

Privacy in scientific research

How to be a star in GDPR!

Stéphanie Catz, Veerle Eggens, Ina Putter, Hans
Welling

This would be handy!

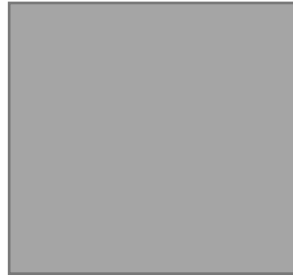
Do's



Don'ts



And this is reality:

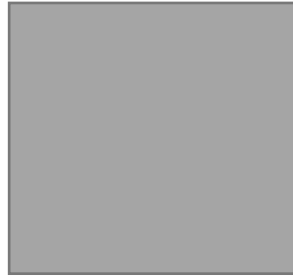


Lucky us!

This means the GDPR is more flexible than you might think.



How to make something practical from this grey box?



When does the GDPR apply?

Data is being processed that relates to an **identifiable living person.**

We call this personal data

Is this personal data according to the GDPR?

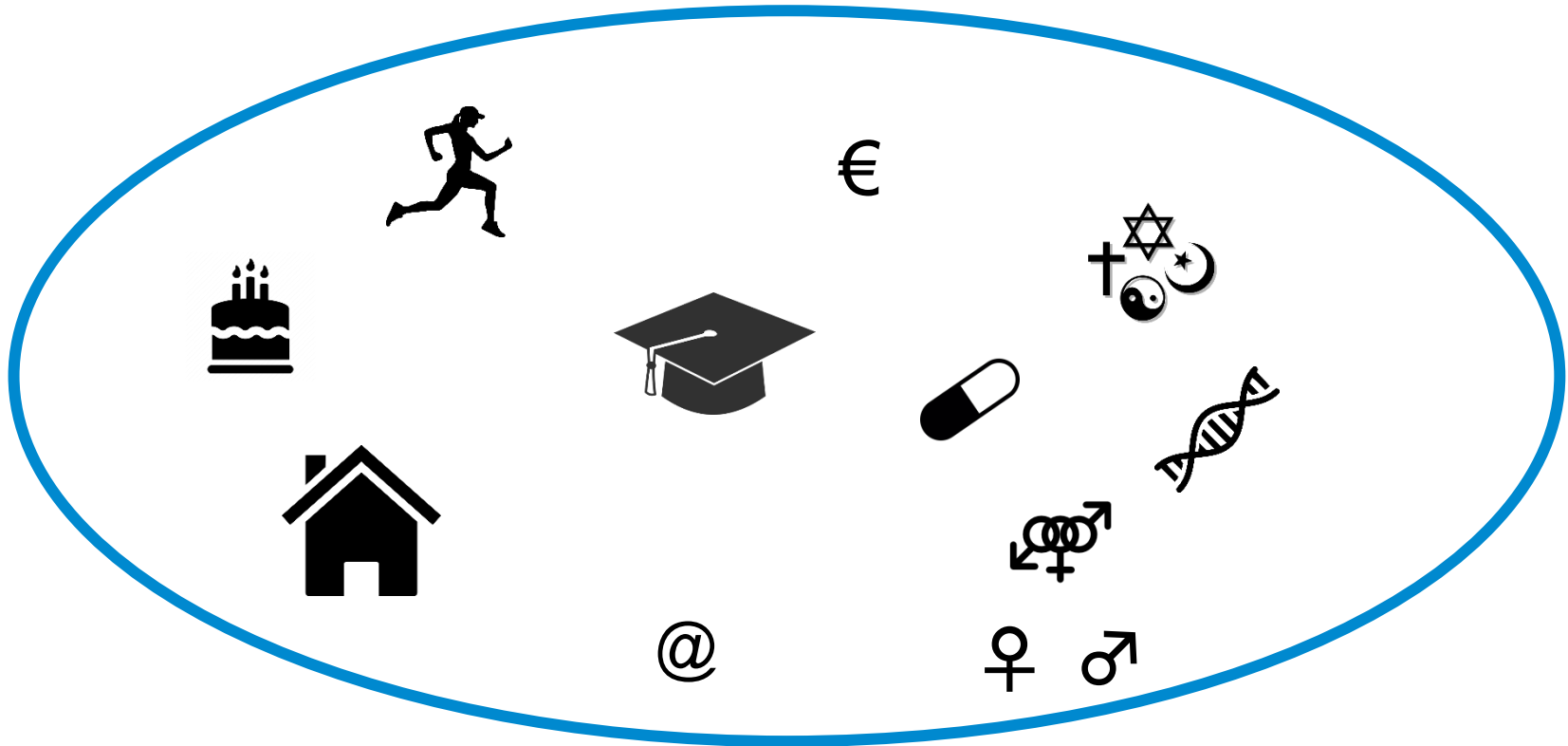
- Rosa de Jong, Mauritskade 10, Amsterdam
- A. Johnson likes soccer

Drug usage in Spakenburg

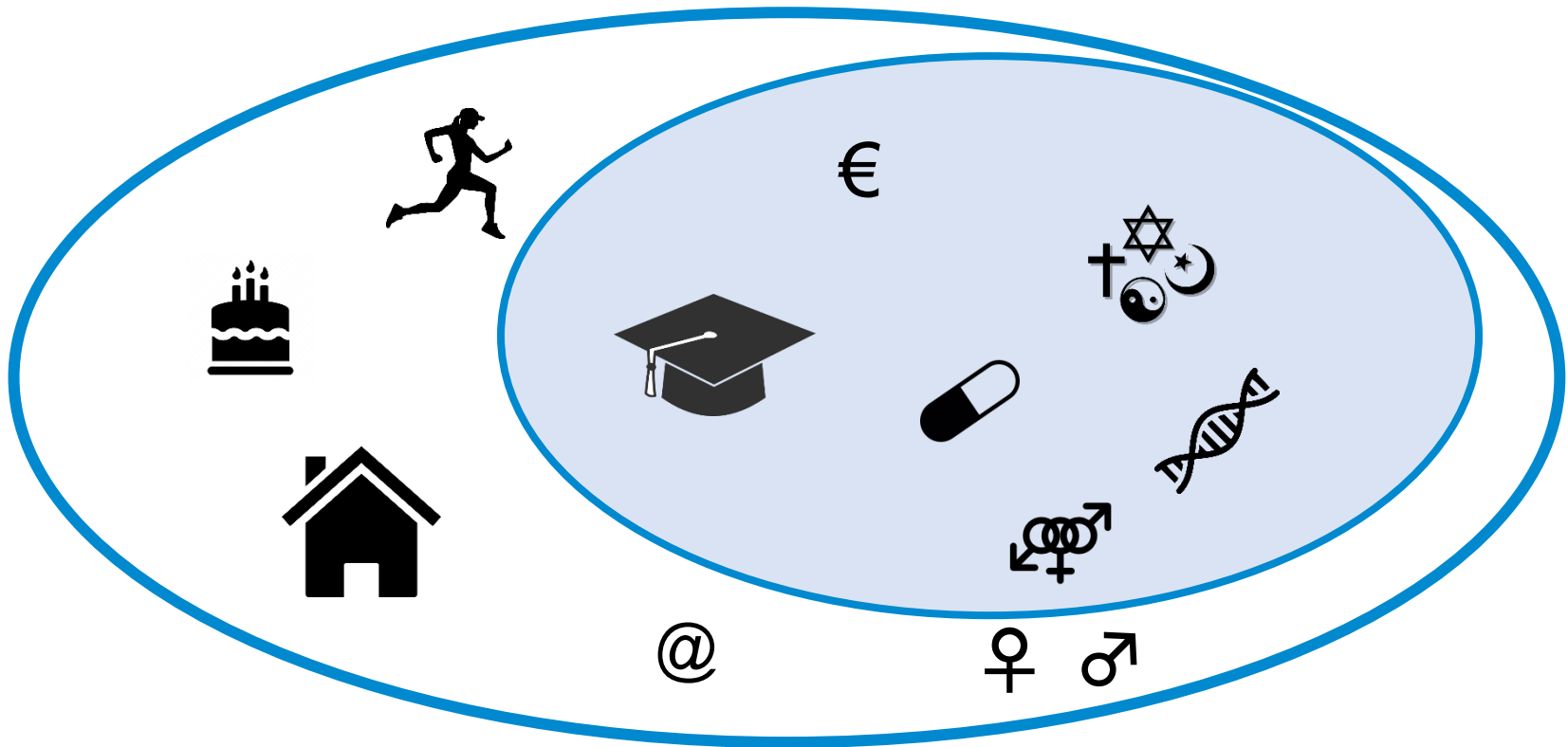
Age	None	Only soft drugs	Hard drugs (and soft drugs)	Total
< 15 years	78	12	13	103
15– 17 years	2	367	12	381
18 - 21 years	-	28	389	417
Total	80	407	414	901

No name ≠ anonymous!
No name = sometimes pseudonymous

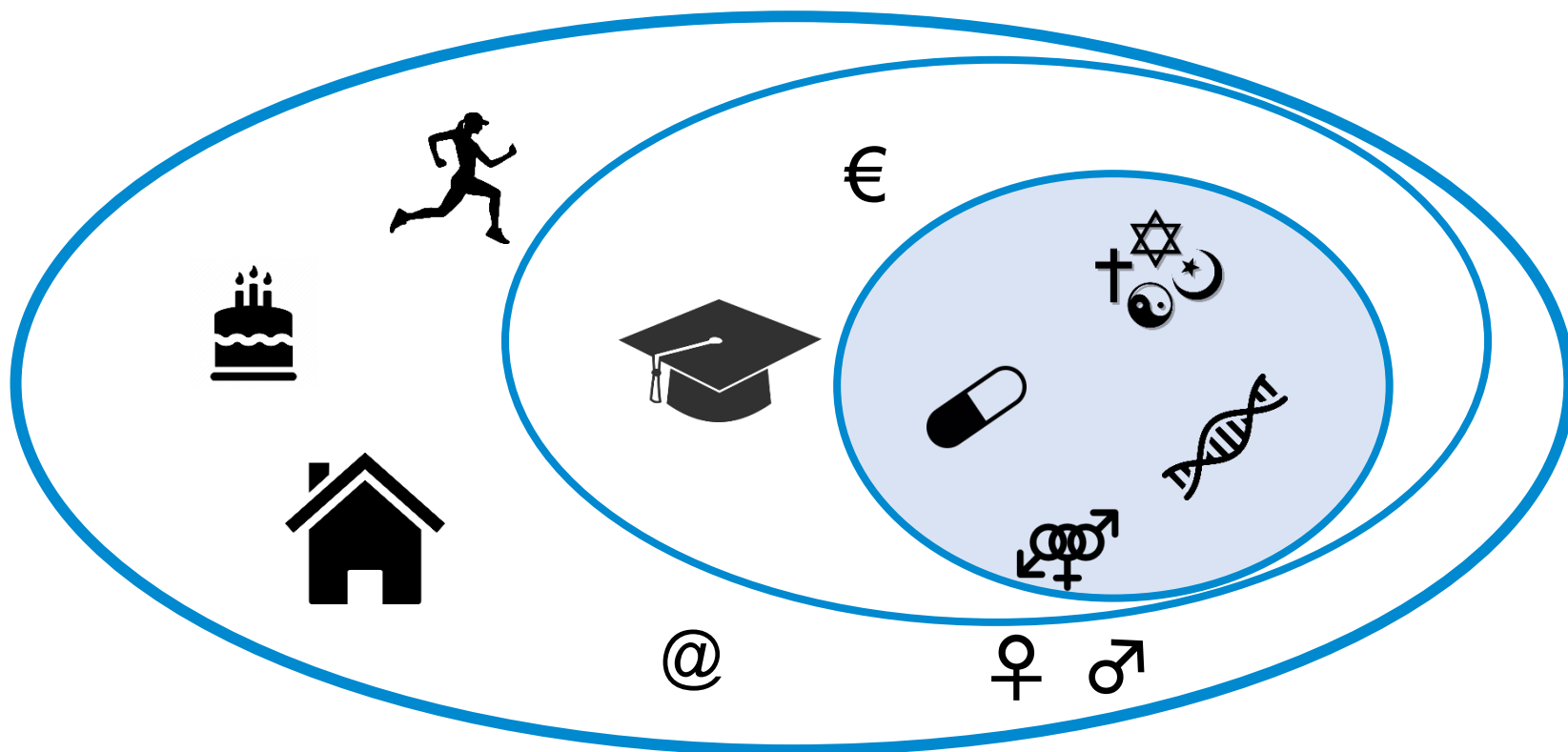
Personal data



Sensitive personal data



Special personal data



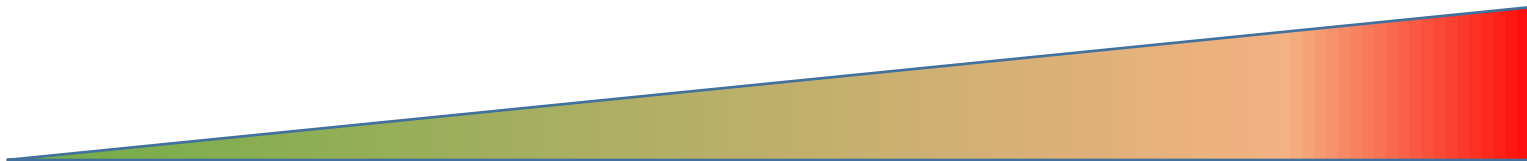
Special personal data

- racial or ethnic origin
- political opinions
- religious or philosophical beliefs, or
- trade union membership
- genetic data
- biometric data
- health
- sex life or sexual orientation
- criminal convictions and offences

Different types of personal data

- > Some are exciting (sensitive or special), like someone's salary or fortune.
- > Some are less exciting, like someone's favourite animal.

The more exciting, the more precautions to take.



When does the GDPR apply?

Data is being
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relates to a
identified or
identifiable living
person.

We call this personal data

What does *processing* mean?

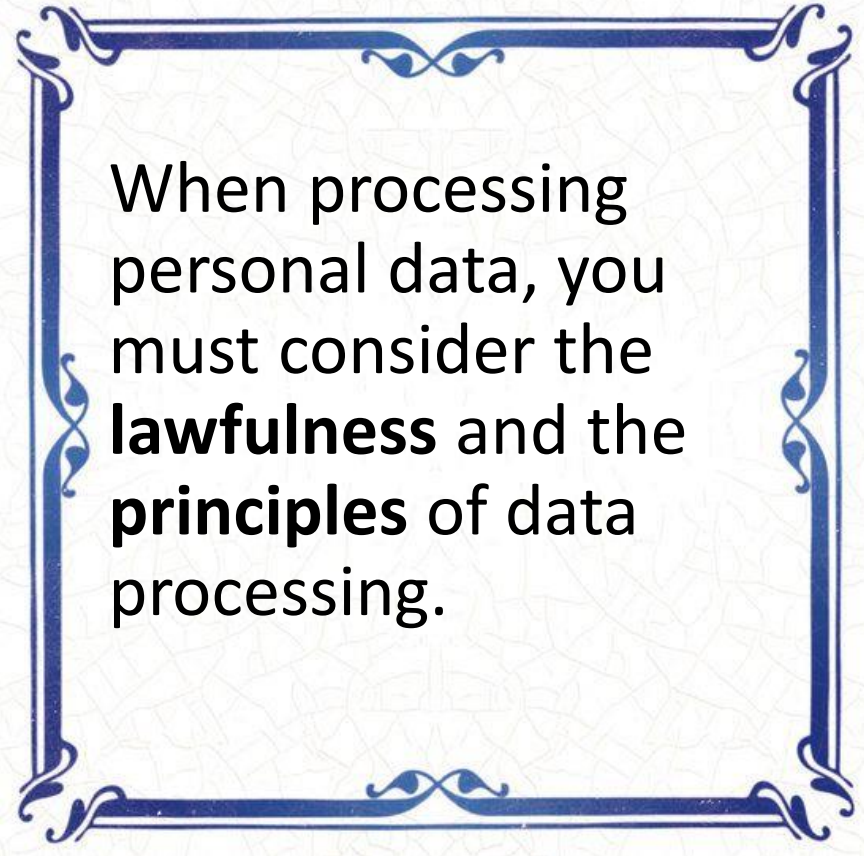
ANY action you can think of!

Even the mere receiving of personal data is processing.

For the geeks:

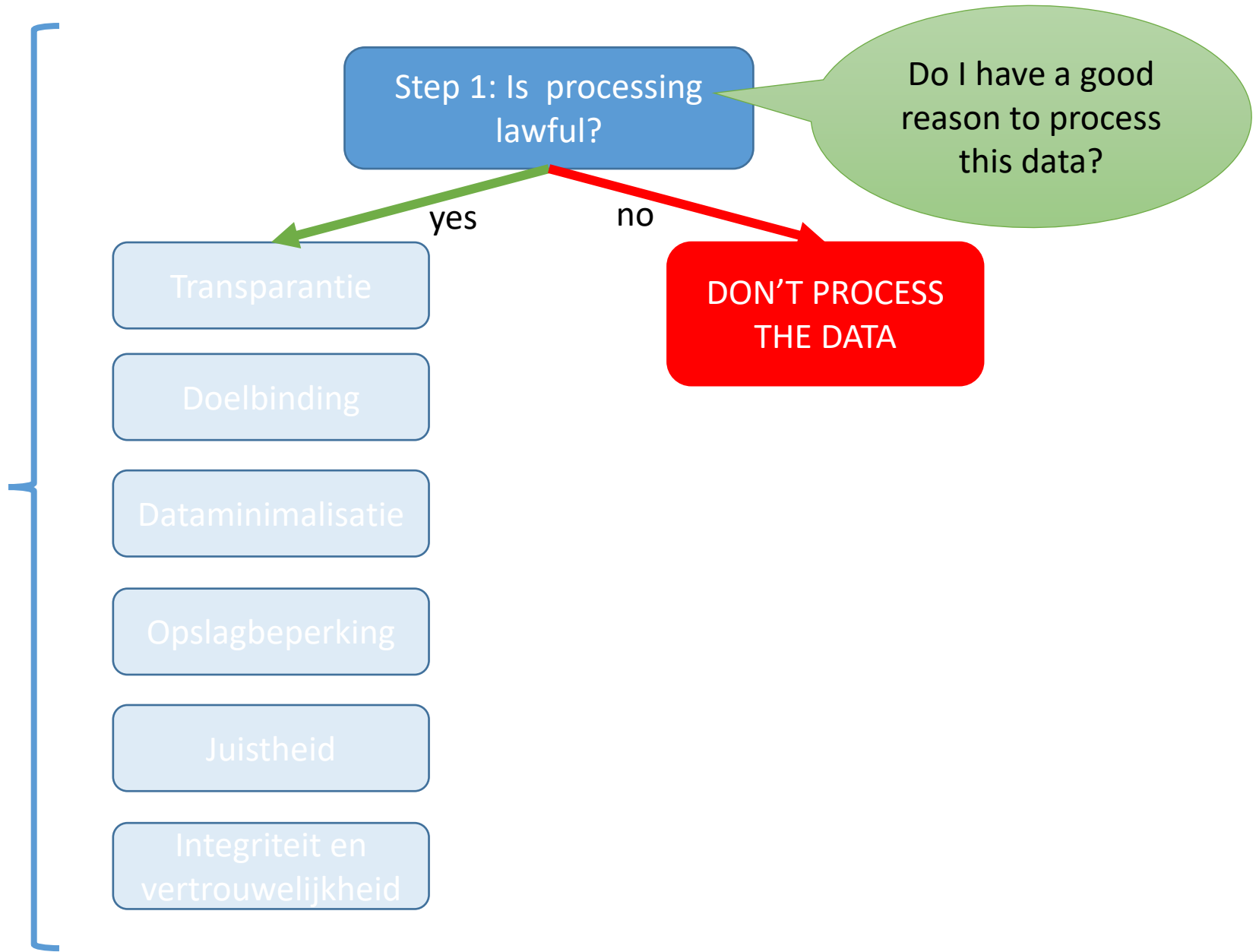
‘processing’ means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as **collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;**

OK, let's start.



When processing personal data, you must consider the **lawfulness** and the **principles** of data processing.

PRINCIPLES



STEP 1

Is processing lawful?

- 1. Consent**
- 2. Legitimate interests**
- 3. Legal obligation**
4. Contract
5. Vital interests
6. Public task

STEP 1

Is processing lawful?

- 1. Consent**
- 2. Legitimate interests**
- 3. Legal obligation**

STEP 1

Is processing lawful?

- 1. Consent**
- 2. Legitimate interests**
- 3. Legal obligation**

Has the subject given consent? Good!

Consent must be:

- Informed
- Voluntarily
- Beforehand

STEP 1

Is processing lawful?

1. Consent
2. Legitimate interests
3. Legal obligation

When consent is not possible:

Consider your needs and interest versus the impact on the subjects.

Legitimate interests

You are a scientific researcher,
so you do scientific research.

That is a legitimate interest, and
now...

... it is up to you to
make sure this
scientific interest
outweighs the
(negative) impact
on the subjects.

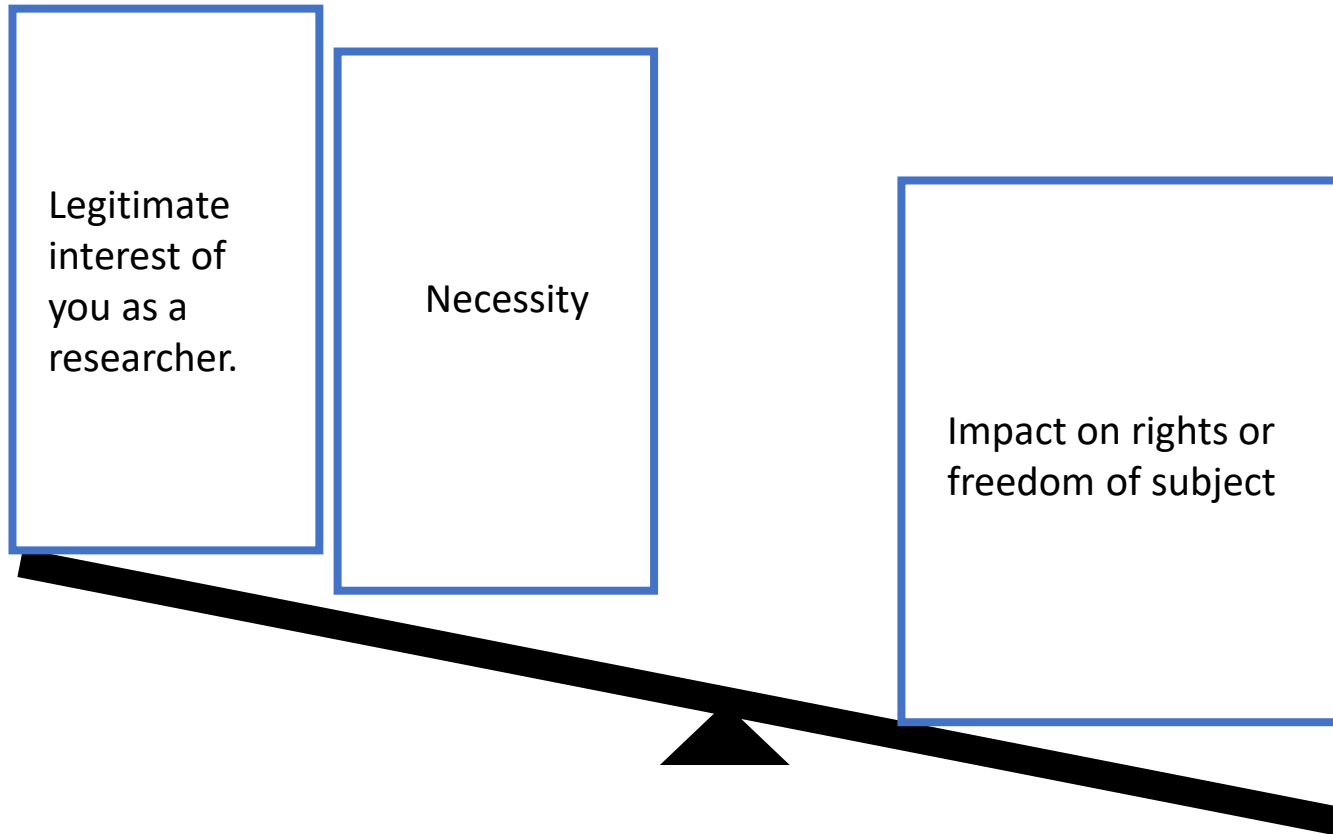
Legitimate
interest of
you as a
researcher.

Necessity

Impact on rights or
freedom of subject



Legitimate interests



STEP 1

Is processing lawful?

1. **Consent**
2. **Legitimate interests**
3. **Legal obligation**

Example: data should be archived for at least 10 years after publication.
(Archiving is also processing!)

...so far for lawfulness.

Back to the overview.

Step 1: Is processing lawful?

yes

no

Transparency

DON'T DO IT

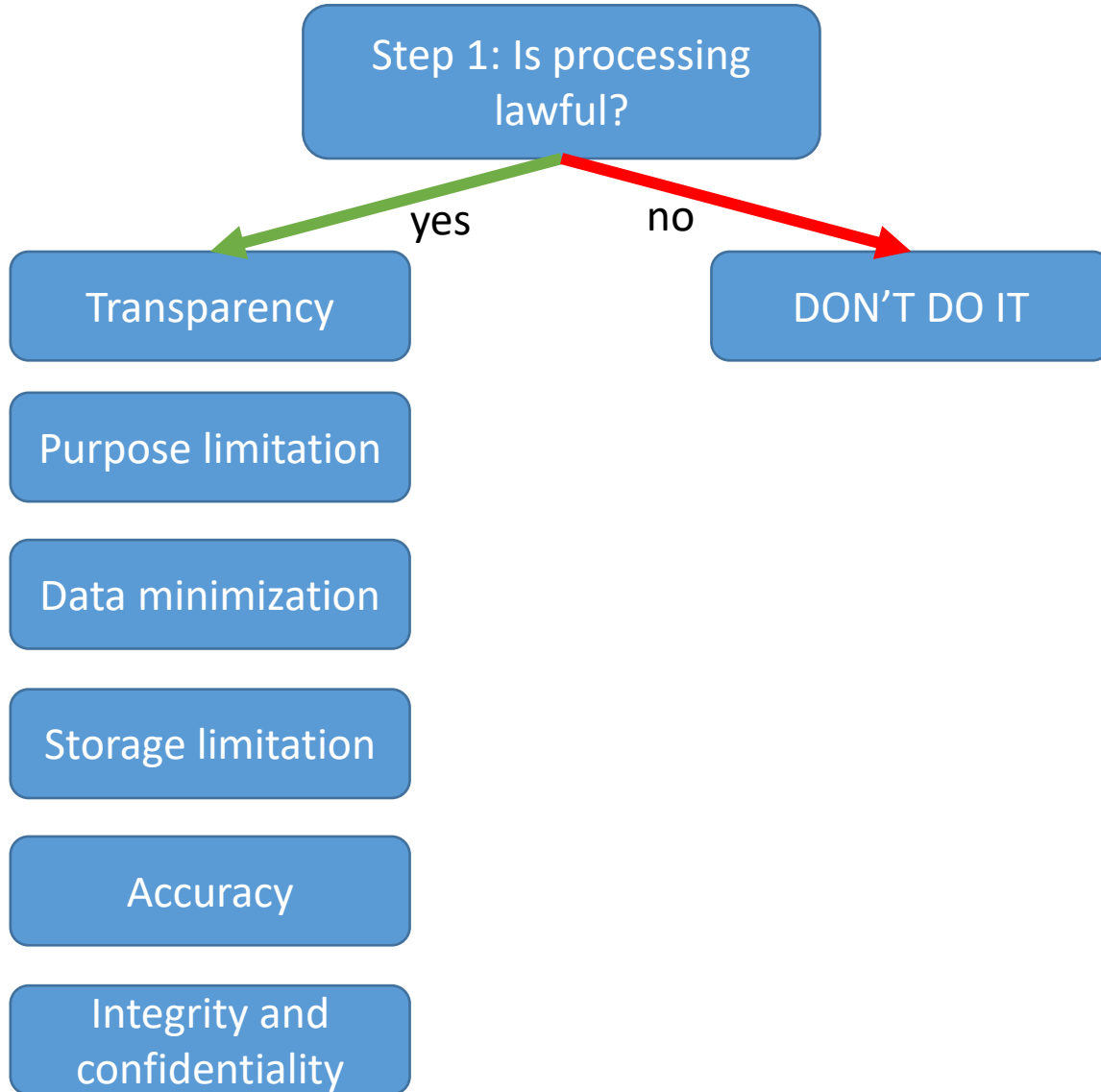
Purpose limitation

Data minimization

Storage limitation

Accuracy

Integrity and confidentiality



Does the person concerned know that I am processing his/her data?

Step 1: Is processing lawful?

yes

no

Transparency

DON'T DO IT

Purpose limitation

Data minimization

Storage limitation

Accuracy

Integrity and confidentiality

Communicate to subjects:

- What data will you collect?
Why?
- Who have access to the data?
- What will happen to the data when the project is finished?
- Etc.

- E.g. in informed consent or information letter.

Step 1: Is processing lawful?

yes

no

DON'T DO IT

Were the data collected for this purpose?

Transparency

Purpose limitation

Data minimization

Storage limitation

Accuracy

Integrity and confidentiality

Do you want to use the data for another purpose?

- In most cases, you can re-use a dataset created for scientific goal A, for scientific goal B.
- But use your gut feeling as well: would you be surprised as a subject?

Step 1: Is processing lawful?

yes

no

DON'T DO IT

Do I really need all this data to answer my question?

Transparency

Use limitation

Data minimization

Storage limitation

Accuracy

Integrity and confidentiality

> Do you really need the home address of subjects?

> Don't share all the data with everybody in collaborations.

Step 1: Is processing lawful?

yes

no

Transparency

DON'T DO IT

Limitation

tion

Storage limitation

Accuracy

Integrity and confidentiality

Do I still need all this personal data?

Delete stuff 😊
Don't use your email inbox as storage place for personal data.

Step 1: Is processing lawful?

yes

no

Transparency

DON'T DO IT

Purpose limitation

Data minimization

Accuracy limitation

Accuracy

Integrity and confidentiality

Is the data (still) correct?

Quite an open door in science.

Step 1: Is processing lawful?

yes

no

Transparency

DON'T DO IT

Purpose limitation

Data minimization

Storage limitation

Accuracy

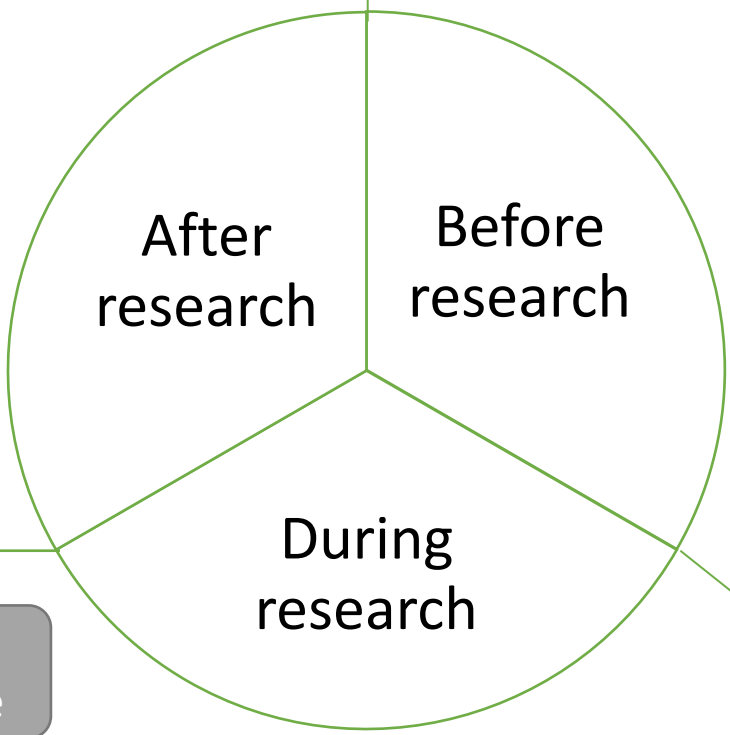
Integrity and confidentiality

Is the data being properly protected?

Shared responsibility of the VU and yourself.

Very nice indeed.

And how should I implement this in my research?



Integrity and confidentiality:

- Archiving data

Transparency:
Informed consent

Data minimization:
Reconsider survey questions.

Storage limitation:

- Delete unnecessary copies of the data
- Delete access right to persons no longer involved

Integrity and confidentiality:

- DPIA
- Processing agreements

Accuracy:
Keep the data up to date

Integrity and confidentiality:

- Storing data
- Sharing data

DPIA

Data Processing Impact Assessment

- What?
 - A DPIA is a process designed to help you systematically analyse, identify and minimize the data risks of a project
- When?
 - Large scale processing of sensitive/special personal data
 - Applicable to your research? [Contact privacy champions](#)

Data processing agreements

- Collaborating with an external party? Set up a data processing agreement.
 - Responsibilities
 - Access to data
 - Other agreements
- Research Office (researchoffice.sbe@vu.nl) can help:
 - Templates of various agreements
 - Refer you to legal experts (this might take a couple of weeks)

Integrity and confidentiality:

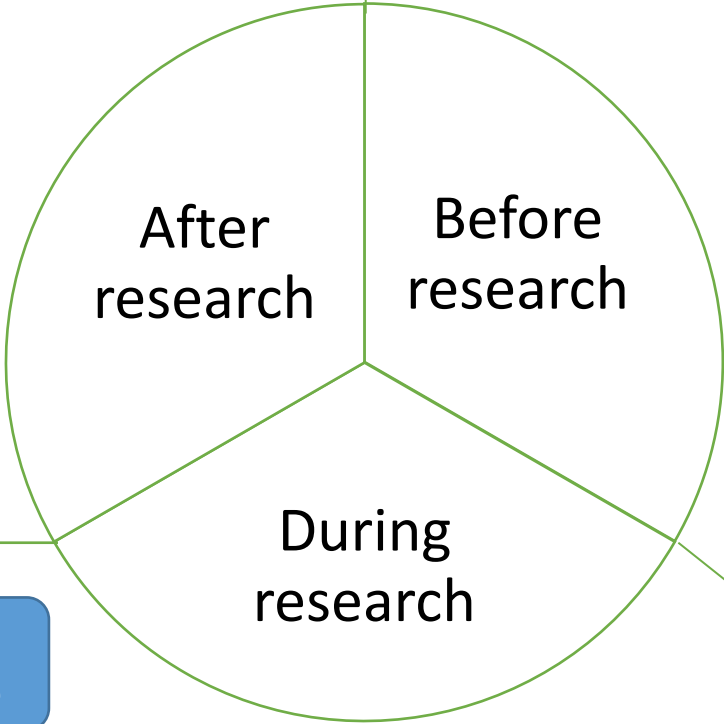
- Archiving data

Transparency:
Informed consent

Data minimization:
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Storage limitation:

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After research

Before research

During research

Integrity and confidentiality:

- DPIA
- Processing agreements

Accuracy:
Keep the data up to date

Integrity and confidentiality:

- Storing data
- Sharing data

Storing/sharing/analyzing data the lowhanging fruits

- Pseudonymize data as soon and as much as possible.
- Store your data on e.g. the VU server, SurfDrive or ResearchDrive.
- Control carefully who has access to personal data.
- Sending data? Use the ZIVVER add-on in Outlook or Surf Filesender.
- Don't use your email inbox for storing personal data.
- Don't use open WiFi, but use Eduroam or [eduVPN](#).
- Encrypt (external) hard disks (Bitlocker / Filevault)
- Lock your computer when leaving for a short while ('Window+L' or 'Control + Command + Q').

Integrity and confidentiality:

- Archiving data

Storage limitation:

- Delete unnecessary copies of the data
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Accuracy:

Keep the data up to date

Transparency:

Informed consent

Data minimization:

Reconsider survey questions.

Integrity and confidentiality:

- DPIA
- Processing agreements

Integrity and confidentiality:

- Storing data
- Sharing data

After research

Before research

During research

Archiving data

- Scientific data should be archived for at least 10 years
- Personal data? Archive in [DarkStor](#).

Take home message

De Telegraaf -test!

When your work appears in the newspaper:

‘VU scientist violates privacy of subjects!’

What is your side of the story?

Are we done? Almost!

Data breach – what to do?

A data breach is a security incident in which personal details may have been lost or may have been **accessed, viewed, changed or used by unauthorised persons.**

To do (immediately!):

- Inform privacy champions (privacy.sbe@vu.nl)
- Call or mail IT Servicedesk:
servicedesk.it@vu.nl
+31 20 59 80000

Need someone to think along?

SBE has four Privacy Champions!

Ina Putter and Veerle Eggens for research.

Hans Welling and Stéphanie Catz for support staff.

All for education.

Contact us via privacy.sbe@vu.nl

(and we all have phone numbers but we don't give you that because of data minimization)

Nice and grey it is,
because every research is different.

