

DATA ETHICS & Nordic Cancer Societies

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CHINA'S SOCIAL CREDIT SYSTEM



DATA DICTATORSHIP

DATA MONOPOLY

or

DATA DEMOCRACY

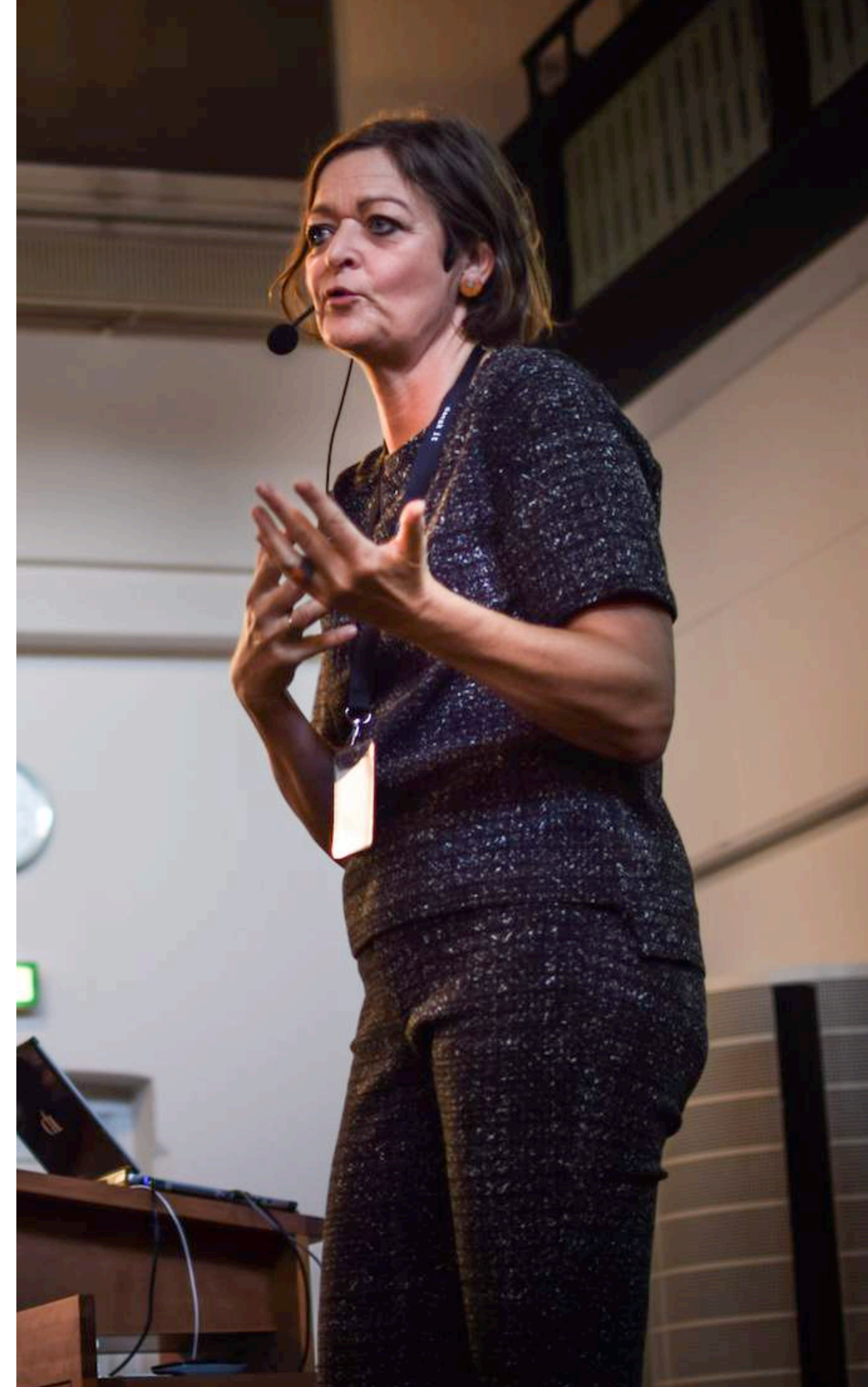


**Advisor in data ethics for companies,
organisations and government**

**Co-founder and executive director of
the thinkDOtank DataEthics.eu**

**Author of 7 book - latest DataEthics
(2016)**

**Former journalist Politiken, editor-in-
chief TÆNK and head of
development Berlingske Media**





Non-personal data like wind, music, product and logistics. Anonymised data like GPS. Predictions on patterns. Regulated science.

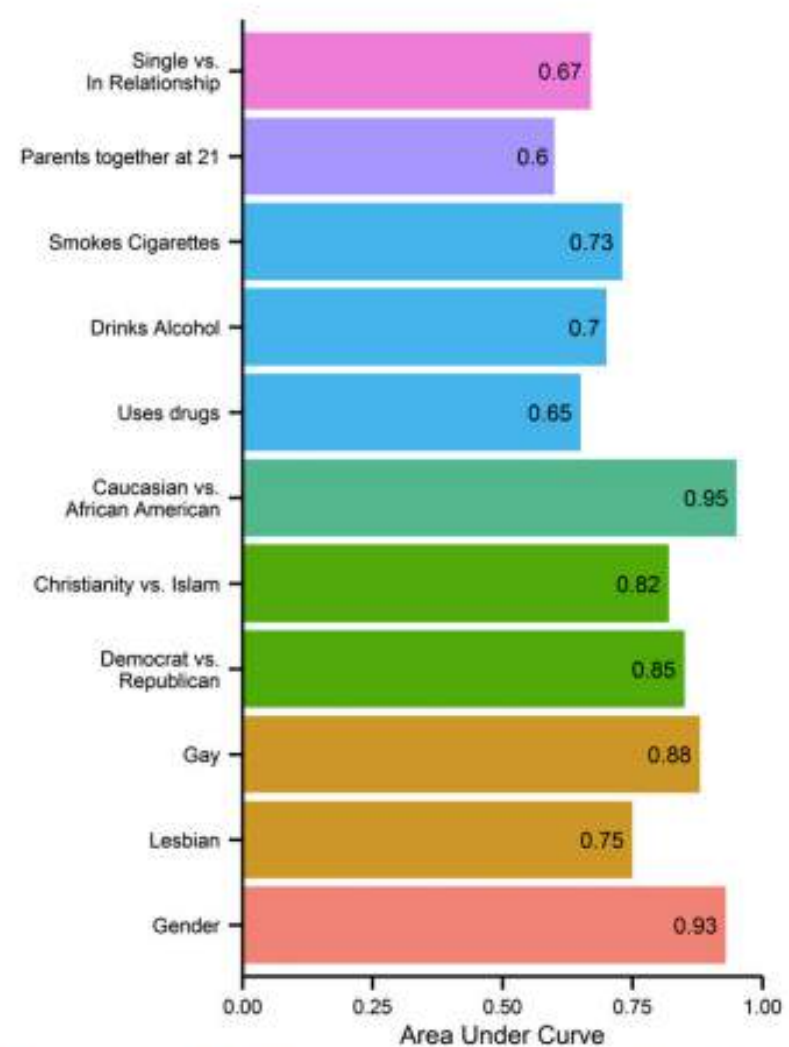
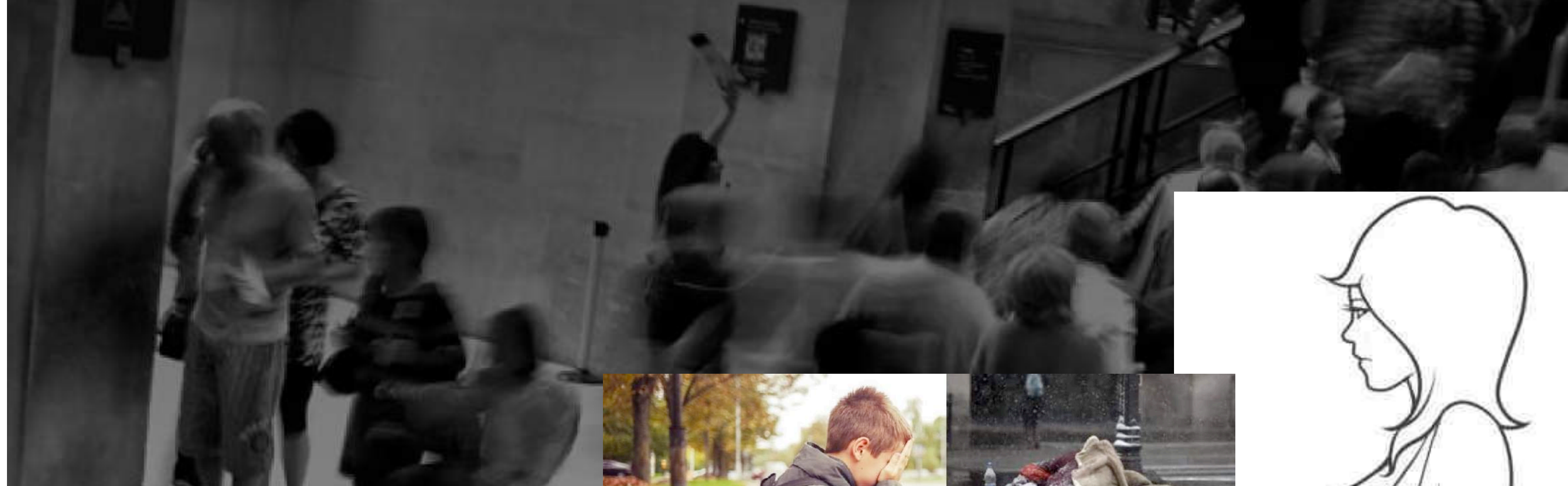


Fig. 2. Prediction accuracy of classification for dichotomous/dichotomized attributes expressed by the AUC.



Profiling, personalisation, microtarifing, discrimination, price differentiation, individual predictions of human behaviour and destinies

- I can't give you her number. Certainly not!

Vores dygtige
Ronditører laver
flødeskager og andre
lækre sager - prøv selv!



0:30 / 1:57





LiveSlides web content

To view

Download the add-in.

liveslides.com/download

Start the presentation.

**Save DEMOCRACY &
HUMANITY**
**Those in power should be
transparent - individuals
don't have to**



The government

- Good data (GDPR), consumer and competition laws but most important: ENFORCE the laws and cooperate in Europe
- Capital: Support the new market for privacy/data ethics
- Be a role model
- Shop data ethically

Individuals

- Learn digital selfdefense
- Learn to activate and use your own data
- Demand ethics from companies and gov
- Chose the good alternatives

Responsibility

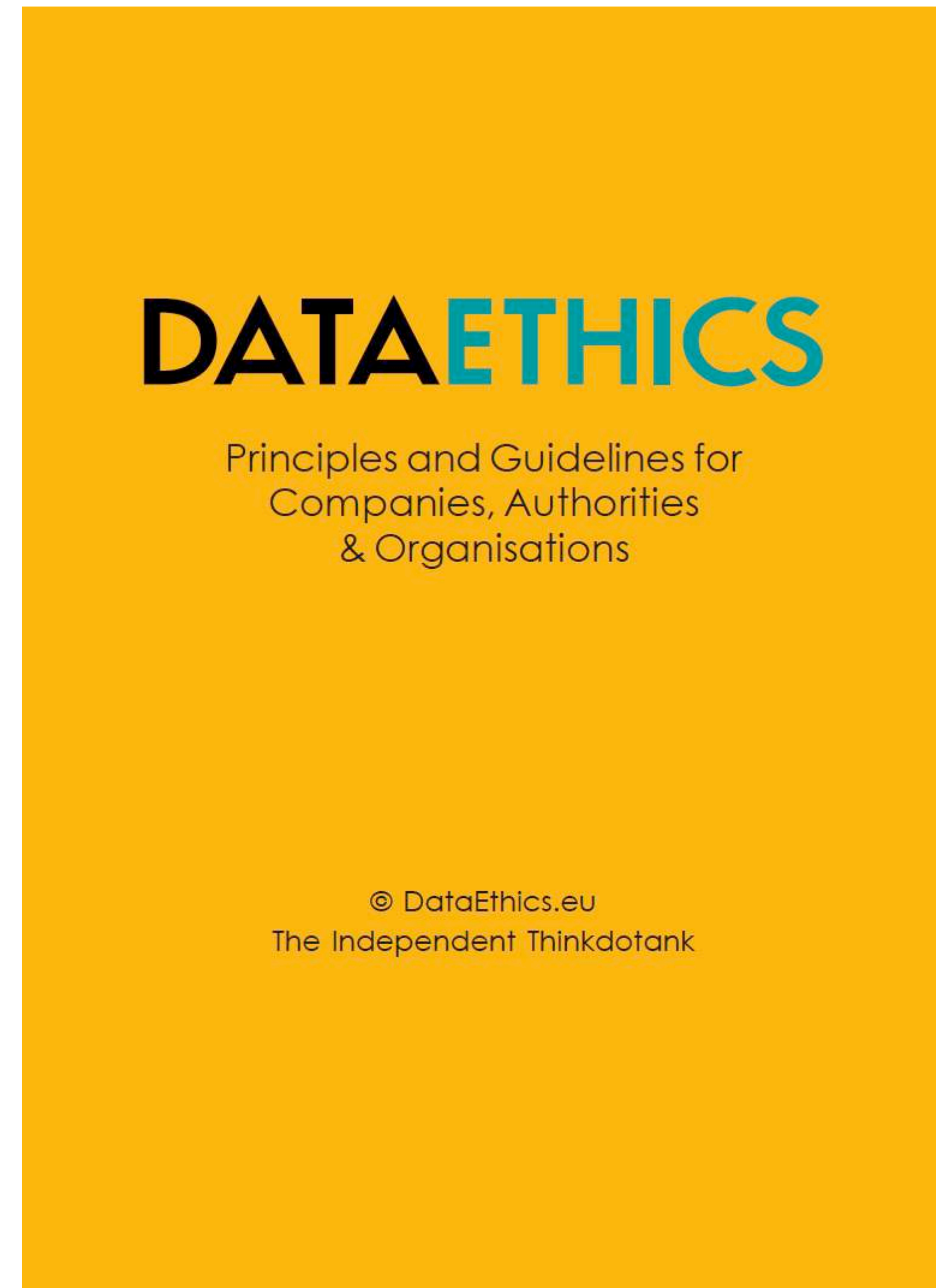
Companies & Organisations

- Create trust with data ethics
- Give your customers/users control over their data
- Innovate with Privacy by Design
- Follow standards, get certifications and independent audits

Definition & Principles

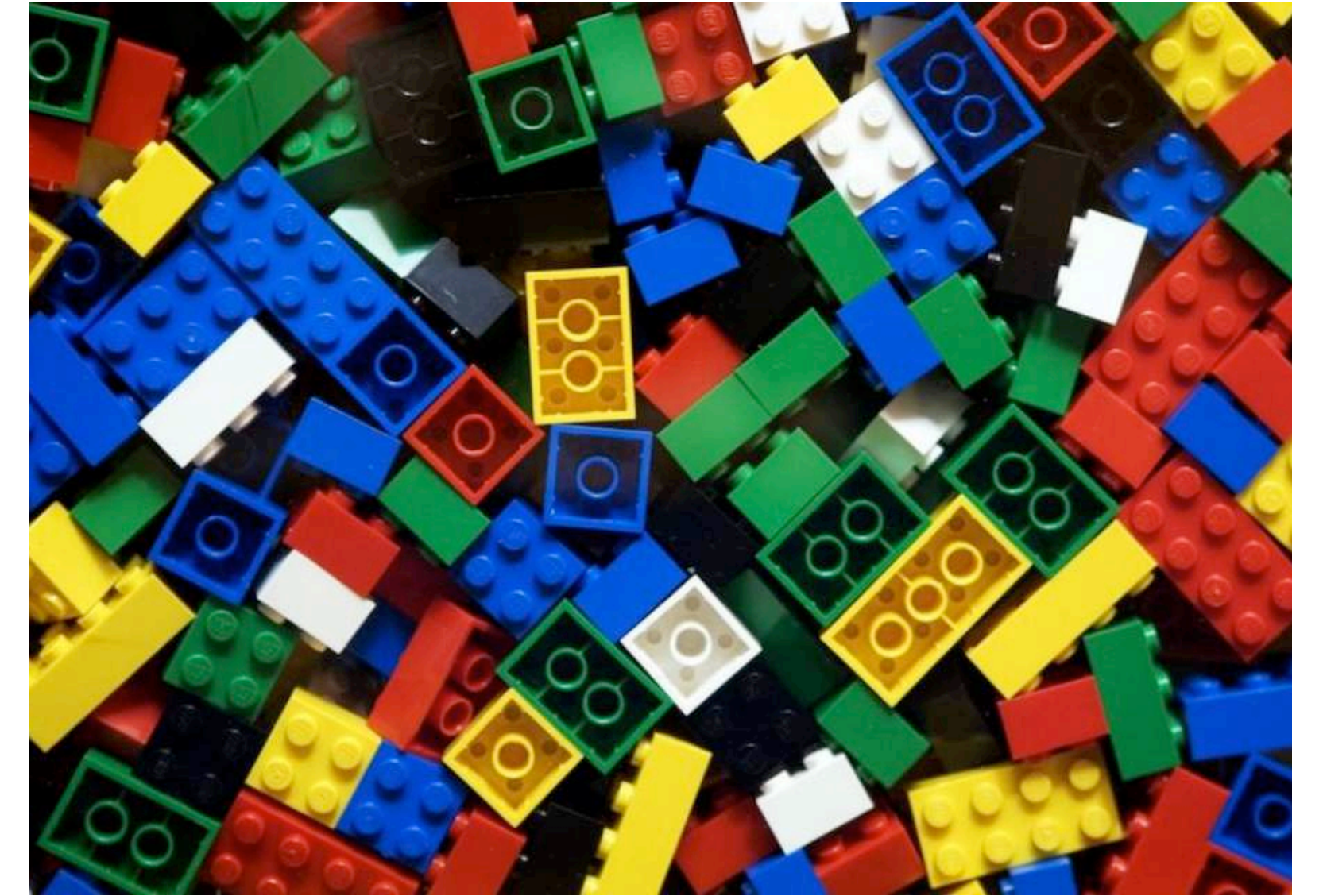
- Data ethics is about responsible and sustainable use of personal data. It is about doing the right thing for people and society. Data ethics is **GDPR++**
- Human at the center
- Individual data control
- True transparency
- Accountability
- Equality

Free guidelines: <https://dataethics.eu/en/data-ethics-principles/>



LEGO & EDULAB

- No 3. party cookies
- No Facebook Connect or SoMe
- No Google Analytics
- Data stored in Denmark / EU
- They moderate everything by human beings
- No manipulating behavioural design (opposite e.g. SnapChat)
- Dataminimisation
- Data Ethics guidelines at Edulab: <https://edulab.dk/en/data-ethics/>



Municipalities

- **No Google Analytics**
- **No AddThis and 3 party cookies (including Youtube and Facebook)**
- **Ingen Google Site Seach**
- **Use of tools like Cludo and SiteImprove where you can get a dataprocessing Agreement**

Breaking News

Danish parliament: how can we stop public websites from leaking data to FB and Google?

VERSION 2



IT-NYHEDER BLOGS DEBAT IT-JOB SEKTIONER

Folketinget: Hvordan kan vi stoppe offentlige hjemmesider, der sladrer til Google og Facebook?

Borgernes retssikkerhed, beskyttelse af borgernes privatliv og persondata, data og overtrædelser af datalovgivning er på programmet på erhvervs-, vækst- og eksportudvalgets lukkede møde.

Tania Andersen  @AndersenTania Onsdag, 13. februar 2019 - 10:49

31



Onsdag den 20. februar holder Folketingets erhvervs-, vækst- og eksportudvalg lukket eks
møde om, hvordan det sikres, at ingen tredjeparter informeres om borgeres besøg på offer
myndigheders hjemmesider.

I Udvalget har inviteret partiernes ordførere samt embedsfolk fra Erhvervsministeriet og



Simple ViewDetailed View

7

kreftforeningen.no

Trackers Blocked: 5

Page Load: 8.77 secs

Trust Site

Restrict Site

Pause Ghostery

202

TRACKERS

Unblock All

Collapse All

Advertising

2 TRACKERS 2 BLOCKED

DoubleClick

Delta Projects

Essential

1 TRACKER

Google Tag Manager

Site Analytics

2 TRACKERS 1 BLOCKED

Google Analytics

List View

kare vid Uppsala universitet hoppas resultat från deras senaste studie leder till träning som ett komplement i cancervården. Enligt forskarna kan träning både motverka orkeslöshet och öka livskvalitet.

Lund, Medicinsk Journalist
uppdaterad 7 mars 2018



cancer.se

Trackers Blocked: 3

Page Load: 0.81 secs

☐ Trust Site

☐ Restrict Site

Pause Ghostery

TRACKERS Unblock A

Collapse All



Advertising

1 TRACKER 1 BLOCKED

~~Google Publisher Tags~~



Essential

1 TRACKER



Google Tag Manager



Social Media

1 TRACKER 1 BLOCKED

Facebook Connect

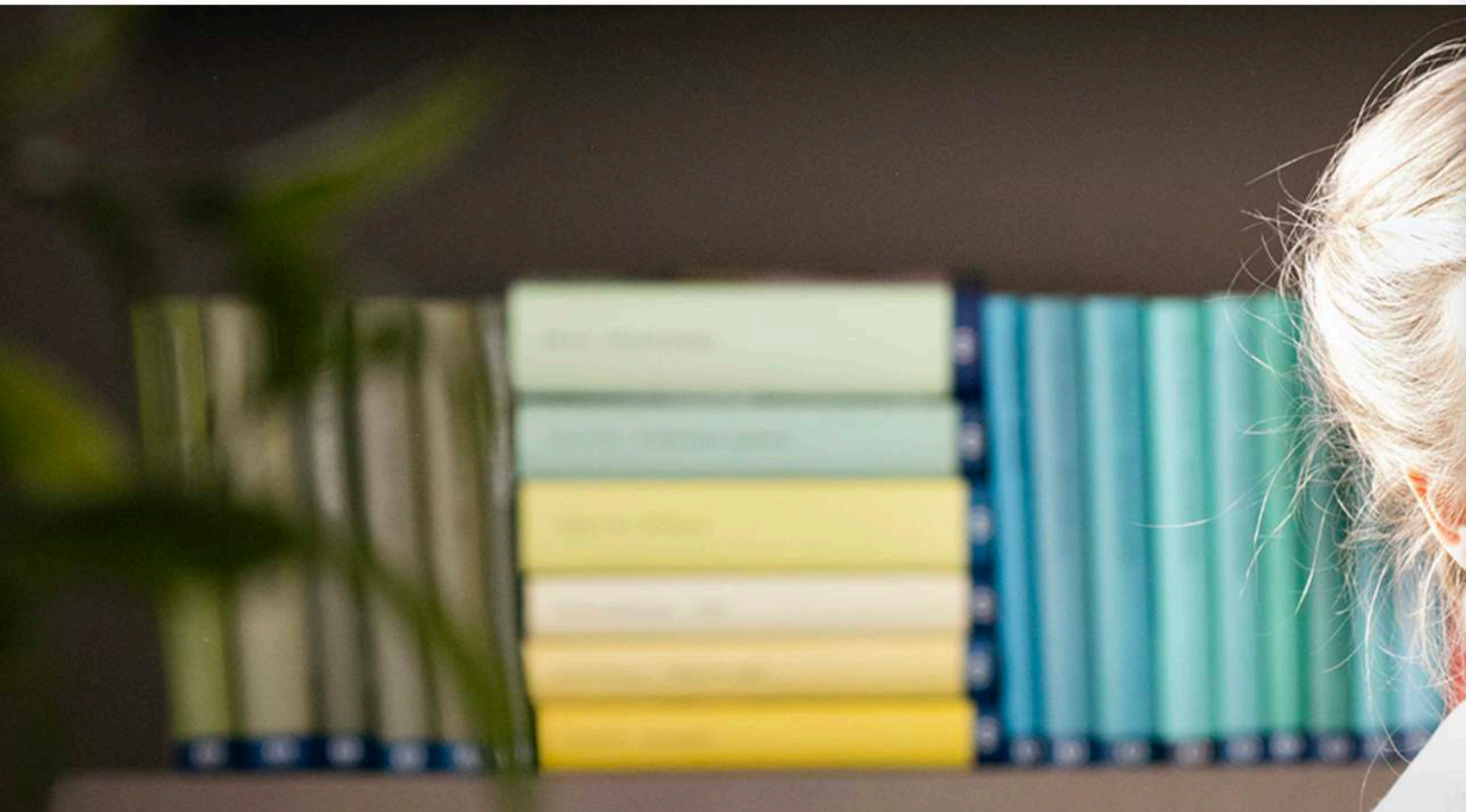
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List View

Cancersjukdomar



Cancer och ärftlighet


Stöd



 GHOSTERY

Simple View Detailed View

 Plus 



10


www.kaikkisyovasta.fi

Trackers Blocked: 8
Page Load: -


☐ Trust Site

☒ Restrict Site


Pause Ghostery




4



0




2




TRACKERS ⚙️


Block All


Collapse All


 Essential

1 TRACKER


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 Google Tag Manager




 Site Analytics


2 TRACKERS 2 BLOCKED


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ScoreCard Research Beacon





Pingdom





 Social Media


1 TRACKER 1 BLOCKED


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 Facebook Social Graph



 List View

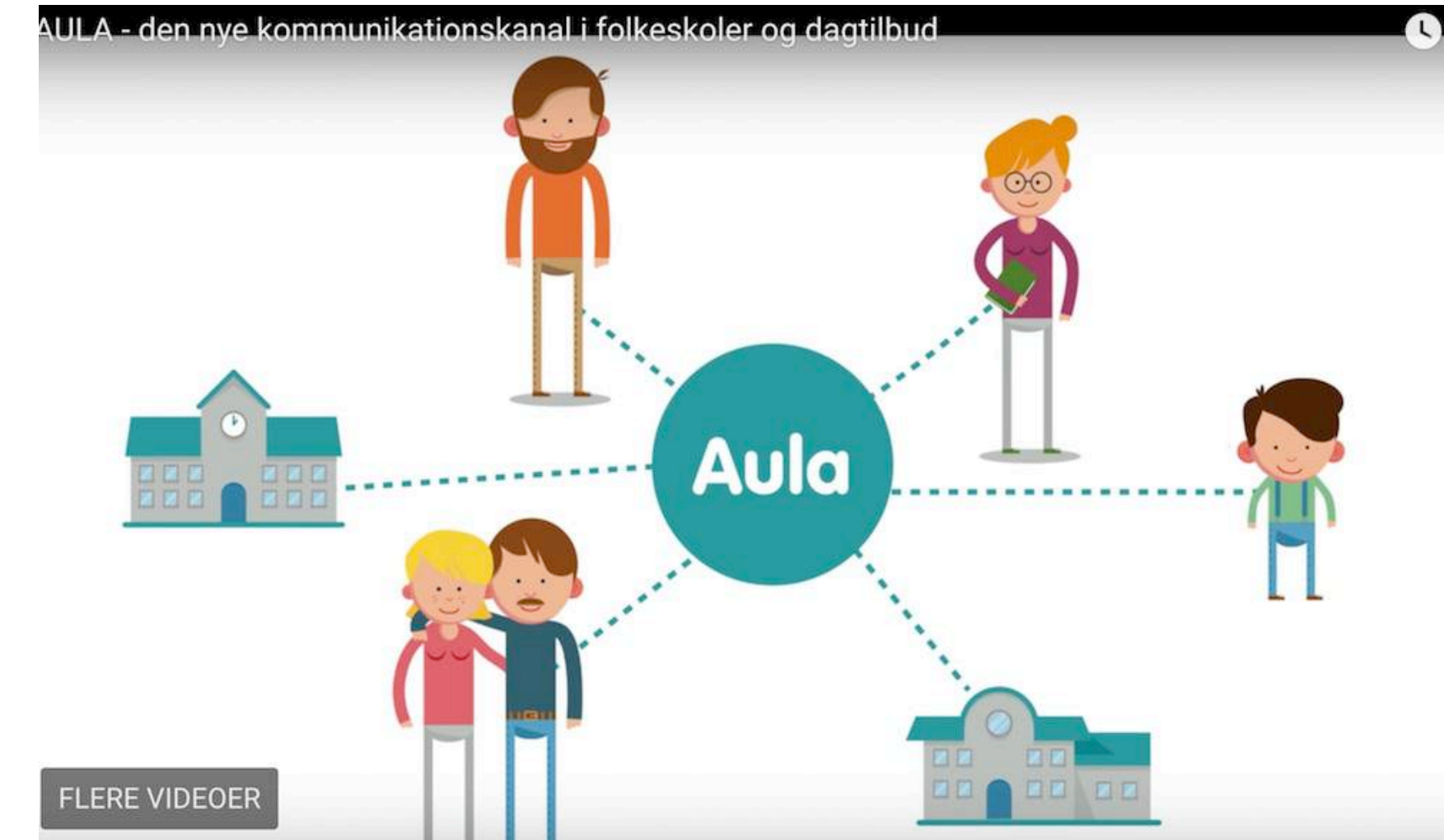




AULA

- New Danish social media platform for kids, teachers and parents to be launched 2019 August
- No third party cookies incl SoMe and Google Analytics
- No profiling or prediction
- No LIKES
- Efficient consent management system
- Human moderation
- Ethics board
- **BUT stored at Amazon!!!**

Disclaimer: I coached them with their data ethics guidelines - storage is not included



Apple

- Everything on your gadget is YOURS. Privacy is a fundamental human right
- On device processing - or anonymisation (role model in differential privacy)
- Privacy experts take part in all new innovative processes
- Privacy-by-default in Safari browser!
- Takes responsibility of their sub-contractors
- But what about taxes? And lack of transparency?

See Tim Cooks keynote Oct 2018: <https://www.youtube.com/watch?v=kVhOLkIs20A&feature=youtu.be>

See Apple's DPO Jane Horvath at CPDP 2017 - 16.00: https://www.youtube.com/watch?time_continue=3&v=nK_T6KLc6l0



CLUE

- Regulation of health data in the US (Glow) and in the EU (Clue)
- Privacy policy for ordinary people
- You can be anonymous
- They store sensitive behavioural data separate from you identity
- They adhere to the 'strictest privacy laws in the world'



Hello from Clue



The most common early pregnancy symptoms

MAIF

- Giving customers real control of own data (part of MyData.org movement)
- Invested in Cozy Cloud
- Invested in Snips.ai
- Don't have access to customers' data without their active participation
- Developing services, so customers can activate own data
- MAIF social club - to educate consumers. Pays off with 500 new customers in 6 months



“Individuals are the only legitimate persons to leverage their own data”

<https://dataethics.eu/en/data-ethics-is-paying-off-for-french-insurance-company/>

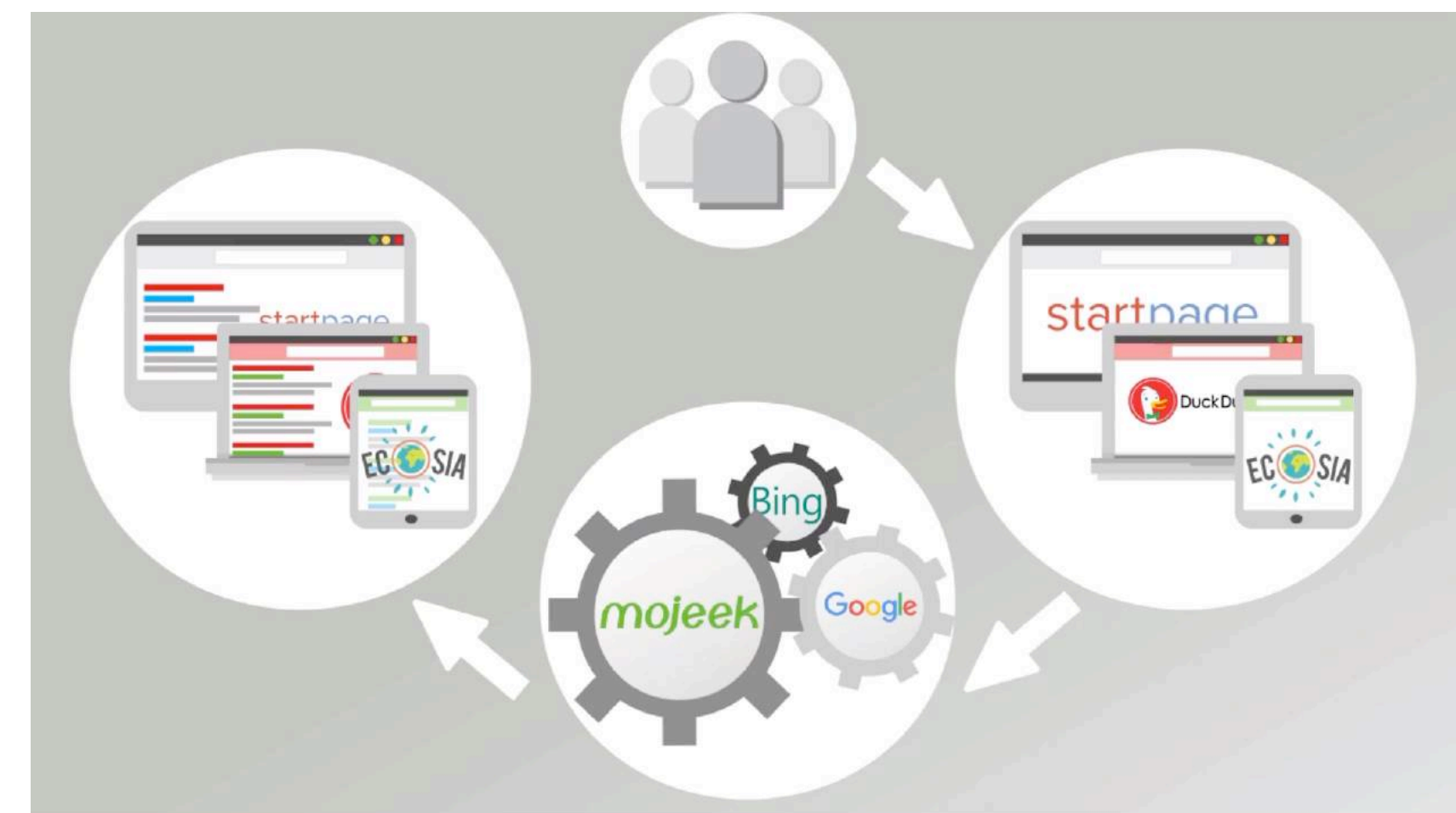
MOJEEK.COM

- Truly private search engine with own index and built from the ground up
- No profiling. Nobody looks over your shoulder or follow you all over the internet
- Unbiased results
- Using the UK's greenest data centers

If you want to be private AND help Margrethe Vestager fight data monopolies, then promise that half of your searches in the future is NOT on Google but MOJEEK, STARTPAGE.COM, QWANT.COM, DUCKDUCKGO.COM

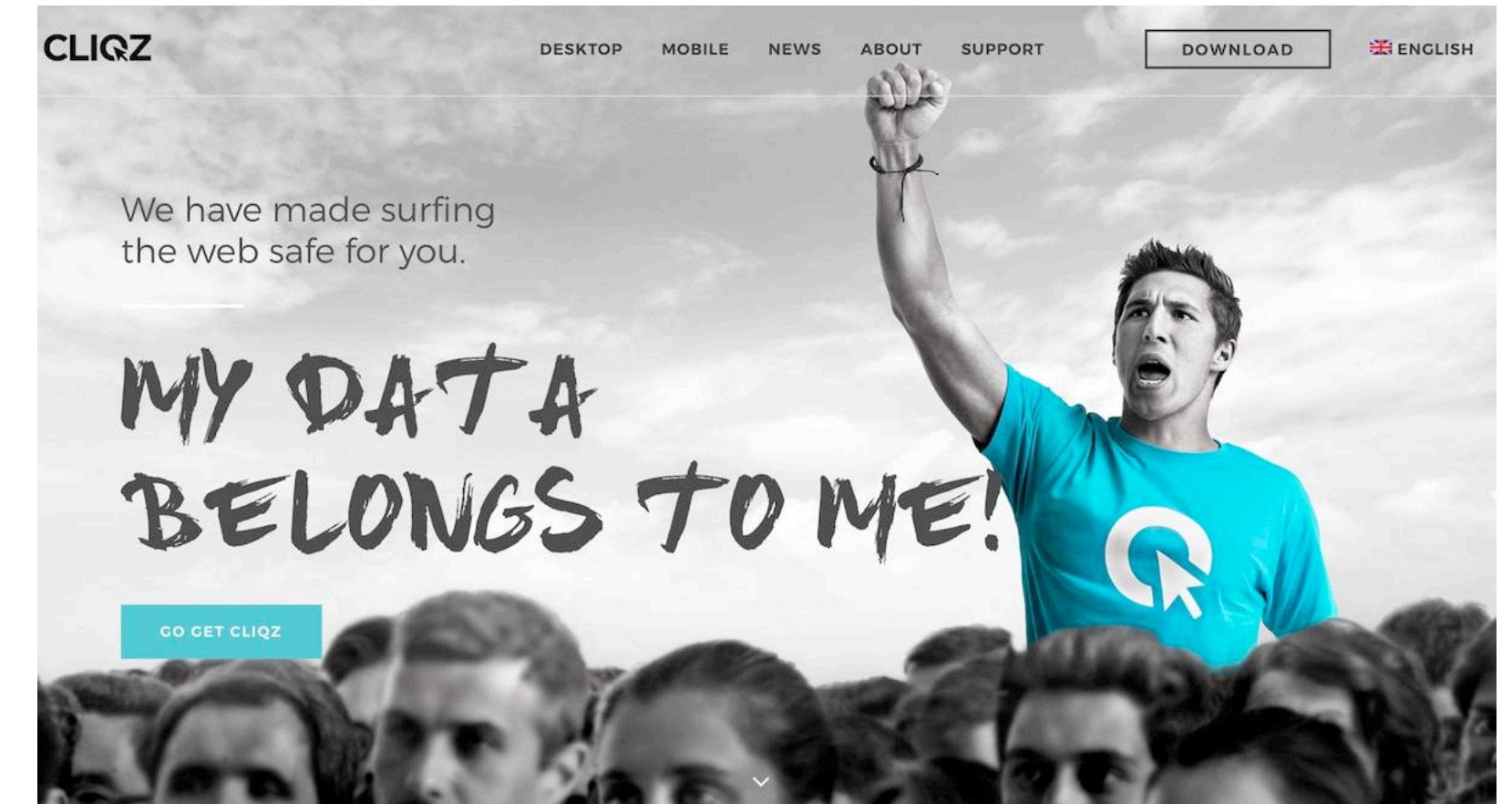
mojeek

Mojeek, the alternative search engine that puts the people who use it first.

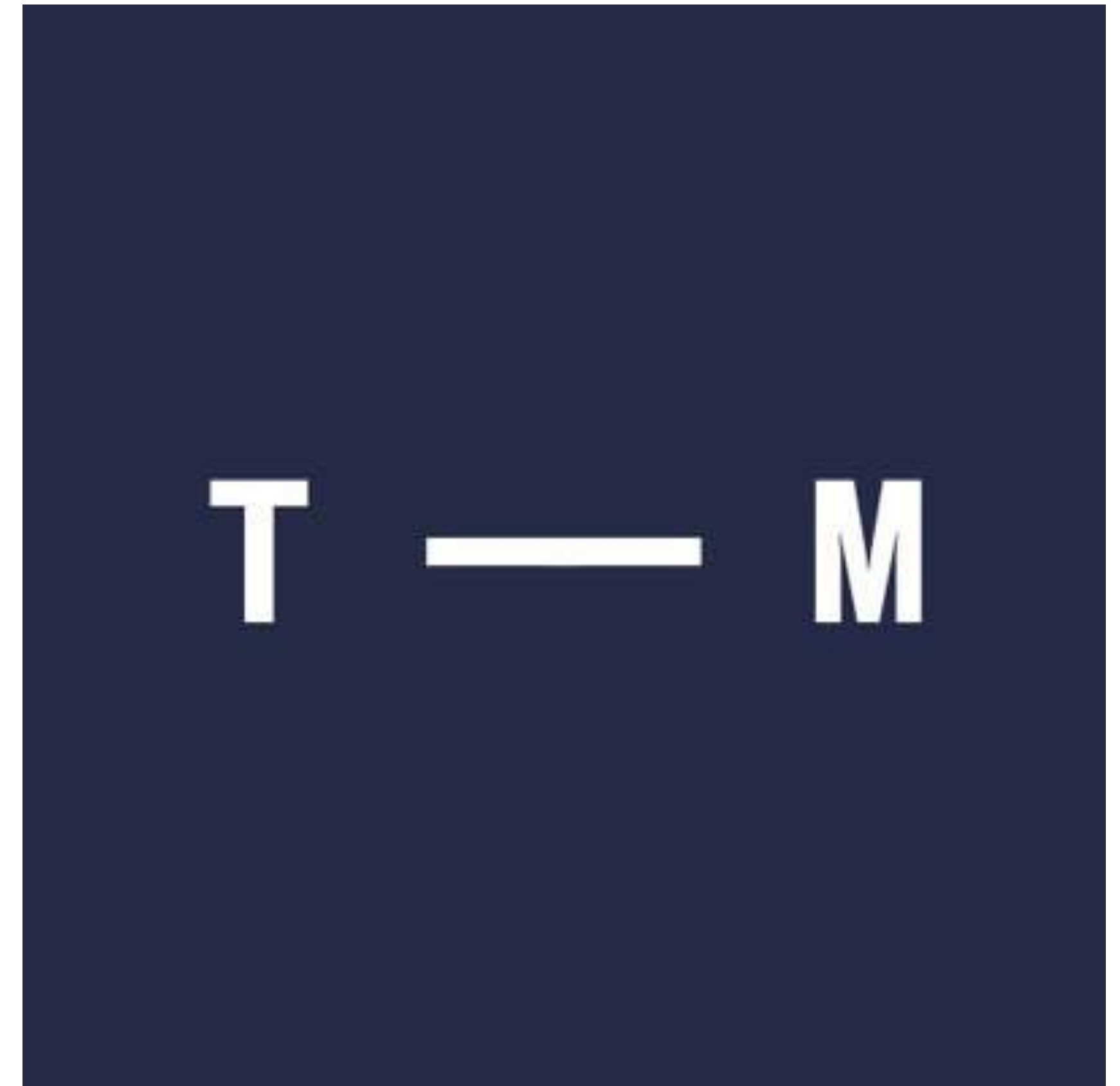


CLIQZ

- German/US browser that protects your privacy and business data!
- Privacy by default (not blocking cookies but overwriting them so you are anonymous)
- On device processing - not indentifiable data leaves your device
- **But Google Search so set another search engine as standard**



New Media - New Ways









SOLUTIONS



Parliament seizes cache of Facebook internal papers

**Documents alleged to contain revelations on data and privacy
controls that led to Cambridge Analytica scandal**



Carole Cadwalladr

🐦 @carolecadwalla

Sat 24 Nov 2018
21.00 GMT





Tools & Services

Qwant/Startpage/Mojeek - not Google Search

Gludo - not Google Site Search

Netminers/Siteimprove - not Google Analytics

CancerForum/own site - not Facebook

Wire - not WhatsApp og Slack

Saxo - not Amazon

Mailjet - not Mailchimp

Vimeo/Twentythree - not YouTube

cliqz.com - not Google Chrome

Use ethically responsible subcontractors

Do's and Dont's



- Get rid of 3rd party cookies
- Personalise ONLY w data you got directly from your users, so they understand why you contact them
- Use only Facebook as a *neutral* bulletin board to get users over on your own site (and use your ressources there)
- Use Facebook less and warn people agains tracking
- Never buy or use list of people related to or neighbor to cancer patients (science can be an exception)
- EU cloud or own cloud in stead of US or Chinese
- Consider a 'mydata' site
- Predict on patters not individuals
- Consider establising an ethics advisory board and/or Chief Ethics Officer

THANKS

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Free PDF of book: dataethics.eu/book

Free booklet: <https://dataethics.eu/en/data-ethics-principles/>

Newsletter: <https://dataethics.eu/en/about/newsletter/>

