

Big Data & Trust

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What is your background?

What are your expectations
of this workshop?

Content

During this workshop, we will talk about:

- Large-scale data collection.
- Trust in data-collecting institutions.
- General Data Protection Regulation (GDPR)
- Open Science & sharing data.

What makes data “big”?

Big Data Definition

Gartner's definition (2001).

Data is 'big' when conventional storage, transport and processing equipment is unable to cope with excesses in terms of:

- *Volume: the sheer amount of bytes that need to be stored.*
- *Velocity: the speed at which new data arrives.*
- *Variety: how many types of data (images, text, video).*

Data is information

Usually, more information is better.



Challenges of big data

But things get complicated when people are involved.

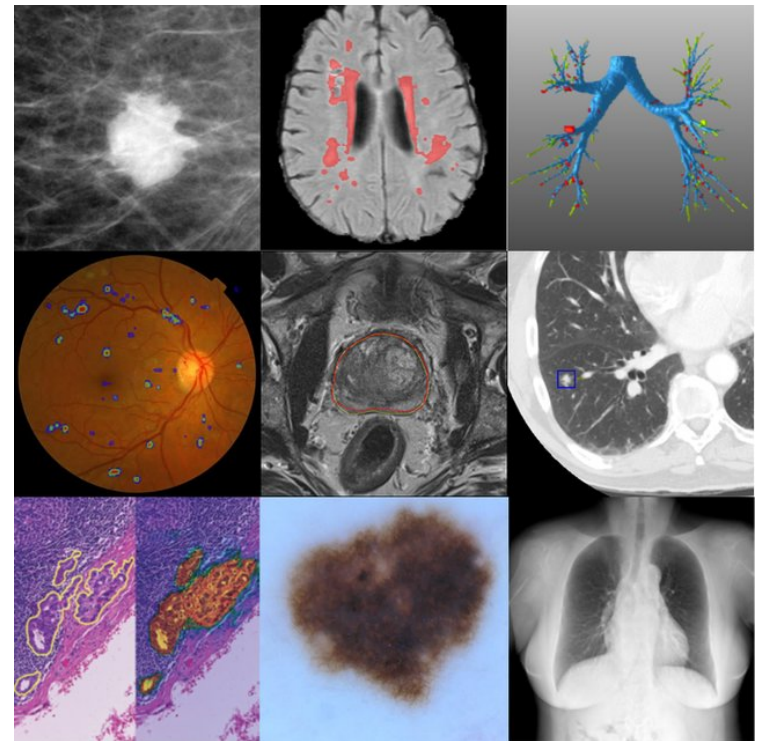
- Medical & health centers
- Companies & advertisers
- Governments & public security

Big Data in Health & Medicine

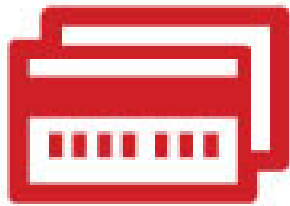
Medical centers collect patient data to diagnose diseases, but also to improve their ability to diagnose.

Data sets can be used to evaluate experimental diagnosis methods.

Intelligent systems can be trained to detect abnormalities in biometric signals or medical images.

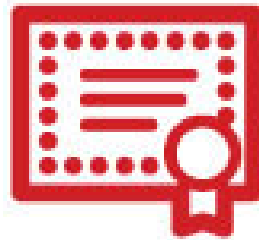


YOUR DATA'S BLACK MARKET VALUE



Social Security
number

\$30



Date of birth

\$11



Health
insurance info

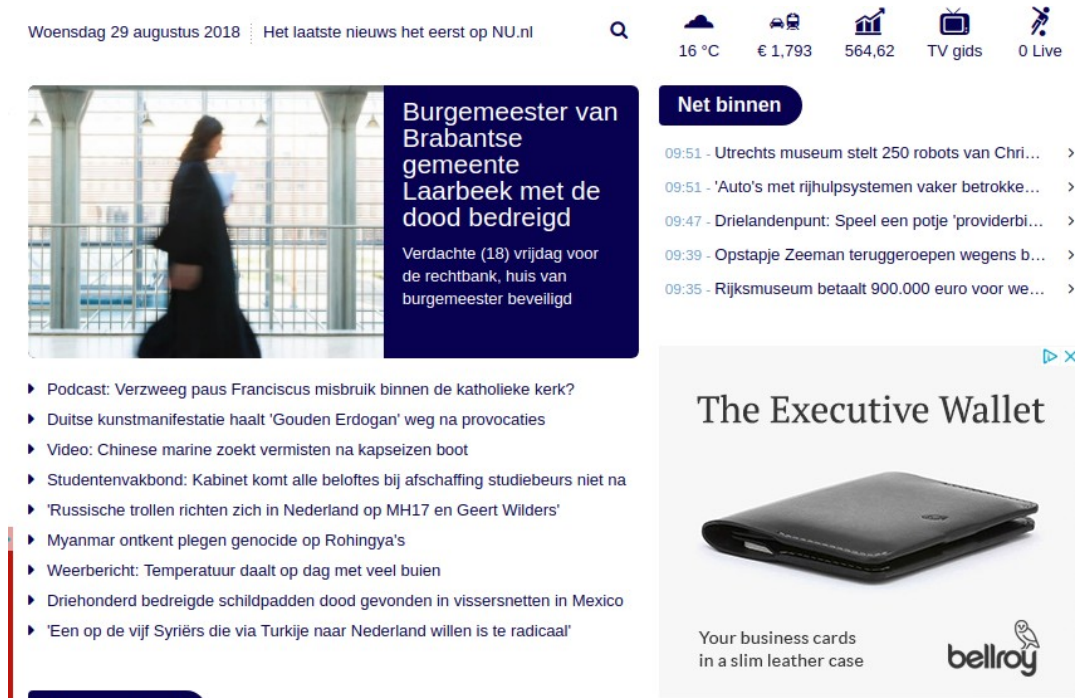
\$20

Big Data in Companies

Companies collect data to understand their customers needs and wants.

Data allows for finding your target market.

Personalized advertisements are more effective.



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- ▶ Duitse kunstmanifestatie haalt 'Gouden Erdogan' weg na provocaties
- ▶ Video: Chinese marine zoekt vermisten na kapseizen boot
- ▶ Studentenvakbond: Kabinet komt alle beloftes bij afschaffing studiebeurs niet na
- ▶ 'Russische trollen richten zich in Nederland op MH17 en Geert Wilders'
- ▶ Myanmar ontkent plegen genocide op Rohingya's
- ▶ Weerbericht: Temperatuur daalt op dag met veel buien
- ▶ Driehonderd bedreigde schildpadden dood gevonden in vissersnetten in Mexico
- ▶ 'Een op de vijf Syriërs die via Turkije naar Nederland willen is te radicaal'

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Big Data in Government

Governments collect data on citizens for public security, urban planning, population census, etc.

Intelligent security camera systems can track humans in train stations to detect suspicious behavior or lost packages.





Is big data a blessing or a curse?

Trust

Central to the question of how data is being used, is the concept of trust:

- How can you trust that data you give out will not be used against you?

How much do you trust institutions?

Regulation

We would like to gain from the benefits, but we would not like to suffer from anyone abusing our data.

- How to prevent data abuse?

→ EU's General Data Protection Regulation (GDPR)

- Has recently gone into effect.



What do you know about GDPR?

GDPR

A number of regulations have been put into place:

- Data processing should be made transparent to the data subject.
- Data collection needs to have a purpose;
no processing should be done incompatible with that purpose.
- Protection against unauthorised/unlawful processing should be in place.
- The data controller is held responsible for GDPR compliance.

GDPR Compliance

But complying to GDPR is not trivial.

- For example, it is hard to determine if a procedure constitutes “enough protection”.

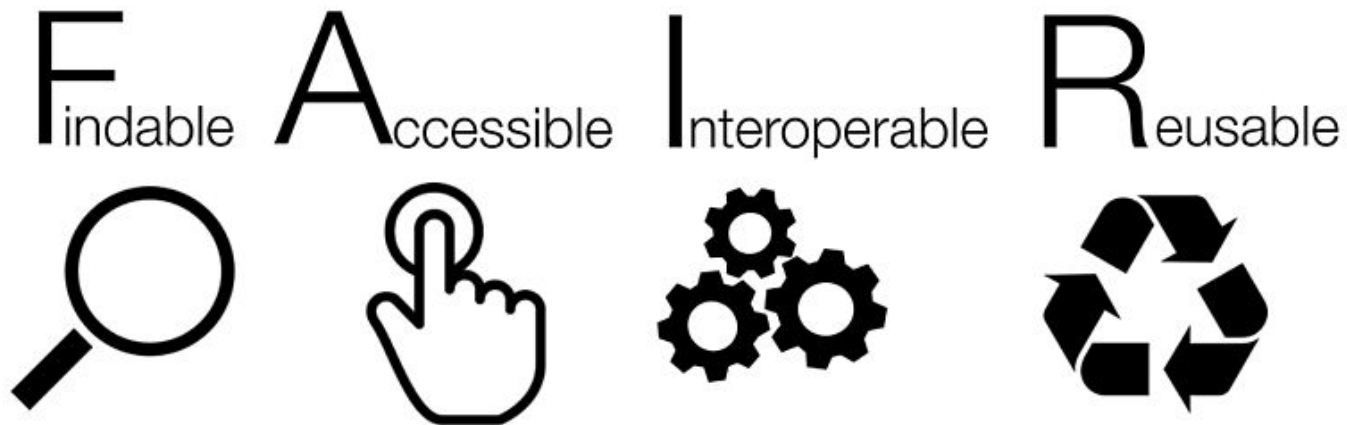
A number of Dutch universities have set up “data stewards”;
designated individuals that are aware of the requirements.

- They can be contacted within their departments / faculties for advice on data storage, how to share data, and how to be secure.

Open Science

With the current ambiguities on GDPR compliance, researchers are discouraged to share data.

This counteracts the open science directive, that aims to make all data public and maximize sharing data.

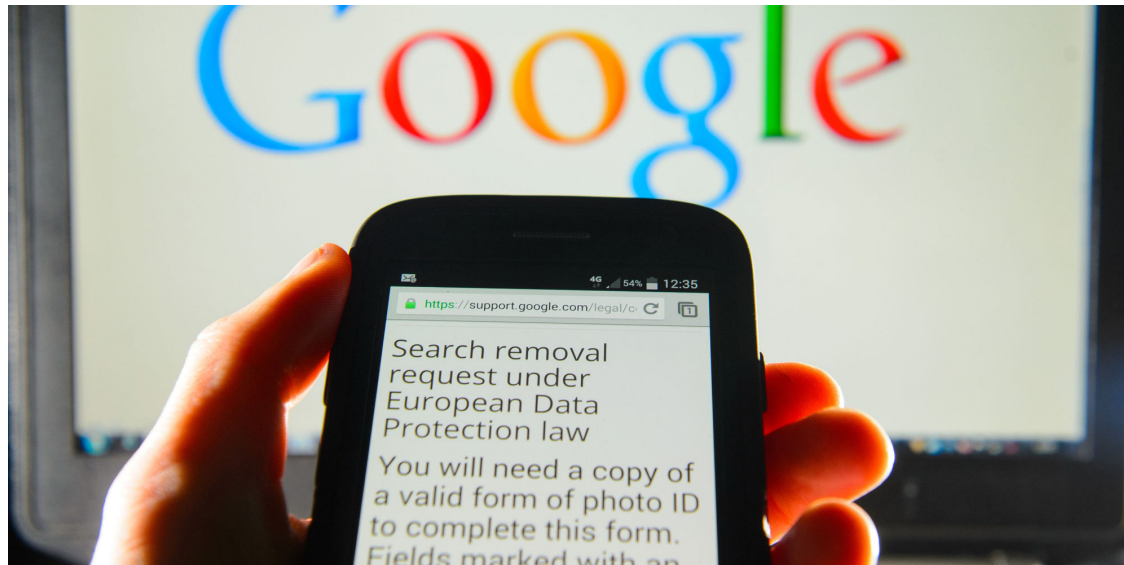


Personal data should be made available if the value to society is greater than the privacy concerns for subjects.

Recommendations

If you're collecting data: understand what articles of GDPR apply to you, and when you should take action.

If your data is being collected: understand your rights.



Additional material

- European Data Protection Supervisor
(https://edps.europa.eu/data-protection/data-protection_en)
- International Association of Privacy Professionals
(<https://iapp.org/news/a/how-gdpr-changes-the-rules-for-research/>)
- Data Archiving and Networked Services
(<https://dans.knaw.nl/nl/over/organisatie-beleid/informatiemateriaal>)