



## ADLS GUIDANCE NOTE

### Can a researcher legitimately process sensitive personal data for research purposes?

This guidance note provides information on processing **sensitive** personal data for research purposes. For information on processing non-sensitive personal data for research please view the companion ADLS guidance note [here](#).

#### 1. What is 'sensitive personal data'?

'Sensitive personal data' is defined in the Data Protection Act (DPA) (section 2) and includes information relating to an individual's:

- Race or ethnic origin
- Political opinions
- Religious beliefs or beliefs of a similar nature
- Trade union membership
- Physical or mental health or condition
- Sexual life
- The commission or alleged commission by the data subject of any offence
- Any proceedings for any offence committed or alleged to have been committed by the data subject, the disposal of such proceedings or the sentence of any court in such proceedings.

#### 2. Processing sensitive personal data for research purposes

In the UK, the sensitive personal data processing conditions are set out Schedule 3 of the DPA and in secondary legislation (there are 9 conditions in the Act and the remainder are in Regulations). Data controllers are forbidden from processing sensitive personal data unless one or more of these 20 conditions are met together with a Schedule 2 condition set out in the Data Protection Act.

Therefore, in order to process sensitive personal data fairly and lawfully specifically for **research purposes**:

- (i) a Schedule 2 condition set out in the Data Protection Act 1998 must be met; and either
- (ii) a Schedule 3 condition set out in the Data Protection Act 1998 must be met; or
- (iii) Paragraph 9 of the Data Protection (Processing of Sensitive Personal Data) Order 2000 or one of the other sensitive data processing conditions must be met.

Given that all personal data processing will be unlawful unless at least one of the Schedule 2 conditions are met, the set of conditions must be regarded as a minimum standard for the processing of personal data.

## **Schedule 2 conditions set out in the Data Protection Act 1998**

The processing of sensitive personal data for research purposes must firstly meet a Schedule 2 condition. For research purposes the two most likely Schedule 2 conditions are:

- (i) The data subject has given his consent to the processing.*
- (ii) The processing is necessary for the purposes of legitimate interests pursued by the data controller or by the third party or parties to whom the data are disclosed, except where the processing is unwarranted in any particular case by reason of prejudice to the rights and freedoms or legitimate interests of the data subject.*

For a brief explanation of the conditions contained in Schedule 2, please see notes in Annex A. Further details on these conditions are also available in a separate ADLS note [here](#).

## **Schedule 3 condition set out in the Data Protection Act 1998**

If the information to be processed is sensitive personal data, in addition to a Schedule 2 condition, the proposed processing will need to satisfy a **further condition** in Schedule 3 DPA or in another sensitive processing condition contained in secondary legislation. The most likely DPA Schedule 3 conditions for research purposes are:

- (i) 'The data subject has given his explicit consent to the processing of the personal data.'* (DPA Schedule 3, condition 1);
- (ii) The information contained in the personal data has been made public as a result of steps deliberately taken by the data subject.* (DPA Schedule 3, condition 5)
- (iii) (1) The processing is necessary for medical purposes and is undertaken by-*
  - (a) a health professional, or*
  - (b) a person who in the circumstances owes a duty of confidentiality which is equivalent to that which would arise if that person were a health professional.**(2) In this paragraph 'medical purposes' includes the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services.* (DPA Schedule 3, condition 8)
- (iv) (1) The processing-*
  - (a) is of sensitive personal data consisting of information as to racial or ethnic origin,*
  - (b) is necessary for the purpose of identifying or keeping under review the existence or absence of equality of opportunity or treatment between persons of different racial or ethnic origins, with a view to enabling such equality to be promoted or maintained, and*
  - (c) is carried out with appropriate safeguards for the rights and freedoms of data subjects.**(2) The [Secretary of State] may by order specify circumstances in which processing falling within sub-paragraph (1)(a) and (b) is, or is not, to be taken for the purposes of sub-paragraph (1)(c) to be carried out with appropriate safeguards for the rights and freedoms of data subjects.* (DPA Schedule 3, condition 9)

The other conditions concern processing for a stated purpose. For a brief explanation of the conditions contained in Schedule 3, please see notes in Annex B.

## **Paragraph 9 of the Data Protection (Processing of Sensitive Personal Data) Order 2000**

Specifically with regard to the processing of sensitive personal data for **research purposes**, one of the additional conditions for processing sensitive personal data is contained in [The Data Protection \(Processing of Sensitive Personal Data\) Order 2000](#) (SI 2000 No.417) made under the DPA. The Schedule to that Order sets out circumstances in which sensitive personal data may be processed in relation to research purposes at paragraph 9:

### *9. The processing-*

*(a) is in the substantial public interest;*

*(b) is necessary for research purposes (which expression shall have the same meaning as in section 33 of the Act;*

*(c) does not support measures or decisions with respect to any particular data subject otherwise than with the explicit consent of that data subject; and*

*(d) does not cause, nor is likely to cause, substantial damage or substantial distress to the data subject or any other person.*

Processing of sensitive personal data falling within this paragraph may be carried out without the explicit consent of the data subject. **Note that a Schedule 2 condition of the Data Protection Act 1998 must still be met.**

See Annex C for an outline of other circumstances in which the processing of sensitive personal data for non-research purposes may be permitted under this Order.

The Explanatory Note to The Data Protection (Processing of Sensitive personal Data) Order 2000 (SI 2000 No.417) gives an example of the sort of processing of sensitive personal data that is envisaged by the Order:

*‘Paragraph 9 of the Schedule covers, for example, processing in the course of maintaining archives where the sensitive personal data are not used to take decisions about any person without their consent and no substantial damage or distress is caused to any person by the keeping of those data.’*

### **Determining what is in the substantial public interest**

The following information considers what may constitute the substantial public interest, in order to satisfy the requirements of paragraph 9 to the Order so as to permit the processing of sensitive personal data for research purposes without the explicit consent of the data subject(s).

In order to help understand what is in the ‘substantial public interest’ it is useful to firstly give consideration to what is in the ‘public interest’.

#### **(i) Public interest**

It is an established principle of English law that what is of interest to the public is not necessarily in the public interest (Carey (2009), p.171).

Determining what constitutes the ‘public interest’ can be problematic, but the Information Commissioner’s Office (ICO) has provided some guidance. In the context of information law, the ICO is ‘the UK’s independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals’. The ICO offers guidance on all aspects of data protection and freedom of information.

#### **ICO guidance on ‘public interest’:**

The general ICO view on the conditions required for processing personal information is that “in determining if you have a legitimate reason for processing personal data, the best approach is to

focus on whether what you intend to do is fair. If it is, then you are very likely to identify a condition for processing that fits your purpose.” See [here](#).

The ICO does give some guidance as to what constitutes ‘the public interest’ in its strategy for promoting openness by public bodies and data privacy for individuals:

- The public interest focuses on activities that best serve the interests of society as a whole;
- Openness by public bodies and data privacy both serve a broad public interest, but they need not be defended and promoted equally;
- In assessing where the public interest lies, account will be taken of the importance the public attach to the different aspects of information rights;
- Sometimes the public interest will be best served by protecting the information rights of minorities or by drawing attention to the downsides of new developments that might otherwise appear attractive;
- Account should be taken of the consequences of public authorities failing to be open or organisations failing to respect data privacy;
- In the context of data privacy of individuals, damage and distress will not always be tangible and quantifiable.

See the ICO information rights strategy for promoting openness by public bodies and data privacy for individuals [here](#).

There is **specific ICO guidance** as to what constitutes ‘the public interest’ in respect of its guidance on the Freedom of Information Act 2000 (FOIA) and the Environmental Information Regulations 2004 (EIR):

*something which is “in the public interest” may be summarised as something which serves the interests of the public. The public interest test entails a public authority deciding whether, in relation to a request for information, it serves the interests of the public either to disclose the information or to maintain an exemption or exception in respect of the information requested. To reach a decision, a public authority must carefully balance opposing factors, based on the particular circumstances of the case. Where the factors are equally balanced, the information must be disclosed.*

These ICO guidance notes must clearly be differentiated from the Data Protection Act and the Data Protection (Processing of Sensitive personal Data) Order 2000, but it is useful to highlight the sort of arguments which might be considered in order to determine what might be in the public interest.

The “public interest” is typically not defined in access to information legislation, because of the need to retain flexibility - legislators and policy makers recognise that the public interest will change over time and according to the circumstances of each situation (Cook (2003) p.11).

## **(ii) Substantial public interest**

The ‘substantial public interest’ test which has to be met in order to satisfy the condition set out in paragraph 9 of the Data Protection (Processing of Sensitive Personal Data) 2000 Order is more exacting than the test applied to the other legislation discussed above. The potential benefit of

processing any sensitive personal data without the data subject's consent must outweigh any consequential, substantial harm done to the individual concerned.

In order to satisfy the requirements of the Data Protection (Processing of Sensitive Personal Data) 2000 Order, any processing of sensitive personal data must be in the substantial public interest and it must be **necessary** for research purposes – the research must therefore only be used for historical or statistical research.

**Also**, such processing must not support measures or decisions relating to any particular individuals without their explicit consent; and the processing must not cause, or be likely to cause substantial damage or substantial distress to an individual. These provisions do not remove the duty to comply with the Data Protection Act 1998 and any personal data should still be processed in compliance with the data protection principles of the Act (notably that personal data shall be processed fairly and lawfully).

If the proposed processing of sensitive personal data is for research purposes that are considered to be in the substantial public interest, the research proposal should include a statement indicating the potential benefits of the research to the public. That alone may not be sufficient to satisfy the requirements of the condition, but if all the other provisions of paragraph 9 are met, the necessary threshold might be reached.

What is clear, is that in order for any processing of sensitive personal data for research purposes to be considered as in the substantial public interest, it is likely to have to be able to demonstrate that:

- It serves the interests of society as a whole
- It promotes openness and transparency by public bodies, whilst also protecting individuals' personal data
- The public attaches some importance to the information being processed
- Individuals are not caused any substantial damage or distress, albeit that damage and distress to a data subject is not always tangible and quantifiable.

The requirements to be met by researchers seeking to process sensitive personal data for research purposes are therefore quite exacting and rigorous. For that reason, wherever possible, a researcher handling sensitive personal data should obtain the explicit consent of the data subject for the processing to take place. Where that is not possible, the condition permitting such processing without consent must be rigorously adhered to, and if possible, it would be advisable to get ICO clearance on the matter before the processing takes place.

### **3. Examples of conditions of processing sensitive personal data likely to apply in the research context**

The following are examples of some of the different conditions that will apply when sensitive personal data are being processed for research purposes.

- A researcher has obtained 'explicit consent' from the data subject. Explicit consent must be specific and informed. In order for consent to be explicit, a data subject must have a full understanding of what is intended to be done with the data. It is advised that a record be kept of any explicit consent obtained from a data subject.  
**DPA Schedule 3, paragraph 1 ('condition 1') applies here.**
- Medical research is being carried out by a health professional or someone who owes a

similar duty of confidentiality to the data subject. This condition would also need to take medical ethics and confidentiality constraints into account (see [here](#)).

**DPA Schedule 3, paragraph 8 ('condition 8') applies here.**

- Personal data is being analysed for equal opportunity purposes.  
**DPA Schedule 3, paragraph 9 ('condition 9') applies here.**
- Or, the processing of the personal data will fall under the Data Protection (Processing of Sensitive Personal Data) Order 2000 because it is in the substantial public interest and is necessary for research purposes and does not support measures or decisions with respect to a particular data subject except with their explicit consent, nor cause or be likely to cause, substantial damage or distress. For example, the transmission of relevant patient files by hospitals to local authority cancer registries can be considered to be in the substantial public interest, because it is vital in protecting and enhancing public health.  
**The Data Protection (Processing of Sensitive Personal Data) Order 2000, Schedule, paragraph 9 applies here.**

**The 'substantial public interest' is, however, a very rigorous test and this condition should only be used with caution.**

An example of using the exemptions provided by the Data Protection Act 1998 for the re-use of sensitive personal data for research purposes is provided by the Scottish Government for their linked Social Care, Housing and Health dataset. Documentation is available from [here](#), pages 36-46.

**Please note that any advice provided by the ADLS is for informational purposes only and not for the purpose of providing legal advice. If you are unsure about any aspect of administrative data research, please consult your legal department or the relevant data holding organisation.**

## References

- Carey, P. Data Protection: A practical guide to UK and EU law (Third Edition) 2009
- [ICO](#)
- [Researchers Guide To The Data Protection Principles, Records Management Section, University of Edinburgh](#)

## **ANNEX A: Schedule 2 of the DPA**

### **Conditions relevant for purposes of the First Principle:**

#### **Processing of any personal data.**

There are 6 conditions set out in Schedule 2 to the DPA which are relevant for the processing of **both** sensitive and non-sensitive personal data:

#### **1. The data subject has given his consent to the processing.**

Consent of the data subject: This condition requires that the individual who the personal data is about has consented to the processing. A data subject's consent to the processing of administrative datasets is likely to be the exception and will not usually be readily available. It will therefore be likely that another condition for processing will have to be relied on to legitimise the processing of such datasets.

#### **2. The processing is necessary –**

- a) for the performance of a contract to which the data subject is a party, or**
- b) for the taking of steps at the request of the data subject with a view to entering into a contract.**

Contractual necessity: Under this condition the processing would be necessary for the performance of a contract to which the data subject is party; or for taking steps at the data subject's request with a view to entering into a contract. This condition is unlikely to be relevant for research purposes concerning administrative data.

#### **3. The processing is necessary for compliance with any legal obligation to which the data controller is subject, other than an obligation imposed by contract.**

Non-contractual legal obligation of the data controller: The processing would be necessary because of a non-contractual legal obligation that applies. This is unlikely to be relevant for research purposes concerning administrative data.

#### **4. The processing is necessary in order to protect the vital interests of the data subject.**

Vital interests of the data subject: This condition applies where the processing is necessary to protect the vital interests of the data subject (which applies in life or death situations). It is difficult to envisage any processing of personal data for research purposes that might fit within this condition where the data subject has not given consent.

#### **5. The processing is necessary –**

- a) for the administration of justice,**  
**[(aa) for the exercise of any functions of either House of Parliament,]**
- b) for the exercise of any functions conferred on any person by or under any enactment,**
- c) for the exercise of any functions of the Crown, a Minister of the Crown or a government department, or**
- d) for the exercise of any other functions of a public nature exercised in the public interest by any person.**

Functions of a public nature: This condition covers certain processing carried out by many public sector data controllers where the processing is necessary for administering justice or for exercising statutory, governmental or other public functions. It is often used to legitimise processing involving a discretionary power.

- 6. – (1) The processing is necessary for the purposes of legitimate interests pursued by the data controller or by the third party or parties to whom the data are disclosed, except where the processing is unwarranted in any particular case by reason of prejudice to the rights and freedoms or legitimate interests of the data subject.**
- (2) The [Secretary of State] may by order specify particular circumstances in which this condition is, or is not, to be taken to be satisfied.**

Legitimate interests of the data controller: This condition is likely to be most relevant to processing administrative data for research purposes.

If the information to be processed is sensitive personal data, the proposed processing will need to satisfy a further condition in Schedule 3 of the DPA in addition to the Schedule 2 condition. These are outlined in Annex B.



## **ANNEX B: Schedule 3 of the DPA**

### **Conditions relevant for purposes of the First Principle:**

#### **Processing of sensitive personal data.**

There are 20 conditions relevant for lawfully processing sensitive personal data - 9 of these conditions are contained in Schedule 3 DPA as set out below; and the remaining 11 conditions are found in Regulations, which are set out in Annex C to this ADLS Guidance Note:

#### **1. The data subject has given his explicit consent to the processing of the personal data.**

Explicit consent of the data subject: The individual who the sensitive personal data is about has given explicit consent to the processing; such explicit consent must be specific and informed.

#### **2. – (1) The processing is necessary for the purposes of exercising or performing any right or obligation which is conferred or imposed by law on the data controller in connection with employment.**

##### **(2) The [Secretary of State] may by order –**

- (a) exclude the application of sub-paragraph (1) in such cases as may be specified, or**
- (b) provide that, in such cases as may be specified, the condition in sub-paragraph (1) is not to be regarded as satisfied unless such further conditions as may be specified in the order are also satisfied.**

Compliance with employment law obligations: This condition requires the processing to be necessary to comply with employment law.

#### **3. The processing is necessary-**

##### **(a) in order to protect the vital interests of the data subject or another person, in a case where –**

- (i) consent cannot be given by or on behalf of the data subject, or**
- (ii) the data controller cannot reasonably be expected to obtain the consent of the data subject, or**

##### **(b) in order to protect the vital interests of another person, in a case where consent by or on behalf of the data subject has been unreasonably withheld.**

Vital interests of the data subject: This condition applies where the processing is necessary to protect the vital interests of:

- the individual (where the individual's consent cannot be given or reasonably obtained), or
- another person (where the individual's consent has been unreasonably withheld).

#### **4. The processing –**

##### **(a) is carried out in the course of its legitimate activities by any body or association which –**

- (i) is not established or conducted for profit, and**
- (ii) exists for political, philosophical, religious or trade-union purposes,**
- (b) is carried out with appropriate safeguards for the rights and freedoms of data subjects,**

##### **(c) relates only to individuals who either are members of the body or association or have regular contact with it in connection with its purposes, and**

##### **(d) does not involve disclosure of the personal data to a third party without the consent of the data subject.**

Processing by not-for-profit organisations: This condition is mainly concerned with processing that is carried out by a not-for-profit organisation and does not involve disclosing personal data to a

third party, unless the data subject consents (and further limitations apply).

**5. The information contained in the personal data has been made public as a result of steps deliberately taken by the data subject.**

Information made public by the data subject: The data subject has deliberately made the information public.

**6. The processing -**

- (a) is necessary for the purpose of, or in connection with, any legal proceedings (including prospective legal proceedings),**
- (b) is necessary for the purpose of obtaining legal advice, or**
- (c) is otherwise necessary for the purposes of establishing, exercising or defending legal rights.**

Legal advice and establishing or defending legal rights: This condition is relevant where the processing is necessary in relation to legal proceedings; for obtaining legal advice; or otherwise for establishing, exercising or defending legal rights.

**7. – (1) The processing is necessary-**

- (a) for the administration of justice,**  
**[(aa) for the exercise of any functions of either House or Parliament,]**
- (b) for the exercise of any functions conferred on any person by or under an enactment, or**
- (c) for the exercise of any functions of the Crown, a Minister of the Crown or a government department.**

**(2) The Secretary of State may by order –**

- (a) exclude the application of sub-paragraph (1) in such cases as may be specified, or**
- (b) provide that, in such cases as may be specified, the condition in sub-paragraph (1) is not to be regarded as satisfied unless such further conditions as may be specified in the order are also satisfied.**

Public functions: For this condition to apply, the processing must be necessary for administering justice, or for exercising statutory or governmental functions.

**[7A(1) The processing-**

- (a) is either-**
  - (i) the disclosure of sensitive personal data by a person as a member of an anti-fraud organisation or otherwise in accordance with any arrangements made by such an organisation; or**
  - (ii) any other proceedings by that person or another person of sensitive personal data so disclosed; and**
- (b) is necessary for the purposes of preventing fraud or a particular kind of fraud.**

**(2) In this paragraph “anti-fraud organisation” means any unincorporated association, body corporate or other person which enables or facilitates any sharing of information to prevent fraud or a particular kind of fraud or which has any of these functions as its purpose or one of its purposes.]**

**8. – (1) The processing is necessary for medical purposes and is undertaken by-**

- (a) a health professional, or**
- (b) a person who in the circumstances owes a duty of confidentiality which is**

equivalent to that which would arise if that person were a health professional.

**(2) In this paragraph 'medical purposes' includes the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services.**

Medical purposes: The processing must be necessary for medical purposes and is undertaken by a health professional or person who owes an equivalent duty of confidentiality.

**9. (1) The processing-**

**(a) is of sensitive personal data consisting of information as to racial or ethnic origin,**

**(b) is necessary for the purpose of identifying or keeping under review the existence or absence of equality of opportunity or treatment between persons of different racial or ethnic origins, with a view to enabling such equality to be promoted or maintained, and**

**(c) is carried out with appropriate safeguards for the rights and freedoms of data subjects.**

**(2) The [Secretary of State] may by order specify circumstances in which processing falling within sub-paragraph (1)(a) and (b) is, or is not, to be taken for the purposes of sub-paragraph (1)(c) to be carried out with appropriate safeguards for the rights and freedoms of data subjects.**

Records on racial equality: This condition applies where the processing is necessary for monitoring equality of opportunity and is carried out with appropriate safeguards for the rights and freedoms of data subjects.

**10. The personal data are processed in circumstances specified in an order made by the [Secretary of State] for the purposes of this paragraph.**

## **ANNEX C: The Data Protection (Processing of Sensitive Personal Data) Order 2000; and The Data Protection (Processing of Sensitive Personal Data) Order 2002**

There are 20 conditions relevant for lawfully processing sensitive personal data - 9 conditions are contained in Schedule 3 DPA as set out in Annex A above. The remaining conditions are found in Regulations: 10 are found in the Data Protection (Processing of Sensitive Personal Data) Order 2000) and 1 in the subsequent Data Protection (Processing of Sensitive Personal Data) (Elected Representatives) Order 2002 (SI 2002/2905).

The following section highlights the conditions relevant for lawfully processing sensitive personal data under the two Orders:

### **Data Protection (Processing of Sensitive Personal Data) Order 2000 Schedule: Circumstances in which sensitive personal data may be processed.**

#### **1. Processing in relation to unlawful activities.**

(Schedule, paragraph 1)

This condition applies to many types of police processing as well as processing by data controllers wishing to detect or report on criminal activities (the condition may extend to breaches of civil law such as negligence, trespass or breaches of contract).

#### **2. Processing necessary for the protection of the public.**

(Schedule, paragraph 2)

The processing must be in the substantial public interest necessary for the protection of the public against dishonesty, malpractice, seriously improper conduct or incompetence by any person, or mismanagement in the administration of, or failure in provision of services by, any body or organisation; and necessarily carried out without the explicit consent of the data subject so as not to prejudice the discharge of that function.

#### **3. Publications about wrongdoing:**

(Schedule, paragraph 3)

This condition largely relates to the processing of particular sensitive personal data for publication purposes (and is therefore relevant to the media).

#### **4. Processing which is necessary for confidential counselling:**

(Schedule, paragraph 4)

This condition applies to the processing of sensitive personal data on a person who is an alleged abuser or someone undergoing counselling (where consent cannot be given; or necessarily without the explicit consent of the data subject, so as not to prejudice the provision of counselling, advice, support or other service).

#### **5. Insurance and pensions – processing of family data:**

(Schedule, paragraph 5)

This condition permits the processing by insurance companies and pension providers of health data on family members of the insured, in certain circumstances, for the purposes of determining relevant issues.

**6. Insurance and pensions – old processing:**

(Schedule, paragraph 6)

This condition permits the processing by insurance companies or pension providers of historic data on individuals, in certain circumstances, as part of the provision of insurance cover in the past.

**7. Processing relating to religion and health:**

(Schedule, paragraph 7)

This condition permits the processing of sensitive personal data regarding religious beliefs or the physical or mental health of the data subject, provided that it is necessary to identify or keep under review the existence or absence of equality of opportunity or treatment between persons holding different religious beliefs or of different physical or mental conditions, with a view to enabling such equality to be promoted or maintained (where no individual data subject is affected without explicit consent; and no substantial damage or distress is caused to any individual). Where any individual has given written notice to a data controller who is processing personal data for such purposes, requiring the data controller to cease such processing at the end of a reasonable period, that data controller must have ceased processing those personal data by the end of the period.

**8. Processing of political opinions:**

(Schedule, paragraph 8)

This condition permits the processing of political opinion data by political parties without the consent of the data subject. Where any individual has given written notice to a data controller who is processing such personal data for these purposes, requiring the data controller to cease such processing at the end of a reasonable period, that data controller must have ceased processing those personal data by the end of the period.

**9. Research data:**

(Schedule, paragraph 9)

This condition is most relevant to researchers seeking to process sensitive personal data for research purposes. The condition is discussed in detail in this ADLS Guidance Note.

**10. Police Processing:**

(Schedule, paragraph 10)

The processing must be necessary for the exercise of any functions conferred on a constable by any rule of law. This condition allows the police to carry out their normal functions in connection with the detection of crime.

**Data Protection (Processing of Sensitive Personal Data)(Elected Representatives) Order 2002**

The exemption created by this Order is designed to allow MPs and other elected representatives to process sensitive personal data in order to carry out their appropriate functions.