

# Personal data and scientific research : does science stop where GDPR begins?

Etienne Wéry & Thierry Léonard

Brussels and Paris Bars

[www.ulysses.net](http://www.ulysses.net)

Wrong idea : “I need your  
consent !”

Part 1

# Back to the **basic principles** (art. 5)

- lawfulness, fairness and transparency
- purpose limitation
- data minimisation
- accuracy
- storage limitation
- integrity and confidentiality
- accountability

# Back to the **basic principles** (art. 5)

- **lawfulness**, fairness and transparency
- purpose limitation
- data minimisation
- accuracy
- storage limitation
- integrity and confidentiality
- accountability

**Fine but ... what is a lawful process under GDPR ?**



Processing shall be **lawful** only if and to the extent that at least one of the following applies (art. 6) ...

- consent
- performance of a contract
- compliance with a legal obligation
- vital interests of the data subject
- public interest
- legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject

Processing shall be **lawful** only if and to the extent that at least one of the following applies (art. 6) ...

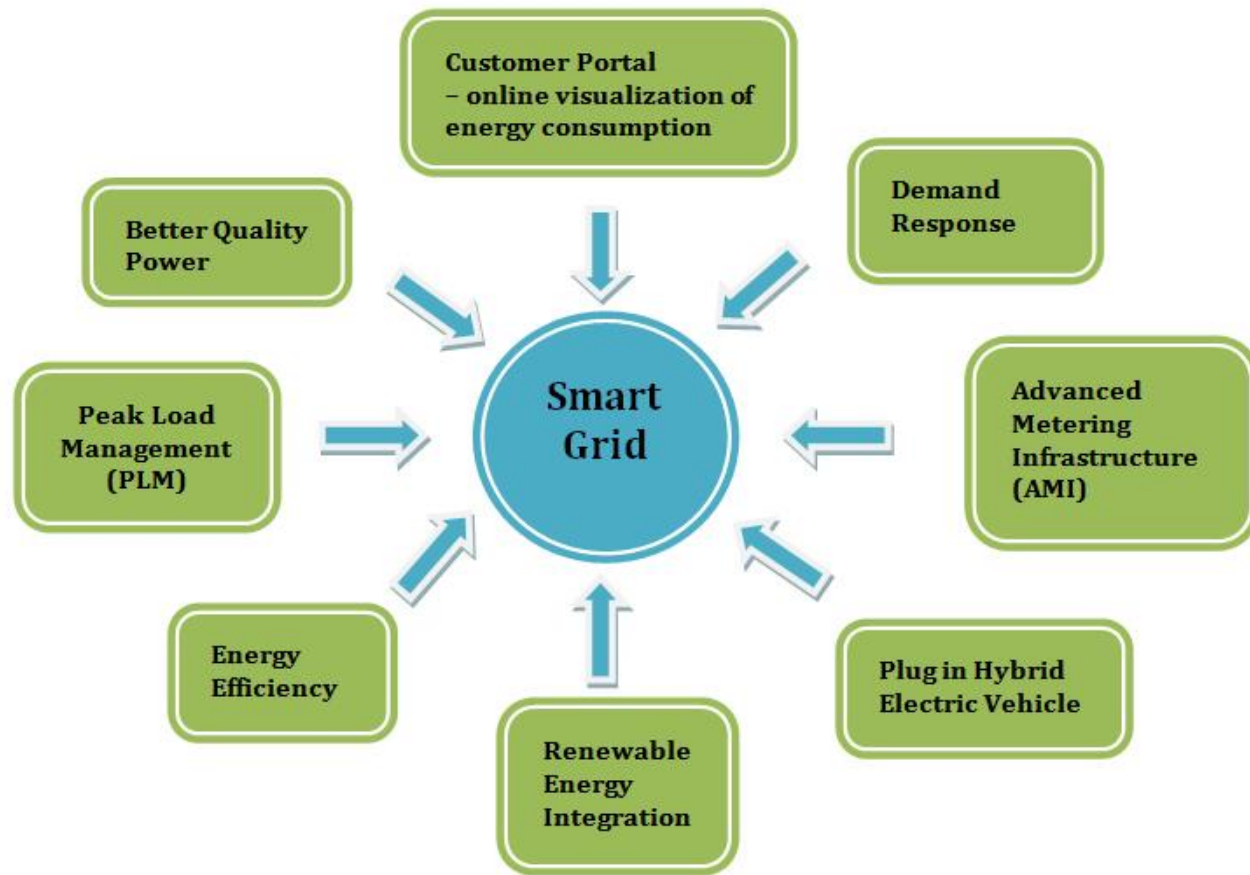
- consent
- performance of a contract
- compliance with a legal obligation
- vital interests of the data subject
- public interest
- legitimate interest of the controller or by a third party, except where the interests are overridden by the interests or rights and freedoms of the data subject

**Don't listen to stupid voices and repeat after me :  
« No ! consent is not always required ! »**

Wrong idea : further process for scientific purposes is not possible and/or require consent

Part 2

# Example : smartgrid



In order to develop a new technology for managing electrical peaks, a company starts a study to identify the needs per house, per person, per season, per age, per size of the house, etc.

Can that company get data from electrical suppliers?

Because the contracts with users are sometime very ancient, it was never specified that such reutilization could occur. The sole purpose announced is "execution of a contract".



# Primary use vs. Secondary use

Purpose limitation :

- personal data shall be collected for specified, explicit and legitimate purposes (**primary use**). In such a case, no legal basis separate from that which allowed the collection of the personal data is required.
- and not further processed in a manner that is incompatible with those purposes (**secondary use : further process**). In such a case, a legal basis separate from that which allowed the collection of the personal data is required (+ full compliance with all requirements of the GDPR). If not ... no further process.

# What is the scope of the primary use ?

- Data processed for specified, explicit and legitimate purposes
- Where personal data relating to a data subject are **collected from the data subject**, the controller shall, **at the time when** personal data are obtained, provide the data subject with : the purposes of the processing for which the personal data are intended as well as the legal basis for the processing (see art. 13 for other info to be provided and exceptions).
- Where personal data **have not been obtained from the data subject**, the controller shall provide the data subject with the following information: the purposes of the processing for which the personal data are intended as well as the legal basis for the processing (see art. 14 for other info to be provided and exceptions + time to provide such information)

# Is my secondary use compatible?

The controller, after having met all the requirements for the lawfulness of the original processing, should take into account, inter alia (recital 50) :

- any link between those purposes and the purposes of the intended further processing;
- the context in which the personal data have been collected, in particular the reasonable expectations of data subjects based on their relationship with the controller as to their further use;
- the nature of the personal data;
- the consequences of the intended further processing for data subjects;
- and the existence of appropriate safeguards in both the original and intended further processing operations.

# Scientific research purposes (art. 5)

*“Further processing for :*

- (1) archiving purposes in the public interest,*
- (2) scientific or historical research purposes or*
- (3) statistical purposes*



*shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes” (art. 5).*



# What are the conditions of art.89(1)?

- Process shall be subject to **appropriate safeguards**, in accordance with this Regulation, for the rights and freedoms of the data subject.
- Those safeguards shall ensure that technical and organisational measures are in place **in particular** in order to ensure respect for the principle of **data minimisation**.
- Those measures may include pseudonymisation provided that those purposes can be fulfilled in that manner.
- Where those purposes can be fulfilled by further processing which does not permit or no longer permits the identification of data subjects, those purposes shall be fulfilled in that manner.

# What are the conditions of art.89(1)?

- Process shall be subject to appropriate safeguards in line with this Regulation, for the rights and freedoms of natural persons
  - Those safeguards shall ensure that measures are in place in order to protect the principle of data minimisation
  - Those measures shall be designed to be effective, and shall be provided that those
- is a good illustration of the basic philosophy of freedom but more responsibility/liability. idea to make an impact assessment*

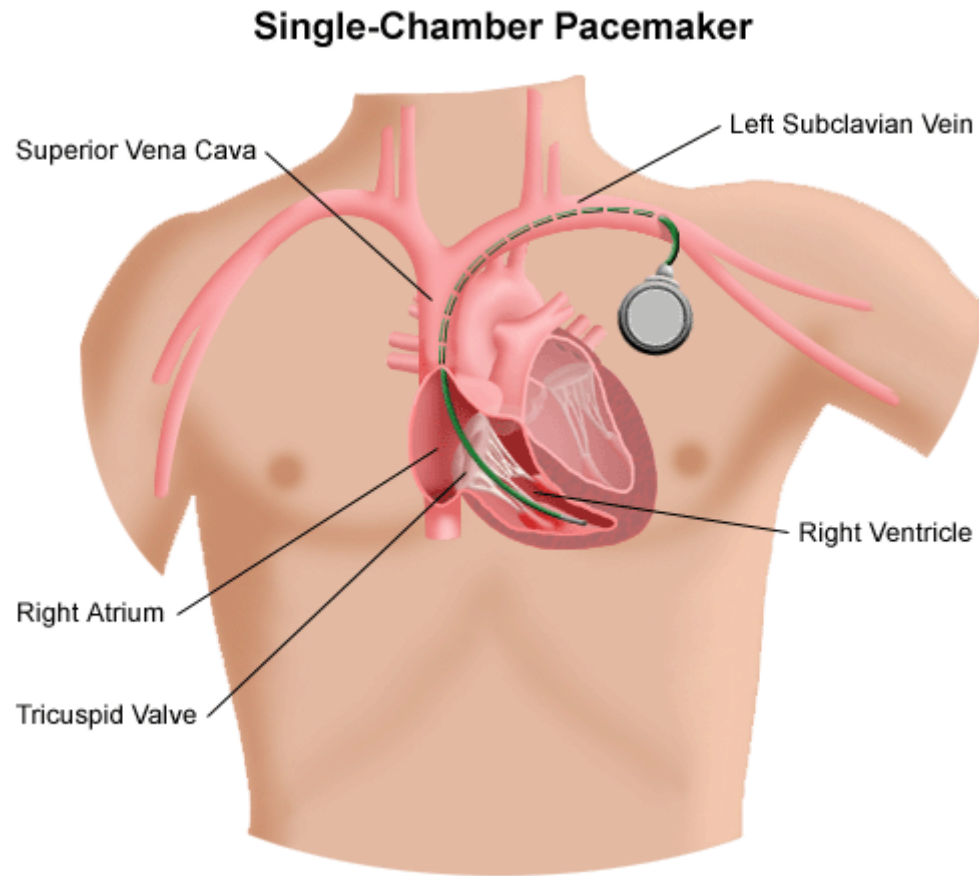
- Process shall be subject to appropriate safeguards in order to protect the interests of the data subject, in particular his or her rights and freedoms, and without prejudice to the provisions of this Regulation, for the rights and freedoms of natural persons.
- Those safeguards shall ensure that measures are in place in order to protect the principle of data minimization.
- Those measures shall include, where appropriate, provided that those measures are necessary, the following:
  - the pseudonymization of data, where appropriate, such that the data cannot be attributed to a specific data subject without the use of additional information;
  - the restriction of processing of data for purposes other than those for which the data were initially collected;
  - the restriction of access to data to only those persons who have been granted access to the data in order to process the data;
  - the restriction of storage of data for a period longer than is necessary for the purposes for which the data were initially collected;
  - the destruction of data when the purposes for which the data were initially collected have been fulfilled in that manner.

GDPR : It could be a good idea to minimize the risks. The purpose shall be fulfilled in that manner.

Wrong idea : “however, consent is always needed if **sensitive data** are processed for scientific purposes”

Part 3

# Example : pace maker



In order to compare the various technologies used by pacemaker manufacturers and have a benchmark of such technology after 20 years, a team of doctors and scientists require hospitals to transfer a full set of data, including : an identification number for each patient, age of the person, type of disease, heart rhythm, age of death (if dead), number of unexpected medical issues and/or surgery and nature of such issues, etc.

Most patients were never informed that their medical data could be reused in that respect. Their expectation is probably that the doctor would keep these data secret and never disclose it to anyone.



# Art. 5 vs. Art. 9

Art. 5 : nice article because further processing for **scientific or historical research purposes** shall, in accordance with **Article 89(1)**, not be considered to be incompatible with the initial purposes (art. 5).

**But** art. 9 : processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of **genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health** or data concerning a natural person's sex life or sexual orientation shall be **prohibited**.

**Does article 5 also apply for sensitive data ?**

Apparently not (at least until the ECJ rules otherwise)

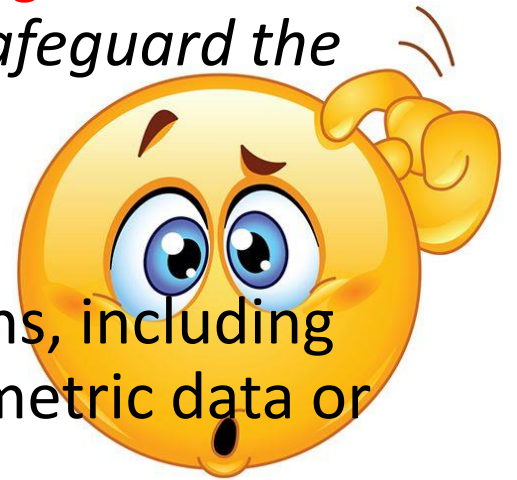
# Good news : there are exceptions ...(art. 9)

- explicit consent
- employment and social security and social protection
- vital interests of the data subject
- membership of foundation, association, non-profit org.
- data which are manifestly made public by the data subject
- legal claims
- substantial public interest (conditions apply)
- preventive or occupational medicine (conditions apply)
- reasons of public interest in the area of public health
- archiving purposes in the public interest, scientific or historical research purposes or statistical purposes. However, conditions apply (see next slide)

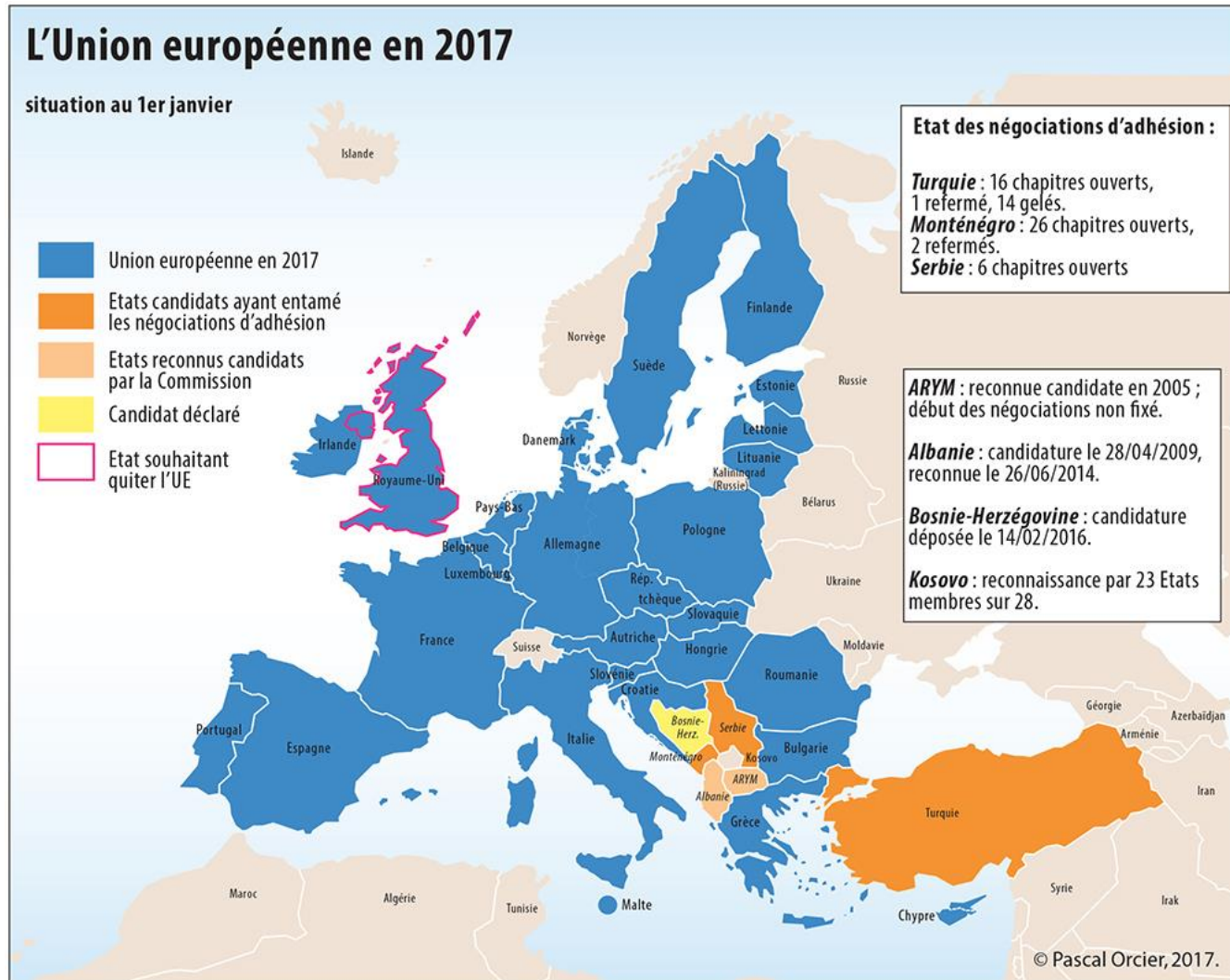
# Focus on art. 9. (2), j)

2. Paragraph 1 shall not apply if one of the following applies : (...) “(j) *processing is necessary for archiving purposes in the public interest, **scientific or historical research purposes** or statistical purposes in accordance with **Article 89(1)** based on **Union or Member State law** which shall be **proportionate** to the aim pursued, **respect the essence of the right** to data protection and provide for **suitable and specific measures** to safeguard the fundamental rights and the interests of the data subject.*”

4. Member States may maintain or introduce further conditions, including limitations, with regard to the processing of genetic data, biometric data or data concerning health.



# Choose the right country !



It is unclear as what would happen if your scientific research is subject to a national law which does not explicitly provide for additional protection and is not regulated by another EU law.

Is art. 89 (1) enough, or is such national law required to benefit from art. 9 (2) j ? The question is still open.

In the meantime, be prudent ...

So far, Belgium, Germany and Austria are to be considered as friendly safe harbors.

# Example : Clinical Trials Regulations (CTR)

- Opinion EDPB [3/2019](#) concerning the Questions and Answers on the interplay between the Clinical Trials Regulation (CTR) and the General Data Protection regulation (GDPR).
- Processing operations expressly provided by the CTR which are related to **reliability and safety purposes [= health]**, can be considered as falling within “legal obligation(s) to which the controller is subject” or legitimate interest.
- Processing operations purely related to **research activities in the context of a clinical trial** cannot, however, be derived from a legal obligation. Depending on the whole circumstances of the trial and the concrete data processing activity, research related activities may either fall under the data subject’s explicit consent (Article 6(1)(a) in conjunction with Article 9(2)(a)), or a task carried out in the public interest (Article 6(1)(e)), or the legitimate interests of the controller (Article 6(1)(f)) in conjunction with Article 9(2)(i) or (j) of the GDPR.

# Other good news for scientists

Part 5

# Data retention (art. 5)

- Personal data shall be 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.

# Information to the data subject (art. 14)

- Where personal data have **not been obtained from the data subject**, the controller shall provide the data subject with the following information (see article 14 for details);
- Paragraphs 1 to 4 shall not apply where and insofar as (...) the provision of such information **proves impossible** or would involve a **disproportionate effort, in particular for** processing for archiving purposes in the public interest, **scientific or historical research purposes** or statistical purposes, subject to the conditions and safeguards referred to in **Article 89(1)** or in so far as the obligation referred to in paragraph 1 of this Article is likely to **render impossible or seriously impair the achievement of the objectives** of that processing.
- In such cases the controller shall take appropriate measures to protect the data subject's rights and freedoms and legitimate interests, including making the information publicly available;



# Right to erasure ('right to be forgotten')

The right to erasure shall not apply to the extent that processing is necessary:

- (a) for exercising the right of freedom of expression and information;
- (b) for compliance with a **legal obligation** which requires processing by Union or Member State law to which the controller is subject or for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;
- (c) for reasons of **public interest in the area of public health** in accordance with points (h) and (i) of Article 9(2) as well as Article 9(3);
- (d) for archiving purposes in the public interest, **scientific or historical research purposes** or statistical purposes in accordance with Article 89(1) 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; or

# The data subject's rights

Part 6

# Art. 89 (2) and (3)

## **Scientific or historical research purposes or statistical purposes**

- Union or Member State law may provide for derogations from the rights referred to in Articles 15, 16, 18 and 21
- subject to the conditions and safeguards referred to in paragraph 1 of this Article
- in so far as such rights are likely to render impossible or seriously impair the achievement of the specific purposes, and such derogations are necessary for the fulfilment of those purposes

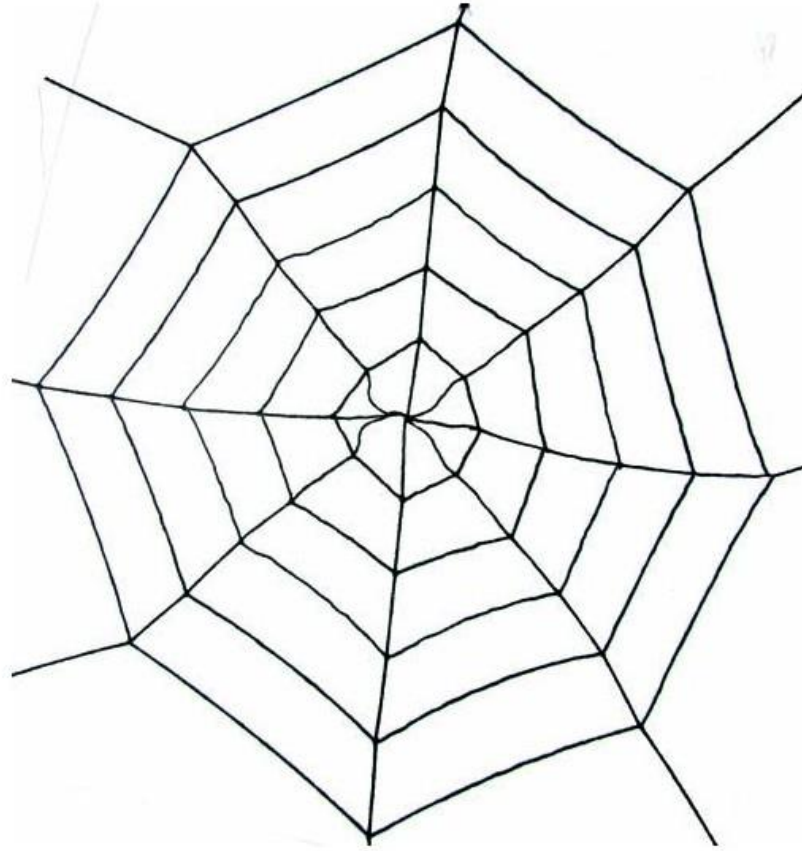
## **Archiving purposes in the public interest**

- Union or Member State law may provide for derogations from the rights referred to in Articles 15, 16, 18, 19, 20 and 21
- subject to the conditions and safeguards referred to in paragraph 1 of this Article
- in so far as such rights are likely to render impossible or seriously impair the achievement of the specific purposes, and such derogations are necessary for the fulfilment of those purposes.

If you followed carefully ...

Part 7

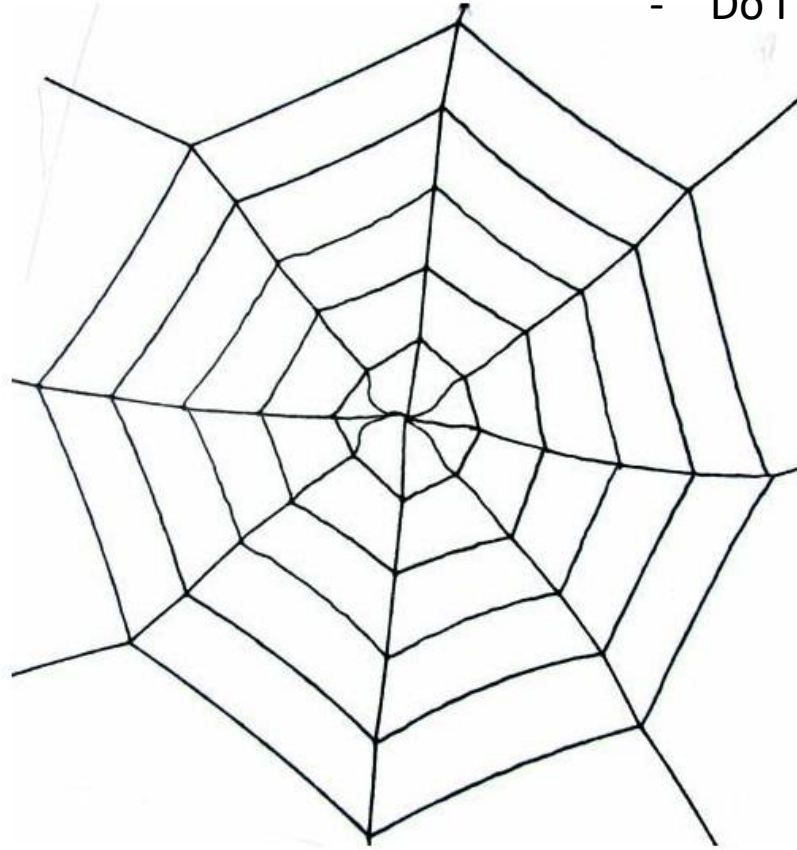
Is the process for scientific research the primary use ? Is the process for scientific research a further process ?



Is the process for scientific research the primary use ? Is the process for scientific research a further process ?

If it is my primary use :

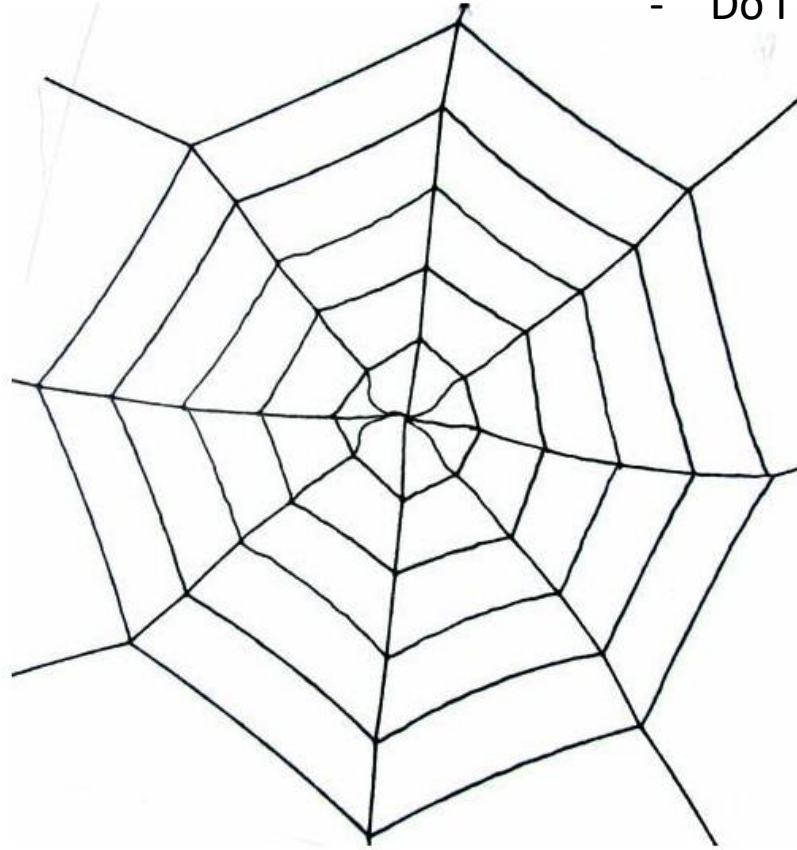
- Do I have a legal basis ?
- Is an impact assessment needed ?
- Do I comply with other requirements of the GDPR?



Is the process for scientific research the primary use ? Is the process for scientific research a further process ?

If it is my primary use :

- Do I have a legal basis ?
- Is an impact assessment needed ?
- Do I comply with other requirements of the GDPR?



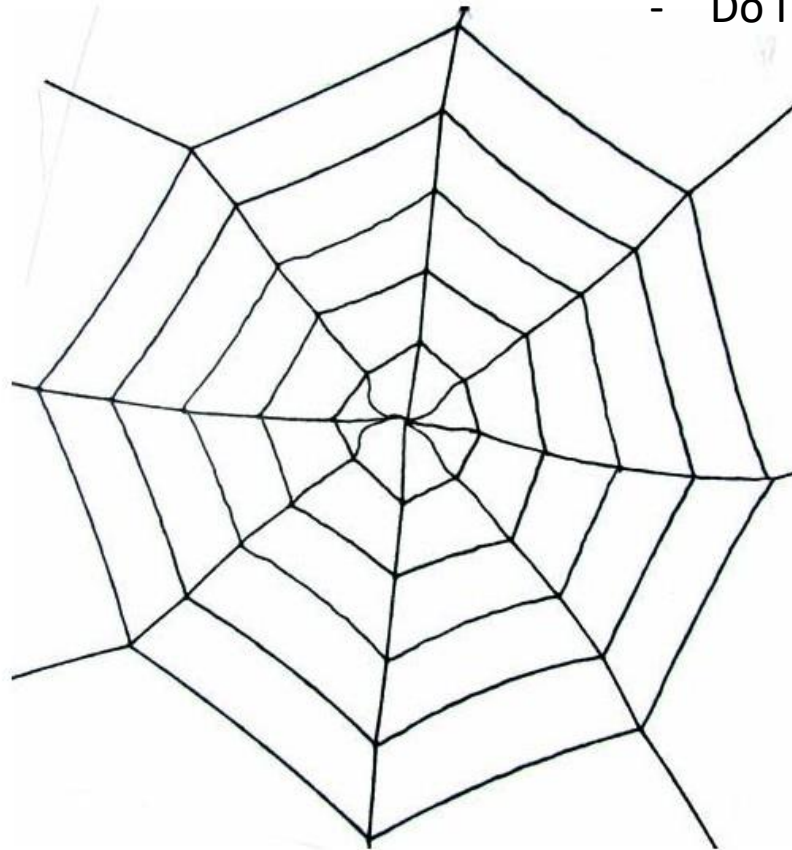
If it is a further process :

- Did I check the lawfulness of the initial process ?
- Did I take appropriate measures under art. 89(1)?

Is the process for scientific research the primary use ? Is the process for scientific research a further process ?

If it is my primary use :

- Do I have a legal basis ?
- Is an impact assessment needed ?
- Do I comply with other requirements of the GDPR?



If it is a further process :

- Did I check the lawfulness of the initial process ?
- Did I take appropriate measures under art. 89(1)?

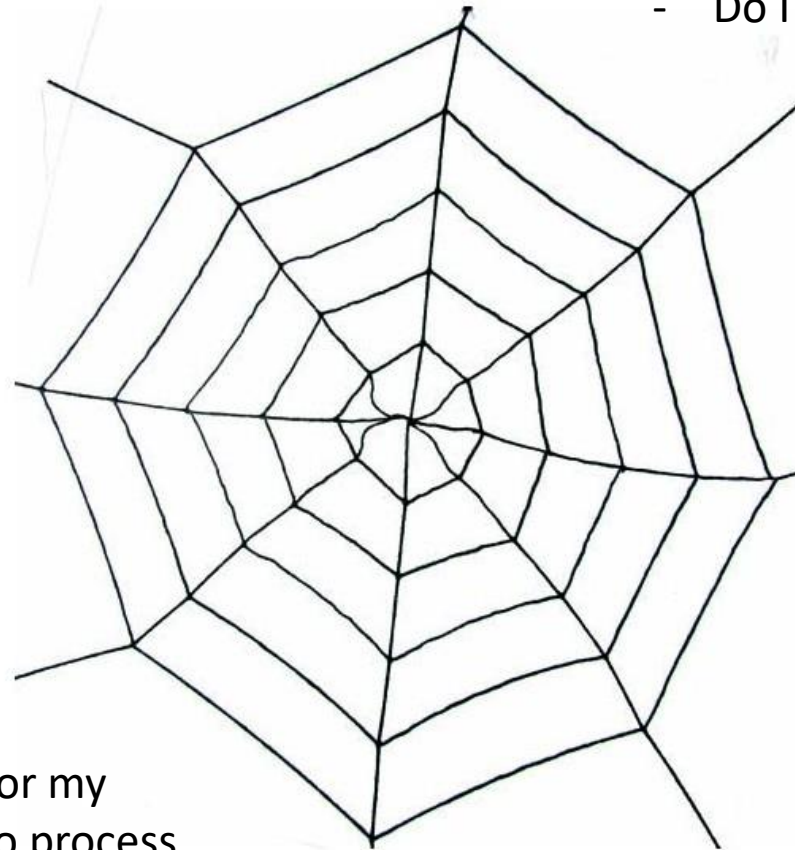
Where are the data coming from ? The data subject or a third party ?



Is the process for scientific research the primary use ? Is the process for scientific research a further process ?

If it is my primary use :

- Do I have a legal basis ?
- Is an impact assessment needed ?
- Do I comply with other requirements of the GDPR?



If it is a further process :

- Did I check the lawfulness of the initial process ?
- Did I take appropriate measures under art. 89(1)?

Do I need « normal » data for my research or do I also need to process « special categories of data » including health, biometric, genetic, ...

Where are the data coming from ? The data subject or a third party ?

Is the process for scientific research the primary use ? Is the process for scientific research a further process ?

If it is my primary use :

- Do I have a legal basis ?
- Is an impact assessment needed ?
- Do I comply with other requirements of the GDPR?

Choose the right country :

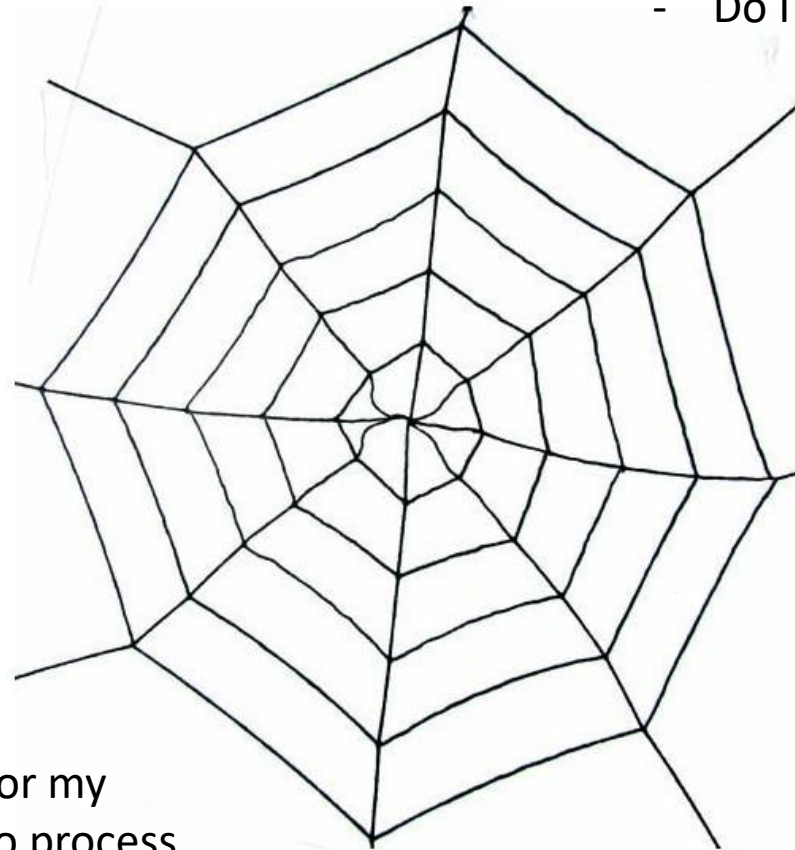
- Because of art. 9.2 j) if you process sensitive data without an adequate EU legal framework;
- In all cases, because of national specificities related to exceptions to the data subjects' rights.

If it is a further process :

- Did I check the lawfulness of the initial process ?
- Did I take appropriate measures under art. 89(1)?

Do I need « normal » data for my research or do I also need to process « special categories of data » including health, biometric, genetic, ...

Where are the data coming from ? The data subject or a third party ?





# Thank you!

Etienne Wéry & Thierry Léonard

Brussels and Paris Bars

[www.ulyes.net](http://www.ulyes.net)