

GDPR – what’s all the fuss about?

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Disclosure

Speaker name:

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I have the following potential conflicts of interest to report:

- Consulting
 - Employment in industry
 - Stockholder of a healthcare company
 - Owner of a healthcare company
 - Other: co-founder of genae
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- I do not have any potential conflict of interest

Background

1995: EU Data Protection Directive

- National legislation → EU differences
- Data breaches
- Court cases, eg the Google case (right to be forgotten)



Background

Publication of the General Data Protection Regulation (GDPR) in 2016

Into force on 25-May-2018



And then....



It's about European Citizens

ABOUT US

GDPR enforcement

Harmonization across and beyond the EU

- Some points are left to possible national laws, eg age to consent can be lowered

Non-EU entities must comply with the GDPR when dealing with data of EU citizens

- One single supervisory authority though

GDPR definition

Personal Data definition

- any information relating to a person who can be identified, directly or indirectly, by reference to an identifier such as a name, an identification number, location data, online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that person

Example: IP address is regarded Personal Data

GDPR – main aspects

Rights of Individuals

- Right to Erasure or Right to be Forgotten
 - Provided certain grounds apply: eg the data is no longer necessary in relation to the purposes for which it was collected

NOTE: clinical trial data cannot be erased when this may endanger their or other people's health or life

Right to be forgotten

Dutch surgeon wins landmark 'right to be forgotten' case

Ruling will ensure doctors no longer judged by Google on fitness to practise, lawyer says

Daniel Boffey in Brussels

Mon 21 Jan 2019 12.47 GMT



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▲ The surgeon's lawyer described the ruling as 'groundbreaking'. Photograph: John Wellings/Alamy

A Dutch surgeon formally disciplined for her medical negligence has won a legal action to remove **Google** search results about her case in a landmark “right to be forgotten” ruling.

The doctor's registration on the register of healthcare professionals was initially suspended by a disciplinary panel because of her postoperative care of a patient. After an appeal, this was changed to a conditional suspension under which she was allowed to continue to practise.

GDPR – main aspects

Rights of Individuals

- Right to be Informed
 - Who is collecting your personal data and what's the purposes for which data controllers are processing it

Facebook browser window showing the "Your Information" page. The browser address bar shows "https://www.facebook.com/". The page title is "Your Information". The navigation bar includes "Search", "Aly", "Home", "Create", and various icons. The main content area is titled "Access Your Information" (circled in red) and contains a paragraph explaining that the page lists Facebook information accessible at any time, categorized by type. Below this is a section titled "Your Information" with an information icon. The content is organized into two columns. The left column lists categories: Posts (with a dropdown arrow), Your Posts, Posts You're Tagged In, Other People's Posts To Your Timeline, Posts Hidden from Your Timeline, Notes, and Polls. The right column lists categories: Photos and Videos, Your Photos, Photos and Videos You're Tagged In, Your Videos, Photos Synced from Your Device, and Likes and Reactions. At the bottom right, there is a "Chat (22)" notification with icons for messages, a group, and settings.

Access Your Information

Here is a list of your Facebook information that you can access at any time. We've categorized this information by type so you can easily find what you're looking for. Our [Data Policy](#) has more information about how we use your information, how it's shared and how long we retain it. It also outlines your rights and how you can exercise them, and how we operate and transfer your information as part of our global services.

You can choose to [download your information](#) if you'd like a copy of it.

Your Information



Posts

Posts you've shared on Facebook and posts you've been tagged in

Your Posts

Photos, videos, text and status updates you've shared on Facebook

Posts You're Tagged In

Posts that people tag you in

Other People's Posts To Your Timeline

Posts other people have shared on your timeline

Posts Hidden from Your Timeline

Posts that you've chosen not to show on your timeline, including posts you've created and posts that other people have created

Notes

Notes you've created or have been tagged in

Polls

Polls you have created



Photos and Videos

Photos and videos you've shared or tagged in

Your Photos

Photos you've uploaded and shared

Photos and Videos You're Tagged In

Photos and videos you've been tagged in

Your Videos

Videos you've uploaded and shared

Photos Synced from Your Device

Photos from your device you've chosen to sync to your Facebook account



Likes and Reactions

Posts, comments and Pages you've reacted to

Chat (22)



GDPR – main aspects

New roles

- Data Protection Officer (DPO)
- Data Processor
- Data Protection Authority (DPA)

GDPR – main aspects

Fines & enforcement:

- Significantly higher fines
 - €10 million or 2% of the entity's global gross revenue for violations of record-keeping, security, breach notification, and privacy impact assessment obligations.
 - €20 million or 4% of the entity's global gross for violations on the processing (including consent...), data subject rights, and cross-border data transfer

Clinical trial data

! Sensitive data

- Patients must be informed about what data is collected, where it's stored, who has access, ..
- Transferring data outside Europe, must be according to GDPR legislation for data collected in the EU!
- Data processors need to be assigned to support this process



Summary

Think about the data you have

The data you intend to collect

What you will do with the data

Document the process, what you capture and who will have access to this

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