

Erasmus School of
Health Policy
& Management

Research Data Management Awareness Campaign

Erasmus University Rotterdam



Working with human participants: personal data

RDM Awareness Campaign @ESHPM

Goals today

Understanding what personal data is

Understanding when personal data is considered sensitive

Remembering the difference between anonymization and pseudonymizing

Knowing appropriate storage solutions

The Erasmus logo, featuring the word "Erasmus" in a stylized, cursive script.

**What are
personal data?**

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Article 4(1) GDPR

'Personal data' means any information...

a) relating to an **b) identified** or
an **identifiable**, **c) natural** person

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a) relating to

- When the data reveals something about you
- When data can be linked to you

b) identified or an **identifiable**

Identified: A natural person that can be uniquely singled out from other persons.

Identifiable: Not yet identified, but possible without unreasonable effort

Directly identifiable personal data: Unique, highly distinctive data (name, address, date of birth)

Indirectly identifiable personal data: Can identify a natural person by itself or if combined with other data (quasi-identifiers).

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Bart-Jan de Vries



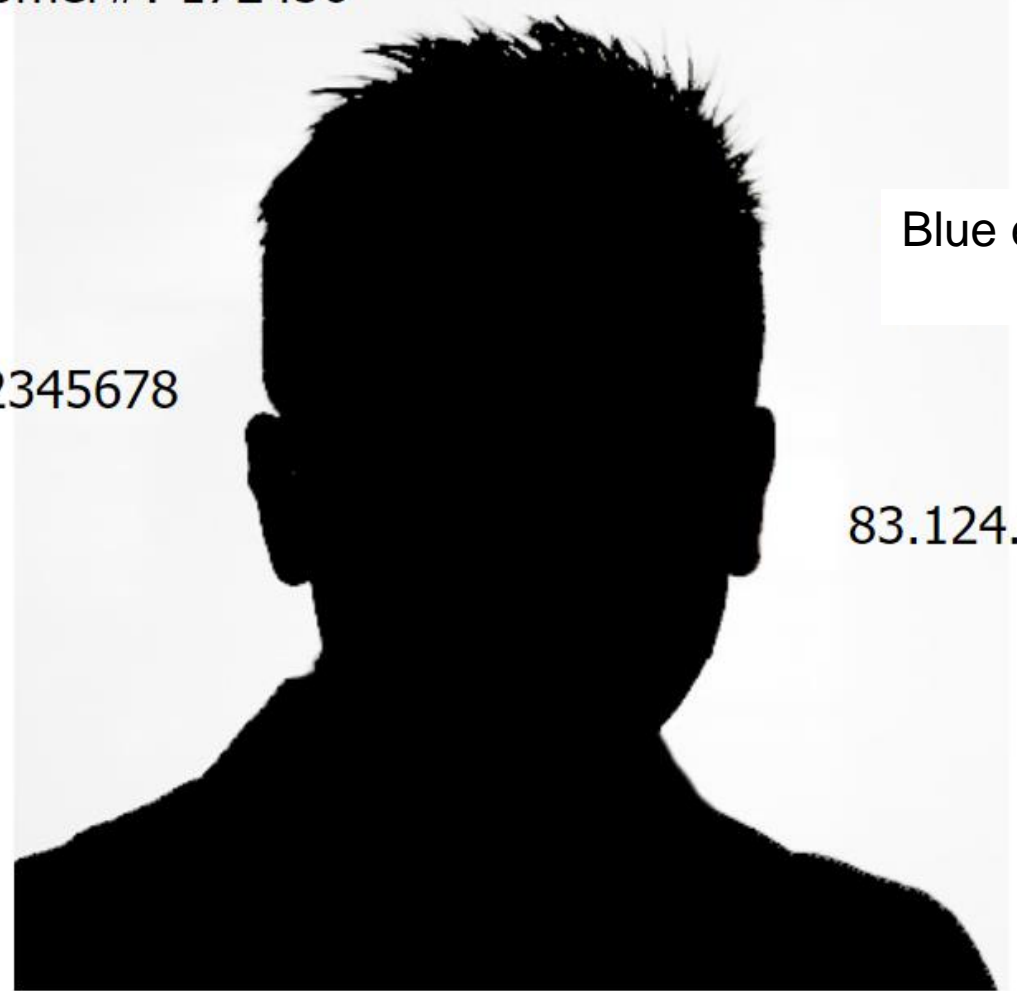
Identified

customer#: 172456

Age: 43

06-12345678

12 February 1978



Blue eyes

83.124.145.21

Identifiable

Directly identifiable personal data

Ask yourself this question:

Can I **DIRECTLY** determine the identity of this person?
By e.g. their name, address or date of birth?

Is your answer 'yes'? Then data is identifiable personal data

Bedrijfsnaam	Aanspreektitel	Naam	Straat en huisnummer	Postcode	Plaats	Land
De Grootte	Dhr.	Kees De Grootte	Lange Hazelaar 25	9000	Gent	
Jansen en Co	Dhr. en mevr.	Cees en Katja Jansen-Bloem	Kei 50	9860	Scheldewindeke	
Firma Leyers	Mevr.	Vera Lune	Vaart 125	9000	Gent	
Fietsenhandel De Croo	Dhr.	Jan De Croo	Leegbracht 5	9000	Gent	
Gebroeders Van Schootten	Dhr. en mevr.	Hans en Cis Van Schootten-Marienhof	Oever 1	9860	Oosterzele	
De Haan	Mevr.	Marleen De Haan	Planetenwijk 31	9000	Mariakerke	
Autoverhuur Kistens	Mevr.	Karlijn Kistens	Lekdijk 34	4124 AZ	Everdingen	Nederland
Fabers Kooltechniek	Dhr. en mevr.	Leo en Miriam Fabers-Van Hoogevoeld	Sint Janskerkhof 42	4104 CT	Culemborg	Nederland
Houthandel De Bruyn	Dhr. en mevr.	Gerard en Katrien De Bruyn-Voerman				
Van Schoten Ijzerwaren	Dhr.	Harald Van Schoten				



Indirectly identifiable personal data

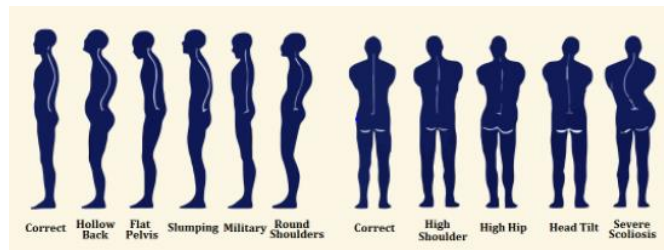
Then, ask yourself this question:

Can I INDIRECTLY determine the identity of this person?

By e.g. a combination of information about this person?

Context is key

Think of height, build, hair colour, profession, income or education



2afm

Natural persons

GDPR only applies to natural persons (that are alive*)

Data about the Erasmus University Rotterdam (company data) are not personal data



**What are sensitive
personal data?**

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Kinds of personal data

- Regular: everything non-special or sensitive
- Special categories, defined by GDPR, as data revealing:
 1. racial or ethnic origin
 2. political opinions
 3. religious or philosophical beliefs
 4. trade union membership
 5. genetic data
 6. biometric data for the purpose of uniquely identifying a natural person,
 7. data concerning health
 8. data concerning a natural person's sex life or sexual orientation

Limitative list!

- Sensitive: can have negative consequences for an individual (not defined by GDPR)

A stylized, handwritten-style logo of the word "Erasmus" in a dark blue or black color, located in the bottom right corner of the slide.

Regular

name
address

Sensitive

financial data
BSN
criminal data

Special

eight categories

Regular
name
address

Sensitive
financial data
BSN
criminal data

Special
eight categories

Legal perspective: regular and special categories

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Regular
name
address

Sensitive
financial data
BSN
criminal data

Special
eight categories

Ethical perspective: risk involved for the data subject

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Privacy compliant research: things to consider

Planning	Data collection	Data preparation	Data storage	Analysis	Publication & Archiving
<div>Purpose specification</div> <div>Legitimacy</div> <div>DPIA</div> <div>Ethical review committee</div>	<div>Selection of data</div> <div>Consent</div> <div>Third party mgt.</div>	<div>Pseudonymizing</div> <div>Anonymization</div>	<div>EUR Document Vault</div> <div>Encryption</div> <div>Access</div>	<div>Access</div> <div>Accuracy</div>	<div>Storage</div> <div>Access</div> <div>Anonymization</div>

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**When is data
anonymous?**

**And what is
pseudonymizing?**

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What is anonymous data?

- Data that is (rendered) unidentifiable and therefore is **not or no longer** related to an identified or identifiable natural person
- Anonymization is “the process of removing personal identifiers, both direct and indirect, that may lead to an individual being identified.”

Name	Address	DoB (y/m/d)	Height (cm)	Religion
	12, Red Road, Amsterdam		156	Atheist
	10, Blue Lane, Rotterdam		167	Muslim
	188, Violet Alley, Utrecht		187	Christian
	56, Yellow Avenue, Breda		175	Jewish
	78, Green Boulevard, Groningen		169	Buddhist
	666, Orange Drive, Alkmaar		177	Pastafarian

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What is anonymous data?

- Other anonymization techniques are grouping/aggregating/generalizing/masking
- Anonymizing data should be irreversible

Name	Address (city)	DoB (y)	Height (cm)	Religion
	Amsterdam	1988	150-160	Atheist
	Rotterdam	1990	160-170	Muslim
	Utrecht	1992	180-190	Christian
	Breda	1960	170-180	Jewish
	Groningen	1962	160-170	Buddhist
	Alkmaar	1980	170-180	Other

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Anonymize the following statement:

Mr. Weber

CEO of Munich Ltd.

earns €10.389.290,89

#321 in Quote 500



What is anonymous data?

- Truly anonymizing personal data is hard
 - because there is always a risk of re-identification (according to EC), and
 - it might affect the value of the data
- Not an option for very detailed datasets, with a lot of granularity
- When data is truly anonymous, GDPR no longer applies. But this shouldn't be a goal in itself!

What is pseudonymizing?

Article 4(5) GDPR:

the processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information

- A security measure that makes the use of the data less risky
 - Tokenization (replacing direct identifiers and/or sensitive data by pseudonyms)
 - Anonymization techniques that do not result in a truly anonymous dataset
- Data is still subject to GDPR

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Tokenization

Name and surname	Address	Sex	Date of birth	Reason for visit	Healthcare institution
Mehmed Ramić	Gračaničkih gazija bb, Gračanica	M	11.01.2006	Vomiting	Dom zdravlja Gračanica
Dinka Kovač	Stupine B17, Tuzla	F	26.03.1997	Hornet sting	Dom zdravlja Tuzla
Mirsad Memić	Fadila Kurtagića 203, Kladanj	M	13.08.1995	Influenca	Dom zdravlja Kladanj
Marina Tomić	Ulica oslobođenja bb, Žvinice	F	08.08.2008	Stab	Dom zdravlja Žvinice
Duško Obradović	VI bosanske brigade bb, Tuzla	M	12.12.1985	Cochlear implant surgery	UKC Tuzla



Token	Sex	Date of birth	Reason for visit	Healthcare institution
662234	M	11.01.2006	Vomiting	Dom zdravlja Gračanica
368744	F	26.03.1997	Hornet sting	Dom zdravlja Tuzla
223365	M	13.08.1995	Influenca	Dom zdravlja Kladanj
234122	F	08.08.2008	Stab	Dom zdravlja Žvinice
112778	M	12.12.1985	Cochlear implant surgery	UKC Tuzla

+

Token	Name and surname	Address
662234	Mehmed Ramić	Gračaničkih gazija bb, Gračanica
368744	Dinka Kovač	Stupine B17, Tuzla
223365	Mirsad Memić	Fadila Kurtagića 203, Kladanj
234122	Marina Tomić	Ulica oslobođenja bb, Žvinice
112778	Duško Obradović	VI bosanske brigade bb, Tuzla

Ezra

Approximation

Name	Address (city)	DoB (y)	Height (cm)	Religion
	Amsterdam	1988	150-160	Atheist
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	Breda	1960	170-180	Jewish
	Groningen	1962	160-170	Buddhist
	Alkmaar	1980	170-180	Other

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DATA DEIDENTIFICATION



Selection of data / Data minimization

Article 5(1)(c) says:

“1. Personal data shall be:

(c) **adequate, relevant and limited** to what is necessary in relation to the purposes for which they are processed (data minimisation)”

In practice, this means:

- a) Data collection and processing should only include as much data as is required to successfully answer the research question(s)
 - Do I need date of birth, or is year of birth or age also sufficient?
 - Income (€35.521,-, or €30.000 - €40.000)
- b) Personal data that is no longer needed, should be deleted
 - Contact data, financial data, key files, recordings*

Data minimization is not the sport of collecting as few personal data as possible

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Data storage

Personal Sensitive or Special Categories Data	<ul style="list-style-type: none">• EUR Document Vault (built-in encryption)• EUR Network Drive (password protected folder)• EUR Surf Drive + encryption
Personal Data (non-sensitive)	<ul style="list-style-type: none">• EUR OneDrive• EUR SURFdrive• EUR SURF Research Drive (for collaborations)

Publishing data

- To learn more about the safeguards necessary for publishing data come to the talk by Antonio Schettino on Thu Oct. 28!

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Archiving data

- Scientific integrity: archive all data
- But:

30. You may be obliged to destroy some data before archiving. Do any of such obligations apply to you?

- ☐ I do not know
- ☐ No
- ☐ Yes - Contractual obligation (e.g. licenses)
- ☐ Yes - Commercial objectives
- ☐ Yes - Privacy law (e.g. personal data of participants)
- ☐ Yes - Other - please specify:

Perspective of scientific integrity

All raw, processed and analysed data

Documentation and/or codebooks necessary for understanding the data

Readme.txt file for understanding the structure and content of the deposit

Data management plan

Approval by an ethics committee

Informed consents forms and information brochure

Audit trails¹

Source: RDM, Radboud University

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Consent

(Legitimacy)

Consent (GDPR):

“I agree with the processing of my personal data for research into X and Y”

Consent from respondents makes scientific research *legitimate*. You have a legal base to collect and further process the personal data of your respondents.

Recital 42 GDPR:

*...where processing is based on the data subject's consent, the controller should be able to **demonstrate** that the data subject has given consent to the processing operation.*

Written consent or recorded oral consent

A handwritten signature in black ink, appearing to read 'Erasmus', located in the bottom right corner of the slide.

Third party management

Sharing or transferring personal data, what to consider?

Data collecting agencies (like Dynata)

- Data is not anonymous, but pseudonymized (agency has key file)
- Data sharing agreement is not necessary, BUT make sure agency is trustworthy (read T&C's!)

Collaboration partners (e.g. other universities/research institutes)

- Data protection responsibilities, who is responsible for what part of processing personal data?
- Intellectual property rights, publication rights
- Liability
- Data sharing agreement/collaboration agreement with data protection clauses (**template** available!)

Sponsor ('opdrachtgever')

- Sharing data, yes/no? Anonymous/pseudonymized? Informing participants
- Scientific integrity
- Overeenkomst voor contractonderzoek + AVCO (**template** available!)

Translation/transcription services

- Read T&C's
- Non-disclosure agreement (NDA) (**templates** available!)

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