Draft guidance on the research provisions within the UK GDPR and the DPA 2018



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What are the research provisions?

At a glance:

- The UK GDPR and the DPA 2018 contain a number of provisions for processing personal data for research purposes.
- These provisions make reference to three types of research related purposes for processing:
 - archiving purposes in the public interest;
 - o scientific or historical research purposes; and
 - o statistical purposes.
- The research provisions are not set out in one location in the UK GDPR or the DPA 2018. Instead, they are contained in a number of articles and paragraphs in both pieces of legislation.
- These provisions cover three broad areas of data protection:
 - the data protection principles;
 - a condition for processing special category data and criminal offence data; and
 - o exemptions from data subjects' rights.

In detail:

The UK GDPR and the DPA 2018 contain a number of provisions for processing personal data for research purposes.

These provisions recognise the importance to society of scientific and historical research and technological development. They ensure that data protection requirements enable technological innovation and facilitate the advancement of knowledge.

The provisions make reference to three broad types of research related purposes for processing personal data:

- archiving purposes in the public interest;
- scientific or historical research purposes; and
- statistical purposes.

In this guidance we refer to these collectively as "research" or "research related purposes", although this is not a term that appears in the UK GDPR or the DPA 2018. Where the provisions differ depending on the specific type of research related purpose, we will refer directly to that purpose.

The provisions for research are not set out in any one location in the UK GDPR or the DPA 2018. Instead, there are a number of articles and paragraphs in both pieces of legislation covering research.

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These provisions cover three broad areas of data protection:

- the data protection principles;
- a condition for processing special category data and criminal offence data; and
- exemptions from data subjects' rights.

In order to make use of these provisions, you need to have <u>appropriate</u> <u>safeguards</u> in place for the rights and freedoms of data subjects.

The table below sets out where the research provisions and requirements about safeguards can be found in the UK GDPR and the DPA 2018.

Area of data protection law affected		Location of research provision
Principles	Purpose limitation	Article 5(b) of UK GDPR: provision for research built into the principle
	Storage limitation	Article 5(e) of UK GDPR: provision for research built into the principle
Conditions for processing	Condition for processing special category data	Article 9(2)(j) of UK GDPR; read with
		Schedule 1 Paragraph 4 of the DPA 2018
	Condition for processing criminal offence data	Schedule 1 Paragraph 4 of DPA 2018
Exemptions	Right to be informed when data collected from source other than the individual	Article 14(5)(b) of UK GDPR: exception for research built into the right
	Right of access	Schedule 2 Paragraphs 27 and 28 of DPA 2018: exemptions for research and statistics, and archiving
	Right to rectification	Schedule 2 Paragraphs 27 and 28 of DPA 2018: exemptions for research

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		and statistics, and archiving
	Right to erasure	Article 17(3)(d) of UK GDPR: exception for research built into the right
	Right to restrict processing	Schedule 2 Paragraphs 27 and 28 of DPA 2018: exemptions for research and statistics, and archiving
	Right to data portability	Schedule 2 Paragraph 28 of DPA 2018: exemption for archiving*
	Right to object	Article 21(6) of UK GDPR: exception for scientific or historical research and statistics built into the right; and
		Schedule 2 Paragraphs 27 and 28 of DPA 2018: exemptions for research and statistics, and archiving**
Safeguards		Article 89 of the UK GDPR; Section 19 of DPA 2018

^{*}Schedule 2 of the DPA 2018 contains an exemption from the right to data portability for archiving purposes in the public interest only. There is no exemption from the right to data portability for scientific or historical research, or statistics.

^{**} Article 21(6) contains a built in exception from the right to object to processing for scientific or historical research and statistical purposes only. However, Schedule 2 Paragraph 28 provides an exemption from the right to object when processing for the purposes of archiving in the public interest.

What is research related processing?

At a glance:

- The research provisions make reference to three types of research related purpose:
 - o archiving purposes in the public interest;
 - o scientific or historical research purposes; and
 - o statistical purposes.
- You must be able to demonstrate that your processing is necessary for one of these research purposes if you wish to make use of the relevant provisions.
- We have developed a set of indicative criteria for each of the three types of research.

In detail:

- What is research related processing?
- What is archiving in the public interest?
- What are some indicative criteria for archiving in the public interest?
- What is scientific or historical research?
- What are some indicative criteria for scientific or historical research?
- What is processing for statistical purposes?
- What are some indicative criteria for statistical processing?

What is research related processing?

Research related processing is processing carried out for any one of the following purposes:

- archiving purposes in the public interest;
- scientific or historical research purposes; or
- statistical purposes.

None of these terms are defined in the legislation, although some additional detail is given about them in the introductory recitals to the UK GDPR. Recitals are not legally binding, but they are useful for understanding the meaning of the articles.

Relevant provisions in the UK GDPR

See Recitals 156-163

The defining feature of each of these types of research related activities is the aim or purpose of your processing. This is key to determining whether your processing is covered by the research provisions. We have developed descriptions of the aim and purposes of each of the types of research related processing, which are set out in the sections below.

When determining whether or not your processing can legitimately make use of the research provisions, you should think carefully about whether your processing is necessary for achieving one of the research related purposes.

We have also developed some indicative criteria for each of the three types of research related purposes. These are non-exhaustive and are intended to show the types of activity that are indicative of each type of research purpose.

These criteria will help you identify which of your processing activities can, for the purposes of data protection law, be defined as for research purposes and therefore able to make use of the research provisions. You can refer to them in your documentation of processing to show that you have considered your use of the provisions and are confident they are necessary.

However, the key feature is the purpose or aim of your processing. You need to demonstrate that your processing is necessary to meet the purpose or aim of the type of research identified.

What is archiving in the public interest?

The purpose of archiving in the public interest is to ensure the permanent preservation and usability of records of enduring value for general public interest.

The aim of archiving is to maintain information and provide access to it for research purposes over the very long term. However, archives will often contain personal data of living, identifiable individuals.

The UK GDPR and the DPA 2018 recognise that there is a public interest in allowing some records containing personal data to be permanently preserved, for the long term benefit of society.

Some archiving in the public interest will be carried out by bodies with a specific legal obligation to archive records of enduring value for the general public interest, such as the National Archives, National Records of Scotland, and the Public Record Office of Northern Ireland. Public bodies such as local authorities may also have a public task set out in statute to maintain archives of records.

However, many organisations undertaking archiving in the public interest will not be under any statutory obligation to perform that task. Archiving in the

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public interest may also be carried out by private or third sector organisations.

Archiving in the public interest should be distinguished from the long-term retention of records for business or legal purposes. The term archiving is sometimes used to refer to the process of sending records to offsite storage, or moving data from a live system. However, for the purposes of the research provisions, if records are being kept solely for current business or legal purposes, and have no potential or confirmed enduring public value, then this is not archiving in the public interest.

The following table sets out examples of when the purpose of processing would be considered to be archiving in the public interest, and when it would not:

Archiving in the public interest	Not archiving in the public interest
 Enabling research and investigations Ensuring long term accountability Preserving personal, community and corporate identities, memories and histories Helping to establish and maintain rights, obligations and precedents Securing records for future educational use 	 Maintaining records for current business needs or legal purposes Storing records for a specified limited time period Retaining records that have no potential or confirmed enduring value to society

What are some indicative criteria for archiving in the public interest?

In order to assist you in considering whether your processing is archiving in the public interest, we have developed a non-exhaustive list of activities and features that are indicative of this kind of processing. Although the key factor is the aim or purpose of your processing, you should also be able to demonstrate that some of these activities are features of your processing.

Although you do not need to meet all of these criteria, we would expect you to be able to meet more than one. The more of these criteria you can satisfy, the more likely it is that your processing meets the definition of archiving in the public interest.

Activities	 Acquisition, selection, appraisal 	
		ľ

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	 Storage and preservation Arrangement and description Provision of access through inspection and publication
Standards	 Compliance with pre-existing archiving policies and procedures Involvement of professional archivists Recognition by the national accreditation scheme
Access	 Making records available for public use – either immediately or at a future date when records are no longer confidential May be entirely open or limited to particular audience May be in response to requests

Example

A museum has created an archive of interviews with individuals discussing their experiences of settling in the United Kingdom after emigrating to the country in the 1950s and 1960s. Many of the individuals interviewed are still alive, and so the archive contains personal data.

The archive is free to access, and is maintained to facilitate social history research, as well as for educational uses in the future.

The archive is maintained by a trained archivist at the museum, and is available for public use.

The processing of this personal data can be regarded as archiving in the public interest.

Relevant provisions in the legislation

UK GDPR Recital 158 (external site)

Further reading – The National Archives

The National Archives is the official archive and publisher for the UK Government and for England and Wales. It has published a <u>guide to archiving personal data</u>.

What is scientific or historical research?

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Scientific or historical research should be understood broadly. It includes research carried out in traditional academic settings, and includes the full range of academic research including for example social sciences, humanities and the arts. But it can also include research carried out in commercial settings, and technological development and demonstration.

As noted above, in order to determine whether your processing can make use of the research provisions, the key feature is the purpose or aim your processing aims to achieve.

The purpose of scientific or historical research is to produce new knowledge or to apply existing knowledge in novel ways, often with the aim of benefiting the public interest.

Scientific or historical research aims to:

- advance the state of the art in a given field or provide innovative solutions to human problems;
- generate new understandings or insights that add to the sum of human knowledge in a particular area; or
- produce findings of general application that can be tested and replicated.

What are some indicative criteria for scientific or historical research?

We have developed a non-exhaustive list of activities and features that are indicative of this kind of processing. Although the key factor is the aim or purpose of your processing, you should also be able to demonstrate that some of these are features of your processing.

Although you do not need to meet all of these criteria, we would expect you to be able to meet more than one. The more of these criteria you can satisfy, the more likely it is that your processing is for scientific or historical research purposes.

Activities	 Formulating hypotheses, isolating variables, designing experiments Objective observation, measurement of data Peer review Publication of findings
Standards	 Ethics guidance and committee approval Peer review Compliance with rules on carrying out research on animals or human participants Compliance with rules on involving the public in your research

	 Supporting diverse and inclusive research Ensuring safeguarding and preventing bullying and harassment in the conduct of research Findings do not lead directly to decisions about individual subjects (except in the case of approved medical research)
Access	 Publication of results, and commitment to sharing findings of research Does not need to be Open Access – can be in academic journal with paid access

Example

A national charity supporting the elderly decides to carry out research into how successful the work of community volunteer groups were in supporting its service users during the national lockdown of 2020. Its aim is to gain a better understanding into how well its service users felt supported by these groups, and whether this helped lessen social isolation. It intends to publish its findings (in an anonymised format), and will use them to help inform how it provides services, as well as contribute to debates on national social policy in the future.

The processing of this personal data can be regarded as scientific research.

Example

A university establishes a research project to investigate the experiences of individuals who emigrated to the United Kingdom in the 1950s and 1960s, and to compare the differing experiences of individuals from different ethnic groups.

The university's researchers obtain personal data from the archive mentioned in a previous example.

The processing of this personal data can be regarded as for historical research purposes.

Relevant provisions in the legislation

UK GDPR Recitals 159 and 160

Further reading

The Health Research Authority has produced detailed <u>GDPR</u> <u>Guidance for Researchers and Study Coordinators</u>

UKRI has developed a <u>Good Research Resource Hub</u> which contains links to policies, standards and guidance for researchers

What is processing for statistical purposes?

Processing for statistical purposes is processing where the main objective is to generate statistics. It is important to note that not all processing that leads to the production of statistical results will count as processing for statistical purposes.

As noted above, in order to determine whether your processing can make use of the research provisions, the key feature is the purpose or aim your processing aims to achieve.

Processing for statistical purposes refers only to those activities where the primary aim or purpose of the processing is to produce statistical outputs. These statistical results may then be used for further purposes, including scientific research.

Processing for statistical purposes may be done by public authorities and bodies with a statutory obligation to produce and disseminate official statistics, such as the Office for National Statistics. But it is also much

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broader than this, and it may also be carried out by private or third sector organisations. Processing for statistical purposes refers to any operation of collection and the processing of personal data necessary for statistical surveys or the production of statistical results.

For processing to be considered to be for statistical purposes the outcome of the processing should either:

- not be used to <u>make decisions or justify measures</u> about individual data subjects; or
- have been rendered anonymous, and therefore no longer be personal data.

You should note that if you hold other information that you could combine with the anonymised results, in order to re-identify linked individuals, then the results will not be truly anonymised, and will therefore still be personal data. This would mean that your processing would not be considered to be for statistical purposes – unless the information is not being used to make decisions or justify measures about individual data subjects.

What are some indicative criteria for processing for statistical purposes?

The following is a non-exhaustive list of activities and features that are indicative of processing for statistical purposes. Although the key factor is the aim or purpose of your processing, you should also be able to demonstrate that some of these are features of your processing.

Although you do not need to meet all of these criteria, we would expect you to be able to meet more than one. The more of these criteria you can satisfy, the more likely it is that your processing is statistical purposes.

Activities	Designing surveys
	Sampling populations
	Interpreting and analysing data
	 Drawing inferences about populations from samples
Outputs	 Not used to make decisions or justify measures about
	individual data subjects
	 Anonymous data, not personal data
Standards	Compliance with pre-existing policies and procedures
	 Adherence to relevant codes of conduct and
	regulatory frameworks

 Where part of a wider research project, this should adhere to recognised standards of research integrity
 ethics committee approval, peer review

Example

A health agency is monitoring rates of covid-19 reinfection. It collects personal data of individuals who have tested positive for covid-19, including data about previous infections, and uses this data to generate statistics about the rates of reinfection. This data is then used by other agencies to make policy decisions in order to try and reduce reinfection rates in the future.

The results of this processing are anonymous, and therefore do not contain any personal data.

The processing of this personal data can be regarded as for statistical purposes.

Relevant provisions in the legislation

UK GDPR Recitals 162

Further reading - The National Archives

The UK Statistics Authority has produced detailed guidance on GDPR and Statistics.

Principles and grounds for processing

At a glance:

- Article 5 of the UK GDPR sets out seven key data protection principles.
 Two of these principles purpose limitation and storage limitation contain special provisions for research related processing.
- The purpose limitation principle says you can reuse existing personal data for research related purposes, as long as you have appropriate safeguards in place. Since this is compatible processing you should be able to use your original lawful basis, unless your original lawful basis was consent.
- The principle of storage limitation says that you can keep personal data indefinitely, if you are processing it for one of the research related purposes, as long as you have appropriate safeguards in place.
- There is no specific lawful basis for research. Depending on your status and context, you are likely to rely on either legitimate interests or public task for this type of processing.
- There is a specific condition allowing the use of special category data or criminal offence data for research purposes, if this is in the public interest and you have appropriate safeguards in place.

In detail:

- What do the data protection principles say about research?
- What does the purpose limitation principle say about research?
- What does the storage limitation principle say about research?
- What lawful basis should we use when processing personal data for research related purposes?
- What about consent?
- What is the research condition for processing special category data?
- What is the research condition for processing criminal offence data?
- What does 'necessary' mean?
- When is research related processing 'in the public interest'?

What do the data protection principles say about research?

Article 5 of the UK GDPR sets out <u>seven key data protection principles</u>. These principles lie at the heart of the general data protection regime. They don't give hard and fast rules, but rather embody the spirit of the general data protection regime – and as such there are very limited exceptions.

However two of these principles – purpose limitation and storage limitation – contain within them special provisions for research related processing.

What does the purpose limitation principle say about research?

Article 5(1)(b) states that personal data shall be:

Quote

"collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes."

The purpose limitation principle requires you to be open and honest about your reasons for obtaining data, and helps guard against 'function creep'. In general, you can only repurpose data if this isn't incompatible with your original purpose. However, the principle specifically says that you can repurpose data for research purposes, as this is automatically considered to be a compatible purpose.

Recital 50 allows that when the new purpose for processing is compatible with the original purpose for which the data was initially collected, you do not need to a new lawful basis for the new purpose. So if you do want to repurpose data for research purposes, you won't need to identify a new lawful basis (unless your original lawful basis was consent).

But you still need to have <u>appropriate safeguards</u> in place and you do need to make sure your processing is otherwise fair and lawful.

When is a new purpose compatible with our original purpose?

Article 5(1)(b) of the UK GDPR specifically says that research related purposes should be considered to be compatible purposes.

This means that if you have already collected personal data for one purpose, and now want to process it for a new research related purpose, this is automatically considered compatible with the original purpose. In most cases, you do not need to identify a new lawful basis for this processing. You

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still need to make sure that your processing is generally fair and lawful, and you should update your privacy information to ensure that your processing is still transparent.

Example

A charity working across the United Kingdom to provide support to economically vulnerable families decides to use the data it collects for the provision of its services to carry out research into the occurrence of malnutrition amongst children in different geographical areas and socio-economic groups. The aims of this research mean that this processing can be classed as 'scientific research'. The original processing was carried out using the legitimate interests lawful basis.

As the new processing is for scientific research purposes, this can be regarded as compatible with the original purpose for processing. Therefore the charity doesn't need to identify a new lawful basis for processing.

However, this does not apply when the personal data was originally collected on the basis of consent. Processing on the basis of consent means giving individuals real choice and control over how their data is used. This means that consent must always be specific and informed. People can only give valid consent when they know and understand what you are going to do with their data. So further processing data collected on the basis of consent for a research related purpose, that the individual did not consent to at the time the data was collected, will unfairly undermine the original consent. See below for What about consent?

If you wish to conduct research using data originally collected for a different purpose on the basis of consent, you will need to seek fresh consent.

Example

If the charity in the previous example originally obtained the data of its service users on the basis of consent, it will now need to seek fresh consent from them in order to use their data to carry out its research.

If you are conducting research using data collected from another organisation, you are collecting new data rather than repurposing data you have already collected. You need to identify your own lawful basis to process the data. You can't just rely on compatibility with the original organisation's purposes.

If you are using data collected from another organisation, rather than data collected directly from the data subject, you should still update your privacy information. However, you may not have to provide this information to the data subjects, if doing so would prove impossible or involve disproportionate effort. See below for What is the exception to the right to be informed?

Example

A health research organisation, carrying out research into the links between childhood malnutrition and other health conditions among certain socio-economic groups, obtains data from the charity about its service users. It also obtains data from GP practices operating in certain areas.

The charity obtained the data on the basis of the legitimate interests lawful basis, whilst the GP practices rely upon the public task lawful basis.

In both instances, the research organisation will have to identify its own lawful basis for processing this data. As it is processing special category data it will also have to identify a condition for processing under Article 9 of the UK GDPR. It will also have to provide privacy information to the data subjects, unless this is impossible or would involve disproportionate effort.

You must also have <u>appropriate safeguards</u> in place for the rights and freedoms of data subjects.

What does the storage limitation principle say about research?

Article 5(1)(e) requires that personal data shall be:

Quote

"...kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods insofar as the personal data will be processed solely for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) subject to implementation of the appropriate technical and organisational measures required by this Regulation in order to safeguard the rights and freedoms of the data subject..."

The principle of storage limitation means that even if you collect and use personal data fairly and lawfully, you cannot keep it for longer than you actually need it.

Although the general rule is that you cannot hold personal data indefinitely just in case it might be useful in future, Article 5(1)(e) provides an exception to the principle of storage limitation for research related processing. This means that you can keep personal data indefinitely, if you are processing it for one of the research related purposes.

However, this must be your only purpose. If you justify indefinite retention on this basis, you cannot later use that data for another purpose – in particular for any decisions affecting particular individuals. This does not prevent other organisations from accessing public archives, but they must ensure their own collection and use of the personal data complies with the principles.

If the data is no longer being processed for any purpose including a research related purpose it must be deleted.

You must have <u>appropriate safeguards</u> in place for the rights and freedoms of data subjects.

Further reading - ICO guidance

<u>Purpose limitation</u> <u>Storage limitation</u>

What lawful basis should we use when processing personal data for research related purposes?

The lawful bases for processing are set out in Article 6 of the UK GDPR. You must have a lawful basis in order to process personal data.

The most appropriate lawful basis will depend on your specific purposes and the context of the processing. However, in the context of research related processing the most appropriate lawful basis is likely to be either:

- Public task the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law; or
- Legitimate interests the processing is necessary for your legitimate interests, or the interests of a third party, unless there is a good reason to protect the individual's personal data which overrides those legitimate interests.

Which of these applies depends on what type of organisation you are. If you are a private or third sector organisation conducting research, the most likely lawful basis for your processing will be legitimate interests. However, if you are a public authority, such as a university or an NHS organisation, public task is likely to be the most appropriate lawful basis.

Remember that this will only arise if you are collecting new data for research purposes, or if you are using data in your research that you have collected from another organisation. If you are reusing data for research that you originally collected for a different purpose, this is covered by <u>purpose</u> <u>compatibility</u>. In that case, you can rely on the existing lawful basis for processing.

Further reading - ICO guidance

<u>Lawful basis</u>
<u>Public task</u>
<u>Legitimate interests</u>

What about consent?

If you are conducting a research study using personal data, such as medical research or a clinical trial, you will probably be required to obtain consent from participants to take part in the trial. Consent is an important ethical standard that ensures the autonomy and privacy of participants in research studies is protected.

However, it is important to note that consent to participate in a research study is distinct from consent as a lawful basis to process personal data Version 1.0 for public consultation

under the UK GDPR. Even if you have a separate ethical or legal obligation to get consent from people participating in your research, this should not be confused with UK GDPR consent.

Just because you need to obtain consent from individuals to participate in your research study, this does not mean that consent is likely to be the most appropriate lawful basis for processing their personal data as part of this study. There is no rule that says you have to rely on consent to process personal data for scientific research purposes. You may well find that a different lawful basis (and a different special category data condition) is more appropriate in the circumstances. In fact, in most cases, consent will **not** be the most appropriate lawful basis.

This is because for consent to be valid under the UK GDPR, the individual must be able to withdraw it at any time. There is no exemption to this for scientific research. This means that if you are relying on consent as your lawful basis and the individual withdraws their consent, you need to stop processing their personal data – or anonymise it – straight away.

If you would not be able to fully action a withdrawal of consent – for example because deleting data would undermine the validity of your research and effective anonymisation is not possible – then you are not able to rely on consent as your lawful basis (or condition for processing special category data). Consent is only valid if the individual is able to withdraw it at any time.

Also, consent is not an appropriate lawful basis for processing where there is a power imbalance between you and the individual whose personal data you are processing. This is particularly likely to be the case if you are a public authority. If you are a research institution undertaking a study, there may be a power imbalance between you and your participants. In these cases, consent may not be freely given, and so cannot be valid.

Therefore, if you are processing personal data for one of the research related purposes, your lawful basis is unlikely to be consent.

If you do want to rely on consent, the UK GDPR acknowledges that if you are collecting personal data for scientific research, you may not be able to fully specify your precise purposes in advance.

If you are seeking consent to process personal data for scientific research, this means you don't need to be as specific as for other purposes. However, you should identify the general areas of research, and where possible give people granular options to consent only to certain areas of research or parts of research projects.

The only time you might have to get consent under the UK GDPR is if you want to reuse data you originally collected on the basis of consent for an

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entirely different non-research purpose – this is to ensure that you don't unfairly undermine the individual's original informed choice to share that data with you for an unrelated purpose.

We have produced a <u>lawful basis interactive guidance tool</u>, to give more tailored guidance on which lawful basis is likely to be most appropriate for your processing activities.

Further reading - ICO guidance

Lawful basis for processing

Consent

Public task

Legitimate interests

Lawful basis interactive guidance tool

What is the research condition for processing special category data?

If you are processing special category data, you need to identify both a lawful basis for processing and a special category condition for processing in compliance with Article 9.

Special category data is personal data that needs more protection because it is sensitive, and is defined as:

- personal data revealing racial or ethnic origin;
- personal data revealing political opinions;
- personal data revealing religious or philosophical beliefs;
- personal data revealing trade union membership;
- genetic data;
- biometric data (where used for identification purposes);
- data concerning health;
- data concerning a person's sex life; or
- data concerning a person's sexual orientation.

The presumption is that this type of data needs to be treated with greater care because collecting and using it is more likely to interfere with the fundamental rights of an individual.

You can only process special category data if you can meet one of the specific conditions in Article 9 of the UK GDPR. One of these conditions is that the processing is necessary for research related purposes.

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Article 9(2)(j) provides a condition for processing if it is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

Schedule 1 paragraph 4 of the DPA 2018 sets out some additional requirements for you to rely on this condition. This states that you can process special category data for research related purposes if the processing is:

- necessary for that purpose it must be a reasonable and proportionate way of achieving your purpose, and you must not have more data than you need;
- subject to <u>appropriate safeguards</u> for individuals' rights and freedoms, as set out in Article 89(1) of the UK GDPR;
- not likely to cause <u>substantial damage or substantial distress</u> to an individual;
- not used for <u>measures or decisions about particular individuals</u>, except for in the case of approved medical research; and
- in the public interest.

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Example

The museum archive mentioned in a previous example aims to record the experiences of certain ethnic groups who had emigrated to the UK in the 1950s and 1960s. The museum will be processing information about those individuals' ethnicity. As such, it will be processing special category data and will need to satisfy an Article 9 condition for processing.

Given the focus of the archive, obtaining personal data on the ethnicity of individuals is necessary for the museum's purposes.

In relation to appropriate safeguards, the museum could consider whether it could make the interviews available in its archive in a pseudonymised format.

However, if it decides not to do this, the processing of this data in this way would not be likely to cause substantial damage or distress to any of the individuals. In addition, the information that it has recorded in the archive will not be used to make decisions about any of the individuals.

The aim of the archive is to facilitate social history research, as well as providing a resource for future educational uses. Taking this into account, the museum can claim that the processing is in the public interest.

Therefore, the museum is able to rely on the condition set out in article 9(2)(j) – on the basis that the processing is necessary for archiving purposes in the public interest.

Relevant provisions in the legislation

Relevant provisions in the UK GDPR see Article 9(2)(j)
Relevant provisions in the Data Protection Act 2018 see
Schedule 1 Paragraph 4

Further reading - ICO guidance

Special category data

What is the research condition for processing criminal offence data?

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The UK GDPR gives extra protection to "personal data relating to criminal convictions and offences or related security measures". We refer to this as criminal offence data.

If you are processing criminal offence data, you will need lawful basis for processing. In addition, you can only process criminal offence data if:

- the processing is under the control of official authority; or
- you meet one of the conditions in Schedule 1 of the DPA 2018.

If you are processing criminal offence data for research related purposes the relevant condition is set out in Schedule 1 condition 4 of the DPA 2018.

This condition means that you can process criminal offence data for research related purposes if the processing:

- is <u>necessary</u> for that purpose it must be a reasonable and proportionate way of achieving your purpose, and you must not have more data than you need;
- is subject to <u>appropriate safeguards</u> for individuals' rights and freedoms, as set out in Article 89(1) of the UK GDPR;
- is not likely to cause <u>substantial damage or substantial distress</u> to an individual;
- is not used for measures or decisions about particular individuals, except for in the case of approved medical research; and
- is in the public interest.

Relevant provisions in the legislation

<u>UK GDPR see Article 10</u> DPA 2018 see Schedule 1 Paragraph 4

Further reading - ICO guidance

Criminal offence data

What does 'necessary' mean?

Use of the research conditions for processing special category and criminal offence data depends on you being able to demonstrate that the processing is 'necessary' for your purpose.

This does not mean that the processing has to be absolutely essential. However, it must be more than just useful or habitual. It must be a targeted and proportionate way of achieving that purpose.

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The conditions do not apply if you can reasonably achieve the same purpose by some other less intrusive means. There is a link here to the <u>data</u> <u>minimisation</u> principle, which you should consider carefully for special category data and criminal offence data.

It is not enough to argue that processing is necessary because it is part of your particular business model, processes or procedures, or because it is standard practice. The question is whether the processing of the special category or criminal offence data is a targeted and proportionate way of achieving your research purposes.

When is research related processing 'in the public interest'?

If you want to rely on the research condition for processing special category or criminal offence data, the DPA 2018 states that this processing must be in the public interest.

The legislation does not define the 'public interest'. However, public interest in the context of research should be interpreted broadly to include any clear and positive benefit to the public likely to arise from that research.

The public interest covers a wide range of values and principles relating to the public good, or what is in the best interests of society. In making the case that your research is in the public interest, it is not enough to point to your own private interests. Of course, you can still have a private interest – you just need to make sure that you can also point to a wider public benefit.

Some examples of the form this benefit could take are:

- improved health and wellbeing outcomes;
- improved financial or economic outcomes for individuals or the collective public;
- the advancement of academic knowledge in a given field; or
- the provision of more efficient or more effective products and services for the public.

It is your responsibility to demonstrate that the processing you are proposing to undertake is in the public interest. You may want to consider the 'breadth and depth' of that public benefit: that is, what proportion of the public are benefitted by your research processing, and by how much. Something that benefits a small number of people by an insignificant amount is unlikely to have a strong public interest case.

However it is possible that processing for the purposes of research which benefits only a small number of people, but where the benefit generated is significant, can be in the public interest. There may be a public interest in something even if it does not benefit the whole of society. For example, there may be a strong public interest in something which confers an important Version 1.0 for public consultation

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benefit on a small subset of the public, so long as it does not also harm society's wider interests. For example, processing for the purposes of research into rare but debilitating medical conditions is likely to be in the public interest. Similarly, research processing that generated only a modest benefit, but to a significantly large number of people, could be in the public interest.

The avoidance of harm to the public will also be a key factor in determining whether or not your research is in the public interest. Clearly, if the processing causes more harm than benefit, it is unlikely to be in the public interest. Additionally, you may not make use of the research provisions, if your processing is likely to cause <u>substantial damage or distress</u>.

Public interest research may be conducted by public sector bodies, or private and third sector organisations. The focus is on the processing activity, not on the status of your organisation. You don't have to be a public body, or have significant public interest objectives as part of your founding organisational goals or mission statement – as long as you can demonstrate that the processing itself is in the public interest.

Example

When the health research organisation in a previous example obtains data from the charity supporting vulnerable families and from GP practices, for its research into links between childhood malnutrition and other health conditions, it will have to:

- identify a lawful basis (as it has obtained this data from other organisations, rather than directly from the individuals); and
- satisfy an article 9 condition, as it is processing special category data.

If the research organisation is a charity, or private sector organisation, the most likely lawful basis will be legitimate interests. However, if it is public authority, such as an NHS organisation or university, it is likely that it can rely upon the public task lawful basis.

Turning to the Article 9 condition for processing, given the nature of the research project, the research organisation is able to argue that it is necessary to process information about the health of individuals, as well as information about their racial or ethnic origin.

The research organisation does intend to publish its findings. However, this will be done in a pseudonymised manner, and none of the individuals concerned will be identifiable.

Because of this, the processing of this data in this way will not be likely to cause substantial damage or distress to any of the individuals concerned.

The aim of the research is to gain new understandings of the links between childhood malnutrition and other health conditions among certain socio-economic groups – to better inform health and social policy decisions. It will not be used to make decisions about any of the individuals.

Finally, given the aims of the research the research organisation is able to claim that the processing is in the public interest.

Therefore, the research organisation is able to satisfy the condition set out in Article 9(2)(j) – on the basis that the processing is necessary for scientific or historical research.

Exemptions

At a glance:

- Individuals have a number of specific rights over their data including rights to be informed, to access, to rectify (correct), to erase, to restrict, to port (move), and to object.
- Some of these rights contain built-in exceptions for research.
- For other rights, you may be able to rely on a separate research exemption, if giving full effect to the right would undermine your research purposes.
- You shouldn't rely on exceptions or exemptions in a blanket manner. You must consider them case by case.
- You should only restrict the exercising of a data subject's rights if the exemption applies and there is a valid reason to apply it.
- If you can give full effect to individual rights without undermining your research purposes, you cannot use the exemptions.

In detail:

- What should we take into account when applying these exemptions?
- What is the exception to the right to be informed?
- What is the exemption from the right of access?
- What is the exemption from the right to rectification?
- What is the exception to the right to erasure?
- What is the exemption from the right to restrict processing?
- What is the archiving exemption from the right to data portability?
- What is the exemption from the right to object?

What should we take into account when applying these exemptions?

Articles 13 to 21 of the UK GDPR set out the rights that individuals have over how their data is used.

There are exemptions from most of these rights available for data processed for research related purposes. These exemptions may apply to the following rights:

- the right to be informed;
- the right of access;
- the right to rectification;
- the right to erasure;

- the right to restrict processing;
- the right to data portability; and
- the right to object.

For some of these rights, there is a built-in exception for research. For others, there is a separate exemption set out in Schedule 2 of the DPA 2018.

You should only restrict the exercising of a data subject's rights if the exemption applies and there is a valid reason to apply it. There should be a causal link between giving effect to the right and the potential prejudicial effect that you have identified.

You should not apply the research related exemptions in a blanket fashion, and only **to the extent that** the application of the specific right would cause the prejudicial effect you have identified. Therefore, the application of the exemptions must be necessary and proportionate. You must consider the application of the exemptions on a case-by-case basis.

You should document your reasons for relying on an exemption and must make this reasoning available to the ICO if required.

You must inform the individual without undue delay and within one month of receipt of the request about:

- the reasons why you have refused the request;
- their right to make a complaint to the ICO; and
- their ability to seek to enforce this right through the courts.

The following sections explain how the research related exemptions affect each of these rights.

Relevant provisions in the legislation

Relevant provisions in the UK GDPR (the exempt provisions)

– Articles 14(1)-(4), 15(1)-(3), 16, 18(1) and 21 (1)

(external link)

Relevant provisions in the Data Protection Act 2018 (the exemption) – Schedule 2, Part 6, Paragraph 27 (external link)

What is the exception to the right to be informed?

The right to be informed covers some of the key transparency requirements of the UK GDPR. It is about providing individuals with clear and concise information about what you do with their personal data.

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Articles 13 and 14 of the UK GDPR specify what individuals have the right to be informed about. We call this 'privacy information'.

However, the UK GDPR recognises that when processing data you have obtained from another organisation, rather than directly from the data subject, this might be very difficult.

Article 14(5)(b) provides an exception from the obligations placed on you by the right to be informed when you have obtained personal data from a source other than the individual, **if** providing this information:

- proves impossible or would involve disproportionate effort; or
- would be likely to render impossible or seriously impair the objectives of the processing.

The UK GDPR recognises that the first of these issues is especially likely to arise in the context of research, where you may sometimes carry out processing for one of the research related purposes using data that was originally obtained a long time ago by a different organisation.

However, even in this situation, you do not have an automatic exception from the requirement to provide privacy information. You must consider whether the provision of privacy information would involve disproportionate effort. To do this, you must take into account the effort and impact required to provide privacy information, and balance this against the potential effect on the individual that your use of their data will have on them.

When assessing whether or not effort would be disproportionate, you should consider:

- the number of data subjects;
- the age of the data; and
- any appropriate safeguards you have adopted.

If you determine that providing privacy information to individuals does involve disproportionate effort, you must still publish the privacy information (eg on your website), and carry out a Data Protection Impact Assessment (DPIA).

This exception also removes the obligation to provide privacy information, if doing so would render impossible or seriously impair the objectives of your processing. However, this exception is most likely to apply in investigative contexts, when alerting an individual that you are processing their personal data would tip them off to the investigation. It is not likely to apply in the research context.

It is important to note that if you are using data for research purposes that you have collected directly from the individual, this exception does **not** apply.

What is the exemption from the right of access?

Under Article 15 of the UK GDPR, individuals have the right to obtain a copy of their personal data, as well as other supplementary information. This is known as the right of access, or subject access.

However, there are exemptions from the right of access if you are processing for research related purposes. These are listed in separate paragraphs of the DPA 2018:

- Schedule 2 Paragraph 27 provides an exemption if you are processing personal data for scientific or historical research purposes or statistical purposes.
- Schedule 2 Paragraph 28 provides an exemption if you are processing for archiving purposes in the public interest.

The exemptions only apply:

- to the extent that providing access to the data would prevent or seriously impair the achievement of the purposes for processing;
- if the processing is subject to <u>appropriate safeguards</u> for individuals' rights and freedoms;
- if the processing is not likely to cause <u>substantial damage or</u> <u>substantial distress</u> to an individual; and
- if the processing is not used <u>for measures or decisions about particular individuals</u>, except for approved medical research.

Schedule 2 Paragraph 27 sets out a further condition on the exemption for scientific or historical research or statistics, which is that research results or any resulting statistics are not made available in a way that identifies individual data subjects. This condition does not apply to archiving in the public interest.

You must be able to show that giving effect to the right of access would prevent or seriously impair your ability to achieve your research purposes.

You should not apply the exemptions in a blanket fashion, and only **to the extent that** the application of the specific right would cause the prejudicial effect you have identified. Therefore, the application of the exemptions must be necessary and proportionate. You must consider the application of the exemptions on a case-by-case basis.

Example

An individual becomes aware that their health data has been passed to an organisation that is processing it for scientific research purposes. They make a request to the organisation for a copy of all the data the organisation holds about them.

The individual's data is part of a relatively small data set, and disclosure of the data would not prevent or seriously impair the research project. As such, the use of the exemption from the right of access is not necessary.

In these circumstances the exemption does not apply and should not be used. The organisation should therefore disclose the information it holds.

What is the exemption from the right to rectification?

Under Article 16 of the UK GDPR, individuals have the right to have inaccurate personal data rectified. When an individual makes a request for rectification, you should normally take reasonable steps to satisfy yourself that the data is accurate and to rectify the data if necessary. You should take into account the arguments and evidence provided by the data subject.

However, there are exemptions from the right to rectification if you are processing for research related processing. These are listed in separate paragraphs of the DPA 2018:

- Schedule 2 Paragraph 27 provides an exemption if you are processing personal data for scientific or historical research purposes or statistical purposes.
- Schedule 2 Paragraph 28 provides an exemption if you are processing for archiving purposes in the public interest.

The exemptions only apply:

- to the extent that rectifying the data would prevent or seriously impair the achievement of the purposes for processing;
- if the processing is subject to <u>appropriate safeguards</u> for individuals' rights and freedoms;
- if the processing is not likely to cause <u>substantial damage or</u> substantial distress to an individual; and
- if the processing is not used for <u>measures or decisions about particular</u> <u>individuals</u>, except for in the case of approved medical research.

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You must be able to show that giving effect to the right to rectification would prevent or seriously impair your ability to achieve your research purposes.

You should not apply the exemptions in a blanket fashion, and only to the extent that the application of the right to rectification would cause the prejudicial effect you have identified. Therefore, the application of the exemptions must be necessary and proportionate. You must consider the application of the exemptions on a case-by-case basis.

What is the exception to the right to erasure?

Under Article 17 of the UK GDPR, individuals have the right to have their personal data erased. This is also known as the 'right to be forgotten'. However, there is a built-in exception for research.

Article 17(3)(d) states that if you are processing data for research related purposes, the right to erasure does not apply **in so far as** giving effect to the right is likely to render impossible or seriously impair the achievement of your research objectives.

Example

A pharmaceutical company is testing a new drug that it hopes will be used in future to treat patients with flu. To test the drug, the company needs to process the personal data of individuals who take part in trials of the drug, including their health data.

Although participants in the drug trial proactively agree to take part in the trial, their personal data is processed on the basis of legitimate interests.

During the trial, a participant chooses to withdraw from further tests. They make a request to the company to erase all of the personal data it holds about them, including their health data generated during the trial.

Complying with this request would undermine the integrity of the company's data set. It would risk skewing the results of the study, and would thus render impossible or seriously impair the achievement of the company's research objectives.

In these circumstances the exception from the right to erasure would apply. The company is justified in refusing the request to erase the individual's personal data.

What is the exemption from the right to restrict processing?

Under Article 18 of the UK GDPR, individuals have the right to restrict the processing of their personal data in certain circumstances. This means that an individual can limit the way that an organisation uses their data. This is an alternative to requesting the erasure of their data.

However, there are exemptions from the right to restrict processing if you are processing for research related processing. These are listed in separate paragraphs of the DPA 2018:

- Schedule 2 Paragraph 27 provides an exemption if you are processing personal data for scientific or historical research purposes or statistical purposes.
- Schedule 2 Paragraph 28 provides an exemption if you are processing for archiving purposes in the public interest.

The exemptions only apply:

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- to the extent that restricting processing would prevent or seriously impair the achievement of the purposes for processing;
- if the processing is subject to <u>appropriate safeguards</u> for individuals' rights and freedoms;
- if the processing is not likely to cause <u>substantial damage or</u> substantial distress to an individual; and
- if the processing is not used for <u>measures or decisions about particular</u> <u>individuals</u>, except for approved medical research.

You must be able to show that giving effect to the right to restrict processing would prevent or seriously impair your ability to achieve your research purposes.

You should not apply the exemptions in a blanket fashion, and only to the extent that the application of the right to rectification would cause the prejudicial effect you have identified. Therefore, the application of the exemptions must be necessary and proportionate. You must consider the application of the exemptions on a case-by-case basis.

What is the archiving exemption from the right to data portability?

Under Article 20 of the UK GDPR, individuals have the right to receive personal data they have provided to a controller in a structured, commonly used and machine readable format. It also gives them the right to request that a controller transmits this data directly to another controller.

The right to data portability only applies when:

- your lawful basis for processing this information is consent or for the performance of a contract; and
- you are carrying out the processing by automated means (ie excluding paper files).

In practice, this right is usually relevant to organisations who are providing a service to a customer, to allow that customer to easily port their own data to other service providers. It's much less likely to apply in the context of research – especially because research processing is not generally carried out on the basis of consent or contract. (See when processing personal data for research related purposes?)

Because the right is unlikely to be relevant in the context of research, this means there is no general exemption for research purposes.

However, Schedule 2 Paragraph 28 of the DPA 2018 provides an exemption from the right to data portability if you are processing for archiving purposes in the public interest.

The exemption only applies:

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- to the extent that upholding the right to data portability would prevent or seriously impair the achievement of the purposes for processing;
- if the processing is subject to <u>appropriate safeguards</u> for individuals' rights and freedoms;
- if the processing is not likely to cause <u>substantial damage or</u> substantial distress to an individual; and
- if the processing is not used for <u>measures or decisions about particular</u> <u>individuals</u>, except for approved medical research.

There is **no** equivalent exemption from the right to data portability if you are processing for scientific or historical research or statistics. However, this is unlikely to be of any practical significance, because for most research related processing the right to data portability will not apply.

What is the exemption from the right to object?

Under Article 21 of the UK GDPR, individuals have the right to object to the processing of their personal data at any time. This right allows individuals to ask you to stop processing their personal data, or requires you to justify why you need to do so.

For more information on this right, see our guidance on the Right to Object.

Where you are processing personal data for scientific or historical research, or statistical purposes, the right to object is more restricted.

Article 21(6) states:

Quote

'Where personal data are processed for scientific or historical research purposes or statistical purposes pursuant to Article 89(1), the data subject, on grounds relating to his or her personal situation, shall have the right to object to processing of personal data concerning him or her, unless the processing is necessary for the performance of a task carried out for reasons of public interest.'

Effectively this means that if you are processing data for scientific or historical research, or statistical purposes, and have <u>appropriate safeguards</u> in place the individual only has a right to object if your lawful basis for processing is:

- public task on the basis that it is necessary for the exercise of official authority vested in you, or
- legitimate interests.

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It is important to note that the individual does **not** have a right to object if your lawful basis for processing is public task because it is necessary for the performance of a task carried out in the public interest.

Article 21(6) therefore differentiates between the two parts of the <u>public task</u> <u>lawful basis</u> (performance of a task carried out in the public interest **or** in the exercise of official authority vested in you).

This may cause difficulties if you are relying on the public task lawful basis for processing, as it may not always be clear whether you are carrying out the processing solely as a task in the public interest, or in the exercise of official authority. Indeed, it may be difficult to differentiate between the two.

If you do intend to refuse an objection on the basis that you are carrying out research related processing solely for the performance of a public task carried out in the public interest you should be clear in your privacy notice that you are only carrying out the processing on this basis.

If someone objects to you processing their personal data, you have an obligation to consider their objection and the reasons they give.

However you can still continue with the processing, if you can demonstrate compelling legitimate grounds for the processing which overrides the individual's interests (including any specific circumstances raised in their objection).

Where research complies with the appropriate safeguards set out in Article 89 of the UK GDPR and Section 19 of the DPA 2018, we would expect that in most cases, the legitimate interests in the research would override an individual objection. This means that in most cases, you won't actually need to rely on the exemption. You can give full effect to the right to object, by considering the objection, and then explaining to the data subject why your legitimate interests in the research override their objection in the specific circumstances.

However, if you consider that even considering the objection would prevent or seriously impair the achievement of your research objectives, you may use the research related exemptions. These are listed in separate paragraphs in the DPA 2018:

- Schedule 2 Paragraph 27 provides an exemption if you are processing personal data for scientific or historical research purposes or statistical purposes.
- Schedule 2 Paragraph 28 provides an exemption, if you are processing for archiving purposes in the public interest.

The exemptions only apply:

- to the extent that upholding the right to object would prevent or seriously impair the achievement of the purposes for processing;
- if the processing is subject to <u>appropriate safeguards</u> for individuals' rights and freedoms;
- if the processing is not likely to cause <u>substantial damage or</u> <u>substantial distress</u> to an individual; and
- if the processing is not used for <u>measures or decisions about particular</u> <u>individuals</u>, except for in the case of approved medical research.

The onus is on you to demonstrate why even considering the objection would prevent or seriously impair your research objectives. This may be difficult to do, given that the exemptions should not be applied in a blanket fashion, but instead should be applied on a case by case basis. In most situations, considering whether or not to apply the exemption in a particular case will have the same practical effect as simply considering the objection.

However, it is feasible that in some contexts, the act of considering objections might prevent or seriously impair your research objectives, because the volume of objections received means that to consider them all would divert limited resources away from your main functions. In this context it would still not be acceptable to apply the exemptions in a blanket fashion. However, it might be possible to have a general policy that objections are not considered, and then consider whether the specific circumstances mean you should deviate from the policy in any particular case.

Given that this situation is unlikely to occur, we consider that in most cases, you will not need to apply the exemption from the right to object. It would be preferable to consider the objection, and then explain to the data subject why your legitimate interests in pursuing the research override the circumstances of their objection.

What are the appropriate safeguards?

At a glance:

- In order to use the research provisions, you need to have appropriate safeguards in place to protect the rights and freedoms of the individuals whose personal data you are processing.
- These safeguards take the form of technical and organisational measures to ensure respect for the principle of data minimisation.
- Where possible, you should carry out your research using anonymous information. This information is not personal data and data protection law does not apply.
- Where it is not possible to use anonymised data, you should consider whether it is possible to pseudonymise the data. Pseudonymous data is still personal data and data protection law applies.
- Use of the research provisions is not permitted if the processing is likely to cause substantial damage or substantial distress to a data subject.
- Use of the research provisions is not permitted if the processing is carried out for the purposes of measures or decisions with respect to particular data subjects, unless the research is approved medical research.

In detail:

- What does the law say?
- What is data minimisation?
- What is pseudonymisation?
- When is processing likely to cause substantial damage or substantial distress?
- What does 'not used for measures or decisions about particular individuals' mean?

What does the law say?

Article 89 of the UK GDPR says that use of the research provisions is dependent on you having appropriate safeguards in place to protect the rights and freedoms of the individuals whose personal data you are processing.

These safeguards take the form of technical and organisational measures, in particular to ensure respect for the principle of data minimisation. This may Version 1.0 for public consultation

involve anonymising or pseudonymising data, where possible for your research.

Section 19 of the DPA 2018 adds to these safeguards by stating that research related processing will not satisfy Article 89 if the processing:

- is likely to cause <u>substantial damage or substantial distress</u> to data subjects; or
- is carried out for the purposes of <u>measures or decisions about</u> <u>particular individuals</u>, except in the case of approved medical research.

What is data minimisation?

Article 5(1)(c) of the UK GDPR says:

Quote

- 1. Personal data shall be:
- (c) adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed (data minimisation)

This means that you should identify the minimum amount of personal data you need to fulfil your purpose. You should hold that much information, but no more.

You should first consider whether it is possible to conduct your research without using personal data. If it would be possible to carry out your research using data that has been anonymised, then processing of personal data is not necessary, and therefore you cannot rely on the research provisions.

Anonymous information is not personal data, and data protection law does not apply.

Anonymisation refers to the techniques and approaches that aim to ensure the data:

- does not relate to an identified or identifiable individual, or
- is rendered anonymous in such a way that individuals are not (or are no longer) identifiable.

However, it may not always be possible to fulfil your research purposes using anonymised data. For example, if individual data subjects are being tracked in a longitudinal study, then aggregated or anonymous data would make the research impossible.

What is pseudonymisation?

Where it is not possible to use anonymised data, you should consider whether it is possible to pseudonymise the data.

Pseudonymisation refers to techniques that replace or remove information that identifies an individual. Pseudonymisation means that individuals are not identifiable from the dataset itself, but can be identified by referring to other information held separately. Pseudonymous data is still personal data and data protection law applies.

You should ensure that anonymisation or pseudonymisation is done at the earliest possible opportunity, ideally prior to using the data for research purposes.

The ICO is currently working on new guidance on anonymisation, pseudonymisation and privacy enhancing technologies. Links to this guidance will be added here when it is published.

Further reading - ICO guidance

Data minimisation

Security

Data protection by design and default

Data Protection Impact Assessments

Link to anonymisation/pseudonymisation guidance when published

When is processing likely to cause substantial damage or substantial distress?

Section 19(2) of the DPA 2018 says that use of the research provisions is not permitted if the processing is likely to cause substantial damage or substantial distress to a data subject.

The legislation does not define what is meant by substantial damage or substantial distress.

However, in most cases:

 substantial damage would include both material and non-material harms, such as financial loss, economic or social disadvantage, physical harm, damage to reputation, loss of confidentiality, or deprivation of rights; and

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 substantial distress would be a level of upset, emotional or mental pain, that goes beyond annoyance, irritation, strong dislike, or a feeling that the processing is morally abhorrent.

What does 'not used for measures or decisions about particular individuals' mean?

Most research will have some influence on how measures and decisions are taken in future, by generating new insights that inform policy-making, or producing new techniques and processes that change how services are offered. These are legitimate objectives for research to pursue, and processing which aims to change how measures and decisions are taken in future will often be able to rely on the research provisions.

However, Section 19(3) of the DPA 2018 says that use of the research provisions is not permitted if the processing is carried out for the purposes of measures or decisions with respect to particular data subjects, unless the research is approved medical research. What this means is that you cannot rely on the research provisions if you are intending to use that data, and the results of your research, to make specific decisions about the data subjects involved, or to inform the services you provide to them.

It also means that once you have relied on the research provisions to justify retaining data past your normal operational retention periods, you can't later decide to reuse that data for the purposes of making decisions about the data subjects involved. Research must be the sole purpose the data is now used for.

The only exception to this is in the case of approved medical research. Approved medical research means medical research that has been approved by a research committee recognised or established by the Health Research Authority, or by another body for the purpose of assessing the ethics of research involving individuals, appointed by any of the following:

- the Secretary of State, the Scottish Ministers, the Welsh Ministers, or a Northern Ireland Department;
- in England, an NHS trust or NHS foundation trust;
- in Wales, an NHS trust or Local Health Board;
- in Scotland, a Health Board, Special Health Board, or the Common Services Agency for the Scottish Health Service;
- in Northern Ireland, a Health and Care social body as defined by Section 1(5) paragraphs (a) to (e) of the Health and Social Care (Reform) Act (Northern Ireland) 2009;
- United Kingdom Research and Innovation or one of the Research Councils; or

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• a research institution as defined by Chapter 4A of Part 7 of the Income Tax (Earnings and Pensions) Act 2003.

Relevant provisions in the Data Protection Act 2018 – Section 19(3) (external link)