



# **Access to personal and sensitive information within our collections**

**August 2020**

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# 1 Introduction

## Scope

Wellcome Collection is committed to maximising public access to our collections (as defined in our [Collections Development Policy](#)) in line with our vision to challenge the way we think and feel about health by connecting science, medicine, life and art. As set out in our [Access Policy](#), we aim to open our collections and collections information as widely as possible, whilst also ensuring that we behave lawfully, ethically and responsibly.

These guidelines set out:

- the criteria we use to assess sensitivity across our collections, both physical and digital (section 2)
- how we manage access to our collections and the bases on which we make these collections available (sections 3 to 6)

Our practice in respect of sensitivity review and access continues to evolve and develop, and in consequence we expect to revise these procedures on a regular basis. We do not generally re-review previously assessed material unless a particular access risk is brought to our attention. Further information on how to appeal an access decision can be found in section 6.

This document does not cover other issues that we may need to consider when making access decisions, such as copyright or the physical condition of material.

## Ethical and legal frameworks

Wellcome Collection's [Access Policy](#) and the procedures in this document are guided by sector ethical codes and relevant legislation, including:

- International Council on Archives [ICA] Code of Ethics, 1996.
- Code of Ethics for Museums, International Council of Museums [ICOM], 2004.
- Ethical Principles and Code of Professional Practice for Library and Information Professionals, CILIP, 2004.
- Code of Ethics, Museums Association, 2015.
- Code of Professional Ethics, Archives and Records Association [ARA], 2016.
  
- Data Protection Act 2018.
- Public Records Act, 1958.

Our practice is also inspired by Wellcome Collection's [Strategic Direction for Access, Diversity and Inclusion](#). This encourages us to consider a range of potential sensitivities – such as cultural sensitivity, as well as personal and commercial sensitivities – to create an access culture where diversity thrives.

## **International Council on Archives' Principles of Access to Archives 2012**

Both our policy and procedures on access to the collections have been formulated in accordance with the ICA's [Principles of Access to Archives](#). We begin with a presumption of openness and only apply access restrictions or closures where necessary. In these cases, we ensure restrictions on access are clearly communicated, together with the review date for the restriction.

In line with the ICA Principles of Access, we provide a mechanism for users to challenge access decisions (see section 6). Where an appeal is rejected, the reasons are provided clearly in writing in a timely fashion.

Wellcome is committed to providing fair and equal access without discrimination. The access status of material applies to everybody and we do not grant privileged access. Neither will we accept records with privileged access conditions. The only exceptions to this are documented in section 3.4.

## **Data Protection Act 2018**

Wellcome Collection commits to safeguard personal information in accordance with the [Data Protection Act 2018](#) (DPA).

Many of our collections fall within the scope of the DPA as they contain *personal data*, i.e. information relating to identifiable living individuals, as well as *special categories of personal data* such as information about the physical or mental health or sexual life of individuals. This data may be *automated* (e.g. digital) or held in *manual filing systems*, where records relating to individuals are held in a sufficiently structured way so as to allow ready access to specific information about those individuals. Data may be held in any format including written documentation, photographs, moving image and sound recordings.

We acquire and make accessible our collections in pursuit of our legitimate interest in challenging the ways we think and feel about health by connecting science, medicine, life and art. Whilst the majority of personal data within our collections will have been collected for other purposes originally, we may further process this data, including special category data, for *archiving purposes in the public interest*. The National Archives have produced [guidance](#) on understanding this term. Our processing activities include acquiring, appraising, describing, storing, communicating, promoting and providing access to records, including the personal data within them.

We may also process data for research purposes, journalistic purposes and purposes of academic, artistic or literary expression in accordance with the DPA.

Anyone who uses personal data from our collections must handle that data subject to safeguards in compliance with the law. Data must not be used in ways that may cause substantial damage or distress to individuals about whom data relates or to inform decisions or actions regarding those individuals.

Individuals have certain rights regarding their personal data held within our collections. Section 3.4 explains how to request access to your personal data.

## **Freedom of Information Act 2000**

As a non-public body, Wellcome is not subject to the Freedom of Information Act 2000 (FOIA). In exceptional circumstances, we may acquire collections from a public authority subject to FOIA, but only where (a) The National Archives approves the acquisition (presentation of records under s.3(6) of the Public Records Act 1958), and (b) the public authority retains legal responsibility for handling FOIA access requests, or the material is exempt from access requests under the s.21 FOIA exemption for material that is already 'reasonably accessible'.

Any information we share with a public body may have to be released if an FOIA request is made to that body. Consequently, our business sensitivity criteria are based on exemptions set out in FOIA (section 2.3).

## **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 collections.

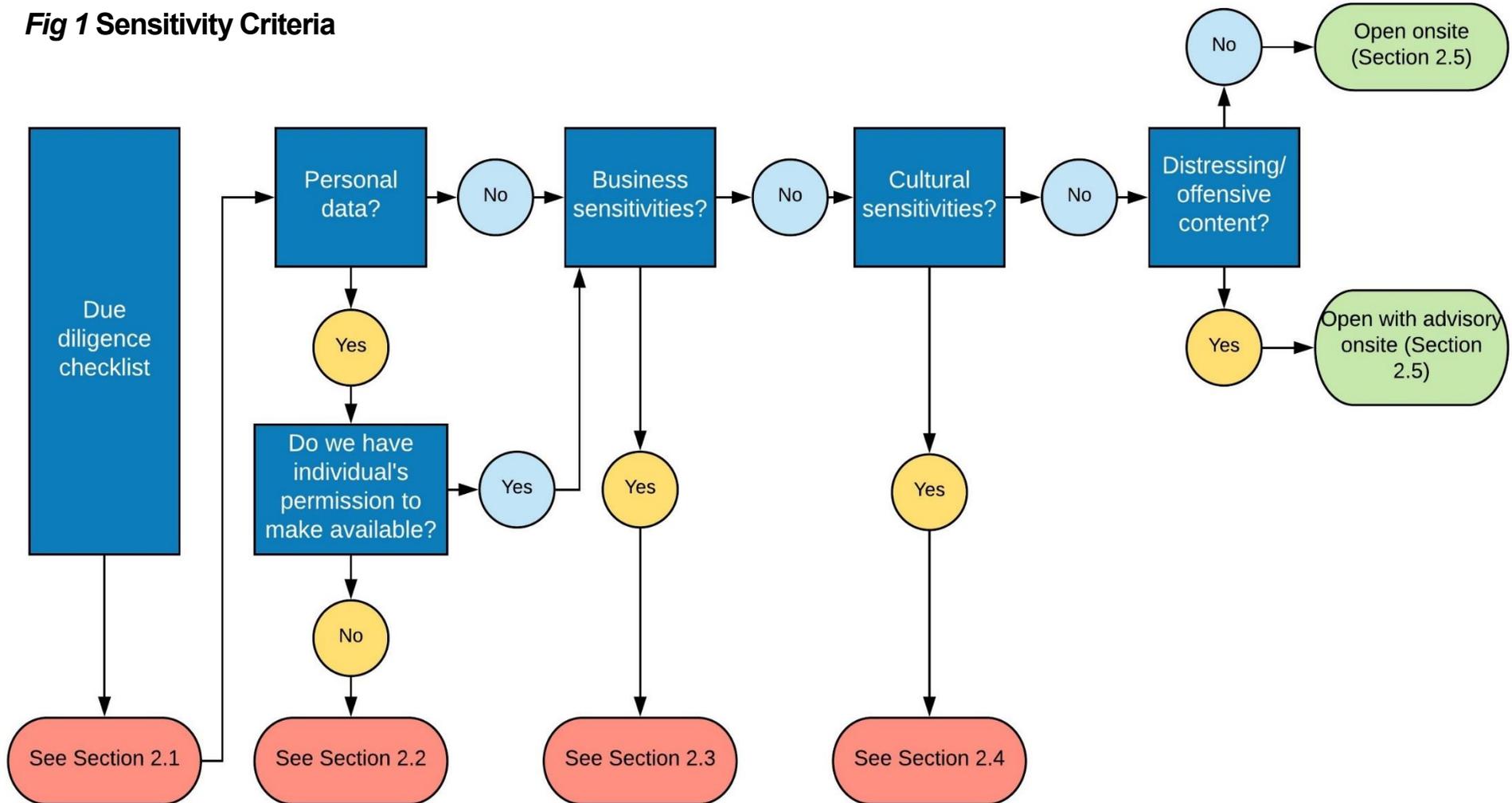
We hold a limited number of records which were created by public authorities, but we hold these on the same basis as privately-created records, on presentation from The National Archives under s.3(6) of the PRA.

Our procedures for assessing and managing business sensitivity are nevertheless based around the PRA's 20-year rule (section 2.3).

# 2 Sensitivity Criteria

We consider a wide range of criteria for sensitivity, and apply a funnel approach to assessing material for each potential sensitivity in turn – initially at acquisition and again (and in more detail) at the point of cataloguing.

Fig 1 Sensitivity Criteria



## 2.1 Due Diligence Checklist

All collections are screened against a checklist of potential risks for collections access, issues which might lead us to commit an offence, or cause reputational damage, including:

- Financial risks e.g. valuation bias; checks against fraud and corruption
- Hazards to health e.g. radioactive material, asbestos, carcinogenic chemicals, mould
- Intellectual property risks
- Legal issues e.g. illicitly traded items, spoils of war, illegal substances, indecent images of children
- Human remains

We do not accept any item or collection unless we are able to resolve or manage any risks flagged during due diligence checks. Any item or collection identified at the point of cataloguing as likely to fail due diligence checks is considered for disposal or repatriation. Full details of the ethical and legal considerations relevant to both acquisition and disposal can be found in our [Collections Development Policy](#).

## 2.2 Personal Data

We first assess the suitability of collections for supervised onsite access for research. Online access is assessed separately (see section 5).

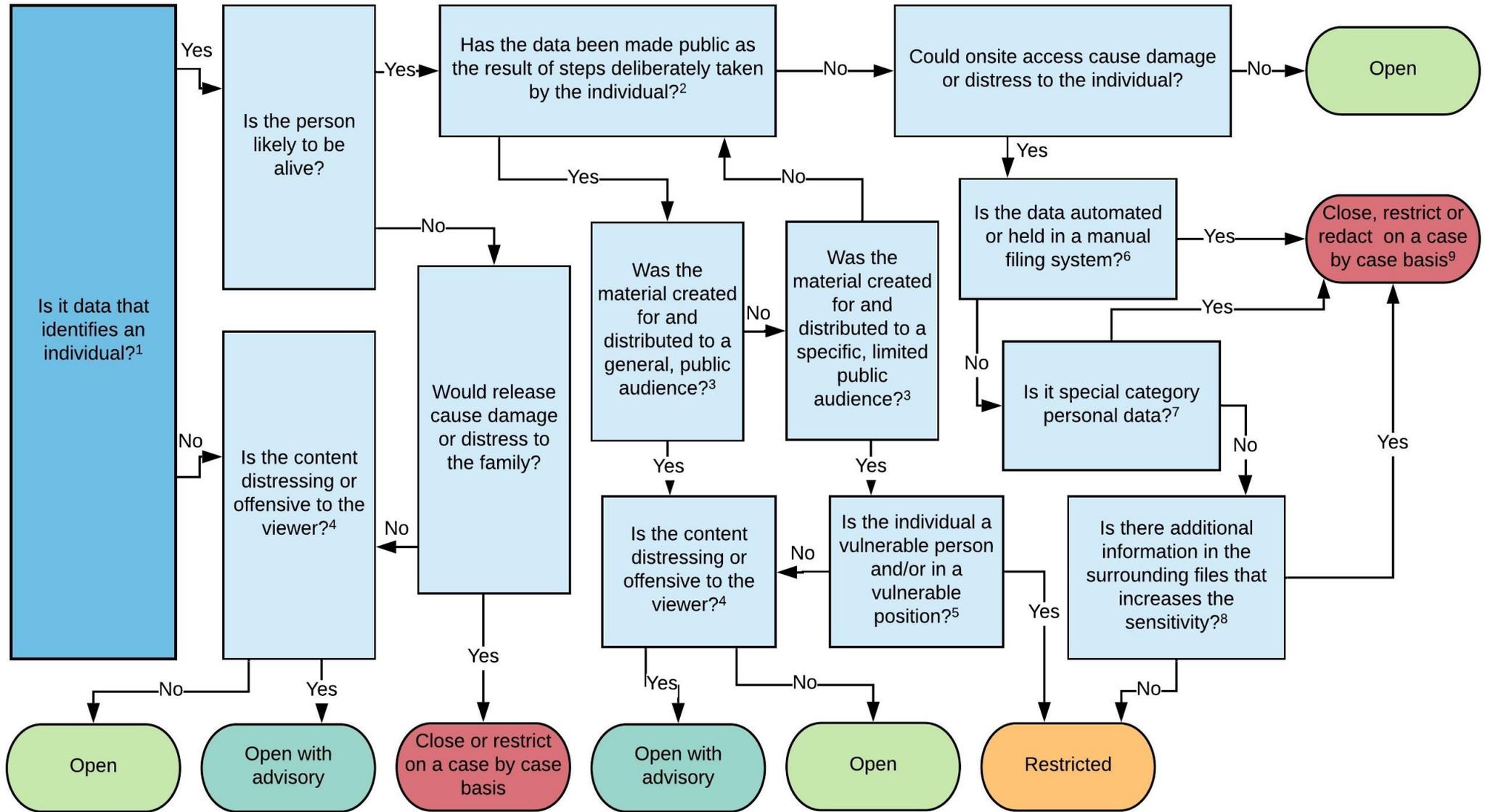
**Material with permissions** from the individual whose *personal or special category data* features in the material

Sometimes the individual whose personal or special category data features in material gives us permission to make that material available for research or other activities. Where we have such explicit consent, material can be made open to view onsite (subject to a review of other forms of sensitivity, including personal data relating to other individuals). We only accept permission for access to all users and do not accept limited permission, such as access only to certain professions.

**Material without permissions** from the individual whose *personal or special category data* features in the material

We use the workflow below (fig. 2) to guide decision making when determining the appropriate access status (section 3.2) for material.

**Fig. 2 Risk assessment for records containing personal data without permission (for onsite access)**



**1. Identifiable individuals**

Information that distinguishes an individual from other members of a group. As well as written information, a person can be identified from their body, most commonly their face, but possibly also other distinguishing body features such as tattoos or birthmarks. Voices are also considered identifying information.

**2. Data has been made public as a result of steps deliberately taken by the individual**

In the absence of documented consent from the individual, we use our judgement to decide whether they have deliberately participated in making their data public, the circumstances around this and thus whether the information can be made available by us. We consider the extent to which the information has previously been made public and whether circumstances have since changed, which might suggest that disclosure could have a detrimental effect on the individual.

**3. Material was created for and distributed to a wide, general public audience/specific, limited public audience**

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)?

**4. Content that is distressing or offensive to the viewer (see section 2.5 for examples)**

Written description, imagery or audio that the viewer may find distressing, uncomfortable or harmful.

**5. Vulnerable people and people in a vulnerable position**

This can include but is not limited to:

- Being associated with something that carries stigma and/or is controversial (i.e. mental health problems, STIs, abortion, learning difficulties)
- Nudity
- Being in severe pain or distress
- Being in restraints or being restrained
- Engaging in animal experimentation

**6. Manual filing system**

A set of records that are held in a sufficiently structured way as to allow ready access to specific information about individuals.

**7. Special category personal data**

These are types of personal information that are considered more sensitive under data protection law and which therefore require more protection. This can include information about an individual's: health; sex life; sexual orientation; race; ethnic origin; genetics; biometrics (where used for ID purposes); political view; and trade union membership. All such information should be considered more carefully when reviewing material.

**8. There is additional information in the surrounding files to increase sensitivity**

Information can be extracted from surrounding records or catalogue metadata to increase the sensitivity of the file. For instance, a photograph of workshop participants with a catalogue description identifying the location as a psychiatric hospital.

**9. Close, restrict or redact on a case by case basis (see section 3.2)**

A decision will be based on the exact nature of the sensitive data, its relevance to the rest of the file and the level of potential distress that could be caused.

## 2.3 Business Sensitivity

When reviewing material for business sensitive content we look for the following types of information, based on the exemptions set out in Part II of the Freedom of Information Act 2000 sections 21 to 44:

- **Information provided in confidence:** closure of records may be required to protect a body's relationship with external parties and/or prevent legal action for breach of confidence.
- **Information that could prejudice a body's interests, activities or relationships with other bodies:** closure of records may be required to protect the regular activities, interests and relationships of the body and related third parties featured or affected by the information. Closure may also be required to protect decision making processes including the need for free and frank internal discussion. However, we expect such closures will only be reasonable in exceptional circumstances. We would not normally collect material which cannot be deployed for our core vision within what we would consider to be a reasonable time-frame (see our [Collections Development Policy](#)).
- **Information subject to legal professional privilege:** closure of records may be required to protect confidential communications between lawyers and their clients
- **Information endangering health and safety:** closure of records may be required to protect the physical or mental health and/or safety of individuals/groups of people and/or to protect the security of an organisation or its premises.
- **Court records:** closure of records may be required to protect existing court access and discovery processes

Records assessed for business sensitive information may be given an access status (see section 3.2) of **open** or **closed**. They cannot be **restricted**, as this procedure is geared towards the protection of personal data sensitivities. Business sensitivity is very dependent on context, and declines at varying rates. We take the Public Record Act's 20-year rule as a starting point for assessing and managing access. Records under 20 years' old are reviewed in greater detail.

## 2.4 Cultural Sensitivity

Wellcome Collection has a unique collection of material depicting the cultural and historical contexts of health and medicine. However, some of the representations of people or cultures are sensitive, distressing or offensive. This is perhaps particularly true of material which was collected in the period before Henry Wellcome's death in 1936, although we continue to acquire collections which present challenges in terms of how we construct their meaning and present them to our audiences. In line with Wellcome's principles, we are bold in taking risks, and seek to embrace a range of perspectives, both contemporary and historical.

We acknowledge that our collections – and collections information – include content that is culturally sensitive or culturally offensive, but which has often been available and accessible for some time. Our collections have complex histories and contexts, and individuals represented in our collections have often been depicted as research subjects. We need to be sensitive to the ways in which we document, display and explain them.

Culturally sensitive material in the collections includes – but is not limited to:

- Discriminatory and/or derogatory imagery and language
- Human remains, and images of human remains
- Collections with unclear or disputed provenance
- Objects and images of objects decontextualised in a way that is offensive to the originating culture
- Representations of individuals – particularly from colonised communities – depicted as either research subjects or curios

It is vital that we think critically and confront institutional and individual bias in the ways in which we present our collections, as well as tackle examples of culturally sensitive content within the collections. Greater exploration and explanation of the provenance of material in the collections is clearly required, as is more engagement with communities from which these materials originated, or descendants of those represented insensitively.

We are actively challenging ourselves to develop better practices in this area as part of Wellcome Collection's [Strategic Direction for Access, Diversity and Inclusion](#). Where we identify culturally sensitive collections or items we can address (if not completely resolve) this immediately in a range of different ways, including:

- Presenting sensitive or offensive terms in quotations, rather than removing or substituting them, as this acts to censor the historical record
- Using subject indexing to apply alternative, inoffensive terms
- Adding explanatory text to contextualise sensitive or offensive terminology or content
- Providing **Open with advisory** content notices

We will update these guidelines to reflect new practices as they are developed.

## 2.5 Distressing or Offensive Content

Our collections include material that some people find distressing or offensive. In addition to the culturally sensitive collections covered in section 2.5, this includes but is not limited to text, images, and/or sound related to:

- Gore and bodily fluids
- Surgery
- Nudity
- Sexually explicit content
- Body mutilation
- Corpses
- People in severe pain or distress
- Animal experimentation and/or cruelty
- Discriminatory and/or derogatory language
- Graphic drug use
- Flashing images
- Death and dying

A new access status **Open with advisory** has been developed for use with material of this kind. The standard conditions of access for open material apply onsite. **Open with advisory** material can also be viewed online following a click-through content notice, but copying and licence terms for download may be restricted.

# 3 Managing Access

This section sets out our procedures for undertaking sensitivity review, recording decisions and providing access to different parts of the collections.

## 3.1 Sensitivity Review

Although an initial review for sensitivity is carried out and documented at the point of acquisition, a more detailed sensitivity review occurs during cataloguing. Sensitivity review is also carried out in response to requests to access uncatalogued material (see section 3.5)

### **Sensitivity review: risk managed v. granular**

We use a risk managed approach where it is not possible to assess the material in detail due to the size or mixed nature of the specific collection (i.e. archive collections, large groups of images). A risk managed review can occur at two levels: item and series:

- Item level: rather than assessing every page, image or second of footage, each item is first skimmed. Greater attention is then paid to sections that are at high risk of containing sensitive information.
- Series level: for homogenous series containing very similar records (e.g. a series of committee meeting papers), a proportion of items in the series can be reviewed and an access decision based on this sample applied to the entire series.

Granular assessment: is carried out only where it would pose an unacceptable risk to review material via spot checks, or where it is feasible or necessary to assess each item in detail. This approach is particularly suitable for assessing sound recordings, which need to be listened through in real time, and it is especially difficult to gauge the sensitivity from spot checks at random intervals.

### **Sensitivity review for born-digital collections**

The volume of born-digital records often requires a risk managed sensitivity review, similar to the approach used to review material for online access (see section 5).

We assign a risk category based on the considerations set out in the table and then review a percentage of the contents based on the category.

Risk category	General nature	Sample size
A (low)	<ul style="list-style-type: none"> <li>▪ Accession information/metadata suggests low risk</li> <li>▪ Low risk file formats and filenames</li> <li>▪ Uniform content</li> </ul>	Up to 5% to check accuracy of folder/file names
B (medium)	<ul style="list-style-type: none"> <li>▪ Accession information/metadata suggests some risk. Or there is a lack of information/metadata</li> <li>▪ Mixed content</li> <li>▪ Some identified trigger words</li> </ul>	Up to 66%, starting with most likely files
C (high)	<ul style="list-style-type: none"> <li>▪ Accession information/metadata suggests very likely risk. Or there is no information</li> <li>▪ Mixed content</li> <li>▪ Obscure file names</li> <li>▪ High proportion of trigger words</li> </ul>	Up to 100%, starting with most likely files

## Redaction

We do not routinely apply redaction to records, but it is considered at the point of cataloguing in cases where it meets the following criteria:

- Most of the item does not contain sensitive data and can be open
- Sensitive data is limited to one or two instances
- Removal of the sensitive information would not disrupt the meaning and context of the record

Redaction is only applied to entire documents; we do not partially redact (i.e. we remove documents from a file, we do not blank out specific words in a document).

## Documenting decisions

The reasoning behind any assigned access status of **Restricted** and **Closed** is documented in catalogue records. Where possible the rationale for access status decisions is communicated publicly via our online catalogue, but we take care that this does not inadvertently reveal sensitive data, including personal or special category data.

## 3.2 Access Statuses

Access status	
<b>OPEN</b>	Available at the library to registered researchers on request and, to the extent permitted by copyright, can be copied for non-commercial use and private study. Digitised surrogates and collections information can be viewed online without the need to register and may be downloaded for use according to the licence terms.
<b>OPEN WITH ADVISORY</b>	Available at the library to registered researchers on request and, to the extent permitted by copyright, can be copied for non-commercial use and private study. Digital material and digitised surrogates can be viewed following a click-through advisory warning. Copying and downloading may be restricted for material which has the potential to cause offence, damage or distress.
<b>RESTRICTED</b>	Available at the library to registered researchers, subject to an approved application for access. Material assessed to be restricted cannot be copied and personal information must be anonymised in any notes made. In limited circumstances, restricted material may be made available online to authenticated users. Access may be restricted by legislation, most commonly statutory protections for personal data or by common law principles, including medical confidentiality, and legal professional privilege.
<b>BY APPOINTMENT</b>	<p>Available at the library to registered researchers, subject to a pre-arranged appointment. Material can be copied, subject to a sensitivity review and condition assessment. An appointment may be necessary:</p> <ul style="list-style-type: none"> <li>• Where additional measures are in place to mitigate against the risk of physical damage or loss</li> <li>• Where access must be closely supervised to ensure recommended health and safety guidance is followed</li> <li>• For formats requiring bespoke arrangements for access (e.g. some obsolete audio-visual or digital material)</li> <li>• For large and/or heavy items that cannot be accessed in the library space</li> <li>• For material held off-site</li> <li>• For uncatalogued material</li> </ul> <p>Where a surrogate copy is available, researchers may be asked to demonstrate why access to the original is required.</p>
<b>DONOR PERMISSION</b>	Available at the library to registered researchers, subject to permission first being granted by the donor. Researchers with permission to view material are also permitted to acquire copies, providing the records are not also restricted. Potential uses of donor permission items beyond private research and study (e.g. exhibition, filming) require additional explicit permission from the donor.
<b>TEMPORARILY UNAVAILABLE</b>	Temporarily unavailable for consultation in the library basis whilst specific actions are being undertaken. This can include: <ul style="list-style-type: none"> <li>• Whilst it is awaiting or undergoing conservation treatment</li> <li>• Whilst it is out on loan for an exhibition</li> <li>• Whilst it is being digitised</li> <li>• Whilst it is undergoing an internal assessment (e.g. an access appeal, see section 6)</li> </ul>
<b>CLOSED</b>	Not available for research, except with the permission of a relevant research ethics committee, where it can be demonstrated that access would not infringe the rights of any individuals mentioned in the material

## 3.3 Restriction and Closure Periods

### Data about individuals

For items containing personal data about individuals, we restrict or close for a finite period, based on an assumed lifespan of 100 years. These restriction and closure periods account for the fact that the individual has already lived a certain number of years by the time the data about them is created:

Age of person	Closure/restriction period
Exact age known	Number of years required for the individual to become 100
Adults (16 years and over)	84 years
Children (7-15 years)	93 years
Infants (0-6 years)	100 years
Material including a mix of these categories	Longest applicable period
Material where it is uncertain whether the individuals are adults, children or infants	100 years

Items become open in the January following the expiry of the restriction or closure period e.g. an infant's patient file from 1988 would be closed for 100 years and become open on 1 January 2089. Where items cover a date range, the restriction or closure period will be calculated based on the later date e.g. an adult's patient file covering 1982-1990 would be closed for 84 years from 1990: 1 January 2075.

### Materials requiring closure or restriction beyond an individual's lifespan

Data protection legislation only applies to *living* individuals. However, we recognise that our ethical responsibilities do not end with the death of an individual, especially where the processing of their personal data could impact 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.

In addition, we may restrict or close items relating to deceased individuals if they contain personal information about another identifiable living person.

Since there is currently no definitive legal guidance on the suitable duration of restricted or closure periods for information relating to deceased individuals, we consider such materials on a case by case basis and 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.

## Common closure and restriction periods

The following table provides examples of common restriction and closure periods we use for both special category personal data and for other sensitivities. It is not exhaustive.

Type of material	Closure or restriction period
Special category personal data e.g. medical case files, hospital daybooks, albums of clinical photographs, recordings of psycho-analysis sessions	Closed/Restricted <sup>2</sup> (84 / 93 / 100 years)
Personal data relating to an individual's professional life e.g. Grant application files containing confidential references or statements of opinion concerning individuals <sup>1</sup>	Closed/Restricted <sup>2</sup> (60 years <sup>3</sup> )
Grant files and applications for grants submitted by the depositor to a third-party funder that contain administrative material but no confidential references	Open/Restricted (30 years) <sup>4</sup>
Grant files and applications for grants received by the depositor from third-party applicants containing administrative material but no confidential references	Restricted (30 years)
Business sensitive data	Closed (20 years followed by review)

Materials whose closure/restriction period has expired but which require a further period of closure/restriction	Assessed on case by case basis
Materials whose data subject is deceased but which require a further period of closure/restriction	Assessed on case by case basis
Materials which fall outside the above categories, but which the donor/depositor feels merit some form of closure/restriction	Negotiated on case by case basis <sup>5</sup>

- 1 This information is restricted/closed to protect both the individual who is the subject of the opinion/reference and the opinion/reference provider.
- 2 See fig.2 for determining whether the record should be closed or restricted
- 3 A 60 year closure period 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.
- 4 See fig.2 for determining whether the record should be open or restricted, specifically the question about whether disclosure would cause damage or distress.
- 5 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 Wellcome to apply a closure or restriction period to specific items which we 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.

## January openings

At the end of each year we assess records due to be open in the upcoming January, to decide whether they require additional closure or restrictions or can be made open for research. When restricted records become open we securely destroy both the paper and electronic copy of the Restricted Access forms.

## 3.4 Access exceptions

Wellcome is committed to providing fair and equal access without discrimination. The access status of material applies to everybody and we do not grant privileged access. Neither will we accept new collections with privileged access conditions. The only exceptions to this are:

### Depositor access

Arrangements may be made for depositor (or a nominated representative) access, subject to our duty of care towards individuals and organisations represented in the material. For nominated representatives, we will usually require written approval from the depositor, or the depositor's legal heirs or executors (where the depositor is deceased), or executive officer / governing body (e.g. Board) of the organisation concerned, before granting access to restricted, closed or uncatalogued material.

- Open material: Depositors or their nominees should register as library members and order records online in the usual way.
- Restricted material: Depositors or their nominees should register as library members and order items online in the usual way. If they wish to acquire copies of any items they will need to contact [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) and their request will be considered on a case by case basis, taking into account the reason(s) for the restriction and the specific items they wish to copy.
- Closed material: Depositors or their nominees wishing to access closed items will need to contact [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) with details of their request. It will be considered on a case by case basis, taking into account the reason(s) for the closure and reason(s) for access.
- Uncatalogued material: Depositors or their nominees wishing to access uncatalogued items will need to contact [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) and follow our procedure for uncatalogued requests as set out in Section 3.5. When viewing the records, requests to make copies of restricted material will be considered on a case by case basis. Guidance for handling uncatalogued material will be provided.

## Donor permission

We operate a rolling programme of collections review, and seek to renegotiate deposit agreements to remove additional donor permission restrictions wherever possible. We no longer accept material on which donors place restrictions so it cannot be deployed for our core vision within what we would consider to be a reasonable time-frame (see our [Collections Development Policy](#)). Under legacy terms of deposit for certain collections, we are, however, obliged to ask researchers to obtain permission from the donor before consulting the material. Where donor permission is specified in catalogue records, researchers should email [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) to obtain contact details for the donor and then write to them requesting permission. Once permission has been obtained, this should be forwarded to [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) and the researcher can then order the items online in the usual way. Researchers with permission to view material are also permitted to acquire copies, providing the records are not also restricted. Potential uses of donor permission items beyond private research and study (e.g. exhibition, filming) require additional explicit permission from the donor.

Orders that have been placed without first acquiring permission will not be fulfilled. The researcher will be contacted and informed that they cannot view the records until they have obtained permission.

## Data subjects (Subject Access Requests)

### Individuals' rights over personal information

Individuals have certain rights regarding their personal data held within our collections. Subject to conditions set out by data protection law, individuals may:

- **Request access** to their personal information (known as a "Subject Access Request"). This enables the applicant to receive a copy of any personal information held about them and to check that it is being lawfully processed.
- **Request the transfer** of their personal information to another party.

The process for handling a Subject Access Request varies depending on the access status of the material:

- Open and restricted records: individuals should register as a library member and consult the relevant records in the library (or online if available). Individuals should contact [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) to obtain copies of their personal information in restricted access material.
- Closed records: individuals may make a written Subject Access Request to Wellcome's Data Protection Officer, either by email: [dataprotection@wellcome.ac.uk](mailto:dataprotection@wellcome.ac.uk) or by post: Data Protection Officer, Wellcome Trust, 215 Euston Road, London, NW1 2BE, United Kingdom. Proof of identity will be requested.

Verifiable proof of identity is required for all Subject Access Requests. We may also ask for additional information to assist in locating relevant personal information. Requests will be processed promptly and at most within one month from the date that the request was received. Copies of personal information provided in response to requests are free of charge and in permanent form (i.e. a paper or electronic copy). If a request is made in electronic form, the information requested will also be provided in a commonly used electronic form (unless you request otherwise).

## Updating personal data

Personal information preserved in our collections is not expected to be kept 'up-to-date' in the same way as data still subject to operational use. Our collections are concerned with historical integrity rather than current accuracy. The following personal data rights apply only in certain circumstances, and do not usually apply to personal information found within our collections, however we will consider requests emailed to [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) on a case by case basis:

- **Request correction** of the personal information that we hold about an individual. This enables individuals to have any incomplete or inaccurate information corrected.
- **Request erasure** of personal information. This enables individuals to ask us to delete or remove personal information where there is no good reason for us to continue to process it.
- **Object to processing** of personal information where we are relying on a legitimate interest (or those of a third-party) and there is something about an individual's particular situation which makes them want to object to processing on this ground. Individuals also have the right to object where we are processing their personal information for direct marketing purposes.
- **Request the restriction** of processing of personal information. This enables individuals to ask us to suspend the processing of personal information, for example if they want us to establish its accuracy or the reason for processing it.
- **Withdraw consent** for Wellcome to use personal information at any time, where we are handling personal information on the basis of an individual's consent.

## 3.5 Uncatalogued Collections

As part of our commitment to reducing barriers to access, we now facilitate managed access to uncatalogued collections, subject to our duty of care to individuals and organisations represented in the material, and where permitted under the terms of deposit. Access to uncatalogued collections also depends on the physical condition and arrangement of the collection, sufficient to enable the identification of material relevant to the request.

### Requesting access to uncatalogued material

Where our online catalogue states that material is uncatalogued, researchers should email [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk) to request access.

We aim to enable researchers to access specific information; we are not able to support in-depth research, or provide access to entire collections before they are catalogued. Where available, we will provide a box list to assist the researcher narrow down their request to five boxes of interest, or fewer. Single uncatalogued printed and published monographs may be catalogued on request.

Requests to view uncatalogued material are reviewed on a case by case basis. Boxes may need to be recalled from off-site storage for review and sensitivity checks (see section 2 for criteria and section 3.1 for review procedures), which can take up to six weeks. The researcher will be notified when material is ready for supervised access in the library's rare materials room, or if we are unable to provide access. Researchers using uncatalogued material will be provided with handling guidance, and may be required to complete a restricted access form if the material contains sensitive material. Boxes will remain available to view in the rare materials room for two weeks.

Copying of uncatalogued material is not generally permitted, except where it consists entirely of published material, or material that is assessed to pose no sensitivity issues. Where uncatalogued material is assessed to include personal and/or sensitive information, researchers are required to complete a Restricted Access form, and copying is not permitted in any form.

We cannot provide access to uncatalogued material where:

- **Nature of request:** it is not possible to locate relevant material from the information provided by the researcher, or from box lists
- **Terms of Deposit:** access to uncatalogued material is specifically precluded under the terms of deposit agreement
- **Sensitivity:** a large percentage of the material is sensitive and/or the risk of inadvertent disclosure of sensitive information is high
- **Condition:** there is an unacceptable risk of loss or physical damage without conservation treatment or extensive repackaging

## 3.6 NHS 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 individual clinicians' personal papers during their career and were subsequently deposited in our collections as part of a personal archive.

Since NHS organisations were not covered by the Public Records Act 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 the FOIA. Accordingly, we judge whether 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 user can provide evidence that they have been granted formal permission by a [Research Ethics Committee](#) (REC) 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. Researchers can use an [online tool created by the Medical Research Council and the NHS Health Research Authority](#) to establish whether they need approval from a Research Ethics Committee.

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 several 20<sup>th</sup> century general practitioner (GP) archives. While many of these archives relate to solely private practices, some relate to NHS practices or to private practices which transferred to the NHS in 1948. They include administrative records and a small number also contain clinical records of patients such as record cards, referrals correspondence and visits registers.

NHS GPs are independent contractors, and as such their records are not covered by 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,<sup>1</sup> later the relevant Family Health Service Authority<sup>2</sup> and subsequently the relevant Primary Care Trust<sup>3</sup>, relevant Clinical

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<sup>1</sup> National Health Service (General Medical and Pharmaceutical Services) Regulations, 1954 (1954: 669), Paragraph 13.

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

<sup>3</sup> Statutory Instrument 2004 No. 291 The National Health Service (General Medical Services Contracts) Regulations 2004, Schedule 6, Part 5.

Commissioning Group<sup>4</sup>, or Primary Care Support England<sup>5</sup>). Currently, NHS general practitioners have a statutory contractual obligation to transfer the clinical records of deceased patients to NHS England, and Primary Care Support England handle research requests to consult deceased patient records in accordance with FOIA.

We have consulted with The National Archives who has advised 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. However, we no longer acquire GP records. GP patient records that we do hold are assessed for sensitivity using the standard criteria outlined in section 2 above.

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<sup>4</sup> NHS England Standard General Medical Services Contract 2017/18: <https://www.england.nhs.uk/wp-content/uploads/2018/01/17-18-gms-contract.pdf>

<sup>5</sup> Primary Care Support England advice on Accessing medical records: <https://pcse.england.nhs.uk/services/gp-records/accessing-medical-records/>

## 4 Access and Copying Conditions

Research access to our collections is provided free of charge and in accordance with our published terms and conditions of use. We require library visitors and some online researchers to register for security and operational purposes and in order to comply with licensing agreements, copyright, and information legislation such as the Data Protection Act.

Access and copying conditions vary depending on the type of material. Details of which materials can be accessed or copied in the library or online are set out in the table and notes below (fig.3).

Researchers must also ensure that any use they make of our collections is responsible, both legally and ethically. Researchers who breach the published terms and conditions of use (including the confidentiality and copyright conditions outlined at registration and in our Restricted Access form) may be banned from access to our collections, services or facilities, and may also be excluded from receiving Wellcome funding for research.

**Fig.3 Access and copying conditions**

Type of material		Access at the library? <sup>1</sup>	Access online?	Make copies / download?
<b>OPEN and OPEN WITH ADVISORY</b>		Yes	Yes, if digitised <sup>2</sup> Except certain materials under 10 years old <sup>3</sup>	Yes
<b>RESTRICTED</b>		Yes Subject to approved Restricted Access application <sup>4</sup>	No Except for authenticated users <sup>5</sup>	No <sup>6</sup>
<b>BY APPOINTMENT</b>	Uncatalogued material	Subject to sensitivity and access review <sup>7</sup>	No	Only in exceptional circumstances <sup>8</sup>
	All other by appointment material	Yes <sup>9</sup>	Yes, if digitised	Yes <sup>10</sup>
<b>CLOSED</b>	NHS patient records, including those held within: general practitioner records; hospital records created before 1958; research project papers	Only with permission from the applicable NHS Research Ethics Committee <sup>11</sup>	No	Only with permission from the applicable NHS Research Ethics Committee <sup>11</sup>
	Private hospital patient records	Only with permission from the hospital <sup>11</sup>	No	Only with permission from the hospital <sup>11</sup>
	All other closed material	No <sup>12</sup>		

Notes to fig.3: Access and Copying Conditions

1 **Consulting material in the library.** Researchers must register on their first visit to the library. Our registration form requires users to comply with UK data protection and copyright legislation, and to acknowledge their responsibilities for care of the collections.

- 2 **Consulting material online.** Researchers do not need to register to view open material online. Open with advisory material can only be viewed following a click-through message acknowledging the researcher's responsibility to comply with UK data protection legislation. Copying and licence terms for download may be restricted for material which has the potential to cause offence, damage or distress.
- 3 **Open material under 10 years old.** We only make such material available online where licensed to do so under UK copyright law, and – for material containing personal data – where it is accompanied by permission from the individual features in the material, or where it has been made public because of steps deliberately taken by that individual.
- 4 **Consulting restricted material.** Once registered, researchers can order restricted access material to view at the library through the online catalogue. Restricted items will be delivered to the rare materials room in the library along with an *"Application for access to restricted material"* form. Researchers must agree (by tick-box and dated signature) to the terms set out on the Restricted Access form before permission is granted. Once the user has agreed to these conditions, the desk supervisor will countersign and approve or decline the application (if the application is declined, a reason will be provided). The form will be held on file and electronically until restrictions in the consulted material expire.
- 5 **Authenticated users.** In limited circumstances, restricted material can be made available online to authenticated users. Authenticated users agree to comply with UK data protection and copyright legislation.
- 6 **Copying restricted material.** Restricted material for which a Restricted Access form has been issued is made available to users in distinctively marked production boxes to make it easier for the desk supervisor to monitor how the materials are used. This material cannot be copied in any form, whether photograph, photocopy, scan or by any other means. Personal information must be anonymised when taking notes or sketches from restricted material.
- 7 **Accessing uncatalogued materials.** Requests to access uncatalogued material are reviewed on a case by case basis (see section 3.5).
- 8 **Copying uncatalogued materials.** Copying of uncatalogued material is not generally permitted, except where it consists entirely of published material, or material that is assessed to pose no sensitivity issues. Where uncatalogued material is assessed to include personal and/or sensitive information, researchers are required to complete a Restricted Access form, and copying is not permitted in any form.
- 9 **Consulting by appointment material.** Researchers can access the material by pre-arranged appointment. Depending on the reason for the appointment access may take place in the library, conservation studio or rooms containing specialist equipment required for access. If there is a surrogate copy an appointment may be refused unless there is a strong research need to see the physical item.
- 10 **Copying by appointment material.** Material can be copied subject to a sensitivity and condition assessment. Copying of physical material may be limited or not permitted if it is deemed too fragile. By appointment material may not be copied if it is also restricted.
- 11 **Obtaining NHS Research Ethics committee permission to consult closed records / permission from a private hospital.** To consult closed NHS patient records, users need to apply for permission from an NHS Research Ethics Committee (REC). To consult patient records from a private hospital, users need to apply to the relevant hospital or successor institution for written permission. Wellcome assumes that such permission will only be granted if both the requirements of data protection legislation and the common law of confidentiality can be satisfied.
- 12 **Changes to the access status.** All requests to challenge the access status of a file will be heard by the Access Review Panel (see section 6). Any individual who is the subject of closed material can provide written permission for Wellcome to open (or restrict) a file which has previously been closed. This will only be undertaken if access will not infringe the data protection rights of any third parties mentioned in the material.

# 5 Online Access

We only make material available online to a general audience if it is classed as **Open** or if it can be redacted so that all sensitive information is removed from the online version. Decisions to make material available online are also subject to copyright and licensing considerations. In limited circumstances, **Restricted** material can be made available online to authenticated users, again subject to UK data protection and copyright law.

We aim as far as possible to identify sensitive material *prior* to online publication by re-assessing all collections due to be made available online.

In addition, we will only make open material under 10 years old available online where licensed to do so under UK copyright law, and – for material containing personal data – where it is accompanied by permission from the person or organisation whose sensitive information features in the material or it has been made public as a result of steps deliberately taken by the individual or organisation. This is because we recognise that material may acquire sensitivity if made available world-wide via online access, especially very recently created material.

## Takedown policy

Our pre-online assessment procedure is supplemented by a [copyright clearance and takedown policy](#). Despite the measures we take to prevent the disclosure of sensitive information online, it is possible that sensitive information may inadvertently be made available online.

All our online collections are subject to this takedown policy. If we are contacted with a challenge about the presence of collections or items online, we will remove the material in question from our website until we have been able to assess the case.

Where material is removed for valid reasons of Data Protection, its removal will be considered as temporary and will be restored at a date decided by an internal Wellcome review panel once its sensitivity is deemed to have subsided. Where material is removed for valid reasons of copyright, its removal will be considered as lasting until copyright in the material expires, or until the rights-holder agrees that the material can be reinstated.

To contact us about removal of material, please email [digitisation@wellcome.ac.uk](mailto:digitisation@wellcome.ac.uk), or write to us at the following address: Wellcome Collection, 183 Euston Road, London, NW1 2BE, UK

## Material with permissions

Sometimes we receive permission to make sensitive material available online from the person or organisation whose information features in the material. We will only make such material accessible online in accordance with the specific permission granted. We may suppress material online for reasons other than the permission level (e.g. taste and decency considerations, third party platform community guidelines).

## Material without permission

For material without permissions we follow one of two assessment procedures, depending on the nature of the material being assessed:

### Risk assessment for multiple item collections

We use a risk assessment 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 access at the library (see fig.2). We do not consider online access for material that is **Restricted** or **Closed**, nor, for unpublished material, that is under ten years old.

While it is not feasible to assess every piece of paper or image 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 (low – medium – high) to material based on its date, nature and detail of cataloguing; and
- Iteratively examining samples from the material appropriate to its risk category, i.e. if 5% or more of the initial sample contains sensitive data, we will check additional samples from the same material.

### Granular assessment for single items

Where we are reviewing a single item for online access (i.e. a film or single audio recording) we omit the risk assessment stage and review the entire item. We assess **Open** and **Restricted** material, but only make **Restricted** items available if they can be redacted so that no sensitive information is openly accessible online or are only available to authenticated users. We do not consider online access for material that is **Closed**.

When sensitivity reviewing for online access we also identify material requiring an **Open with advisory** notice. See Section 3.5 for more details.

We use the flowchart (fig.2) and criteria below to guide decision making:

### **Personal data**

We check the sample or item to assess whether it contains any of the following special category data:

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

We also check the sample material for other types of personal information that might be sensitive, for instance:

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

### **Business sensitive information**

We check the sample or item to assess whether it contains any business sensitive information, including: (see Section 2.3 for detailed definitions)

- Information provided in confidence
- Information that could prejudice a body's interests, activities or relationships with other bodies.
- Information covered by Legal Professional Privilege
- Information that could endanger public health and/or safety
- Court records

# 6 Access Appeals

Requests to change the access status of material include:

- Requests to access **Closed** records (excluding Subject Access Requests, these are covered in section 3.4)
- Requests for **Restricted** records to be **Opened** or **Closed**,
- And/or requests for **Open** records to be **Restricted** or **Closed**.

Requests that would contravene data protection legislation will not be considered (e.g. a request to **Open** a **Closed** medical case file relating to an identifiable living person), nor will requests regarded unfounded (e.g. a request to **Close** a file that contains only press cuttings) or vexatious.

Any changes made on appeal to the access status of collections or items will subsequently apply to all Wellcome Collection users. Final decisions after access appeal will not ordinarily be re-reviewed within ten years, except in exceptional circumstances.

## Making a request

Access appeal requests should be emailed to [collections@wellcome.ac.uk](mailto:collections@wellcome.ac.uk), including the following information:

- Which item(s) your appeal relates to i.e. which item(s) you are interested in accessing (if currently **Closed**), or which **Open** or **Restricted** items you suggest should be re-reviewed
- The grounds on which you are requesting an access appeal / re-review

If a change in access status is incontrovertible (e.g. if highly sensitive medical data is found in an **Open** file) we will process the request immediately. Other admissible requests will be heard by the Access Advisory Panel. This group consists of internal departmental representatives and external expert reviewers who together review each access appeal case (independently of the staff involved in cataloguing and sensitivity review), and make advisory recommendations to the Head of Collections and Research. In the event that the Panel cannot agree on recommendations, the decision is passed to Wellcome's Information Governance Group.

Meetings of the Access Advisory Panel take place quarterly, if there is business to be discussed. Where feasible, requests will be heard at the next Access Advisory Panel. We endeavor to report the final decision and make any approved changes to the access status of item(s) within 4 weeks of this meeting.