considered to be sensitive material, our collections include materials 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, correspondence by or about an individual, and moving image or sound recordings.

We process 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 library (Paragraph 6(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 has the same meaning as in s.33 of the DPA);

c. does not support measures or decisions with respect to any particular individual otherwise than with the explicit consent of that individual; and

d. does not cause, nor is likely to cause, substantial damage or substantial distress to the individual or any other person.

Under Part IV of Schedule 8 of the DPA, it is possible to claim exemption from the first (except in so far as it requires compliance with Paragraph 2 of Part II of Schedule 1), second, third, fourth and fifth data protection principles for ‘eligible manual data’ which are processed only for the purpose of historical research in compliance with the ‘relevant conditions’ (as defined in s.33(1) of the DPA). Such eligible data are defined in Schedule 8 paragraph 1(1) of the DPA as data that are subject to processing which was already underway immediately before 24th October 1998.
Appendix 4.1
Legal framework (cont.)

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 we can rely on 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).

(ii) Use for Non-Research Purposes:
We hold and make available personal data for a variety of purposes in pursuit of our legitimate interest of promoting the understanding of medicine and its role in society, past and present. Where the material contains sensitive personal data which has not otherwise been made public as a result of steps taken deliberately by the subject of that data, we only make this material available with the explicit consent of that person.

Records created by public authorities
We are not a recognised ‘Place of Deposit’ under s.4(1) of the Public Records Act 1958 (PRA) and so do 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 our research collections.

We do hold a limited number of records which were created by public authorities, but we hold these on the same basis as privately-created records on approval from The National Archives (formerly the Public Record Office):

Public records presented under the PRA
We hold 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 (e.g. the archive of the Association of Community Health Councils for England and Wales, reference SA/CHC).
Appendix 4.1
Legal framework (cont.)

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.

**NHS hospital records within personal papers**

A limited number of our 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 e.g. 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 body of which are held by 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 they 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, we judge whether or not pre-1958 stray NHS hospital records are suitable to be made available to researchers on the same basis as the privately created records in our collections.

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

As far as we are aware, we do not hold any post-1958 stray NHS hospital records.

**NHS General practitioner records**

Our archive collections include a number of 20th century general practitioner (GP) 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. A small number of these GP collections also contain clinical records of deceased and non-deceased patients including record cards, referrals correspondence, visits registers etc.
Appendix 4.1
Legal framework (cont.)

NHS GPs 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). Their non-clinical, administrative records are thus in effect private business records.

However, the GP terms of service laid out in NHS Regulations since the inception of the NHS indicate that NHS GPs have always been obliged to maintain patient records under the terms of their contract, and on the death of the patient to forward these to the relevant local NHS authority (originally the local Executive Council, later the relevant Family Health Service Authority and subsequently the relevant Primary Care Trust). Currently, NHS general practitioners have a statutory contractual obligation to transfer the clinical records of deceased patients to the relevant Clinical Commissioning Group, and must handle research requests to consult deceased patient records in accordance with FOIA.

Given the contractual requirement for NHS GPs to transfer clinical patient records to the appropriate NHS body, we would no longer seek to acquire such records. As regards our existing holdings, we have consulted with The National Archives in order to clarify whether we are legally entitled to hold our historically acquired collections of NHS GP patient records.

The National Archives advises that it is reasonable to assume that we can continue to hold these historically acquired NHS GP patient records, depending on the age of the records. While the GPs in question may technically have acted in breach of their contracts in donating patient records to the library, it would be difficult to be certain of the circumstances in each case given the passage of time, particularly given the lack of objections by the relevant NHS bodies at the time of donation. Since the records never became integrated into the records of the appropriate NHS bodies and thus never became public records, the fact that the library is not a recognised Place of Deposit for public records under s.4(1) of the PRA is not problematic. However, the date at which the NHS GP patient records were created affects the basis on which we might continue to hold the records. As a rule of thumb, The National Archives advises that we can safely hold such records created before 1998, since it is reasonable to assume that it would be unfeasible to enforce the relevant GP contracts retrospectively. For NHS GP patient records created from 1998 on, The National Archives advises that we must confirm record-keeping and access arrangements with the relevant Clinical Commissioning Group.

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1 National Health Service (General Medical and Pharmaceutical Services) Regulations, 1954 (1954: 669), Paragraph 13.
3 Statutory Instrument 2004 No. 291 The National Health Service (General Medical Services Contracts) Regulations 2004, Schedule 6, Part 5.
4 Email communication with Kevin Mulley, Research & Strategy Manager (subsequently 20 Year Rule Senior Adviser (NHS&E)), Archives Sector Development, TNA, 26 January 2012.
Appendix 4.2

Transfers of personal data outside the European Economic Area

Placing online digital versions of materials that contain personal data with the intention that such data be accessed globally, or providing copies of materials containing personal data in response to enquiries from researchers based outside the European Economic Area (EEA), constitute transfers of personal data outside the European Economic Area (EEA) for the purposes of the DPA’s eighth data protection principle.

The eighth data protection principle states that personal data cannot be transferred to a country outside the EEA (including the USA, Australia and African countries) unless that country offers an adequate level of protection for the rights and freedoms of the individuals whose personal data is being transferred. 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 individual concerned has given consent to the transfer of their personal data outside the EEA, or the condition that the transfer is necessary for reasons of substantial public interest.

We make clinical images in the Wellcome Images Biomedical Collection available online to approved healthcare professionals based worldwide on the basis of consents obtained from the subjects of the images consenting to their images being disseminated via publication or broadcast including online access. However, we would not generally expect to be able to satisfy any of the Schedule 4 DPA conditions permitting transfers of personal data outside the EEA as we do not make personal data transfers outside the EEA on the basis of the scenarios set out in Schedule 4 DPA.

We may, however, transfer personal data outside the EEA if we assess that in the particular circumstances there is an adequate level of protection for the rights and freedoms of the individuals whose personal data is being transferred. This assessment of adequacy takes into account the nature of the data being transferred, the countries to which it will be transferred, how the data will be used and the security measures to be taken in respect of the personal data in the country or territory where the data will be received. Therefore, where the data is taken from material classed as open and such material is already made available for research purposes on an unconditional basis (the decision having already been made that disclosure of such data will not adversely affect the individual concerned), the library as data controller may assess such transfers as adequate in accordance with Paragraph 13 of Part II of Schedule 1 of the DPA.

We will only transfer such personal data once we have undertaken a risk assessment to establish that no substantial damage or distress would be caused to individual concerned by making the data available in this way.

In cases where we provide online access to digitised or born-digital material, researchers are permitted to download copies of online material for their personal research.
The sixth data protection principle requires us to handle personal data held in our research collections in accordance with the rights of the individual concerned:

**Subject access requests**

An individual is entitled, under s.7 of the DPA, to obtain a copy of their personal data held in our collections and to be informed as to how this data is used and accessed.

If an individual wishes to view their personal data held within our research collections, they may do so in one of two ways, depending on whether the material is classed as **open, closed or restricted**, as follows:

(i) By making a written subject access request to the Wellcome Trust’s Data Protection Officer, by email at `data.protection@wellcome.ac.uk` or by writing to us at the following address: Data Protection Officer, Wellcome Trust, 215 Euston Road, London NW1 2BE, UK

When an individual makes a formal subject access request, the following shall apply:

- We will request proof of identity to verify the identity of the individual and may request additional information to assist in locating the individual’s personal data;

- We will charge a £10 admin fee for responding to such request;

- Requests will be processed promptly and at most within 40 calendar days from the date that we have received a duly completed subject access request form, proof of the individual’s identity and the £10 fee; and

- A copy of personal data provided in response to the subject access request will be provided in permanent form (i.e. a paper or electronic copy), unless providing the data in such form would involve a disproportionate effort on our part or the individual agrees otherwise.

(ii) Alternatively, if the individual wishes to view their personal data within materials which are classed as **open or restricted**, they may register as a library reader and then consult the relevant material in the library (or online if available).
Appendix 4.3
Rights of the individual (cont.)

Requests to correct personal data held in research collections

An individual is entitled under s.14 DPA to request an amendment to their personal data held in our collections if the individual 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 Information Commissioner’s Office (ICO) does not require us to regularly update such data as this would defeat the purpose of maintaining the historical record. In addition, the ICO would not 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 we would use supplementary statements to make rectifications to the personal data without damaging archival integrity.

If an individual wishes to make an amendment to personal data held in our research collections, a data amendment request form can be obtained by emailing our Special Collections team at arch+mss@wellcome.ac.uk, or by writing to us at: Wellcome Library, 183 Euston Road, London NW1 2BE, UK.

On receipt of the individual’s completed data amendment request form and proof of identity, our Special Collections team will forward the request to the appropriate curator for processing. Where applicable, we will place a copy of any supplementary statement on the relevant collection’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 or linked to the online version of the archive).

Requests to prevent use of personal data that is likely to cause damage or distress

Under s.10 DPA an individual has a right to object to the use of their personal data where this causes, or is likely to cause, unwarranted and substantial damage (i.e. financial loss or physical harm) or distress (i.e. a level of upset, or emotional or mental pain, that goes beyond annoyance or irritation, strong dislike, or a feeling that the use is morally abhorrent).
An individual who wishes to exercise this right must put their objection in writing to the library either by writing to or emailing our Special Collections team at the address above. Individuals must state why the use of their data is causing unwarranted and substantial damage or distress and what they require us to do to address this. An individual can only object to the library using their own personal data, although an individual may make an objection on behalf of another person.

On receipt of a such a request, we will respond in the first instance by suppressing research access to the material in question. Requests will then be assessed by a review panel who will consider each request on its merits. We will respond within 21 days of receiving any objection to processing and the response will state what we intend to do and, if we do not intend to comply with the objection in some way, give reasons for that decision.

Where we decide to comply with the individual’s request, the relevant material containing the individual’s personal data will be classified as closed until such point as it is no longer deemed to be sensitive. In cases where the material is available in digital form on our website, it will be suppressed from online access in accordance with our Takedown Policy (see Appendix 4.4).
Appendix 4.4

Takedown policy

Despite the measures we take to assess material for online access and to prevent the disclosure of sensitive information, it is possible that sensitive information hidden in apparently non-sensitive material may occasionally be made available online.

In these circumstances, we will consider requests to take down the material in question. On receipt of a request to take down material from our website, we will respond by immediately removing the material in question. Requests will then be assessed by a review panel who will consider each request on its merits. The panel will aim to respond definitively within four weeks, but may require additional time to seek external advice where appropriate.

The panel may approve continued withdrawal of the material if one or more of the following criteria is met:

- The material is in copyright, and the copyright-holder refuses permission for it to be made available online;
- The material is personal information about someone who is still alive and continued online access would be unlawful or unfair to him under the Data Protection Act 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 in accordance with our policy on access to personal data;
- The material is defamatory or obscene;
- The material acquires sensitivity by virtue of being made available online.

Where material is removed for reasons of Data Protection or sensitivity, its removal will be considered as temporary and will be restored at a date decided by the panel once its sensitivity is deemed to have subsided. Where sensitive material is taken down from online access, we will review the specified hardcopy materials and retrospectively change their access status from open to restricted or closed, as appropriate.

All takedowns will be signalled openly on our website.

To contact us about removal of material, please email our Digital Services team at copyright@wellcome.ac.uk, or write to us at the following address:

Wellcome Library
183 Euston Road
London NW1 2BE, UK

For full details of our Copyright Clearance and Takedown policy click here.
Appendix 4.5
Closure and restriction periods

Closure/restriction periods based on 100-year lifespan

We generally close or restrict material for a finite period based on an assumed lifespan for each individual of 100 years. Our standard 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:

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

When material 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 the material, we apply the closure or restriction period to the last date in the record. The material becomes open in 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.

Materials requiring closure or restriction beyond data subject’s lifespan

The DPA is only concerned with how we handle personal data relating to living individuals. However, we recognise that our ethical responsibilities do not end with the death of an individual where the processing of the personal data of a deceased person could have an impact on third parties who are connected to the deceased person or referred to in the data e.g. in the case of an individual who died of a highly heritable genetic condition.
Appendix 4.5
Closure and restriction periods (cont.)

We are not subject to FOIA, nor do we acquire materials 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.

In addition, we may need to close or restrict unpublished materials relating to deceased individuals if they contain personal information about another identifiable living person, as this would be classed as personal data under the DPA.

In light of this, for materials whose closure or restriction period has expired, and for newly-catalogued materials relating to a deceased individual, we review the material to check whether it is suitable to be opened 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, we consider such materials on a case by case basis in order to take into account the interests and expectations of the individuals. We use the following criteria when reviewing the sensitivity of such materials:

- 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; and
- Whether the data contains personal information about another identifiable living person.

We annually re-review in December the sensitivity of materials whose closure/restriction period is about to expire on 1 January, in order to decide whether they require additional closure or restriction or can be made open for research.
### Common closure/restriction periods

<table>
<thead>
<tr>
<th>Type of material</th>
<th>Closure or restriction period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitive personal data</td>
<td>Closed (84 / 93 / 100 years)</td>
</tr>
<tr>
<td>e.g. medical case files, hospital daybooks, albums of clinical photographs, recordings of psycho-analysis sessions</td>
<td></td>
</tr>
<tr>
<td>Structured personal data that is not sensitive under the terms of the DPA but is sensitive in a general sense</td>
<td>Closed (60 years)</td>
</tr>
<tr>
<td>e.g. Personnel or grant application files containing confidential references or statements of opinion concerning individuals</td>
<td></td>
</tr>
<tr>
<td>Unstructured materials which contain incidental sensitive material</td>
<td>Restricted (84 / 93 / 100 years)</td>
</tr>
<tr>
<td>e.g. informal notes on individuals’ health in a diary, correspondence touching on sexual life, photographs of patients scattered within a non-clinical file, oral history interviews which touch on sensitive matters relating to third parties, signed artworks produced by patients within a mental health institution</td>
<td></td>
</tr>
<tr>
<td>Unstructured materials which contain confidential personnel or grant application references or statements of opinion concerning individuals</td>
<td>Restricted (60 years)</td>
</tr>
<tr>
<td>Personnel or grant application files containing administrative material but no confidential references</td>
<td>Restricted (30 years)</td>
</tr>
<tr>
<td>e.g. applicant contact details or personal statements</td>
<td></td>
</tr>
<tr>
<td>Materials whose closure/restriction period has expired but which require a further period of closure/restriction</td>
<td>Assessed on case by case basis</td>
</tr>
<tr>
<td>Materials whose data subject is deceased but which require a further period of closure/restriction</td>
<td>Assessed on case by case basis</td>
</tr>
<tr>
<td>Materials which fall outside the above categories, but which the donor/depositor feels merit some form of closure/restriction</td>
<td>Negotiated on case by case basis²</td>
</tr>
</tbody>
</table>

1 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 or job application, and thus will have completed their career by the time the closure period expires.
We aim to make our collections available for research when there are no sensitivity issues involved. Occasionally, however, a donor or depositor may for organizational reasons ask the Library to apply a closure or restriction period to specific items which the Library would otherwise open. Whilst we generally prefer not to negotiate access terms, we may from time to time agree to such closures or restrictions in order to guarantee the long term preservation of important research materials.
Appendix 4.6
Useful resources

ICO guidance for organisations 'Can I send personal data overseas'*

ICO topic guide 'Anonymisation'*

ICO detailed specialist guide 'Determining what information is 'data' for the purposes of the DPA', Annexe 2 on non-text information, 2012

ICO guidance 'Information about the deceased', 31 July 2013

JISC Digital Media guidance note on data protection for photographs and digital images, 2005

JISC guidance 'Making and Using Clinical and Healthcare Recordings for Learning and Teaching', 2011

Oral History Society www.ohs.org.uk > Advice > Is your oral history legal and ethical?*

Society of Archivists Best Practice Guideline 8: After the Hundred Year Rule, 2004


*website accessed 13 August 2014
Acknowledgments

The Wellcome Library has written this policy in consultation with the Information Commissioner’s Office.

The Wellcome Library’s Senior Management Team adopted the policy in August 2014. The policy is owned by the library’s Special Collections team, who will review it every two years.

The Wellcome Trust is a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health.

We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health.

We are independent of both political and commercial interests.