

Data Privacy Handbook

Utrecht University

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Intro

Data Privacy Handbook



Utrecht University

Data Privacy Handbook

Utrecht University, 07 October 2022

The Data Privacy Handbook is a guide on handling personal data in scientific research, in line with European data protection and privacy regulations. It consists of:

- A **knowledge base** which explains how the EU General Data Protection Regulation (GDPR, Dutch: Algemene Verordening Gegevensbescherming) applies to scientific research, including guidelines and good practices in carrying out GDPR-compliant scientific research;
- An overview of privacy-enhancing **techniques & tools** and practical guidance on their implementation;
- **Use Cases** in the form of research projects with privacy-related issues, for which a reusable solution (e.g., tool, workflow) has been developed.

The Data Privacy Handbook synthesises information across various sources and presents it a *practical* format. This includes workflows, tools, and practical translations of the GDPR, which could be used by researchers and (data) support staff within Utrecht University and beyond.

The Data Privacy Handbook is an initiative of Research Data Management Support at the Utrecht University Library, in collaboration with privacy and data experts at Utrecht University. It is part of a larger project, the Data Privacy Project, which aims to develop knowledge, tools, and experience on how researchers can and should deal with personal data. This project is funded by

the Utrecht University Research IT Program and an NWO Digital Competence Center grant.

This is an Utrecht University (UU) community-driven, open-source project. We welcome feedback and contributions of any type, please read our contributing guidelines for more information.

0.1 How to use this Handbook

The Data Privacy Handbook aims to make knowledge and solutions on handling personal data *Findable, Accessible, Interoperable, and Reusable* (FAIR) and present them in a practical format.

The Handbook need not be read like a textbook. You are invited to navigate to the topic you need based on the table of contents, or use the guide below.

0.1.1 What are you looking for?

I want to...:

Learn about the GDPR in the context of scientific research

Introduction to the GDPR

Definitions

Plan a GDPR-compliant research project

Assessing your design

Informing participants

Obtaining consent

Collaborating on personal data

Work safely with personal data

Storing personal data

Using GDPR-compliant tools and services

Reducing the sensitivity of personal data

Sharing personal data during research

Share personal data with others

Sharing data legally

Sharing personal data during research

Reducing the sensitivity of personal data

- Using GDPR-compliant tools and services
- Publishing personal data
- Sharing personal data case by case
- Learn from other projects
- Publishing metadata only
- Pseudonymising different types of data
- Minimising personal data processing in a survey
- Get help or information
- Getting help at Utrecht University
- Definitions
- References

0.2 License and Citation

The Data Privacy Handbook is licensed under a Creative Commons Attribution 4.0 International License. You can view the license [here](#).

0.3 Disclaimer

The content presented in the Data Privacy Handbook has been carefully curated by Research Data Management Support, in collaboration with privacy officers and data experts of Utrecht University.

The Data Privacy Handbook is a ‘living’ book that is continually being written, updated and reviewed. Its contents can therefore change, or become outdated or redundant. Hence, the information presented is provided “as is”, **without guarantees of accuracy or completeness**.

As scientific research may differ depending on the discipline, topic, and context, measures needed or taken to ensure GDPR-compliance will vary across research projects. The authors can therefore **not be held responsible, nor accountable** for any negative consequences arising from interpretation and use of the content of the Data Privacy Handbook.

The Handbook is not endorsed by the Board of Utrecht University and does not constitute a mandatory directive. For the most up-to-date and official/authoritative information, please refer to the university website and intranet, to which this Handbook is a hands-on, practical supplement. Moreover, before implementing the guidance laid out in this Handbook, always seek the advice of

your privacy officer or RDM Support to confirm the suitability of any proposed solution to your project.

Throughout the Data Privacy Handbook, links to external webpages may be provided for additional information or assistance. The authors of the Data Privacy Handbook are **not responsible for the content of any such linked webpages**, nor is the content of external webpages necessarily endorsed by Utrecht University.

Utrecht University is committed to sharing knowledge in line with the principles of open science and therefore welcomes readers from outside of the organization. However, the contents of the Data Privacy Handbook may not be in line with readers' institutions' policies or views. For more authoritative information, these readers should refer to resources from their own institutions.

0.4 Contributions

The Data Privacy Handbook is a collaborative effort, made possible by a large number of contributors (also to be viewed in our [GitHub repository](#)):

Neha Moopen, Dorien Huijser, Jacques Flores, Wies Cipido, Joris de Graaf, Judith de Haan, Saskia van den Hout, Frans Huigen, Artan Jacquet, Sanne Kleerebezem, Annemiek van der Kuil, Danny de Koning-van Nieuwamerongen, Frans de Liagre Böhl, Francisco Romero Pastrana, Najoua Ryane, Johanneke Siljee, Ron Scholten, Garrett Speed, Robert Steeman, Liliana Vargas Meleza, Martine de Vos, and others.

Would you like to contribute to this Handbook yourself? Please read our [Contributing Guidelines](#).

Chapter 1

Privacy FAQs

On this page you can find some often-heard questions about handling personal data in research. Click a question you have to read its answer.

This is a first FAQ. More will follow!

Am I a processor as employee of my university?

No. As an employee you are still determining your own why (research question) and how (methods) of personal data processing. This makes you a controller, acting as an “agent” of the legal controller (your university). Read more on the difference between processors and controllers on the definitions page.

Knowledge Base

The GDPR

This chapter will present the most important definitions, principles and rights of data subjects outlined in the GDPR and how it applies to your research. Most of the practical advice that we provide in this Handbook will be rooted in and builds on the concepts presented here.

1.0.1 Chapter summary

The GDPR is a EU-wide regulation that controls the processing of personal data. If you process personal data, you should:

- Make sure you have a legal basis to process the data. In research, this is often informed consent.
- Be transparent and fair towards data subjects.
- Be specific in which personal data you process and for what purposes. Limit the amount of data you process to what is necessary, and only store the data for that necessary amount of time.
- Protect the confidentiality of the data by incorporating privacy by design into your project from the start.
- Make sure your data subjects can exercise their data subjects' rights, and they know how to do so.

1.1 What is the GDPR?

The General Data Protection Regulation (GDPR, Dutch: *Algemene Verordening Gegevensbescherming* [AVG]) is an EU-wide regulation meant to protect the privacy of individuals within a rapidly growing technological society. The GDPR facilitates the free movement of personal data within the European Economic Area (EEA). Its data processing principles are meant to ensure a fair balance between competing interests – for example, the right to conduct research vs. the right to protect personal data (Articles 13 and 8, from the Charter of Fundamental right of the EU).

1.1.0.1 The GDPR in a nutshell

All articles and recitals of the GDPR can be found online via <https://gdpr-info.eu/>. The video below highlights some important aspects of the GDPR:

Click to read the English video transcript

The General Data Protection Regulation (GDPR) regulates what we can and cannot do with personal data such as a person's name, sexual orientation, home address and health. This also applies to personal data used in research and education. The regulation consists of 88 pages. Fortunately, the basics are easy to remember in 3 steps:

First, there must be a clear legal basis for processing personal data. This can include consent, a legal obligation, or public interest.

Second, appropriate technical and organisational measures must be taken while processing personal data to ensure maximum privacy.

Lastly, the persons whose data you have collected must always have the option of inspecting, changing, or removing their personal data.

That is the GDPR in a nutshell.

1.1.0.2 When does the GDPR apply?

The GDPR has been applicable from May 2018 onward and applies when:

- you are processing personal data (material scope, art. 2).
- the controller or processor of the data *resides* in the EEA (territorial scope, art. 3). This is independent of whether the actual processing takes place in the EEA. In some cases, the GDPR also applies when the controller or processor is not established in the EEA, but is processing data from EU citizens.

If you are collecting or using data that originated from individuals (or is related to individuals), it is very likely that the GDPR applies to your project.

1.1.0.3 Implementation

While the GDPR is a regulation for the entire EEA, each EEA country can additionally implement further restrictions and guidelines in national implementation laws. The Dutch implementation law is called “Uitvoeringswet AVG (UAVG)” (most recent version). The UAVG determines, for example, that it is forbidden to process Citizen Service Numbers (BSN), unless it is for purposes determined by a law or a General Administrative Order (AMvB).

1.2 Definitions in the GDPR

Below, you will find a selection of important terms in the GDPR that you should become familiar with when working with personal data (also included in the Definitions). Click a term to see the definition.

Data subject

A living individual who can be identified directly or indirectly through personal data. In a research setting, this would be the individual whose personal data is being processed (see below for the definition of processing).

Personal data

Any information related to an identified or identifiable (living) natural person. This can include identifiers (name, identification number, location data, online identifier or a combination of identifiers) or factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of the person. Moreover, IP addresses, opinions, tweets, answers to questionnaires, etc. may also be personal data, either by itself or through a combination of one another.

Of note: as soon as you collect data related to a person that is identifiable, you are processing personal data. Additionally, pseudonymised data is still considered personal data. Read more in Designing a GDPR-compliant research project.

Special categories of personal data

Any information pertaining to the data subject which reveals any of the below categories:

racial or ethnic origin

political opinions

religious or philosophical beliefs

trade union membership

genetic and biometric data when meant to uniquely identify someone

physical or mental health conditions

an individual's sex life or sexual orientation

The processing of these categories of data is prohibited, unless one of the exceptions of Article 9 applies. For example, an exception applies when:

the data subject has provided explicit consent to process these data for a specific purpose,

the data subject has made the data publicly available themselves,

processing is necessary for scientific research purposes.

Contact your privacy officer if you wish to process special categories of personal data.

Processing

Any operation performed on personal data. This includes collection, storage, organisation, alteration, analysis, transcription, sharing, publishing, deletion, etc.

Controller

The natural or legal entity that, alone or with others, determines or has an influence on why and how personal data are processed. On an organisational level, Utrecht University (UU) is the controller of personal data collected by UU researchers and will be held responsible in case of GDPR infringement. On a practical level, however, researchers (e.g., Principal Investigators) often determine why and how data are processed, and are thus fulfilling the role of controller themselves.

Processor

A natural or legal entity that processes personal data on behalf of the controller. For example, when using a cloud transcription service, you often need to send personal data (e.g., an audio recording) to the transcription service for the purpose of your research, which is then fulfilling the role of processor. When using such a third party, you must have a data processing agreement in place.

Legal basis

Any processing of personal data should have a valid legal basis. Without it, you are now allowed to process personal data at all. The GDPR provides 6 legal bases which are explained further in this chapter.

Anonymous data

Any data where an individual is irreversibly de-identified, both directly (e.g., through names and email addresses) and indirectly. The latter means that you cannot identify someone:

by combining variables or datasets (e.g., a combination of date of birth, gender and birthplace, or the combination of a dataset with its name-number key)

via inference, i.e., when you can deduce who the data are about (e.g., when profession is Dutch prime minister, it is clear who the data is about)

by singling out a single subject, such as through unique data points e.g., someone who is 210 cm tall is relatively easy to identify)

Anonymous data are no longer personal data and thus not subject to GDPR compliance. In practice, anonymous data may be difficult to attain and care must be given that the data legitimately cannot be traced to an individual in any way. The document Opinion 05/2014 on Anonymisation Techniques explains the criteria that must be met for data to be considered anonymous.

Pseudonymous data

Personal data that cannot lead to identification without additional information, such as a key file linking pseudonyms to names. This additional information should be kept separately and securely and makes for de-identification that is reversible. Data are sometimes pseudonymised by replacing direct identifiers (e.g., names) with a participant code (e.g., number). However, this may not always suffice, as sometimes it is still possible to identify participants indirectly (e.g., through linkage, inference or singling out). Importantly, pseudonymous data are still personal data and therefore must be handled in accordance with the GDPR.

1.3 Principles in the GDPR

The GDPR has a number of principles at its core which dictate the (method of) data processing. Every type of processing has to comply with these principles. Understanding these principles is the first step to determining what type of personal data can be collected and how they can be processed.

The GDPR principles are explained further below the image. The next chapter will describe how to implement these principles in your research. You can also always contact your privacy officer for help.

1.3.0.1 1. Lawful, fair and transparent

When working with personal data, your processing should be:

Lawful Make sure all your processing activities (e.g., data collection, storage, analysis, sharing) have a legal basis. Ideally, you should have determined your processing purposes (e.g., research questions) in advance.

Fair

Consider the broad effects of your processing on the rights and dignity of the data subject.

Give data subjects the possibility to exercise their rights.

Avoid deception in the communication with data subjects: processing of personal data should be in line with what they can expect.

The processing of personal data should not have a disproportionate negative, unlawful, discriminating or misleading effect on data subjects.

Transparent Be transparent in the communication to your data subjects about who is processing the personal data (controllers, processors), which personal data is processed, as well as why and for how long, and how data subjects

can exercise their rights (see the Legal documents chapter). The information provided should be unambiguous, concise, easily accessible and relevant and shared with data subjects before the start of your research.

1.3.0.2 2. Purpose limitation

You can only process (i.e., collect, analyse, store, share, etc.) personal data for a specific purpose and only for as long as necessary to complete that purpose. For example, if you specified that you would use the personal data only to answer your specific research question, you cannot further share the personal data for reuse purposes, as this would be an additional processing purpose. This means that you need to **plan what you will do with the (collected) personal data in advance and stick to that plan in order to be GDPR-compliant**.

In some cases (e.g., for cohort studies), it may not be possible to communicate a specific research purpose in advance. In those cases, you may be able to use “broad consent” when possible. For more information on broad consent and which conditions must be met in that case see the Legal Documents chapter.

1.3.0.2.1 Further processing It may happen that you want to process personal data for **similar, but other purposes** than previously specified, for example because you formulated a research question that was not communicated with the data subjects. In these cases, the GDPR provides some leeway: you can still process the personal data if the new processing (e.g., the new research question) is **compatible** with the original purpose. Your privacy officer can help you assess whether this is the case. Of note, **archiving** personal research data after your research is finished is allowed in a research context (art. 5.1(b)), but provided that you still apply the GDPR’s principles and put in place appropriate safeguards (rec. 156).

1.3.0.3 3. Data minimisation

You can only process the personal data you need to for your predefined purpose(s), and not more just because they may “come in handy later”. This principle makes sure that, for example, in the event of a data breach, the amount of data exposed is kept to a minimum.

1.3.0.4 4. Accuracy

The accuracy of personal data is integral to data protection. Inaccurate data can be a risk for data subjects, for example when they lead to a wrong treatment in a medical trial. You therefore need to take every reasonable step to remove or rectify data that is inaccurate or incomplete. Moreover, data subjects have

the right to request that inaccurate or incomplete data be removed or rectified within 30 days.

1.3.0.5 5. Storage limitation

You can only store personal data for as long as is necessary to achieve your (research) purpose. Afterwards, they need to be removed. If the personal data are part of your research data (and not, for example, to simply contact data subjects), you are allowed to store (archive) them for a longer period of time, provided necessary safeguards are in place. This is an exemption that applies to data storage for scientific archiving purposes. You need to inform the data subjects on this storage duration beforehand.

If identification of the data subject is no longer needed for your (research) purposes, you do not need to keep storing the personal data just to comply with the GDPR, even if it means your data subjects cannot exercise their rights (art. 11).

1.3.0.6 6. Integrity and confidentiality

You have to process personal data securely and protect against unauthorised processing or access, loss or damage. To this end, you should put in place appropriate organisational and technical measures. The next chapter will go into such measures in more depth.

1.3.0.7 7. Accountability

The controller is ultimately responsible for demonstrating GDPR-compliance. As a researcher working with personal data, you are representing your institution (e.g., Utrecht University) and you should therefore be able to demonstrate that you process personal data in a compliant manner. Additionally, you should also have some knowledge of data protection so that you can implement the right measures into your research project.

1.4 When can I work with personal data?

You can only process personal data if you have a **legal basis** to do so, which should be registered, among other information, in the processing register and communicated to data subjects. There are 6 possible legal bases which are outlined below. In research, the legal bases ‘informed consent’, ‘legitimate interests of the controller’ and ‘public interest’ are most often used.

For different purposes in your research project, a different legal basis may apply. For example, you may contact data subjects before they start participating based on a legitimate interest and use informed consent for collecting, storing, analysing and publishing the data.

1.4.1 Legal bases suitable for research

Informed consent

Informed consent is the most frequently used legal basis in research and is often not only a legal (GDPR-consent), but also an ethical obligation (e.g., METC informed consent). When using informed consent, you should be able to demonstrate that the data subject was informed and has given consent, and for which purpose(s) they gave their consent. In all cases, consent has to be freely given, specific, informed and unambiguous. Please refer to the Informed consent section for guidance on applying informed consent in your research.

Legitimate interest of the controller

You can use this legal basis when processing personal data is necessary for the legitimate interests of the controller (e.g., Utrecht University). For example, this can be the case when you need to process contact information to approach data subjects to participate, and you can only obtain their consent after contacting them. Since contacting data subjects is a prerequisite to perform your research, it can be in the university's legitimate (research) interest to process their contact information. To evaluate whether you can use legitimate interest as a legal basis, you always need to weigh the interests of the controller (e.g., Utrecht University) and the data subjects in a Legitimate interest assessment. Please contact your privacy officer to assess whether you can use this legal basis in your research.

Public interest

This legal basis can only be used if it can be demonstrated that there is an urgent social necessity for the processing of personal data. This means that there must be an explicit increase in knowledge in the interest of society. There is currently some disagreement as to when this legal basis can be applied in research. Therefore, please contact your privacy officer to assess whether you can use this legal basis in your research.

1.4.2 Legal bases not suitable for research

Processing is necessary because of a legal obligation of the controller

This basis is not suitable for research. As an example, Utrecht University has to share tax data with the Dutch tax administration in order to comply with tax legislation.

Processing is necessary for the performance of a contract

This basis is not suitable for research. As an example, Utrecht University has contracts with its employees, which require it to manage the employees' financial data.

Processing is necessary to protect a person's vital interests

This basis is generally not suitable for research. If processing someone's personal data is crucial to their health or even life, that processing is allowed under the GDPR.

1.5 Data Subject's Rights

The GDPR provides data subjects with several rights that gives them a relatively high degree of control over their own personal data. Below, we list these rights and how you can apply them in your research:

Right to be informed

Data subjects need to be clearly informed about what you are doing with their personal data (a.o. art. 12). This usually happens via a *privacy notice* or *information letter*. This right does not apply if your research will be seriously harmed by meeting it and if you haven't obtained the personal data directly from the data subjects themselves.

Right of access

Data subjects have the right to access a copy of the personal data you have on them and to know what you are doing with that personal data and why (art. 15).

Right to rectification

Data subjects have the right to correct and complement the personal data that you have of them art. 16).

Right to erasure/Right to be forgotten

Data subjects have the right to have their personal data removed (i.e., equivalent to the right to withdraw consent, art. 17). This right does **not** need to be granted if:

the personal data are published and need to be archived for validation purposes.

it would seriously obstruct the research purpose(s).

it would hinder complying with a legal obligation or carrying out a task in the public interest.

If the personal data have already been made public or shared, you need to take reasonable measures to inform other users of the data of the erasure request. A privacy officer can help you with this.

Right to restriction of processing:

Data subjects have the right to have you process less of their personal data (art. 18), for example if their personal data are inaccurate or your processing of it is unlawful or no longer needed.

Right to data portability:

Data subjects have the right to have their personal data transferred to another party (art. 20).

Right to object:

Data subjects have the right to object to what you are doing with their personal data. This right applies when the processing is based on legitimate or public interest (art. 21). In case of objection, you have to stop your processing activities, unless you can demonstrate grounds for overriding the data subject's rights.

1.5.0.1 How can data subjects exercise their rights?

Data subjects need to be **informed** about their rights and who to contact in order to exercise them, including when you use a legal basis other than informed consent. In research, this is usually done via a privacy notice or information letter, which states a contact person responsible for handling questions and requests.

Incoming requests need to be **coordinated with a privacy officer**, so that they can be picked up in accordance with the GDPR. Additionally, at Utrecht University, data subjects can always contact privacy@uu.nl (the Data Protection Officer) for requests or complaints.

1.5.0.2 What to do when receiving a request concerning data subjects' rights?

You have to provide a substantive response to the data subject **within 30 days**, in the same way as you received the request. Depending on the complexity and number of requests, the response period may be extended by 2 months. In that case, you must inform the data subject about this extension (including the motivation) within one month. If needed, you can (and sometimes should) ask for additional information to confirm the data subject's identity.

For granting requests about data subjects' rights, there should be a procedure in place, in which you should at least consider:

- how you are going to retrieve the data (e.g., using a name-number key)
- who is responsible for granting the request and informing the data subject about it (e.g., a data manager)

- how the request is going to be granted, for example how they will be sent securely (access, portability), removed (forgotten, object, restriction) or corrected (rectification)

For larger projects, it may be wise to put a Standard Operating Procedure (SOP) in place.

1.5.0.3 What if the data have already been anonymised?

The principles of data minimisation and storage limitation are considered more important than keeping personal data just for the sake of identification (art. 11). Therefore, when receiving a request about anonymised data, you can make it clear that you cannot retrieve the data subject's personal data, because they have been anonymised. In this case, **the data subject cannot exercise their rights anymore**. If you can still retrieve the data subject's personal data in some way (i.e., when data are pseudonymised), you are **obliged to retrieve them**. In order to do so, you can (and sometimes should) ask for additional information that can confirm the data subject's identity.

Chapter 2

What are personal data?

In order to know whether you should comply with the GDPR in your research project, the first question to answer is: do you process personal data? To answer this question, we need to know: (1) What exactly are personal data, and (2) how do you know if you are working with personal data in your research?

2.1 Definition of personal data

According to the GDPR, personal data are “any information relating to an identified or identifiable natural person” (art.4(1)):

- **Natural person:** Data by themselves (numbers, text, pictures, audio, etc.) are not inherently personal. They only become personal when they refer to or relate to a **living individual**. When data refer to an organisation, deceased person, or group of individuals, they are not considered personal data under the GDPR.
- Data are personal if they **relate** to an individual. This means practically anything that someone is, has said or done, owns, may think, etc.
- The person should be **identified or identifiable**. This is the case not only through **directly** identifying information, such as names and contact information, but also through **indirectly** identifying information, for example if you can single someone out or identify them by combining datasets (see the next page).

2.2 How to assess whether data contain personal data?

Whether your data contains personal data depends on which data you are collecting (nature) and under which circumstances (context). A date like “12 December 1980”, is not personal data – it is just a date. However, that date becomes personal data if it refers to someone’s birthday.

In assessing whether data are personal, you should take into account all the means that you and others may **reasonably likely** use to identify your data subjects, such as the required money, time, or (future) developments in technology (rec. 26).

Data can be identifiable when:

- They contain **directly identifying information**.

Examples

name, image, video recording, audio recording, patient number, IP address, email address, phone number, location data, social media data

- It is possible to **single out** an individual, for example when there are unique data points or unique behavioural patterns which can only apply to one person.

Examples

You have a data subject who is 2.10 meters tall. If this is a unique value in your dataset, this distinguishes this person from others and thus can make them identifiable.

You have a data subject who only follows far-right accounts on Twitter. If they are the only one in your dataset who do so, this distinguishes this person from others and can make them identifiable.

- It is possible to **link records** relating to an individual or to **infer information** about an individual. This can happen when combining multiple variables within your dataset (e.g., demographic information, indirect identifiers). However, it can also happen when combining your dataset with other datasets (the “Mosaic effect”). In that case, your data still contain personal data, even if the data in your dataset are not identifiable by themselves.

Examples

Inference or linkage are often possible with demographic information (age, gender, country of origin, education, workplace information, etc.) and indirect identifiers (pseudonyms, device ID, etc.), for example:

In the year 2000, 87% of the United States population was found to be identifiable using a combination of their ZIP code, gender and date of birth.

An agricultural company’s Uniek Bedrijfsnummer (UBN) can be used to search for the address of the company in the I&R mobile app. Often, this address is also the owner’s home address.

- De-identification is still **reversible**. This often happens when data are pseudonymised, but there is still a way to link the pseudonymised data with identifiable data, for example when a name-pseudonym key still exists.

In short, even if you cannot find out someone's real identity (name, address), the data you process can still contain personal data under the GDPR. Besides the examples mentioned here, there are many other examples of personal data. If you need help assessing whether or not your data contain personal data, please contact your privacy officer or data manager.

2.3 Special types of personal data

There are a few special types of personal data that are worth taking note of: special categories of personal data, and otherwise sensitive personal data. These types of personal data have additional requirements. If you want to process them, please contact your privacy officer first.

2.3.1 Special categories of personal data

The GDPR explicitly defines seven 'special categories of personal data'. It is information that reveals:

- racial or ethnic origin
- political opinions
- religious or philosophical beliefs
- trade union membership
- genetic or biometric data when meant to uniquely identify someone
- physical or mental health conditions
- sex life or sexual orientation

It is in principle **prohibited** to process these types of personal data, unless an exception applies (art.9). For example, it is allowed to process these if:

- Data subjects have provided explicit consent to process these data for a specific purpose
- Data subjects have made the data publicly available themselves
- Processing is necessary for scientific research purposes (incl. historical and statistical purposes)

Even if you can make use of one of these exemptions, special categories of personal data warrant additional security measures to make sure they are protected. Always contact your privacy officer if you intend on processing these types of data.

2.3.2 Data that are otherwise sensitive

Other types of data can also be sensitive, because they can carry higher risks for the data subjects. These types of data can either not be processed at all, or only under certain circumstances. Either way, they require additional security measures. Always contact your privacy officer if you intend on using these types of data.

Examples are:

- Financial data
- Data about relationship problems
- Data that can be misused for identity fraud, such as the Dutch Citizen Service Number (BSN). In principle, the BSN cannot be used in research at all.
- Criminal or justice-related data: they can only be processed under governmental supervision or when a derogation exists in national legislation (art. 10).

Chapter 3

Designing your project

Chapter 4

Privacy & Security Assessment

Chapter 5

Documents & Agreements

This chapter addresses privacy-related documentation that is most commonly used within research. For each type of documentation, it explains what it entails, when to use it, and how.

The following documents are addressed:

- Privacy notices
- Informed consent forms
- Privacy scan
- Data Protection Impact Assessment
- Data classification
- Legitimate interest assessment
- Data Transfer Impact Assessment
- Several agreements, such as the non-disclosure agreement, data processing agreement, data transfer agreement, joint controller agreement, and data use agreement.

This chapter is a work in progress: sub-chapters are added continuously.

5.1 Privacy notices

A privacy notice is any information given to data subjects about what is happening with their personal data. In research, a privacy notice is usually combined with general information about the research project and often with an informed consent form, to satisfy both privacy and ethical concerns. Generally, the aim of a privacy notice is to inform data subjects on how and why their data are being processed. Providing that information is the “cornerstone of data subjects’ rights”, as without it, data subjects cannot exercise their other privacy rights.

5.1.1 When to use a privacy notice?

Informing data subjects is always required, for **all legal bases** (so not only when you use informed consent). Being properly informed is a data subject's right in itself (art. 12): it is necessary so that data subjects can exercise their other rights (e.g., right to be informed, right to object, etc.).

You need to inform data subjects **before** you start processing their personal data (so before the start of your research project). When you use data from another source (art. 14), you have to inform your data subjects within a month after obtaining their data. If the data are shared with an external party, this can happen at the latest when first sharing those data with that external party.

5.1.2 Content and examples of privacy notices

Below you can find a list of items to include in your information to data subjects (Template) and some example sentences to (not) include in your privacy notice (click to expand).

Template privacy notices

Example sentences

Bad promise

Alternative

“After the project ends, we will delete all of your data, so that you will not be identifiable anymore.”

“After the end of the study, we will delete the code linking your data to your name. We will store your de-identified data for 10 years for integrity purposes.”

“Your data will be fully anonymised before they are shared with others.”

“We will remove personal information that could reasonably identify you before we share any files with other researchers.”

“All data that you will provide will be kept strictly confidential and will not be shared further.”

“The main researcher will keep a link that identifies you to your coded information. They will keep this link secure and available only to the selected members of the research team.”

“Your data will only be accessible by the research team, and no one else.”

“We will only share your de-identified data with other researchers if they agree to treat your data confidentially and only after approval from the original research team.”

“You can withdraw your consent from this study at any time up until the end of the research project. If you withdraw your consent, we will delete all your data from our dataset immediately.”

“You can withdraw your consent from this study at any time, without stating a reason why and without any repercussions. Please inform the researcher about your decision. We will then delete any personal data referring to you that we still have. However, if we somehow processed your data before you withdrew your consent, such processing does not need to be undone.”

5.1.3 Form of a privacy notice

The format of the privacy notice is also crucial. Even if you include all necessary components in your privacy notice, it will **not be GDPR-compliant** if you fail to provide the information in an appropriate form, shape and time.

The information you provide to data subjects should also be:

- **Clear and understandable** A privacy notice is not a legal document, so do not write it like you would write a legal contract. The information should be understandable for data subjects and it should have a clear and concrete meaning. For example, avoid using words like “may”, “some”, “often” and write active and short sentences.
- **Easily accessible** Data subjects should be able to find the information easily. For example, publish the privacy notice on your project website, give participants a copy, or provide a QR-code or short URL.
- **Via multiple channels (when appropriate)** Textual information sheets are by no means the only way to inform data subjects. If appropriate, you can provide the information via other channels too, e.g., oral statements, images, audio, video (example), etc. For some data subjects, such other channels of informing can lead to a better understanding of your processing activities.
- **Layered (when appropriate)** To balance being complete with being understandable, you can layer the information you provide. For example, provide concise information up front and provide more detailed information elsewhere (e.g., via a link or dropdown menu).

If you are uncertain about the level of intelligibility and transparency of the information, you can test these, for example through user panels, readability testing, or by interactions with data subjects themselves (or their representatives).

5.2 Informed consent forms

5.3 Privacy scan

5.4 Data Protection Impact Assessment

5.5 Data classification

5.6 Legitimate interest assessment

5.7 Data Transfer Impact Assessment

5.8 Agreements

5.8.1 How to set up an agreement?

5.8.2 Non-disclosure agreement

5.8.3 Data processing agreement

5.8.4 Data Transfer Agreement

5.8.5 Joint controller agreement

5.8.6 Data Use Agreement

Techniques & Tools

Chapter 6

Privacy-Enhancing Techniques in Working With Personal Data

6.1 Anonymization

6.2 Pseudonymization

6.3 Encryption

6.4 Synthetic Data

6.5 Federated Analysis

Chapter 7

Tools & Services

7.1 `tools.uu.nl`

7.2 Survey Tools

7.3 Transcription Tools

Storage, Sharing, Publication

Chapter 8

Storing personal data

In research, storage of personal data is one of the most common processing activities. Assuming you have a legal basis to store personal data, you then need to:

- Choose a storage medium that is GDPR-compliant and that provides a sufficient level of data protection;
- Take into account procedural and legal aspects, e.g., how will you handle the data once they are stored, and for how long will you store the data?

These aspects of storing personal data are discussed in this chapter.

8.0.1 Chapter summary

Where should I store personal data?

Use a medium that has been approved by your institution. If you work at Utrecht University, and your preferred storage medium is not included in the Storage Finder, then please contact RDM Support or your privacy officer to find an alternative solution.

How to store personal data?

- Apply organisational and technical safeguards, e.g., restrict access, encrypt data, pseudonymise data, specify responsibilities, etc.
- Store (personal) data preferably in a structured, commonly used, machine-readable and interoperable format: others should be able to open, understand and work with your data.

For how long should I store personal data?

- Delete or fully anonymise personal data when they are no longer necessary, and preferably determine when you will do this in advance.
- In research, you can archive personal data that are necessary for validation purposes for a longer period of time, e.g., 10 years or longer.

8.1 Where should I store personal data?

8.1.1 Storage media at UU

If you work at Utrecht University (UU), you can find a suitable storage medium for digital research data via the Storage Finder (see below). For personal data, select Basic, Sensitive or Critical (depending on the sensitivity of your data) under question 4 about Confidentiality.

Most storage media in this overview are suitable for storing personal data, either because they are controlled by UU (e.g., U- and O-drive, Beta File System) or because UU has a Data Processing Agreement in place with the storage supplier (e.g., Microsoft Office 365, Yoda, SURFdrive).

Is your preferred storage medium not included in the storage finder? Contact RDM Support, your data steward, or your privacy officer to find an alternative solution.

- Consider encrypting your data, especially when using **portable devices** (e.g., memory sticks, phones). Portable devices are also not suitable as back-up, due to bit rot and being easily lost.
- Physical personal data (e.g., paper questionnaires, informed consent forms) should be stored securely too, e.g. in a locked room, cabinet or drawer. You should also avoid leaving unsecured copies lying around (e.g., on a desk or printer).

Do not store research data containing personal data on public cloud services, e.g., Google Drive, Dropbox, OneDrive, Box, Mega, iDrive, iCloud, NextCloud, etc. These services are not (always) GDPR-compliant and/or may not offer sufficient data security. Moreover, UU does not have any formal agreements with these services, enabling them to use the data stored on their platforms for their own purposes.

If you work at UU, please find a suitable storage medium below

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[illegible]

If the Storage Finder does not display correctly, you can also easily check it out online.

8.2 Requirements for a suitable storage medium

Whether a storage medium is suitable for storing personal data depends on 1) who is controlling the personal data, and 2) the security measures of the storage medium. If you want to use a storage medium not recommended/offered by UU, please consult with RDM Support, your data steward, or your privacy officer.

8.2.1 1. Who is storing the personal data: arrange an agreement

When you use an external storage provider, the data is not under the (full) control of your employer. In this case, it is required to ensure GDPR compliance of the storage provider using (art. 46):

- A Data Processing Agreement - when storing personal data within the European Economic Area (EEA) or a country with an adequate level of data protection.
- Standard contractual clauses (SCCs) - when storing personal data with a supplier outside of the EEA. These make sure the storage medium will use sufficient measures to protect the personal data and enable data subjects to exercise their rights.
- Explicit consent of data subjects who have been informed on the risks involved - in the absence of an agreement. Please contact your privacy officer if you are considering this option.

You can assume agreements are in place for the storage media recommended by UU. If there is no agreement in place between UU and the storage provider, using this storage provider is **not allowed**, even if they are located within the EEA, have an adequate level of data protection, or have high security standards. The only exception is when data are always end-to-end encrypted, because then the storage provider cannot learn anything from the data.

8.2.2 2. Security of the storage medium

The storage medium should employ good security practices, such as regular back-ups in distinct geographical areas (preferably in replication rather than on tape), regular integrity checks, encryption at rest, multi-factor authentication, etc. Most of these aspects will likely be covered in the agreement. Information security can help determine all necessary security requirements.

8.3 How should I store personal data?

Once you have chosen a suitable storage medium, you should act in accordance with the nature of your data as well, for example through:

- Controlling access: make sure that only the necessary people have the right kind of access (e.g. read/write) to the personal data, and remove their access when they do not longer need it (e.g. when someone leaves the research project).
- Specifying responsibilities, e.g. who is responsible for guarding access to the data on both the short and the long term? Make people aware of the confidential nature of the data. Tell them what to do in case of a data breach.
- Procedural arrangements, e.g. capture access conditions in agreements like the consortium agreement, data processing agreement or non-disclosure agreement.
- Storing different types of personal data in different places, e.g., research data should be stored separately from data subjects' contact details.
- Applying other safeguards where appropriate, e.g., encryption, anonymisation, pseudonymisation, etc. (see chapter Privacy-enhancing techniques).

See Designing a GDPR-compliant research project for more tips.

Personal data should be stored in a **“structured, commonly used, machine-readable and interoperable format”** (rec. 68). In practice, this means that you should consider whether your files are structured and named in a logical way, use sustainable file formats, and provide understandable metadata so that others can interpret the data. You can read more about this in the RDM guide “Storing and preserving data”.

8.4 For how long should I store personal data?

As per the GDPR, anyone processing personal data can only store those for as long as is necessary for prespecified purposes (art. 5(e)). Afterwards, the personal data have to either be fully anonymised or deleted. However, there is an exemption for research data, as described below.

In research, we often see a division in two types of retention periods:

- If the personal data underpin a scientific publication, it is usually necessary to archive some personal data for **integrity and validation purposes** (art. 5(e)), because they are part of the research data. At UU, any

research data necessary for validation should be archived for at least 10 years (UU research data policy). If this includes personal data, they too should be archived. Importantly, this still means that you need to **protect** the personal data, and **limit** the personal data stored to the amount necessary for validation (art. 89)! This also implies that you should keep the documentation about the legal basis used (e.g., consent forms) during that time, so that you can demonstrate GDPR compliance.

- Personal data that were used for purposes other than answering your research question (e.g. contact information) should have their own retention policy: they should be removed or anonymised after the retention period (e.g. the research project) has ended.

For all types of data in your project (incl. to be archived research data), we recommend to formulate which data you will retain and for how long (for example in your Data Management Plan), and communicate the (possibly different) retention period(s) to data subjects. If you want to change the storage term you initially set and communicated for your personal data, please contact your privacy officer.

8.4.1 Deleting personal data

If you do not need personal data anymore, you must delete it, except when the data should be archived for validation purposes. Data deletion should be done in a reliable manner, for example to ensure that there are no visible or hidden copies being left behind on any device. The Storage Finder will soon include information on how to do this for each UU-approved storage medium. Additionally, you can read more on how to safely delete data in the RDM guide “Storing and preserving data”.

Chapter 9

Sharing data with collaborators

This chapter addresses guidelines to take into account when you want to share personal data with collaborators outside of your own institution **during** your research project. For guidelines to share personal data after a research project, please refer to the chapter on Data sharing for reuse.

To be able to share personal data with external collaborators, you should:

1. Make sure you have a legal basis and inform data subjects

Make sure data subjects are well-informed about your intentions to share the data with collaborators. Include information in your privacy notice on the identity of your collaborators, which data are shared with them and why, how, and for how long. Avoid using statements that preclude sharing such as “Your data will not be shared with anyone else”.

Make sure you have a legal basis to share the data, e.g., informed consent or public interest. If you use consent, make sure that data subjects are aware that they are also providing consent to share their data with your collaborators.

Inform data subjects timely - before you start processing their data - and proactively - directly if possible.

2. Protect the personal data appropriately

Assess the risks of sharing the data and the measures you will take to mitigate those in your Data Management Plan, Privacy scan, or if applicable, Data Protection Impact Assessment. This is especially important if you will share your data with collaborators outside of the European Economic Area.

Share only the data that the collaborator needs (data minimisation), for example by deleting unnecessary data, pseudonymising the data, and sharing only with those who need access to the data.

Make sure data subjects can still exercise their data subjects' rights. For example, if a data subject withdraws their consent, not only you, but also your collaborators will have to stop processing the data subject's personal data. It is important to make clear how you and them will do so.

3. Come to agreements with collaborators

In order to protect the personal data effectively, it is important to determine which role every collaborator has: controller or processor? And if there are multiple controllers, are they separate or joint controllers? For example, in many collaborative research projects (e.g., in consortia), there are multiple controllers that collectively determine why (e.g., research question) and how (e.g., methods) to process personal data. These parties are then joint controllers, and agreements need to be made in a joint controllers agreement.

In any collaboration in which data are shared, you need to (art. 26):

Come to a formal agreement on:

The role of each party in the research project

Respective responsibilities in terms of data protection, such as informing data subjects and handling requests relating to data subjects' rights

Who is the main point of contact for data subjects

Communicate (the essence of) the agreement to data subjects.

Your privacy officer can help you draw up a valid agreement.

4. Pay special attention to third-country transfers

If you share personal data with international collaborators (for example, with countries that have no adequacy decision), you may need to take additional measures. Usually, these measures include drawing up an agreement to make sure the other party is GDPR-compliant and uses the necessary security measures (if you haven't already done so). The exact type of agreement will depend on your specific situation: your privacy officer can help you choose and set up the right one.

The flowchart below indicates conditions under which you can share data internationally. Note that they assume that you have taken sufficient safeguards to protect the personal data. To determine the possibilities of sharing data internationally in your project, we strongly advise you to consult with your privacy officer. In some cases a Data Transfer Impact Assessment may be required, which can take some effort.

5. Use a secure way to share the data

Granting access: It is preferable to grant a user access to an existing and safe infrastructure (e.g., add someone to a Yoda group or OneDrive folder), rather than physically sending the data elsewhere. This allows you to keep the data in one place, define specific access rights (read/write), have users authenticate,

and easily revoke access to the data after your collaboration has ended. It is also a good idea to take measures to prevent the data from being copied elsewhere.

Transferring data: When it is absolutely necessary to transfer the files to a different location, you must do so securely. Researchers at Utrecht University can use SURF Filesender with encryption.

Chapter 10

Sharing data for reuse

10.1 Publishing Personal Data

10.2 Data vs. Metadata

10.3 Repositories

10.4 Licenses

Chapter 11

(PART*) Use Cases

Chapter 12

Publishing metadata

In 2020, the Open Science Programme of Utrecht University sent out the first Open Science monitor. The aim was to gain insights into the awareness, attitudes, practices, opportunities and barriers of employees of Utrecht University and Utrecht University Medical Center regarding several Open Science practices. As the dataset contained a lot of demographic information (e.g., gender, age, nationality, position, type of contract, etc.), and all of those variables combined could lead to identification, it could not be shared publicly. For this particular dataset, full anonymisation was not desirable, as that would greatly decrease its scientific value. Therefore, the Open Science Programme chose to publish only the metadata and documentation, without sharing the data, in order to protect participants' data while still complying with the FAIR principles.

Here's the strategy they took:

- They published the dataset under restricted access on Yoda, so that the dataset was at least Findable and Accessible.
- They shared other relevant documentation publicly:
 - The preregistration.
 - The questionnaire itself, including the information provided to participants.
 - The final report written about the dataset.

Note that in the metadata of all these publications, cross-references to the other publications are included to allow for maximum findability of the project's outputs.

Chapter 13

Data pseudonymisation

Chapter 14

Data minimisation in a survey

For a course, a teacher at the faculty of Veterinary Medicine collected data on the health of pets and the pets' owners. The initial purpose of the survey was to create simply datasets for students to learn about statistics. However, besides for the course, the teacher also wanted to use the collected data for research purposes and share the data with others. In order to do so, the teacher created a new version of the survey that asked for less identifiable information and could be more easily anonymised. Additionally, the new version of the survey informed participants about the legal basis used to process their personal data.

Here, you can find the survey before and after data minimisation:

Before minimisation After minimisation

Note that the new version of the survey:

- minimises the amount of personal data collected:
 - Student number and pet names are not asked in the new version of the survey.
 - Instead of Age, the new version asks the Age category of the owner/caretaker.
 - The survey includes questions on Weight and Height. For data publication, they are used to calculate the Body Mass Index (BMI) and deleted after this calculation.
- contains information about the legal basis used to be able to use (legitimate interest) and publish (consent) the data for purposes other than education.

Resources

Chapter 15

Seeking help at Utrecht University

The glossary consists of frequently used jargon concerning the GDPR and research data.

15.0.0.1 A

Anonymous data

Any data where an individual is irreversibly de-identified, both directly (e.g., through names and email addresses) and indirectly. The latter means that you cannot identify someone:

by combining variables or datasets (e.g., a combination of date of birth, gender and birthplace, or the combination of a dataset with its name-number key)

via inference, i.e., when you can deduce who the data are about (e.g., when profession is Dutch prime minister, it is clear who the data is about)

by singling out a single subject, such as through unique data points (e.g., someone who is 210 cm tall is relatively easy to identify)

Anonymous data are no longer personal data and thus not subject to GDPR compliance. In practice, anonymous data may be difficult to attain and care must be given that the data legitimately cannot be traced to an individual in any way. The document Opinion 05/2014 on Anonymisation Techniques explains the criteria that must be met for data to be considered anonymous.

15.0.0.2 C

Controller

The natural or legal entity that, alone or with others, determines or has an influence on why and how personal data are processed. On an organisational level, Utrecht University (UU) is the controller of personal data collected by UU researchers and will be held responsible in case of GDPR infringement. On a practical level, however, researchers (e.g., Principal Investigators) often determine why and how data are processed, and are thus fulfilling the role of controller themselves.

15.0.0.3 D

Data subject

A living individual who can be identified directly or indirectly through personal data. In a research setting, this would be the individual whose personal data is being processed (see below for the definition of processing).

15.0.0.4 E

European Economic Area (EEA)

The member states of the European Union and Iceland, Liechtenstein, and Norway. In total, the EEA now consists of 30 countries. The aim of the EEA is to enable the “free movement of goods, people, services and capital” between countries, and this includes (personal) data (source: Eurostat).

15.0.0.5 L

Legal basis

Any processing of personal data should have a valid legal basis. Without it, you are now allowed to process personal data at all. The GDPR provides 6 legal bases: consent, legitimate interest, public interest, legal obligation, performance of a contract, vital interest. Consent and public and legitimate interest are most often used in a research context.

15.0.0.6 P

Personal data

Any information related to an identified or identifiable (living) natural person, for example identifiers (name, identification number, location data, online identifier or a combination of identifiers) or factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of the person. Moreover, IP address, opinions, tweets, answers to questionnaires, etc. may also be personal data, either by itself or through a combination of one another.

Of note: as soon as you process data related to a person that is identifiable, you are processing personal data. Additionally, pseudonymised data is still considered personal data. Read more in *Designing a GDPR-compliant research project*.

Processing

Any operation performed on personal data, including collection, storage, organisation, alteration, analysis, transcription, sharing, publishing, deletion, etc.

Processor

A natural or legal entity that processes personal data on behalf of the controller. For example, when using a cloud transcription service, you often need to send personal data (e.g., an audio recording) to the transcription service for the purpose of your research, which is then fulfilling the role of processor. When using such a third party, you must have a data processing agreement in place.

Pseudonymous data

Personal data that cannot lead to identification without additional information, such as a key file linking pseudonyms to names. This additional information should be kept separately and securely and makes for deidentification that is reversible. Data are sometimes pseudonymised by replacing direct identifiers (e.g., names) with a participant code (e.g., number). However, this may not always suffice, as sometimes it is still possible to identify participants indirectly (e.g., through linkage, inference or singling out). Importantly, pseudonymous data are still personal data and therefore must be handled in accordance with the GDPR.

15.0.0.7 S

Special categories of personal data

Any information pertaining to the data subject which reveals any of the below categories:

racial or ethnic origin

political opinions

religious or philosophical beliefs

trade union membership

genetic and biometric data when meant to uniquely identify someone

physical or mental health conditions

an individual's sex life or sexual orientation

The processing of these categories of data is prohibited, unless one of the exceptions of art. 9 applies. For example, an exception applies when:

```
<ul>
  <li>the data subject has provided explicit consent to process these data for a spe
  <li>the data subject has made the data publicly available themselves </li>
  <li>processing is necessary for scientific research purposes</li>
</ul><p>Contact
your <a href="https://intranet.uu.nl/en/knowledgebase/contact-privacy" target="_blank">
if you wish to process special categories of personal data.</p>
```

For further reading, we prepared a Zotero library with additional resources, some of which are specific to Utrecht University, others more general. Below you can download the library (left image) or see the most recent version online (right image).