**Consent manual**

The **manual concerning GDPR’s consent** is (with the manual on the GDPR’s DPIA) a crucial part of **D3I’s legal and ethical** **considerations researchers must pay attention to.** Without a participant’s consent, researchers cannot lawfully process a participant’s personal data. To obtain lawful consent, researchers must pay attention to making that consent specific, informed and unambiguous (see below how this can be achieved).

The D3I-consent documentation involves:

* a **manual** about obtaining **lawful** consent for **scientific researchers** (this document)
* a **template** for a privacy policy for **participants** (separate document to be filled by the researcher(s))
* a **template** for an **informed** **consent form** for **participants** (separate document to be **filled** and **signed** by the **researcher and** to be **signed** by the **participant)**

This **consent manual** and **templates** will be **used** and **tested** throughout the **three pilots** in the D3I-project. The consent manual’s and templates’ **design**, its **effectiveness** and **GDPR compliance** will be **analysed** and where necessary be **adjusted** to the specific context of application in the D3I-research. These analyses will be based on the **experiences** collected during each of the **pilots**, after discussions with the **University DPOs, data stewards** and **ERBs** of the FSW departments. The documentation must also **align** with the **technical architecture** and **operational aspects**, and **vice versa**.

* We stay close to the **current consent documentation** as used by the **UvA**.
* After **gaining experiences** from the **pilot**, we may have to **adjust** the consent **documentation** where that is **necessary** to adequately **safeguard** the **rights** and **interests** of the data subjects (**participants**) and/or to **clarify** the documentation for the **researchers** (data controllers).

# **1. Introduction**

Generally, **consent** can only be **lawful** if a **data subject** is offered some form of **meaningful control** over the processing of **their personal data**, meaning that they are offered a **genuine choice** regarding **accepting** or **declining** the **terms offered** or **declining** them **without detriment**.

When **asking** for **consent**, a **researcher** has the **duty** to **assess** whether **that consent** will meet **all** the **requirements** to **obtain** ***valid* consent**. If obtained **in full compliance** with the **GDPR**, consent is a **tool** that gives **data subjects** **control** over **whether or not** **personal data concerning them** will be **processed**. **If not**, the data subject’s control becomes **illusory** and **consent** will be an **invalid basis** for **processing**, **rendering** the processing activity **unlawful**. Inviting people to **accept** a **data processing operation** concerns the **fundamental right** of **data subjects** and is therefore subject to **rigorous requirements**. We introduce these next.

# **2. Consent in the GDPR**

Article 4(11) of the GDPR defines consent as:

* any **freely given**,
* **specific**,
* **informed**, and **unambiguous** **indication**

of the **data subject's wishes** by which he or she, by a **statement** or by a **clear affirmative action**, signifies **agreement** to the **processing** of personal data relating to him or her.

We elaborate these elements next.

## **2.1 Freely given**

The element “free” implies **real** and **meaningful** **choice** and **control** for **data subjects**. As a rule of thumb, the **GDPR prescribes** that if the data subject has **no real choice**, feels **compelled to consent** **or will endure negative consequences** if they do **not consent**, then consent will **not** be considered **freely given**, and thus be **invalid**. If consent is **bundled up** as a **non-negotiable part of terms** **and conditions,** it is **presumed** **not** to have been **freely given**. Accordingly, consent will **not be free** if the data subject is **unable to refuse or withdraw his or her consent without detriment**.

The potential **disbalance** between the **researcher** and the **data subject** must also be considered (such disbalance is often present in relationships between employer-employee, or public organisation and citizen). In general terms, **any element** of **inappropriate pressure** or **influence** upon the data subject (which can be manifested **in many different ways**) which **prevents** a **data subject** from **exercising** their **free** will, **shall render the consent invalid**. An **example** might explain how consent works:

“A mobile app for photo editing asks its users to have their GPS localisation activated for the

use of its services. The app also tells its users it will use the collected data for behavioural advertising purposes. Neither geo-localisation nor online behavioural advertising are necessary for the provision of the photo editing service and go beyond the delivery of the core service provided. Since users cannot use the app without consenting to these purposes, the consent cannot be considered as being freely given”.[[1]](#footnote-1)

Some researchers **offer participants small gifts** for their participation – and thus for their consent. In relation to **gifts** **for participation**, it is important that the **researcher demonstrates** that it is **possible** to **refuse** or **withdraw** **consent *without detriment***.[[2]](#footnote-2) For example, the researcher needs to prove that withdrawing consent does not lead to any costs for the data subject and thus no clear disadvantage for those withdrawing consent.

## **2.2 Specific**

Consent of the data subject must be given in relation to **one or more *specific* purposes** and a **data subject must have a choice in relation to each of them**.That consent must be **specific,** **aiming** to **ensure** a **degree of user control** and **transparency** for the data subject. This requirement is closely linked to the requirement of **informed** consent (see below 2.3). At the same time, specific consent must be interpreted in line with the **requirement for granularity** to obtain 'free' consent as explained in 2.1.

In the context of **scientific research,** and thus for the **D3I-research,** the GDPR brings some **flexibility** to the degree of **specification** and granularity of consent:

“It is often not possible to fully identify the purpose of personal data processing for scientific research purposes at the time of data collection. Therefore, data subjects should be allowed to give their consent to certain areas of scientific research when in keeping with recognised ethical standards for scientific research. Data subjects should have the opportunity to give their consent only to certain areas of research or parts of research projects to the extent allowed by the intended purpose.”

This does **not dismiss** the obligations related to the **specificity** requirement. **As a rule**, scientific research can **only** include personal data based on **consent** if they have a **well-described** **purpose**. For situations where purposes for data processing within a scientific research project **cannot** be **specified** at **the outset**, Recital 33 **allows** as an **exception** that the purpose **may be described** at a **more general level**.

Note however that the **strict conditions** that apply to **special category data** (ethnic origin, religion and beliefs, sexual preference etc.) will still be subject to a **stricter interpretation**, as special category data also requires a **high degree of scrutiny** (i.e., more weighty reasons for the processing of that data).

## **2.3 Informed**

The GDPR requires that consent must be **informed**. The requirement of **transparency** is one of GDPR's **data processing** **principles**, closely related to the principles of **fairness** and **lawfulness**. **Providing appropriate information** to data subjects ***prior***to **obtaining consent** is ***essential*** to **enable** them to take **informed** **decisions**, **understand** what they are **agreeing** to, and exercise their **right to withdraw their consent**.

If the researcher does **not** **provide accessible information**, **user control** becomes **illusory** and **consent** will be an **invalid basis** for processing. The **consequence** of not complying with the requirements for informed consent is that **consent will be invalid** and the **researcher** will be **in breach** of the GDPR.

For consent to be **informed**, it is necessary to **inform** the data subject of certain **elements** that are **crucial** to make an **informed** **choice**. Therefore, the **EDPB** is of the opinion that **at least** the **following information** is required for obtaining valid consent:

* the researcher’s **identity**;
* the **purpose** of each of the processing operations for which consent is sought;
* what (**type of) data** will be **collected** and **used**;
* the **existence** of the right to withdraw **consent**;
* **information** about the **use** of the data for **automated decision-making** in accordance with Article 22 (2)(c) GDPR where relevant; and
* on the possible **risks** of **data transfers** **outside the EU** due to absence of adequate data protection.

## **2.4 Unambiguous indication of wishes**

Consent requires a **statement** from the data subject, or a **clear affirmative act**, which means that it must **always** be given through an **active motion or declaration**. It must be obvious that the data subject has consented to the particular processing. It means that the data subject must have taken a **deliberate action** to **consent** to the **processing**.[[3]](#footnote-3) Consent can be collected through a **written** or (a **recorded**) **oral** **statement**, including by **electronic means**. **Written statements** can come in **many shapes** and **sizes** that could be **compliant** with the **GDPR**.

**Consent in the context of D3I-related research: little room for derogation**

* Obtaining valid consent/explicit consent in the **scientific research** context
  + The requirement of consent being “specific”: there is a **restricted scope of derogation** where the **research purpose** is concerned (specificity of the research purpose in research contexts **can be a bit less specific,** see the **background document** on the **GDPR).**
  + Make a comprehensible research plan available to participants.
  + Consider **visualisation** of the data processing if you want **participants** to take a **reasoned** **decision** about what data they can **delete.**
  + **Special contact person** (Finnish personal data act[[4]](#footnote-4)).
  + **Withdrawal** of consent: **no exception** for **scientific research.**
  + Make **withdrawal** as **easy** as **giving consent** (prescribed by the GDPR).
  + Consider the use of **pseudonymisation** and **anonymisation** techniques.

## **2.5 Other considerations that are relevant for D3I-researchers:**

**How** do you **inform** the **participant (the data subject)?**

1. By way of a **privacy policy** that was adjusted to the **participant’s level** of **comprehension**.
2. By **providing** them a **link** to and/or reference to the **University’s privacy statement.**
3. By the **organisation** that is the **source** of the **personal data** obtained **consent** in a GDPR compliant manner will be informed.

In the context of **D3I**, we **inform participants according** to **(a)** and **(b)**. Littera **(c)** does **not** apply because the personal data is **retrieved** from the **participants** themselves, and not via third parties.

**Information that must be provided to the data subject (participant in D3I-projects) under Article 13 GDPR:**

The **GDPR** obliges the **researcher** to **properly inform** the **data subject** (participant) about the research. As in the context of D3I data are retrieved from the **participants themselves**, the following (i) **general** and (ii) **GDPR-specific questions** need to be **answered** by the researcher:

**(i) Generic considerations for researchers to respond to (and that are embedded in the privacy policy template):**

1. Do **participants know** that you **as researcher** are processing their personal data **for your specified research purpose**?
2. **How** are participants **informed** about this? For example: by way of a **consent form** and a **privacy policy**?
3. If Informed consent is soughtfrom **participants** for the processing: **where** are the **consent forms** **stored**?
4. If Informed consent is sought from **participants** for processing: **how** can the **participant withdraw** **consent** at a **later date**? **Withdrawal has consequences for your research: a**ccording to Article 7 (3) **GDPR**, the withdrawal of consent does **not affect** the **lawfulness** of processing based on consent **before** it was withdrawn.
5. Does the **processing** provide **opportunities** for data subjects (participants) to **request/view/edit/delete** his/her **personal data themselves** (think of **self-service functionalities** or **procedures**)? How are these made **comprehensible** and **manageable** for **participants** to convey them some **actual** **control** over **aspects** of the processing of **their** personal data?
6. Are the personal data also **used** for **other business processes** or **purposes** than those for which they were **originally collected**? Or do you **expect** that this **could happen**? Also

(ii) **GDPR-specific requirements[[5]](#footnote-5)**; the **responses** will be part of the privacy policy that informs the **participants:**

1. The **researcher** must, **before or at the time when personal data are collected**, provide the **participant** with **all of the following information**:
   1. the **identity** and **contact details** of the researcher and, if that applies, their representative;
   2. the **contact details** of the **data protection officer**;
   3. the **purpose** of the processing for which the personal data are intended as well as the **legal basis** for the processing (in the context of D3I, the legal basis for processing is “consent”);
   4. *if this applies*, the **recipients** or **categories** of recipients **of the personal data** (i.e., whether data transfers to a third-party can occur);
   5. *if this applies*, the fact that the **researcher** intends **to transfer** the personal data to a country **outside the EU** (where the GDPR does not apply and risks to the data processing can emerge).
2. In addition, **researcher** provides the **participant** **at the time where personal data are collected**, with information necessary to **ensure fair** and **transparent processing**:
   1. the **period** for which the data will be **stored**;
   2. the **existence** of the **participant’s right** to **request** **access** from the **researcher** **to** their **personal data** held by the researcher, and the **participant’s rights** to **rectification** of their **personal data** or **restriction** of processing concerning him or her, and the right to **port** their data to another data controller which can be for instance a researcher at another university (“subject access rights”[[6]](#footnote-6)). A participant’s **right to have their data erased** is, however, **restricted** in the context of **scientific research[[7]](#footnote-7)**;
   3. where the processing is based on **consent** or **explicit consent**, the existence of the **right** to **withdraw consent** at **any time**, **without** affecting the **lawfulness** of **processing** ***before*** the **withdrawal**;
   4. the right to lodge a **complaint** with the **supervisory authority** (in the Netherlands: the Autoriteit Persoonsgegevens);
   5. *where that applies*, the **existence** of **automated decision-making**, including **profiling** (as defined in Art. 22(1) GDPR). The researcher must in these situations provide the participant with **meaningful information** about the **logic involved**, and the **significance** and **consequences** of such **processing** for the **data subject** (participant);

3. Where the researcher **intends** to **use** the data for a **purpose different** than that for which the data was **originally collected**, the researcher provides the participant **prior** to that **further** **processing** with **information** about that **other purpose**, and with any other relevant information mentioned in 1 and 2. In the **context of D3i**, researchers may have to consider, for example, the **use** of the personal data **for follow-up research**. If that applies, the researcher must inform the participant.

## 3. GDPR text

**Article 6(1)(a) GDPR Consent as lawful ground for data processing**

Processing shall be lawful only if and to the extent that […] the data subject has given consent to the processing of his or her personal data for one or more specific purposes.

**Article 7 GDPR Conditions for consent**

(1) Where processing is based on **consent**, the **controller** shall be **able to demonstrate** that the **data subject** has **consented** to processing of his or her personal data.

(2) If the data subject's consent is given in the context of a written declaration which also concerns other matters, the request for consent shall be presented in a manner which is clearly distinguishable from the other matters, in an intelligible and easily accessible form, using clear and plain language. Any part of such a declaration which constitutes an infringement of this Regulation shall not be binding.

(3) The data subject shall have the right to **withdraw his or her consent at any time**. The withdrawal of consent shall **not** affect the **lawfulness** of processing **based on consent before its withdrawal**. Prior to giving consent, **the data subject shall be informed thereof**. It shall be **as easy to withdraw** as **to give consent**.

(4) When assessing whether consent is freely given, utmost account shall be taken of whether, inter alia, the performance of a contract, including the provision of a service, is conditional on consent to the processing of personal data that is not necessary for the performance of that contract.

## 4. Further reading

European Data Protection Board (EDPB) Guidelines 05/2020 on consent under Regulation 2016/679

Version 1.1 Adopted 4 May 2020 <https://edpb.europa.eu/sites/default/files/files/file1/edpb\_guidelines\_202005\_consent\_en.pdf>.

European Data Protection Supervisor (EDPS) A preliminary opinion on data protection and scientific research. Adopted 6 January 2020, p. 18 – 20.

< https://edps.europa.eu/sites/edp/files/publication/20-01-06\_opinion\_research\_en.pdf>.

1. Example borrowed from EDPB’s Guidelines 05/2020 on consent under Regulation 2016/679, adopted on 4 May 2020. [↑](#footnote-ref-1)
2. Recital 42 GDPR. [↑](#footnote-ref-2)
3. Recital 32 sets out additional guidance on this. [↑](#footnote-ref-3)
4. Such a possibility can be found in Article 14(1) of the current Personal Data Act of Finland (Henkilötietolaki,

   523/1999). [↑](#footnote-ref-4)
5. Art. 13 GDPR. [↑](#footnote-ref-5)
6. Subject access rights can be found and are defined in Arts. 13–22 GDPR. [↑](#footnote-ref-6)
7. See Art. 17 (3)(d) GDPR: “[The right to have one’s personal data erased by the controller does not apply] to the extent that the processing is **necessary** for archiving purposes in the public interest, **scientific** or historical **research** purposes or statistical purposes in accordance with Article 89(1) [GDPR] **in so far as the right referred to in paragraph 1 is likely to render impossible or seriously impair the achievement of the objectives of that processing.** [↑](#footnote-ref-7)