

Privacy, healthcare and data science
RSE-KVAB Workshop April 17th, 2018
Palace of the Academies, Brussels

Welcome & Introduction:

What is at stake with our privacy and
what is the role of the Academies?

Joos Vandewalle, President KVAB

Private data = hot topic

- Facebook = ideal people search engine -> 2,2 billion Facebook profiles leak to data slurpers
- Cambridge Analytica scraping scandal collected data from 87 million Facebook-users
- Facebook campaign in recent weeks : users have control over their private data
- GDPR May 25, 2018 active in Europe
- American technology website The Verge headline 'How Europe's new privacy rule is reshaping the internet'.
- Progress in AI, deep learning, computing power, the cloud
- Opportunities for better services, medicine, ..
- Commercial interest immense

How can we strike a good balance ??

Did Facebook fix the privacy for GDPR?



ANOTHER FACEBOOK
PRIVACY SETTINGS TIP:

SEE WHERE IT SAYS "AUTOMATICALLY SHARE MY PERSONAL INFORMATION WITH IDENTITY THIEVES, SEX OFFENDERS AND ALL MY PSYCHO EXES?" YEAH, YOU'RE GONNA WANNA UNCLICK THAT BOX.

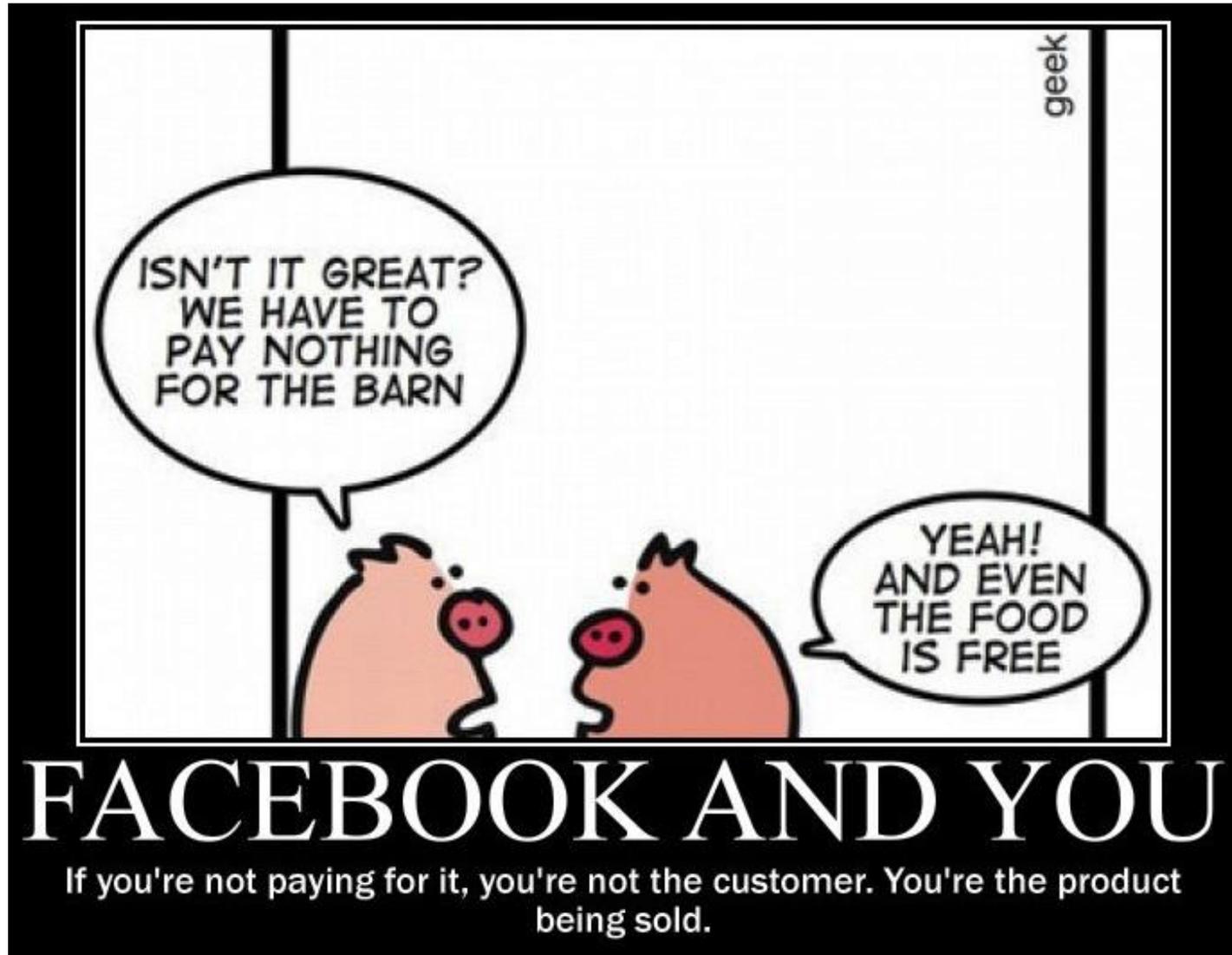


-brion.

Not so nice



Social media and search engines are not free



Facebook Gets Slap on the Wrist From 2 European Privacy Regulators



The French CNIL has sanctioned Facebook with a 150,000 EUR fine, and the regulator from Netherlands is considering a similar action. Regulators are concerned with new privacy policies of Facebook, lack of transparency, cookie handling and tracking Facebook users on third-party sites -- all without user knowledge or control. Such coordinated move is unprecedented in the history of European data protection regulators. New York Times May 16, 2017

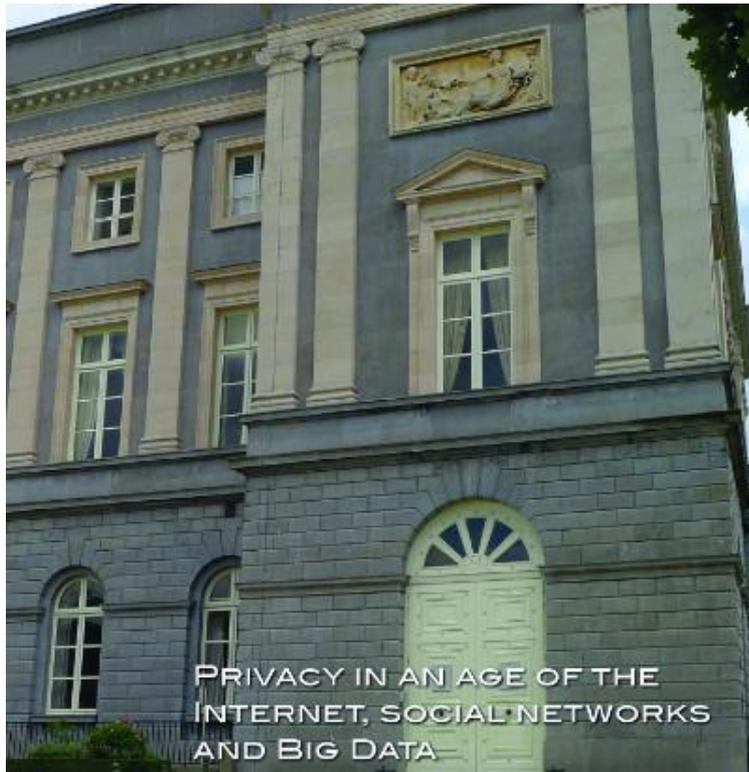
Role of the Academies : the case of KVAB

KVAB :

- Position papers and thinker's programme on topics with societal value on the initiative of the members
- Emphasis on mid- and long-term issues
- Working groups of competent members complemented with ad hoc external experts
- Scientific /Evidence based recommendations
- Pros and con scientific arguments for different scenarios

VARIO : policy advices on topics requested by the government

2 recent position papers first in Dutch now in English



**Yolande Berbers
Mireille Hildebrandt
Joos Vandewalle (et al)**



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voor Wetenschappen en Kunsten, 2018
Standpunten 49 b



**Pascal Verdonck
Marc Van Hulle (et al)**

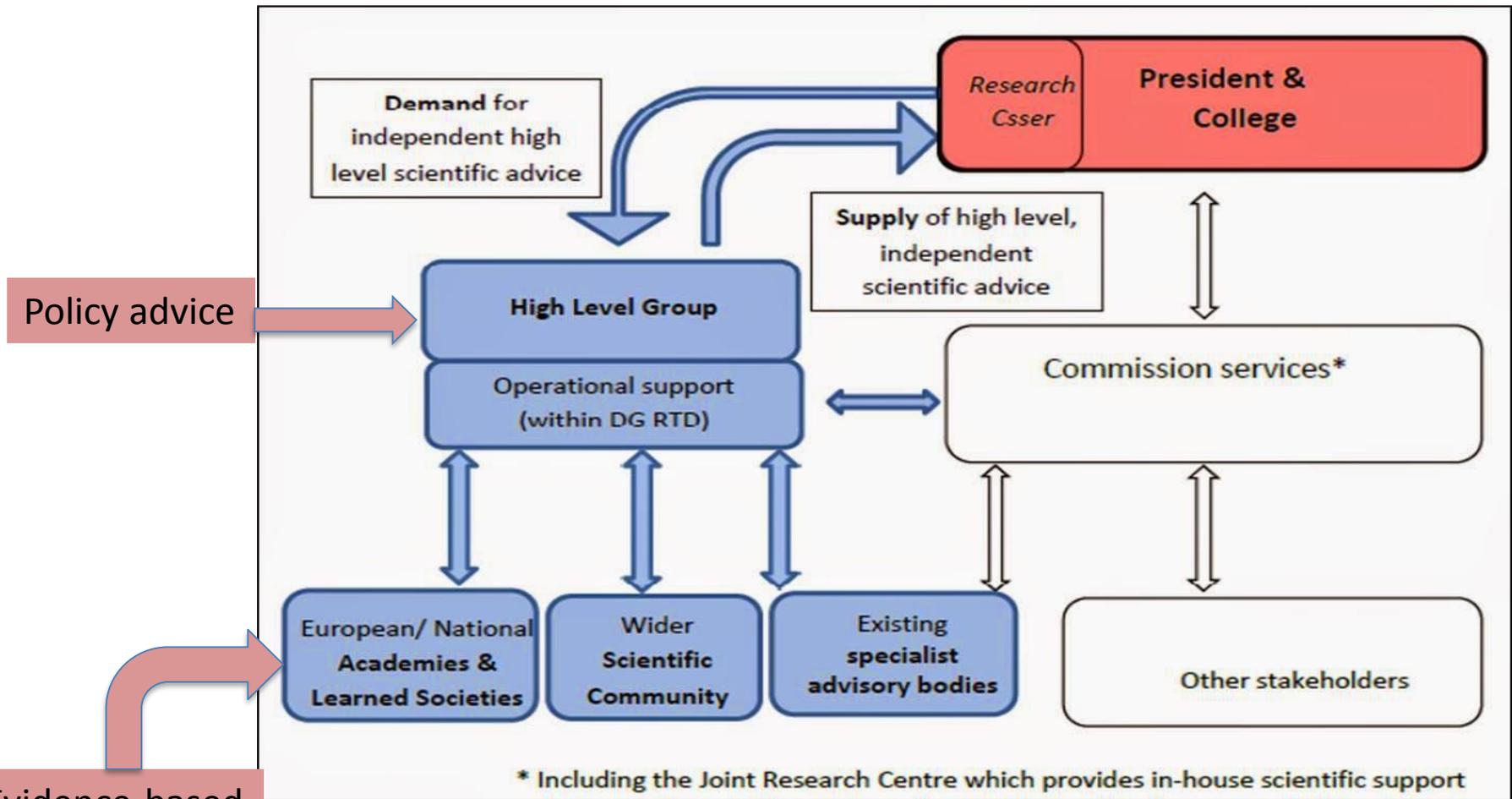


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History of the working group on privacy

- Working group active from spring 2016 till spring 2017
- Topic of growing attention: newspapers, GDPR in EU, profiling, law suits, right to be forgotten, data leaks
- Ambition : societally relevant document that digs deeper than newspapers, readable by students finishing high school
- Focus : *Generic* theme of privacy : Complementary to position paper 'Data science and health care' and report Belgian privacy commission CBPL (more for professionals)
- Recommendations supported by working group & methodology supported by Academy
- Public workshop on 14 november 2017 with reflections from State Secretary of privacy Mr Philippe De Backer

The 'Science Advice Mechanism' of the European Commission



Evidence-based Advice=SAPEA



Science Advice for Policy by European Academies

SAPEA brings together knowledge and expertise from across Europe as part of the European Commission Scientific Advice Mechanism

SAPEA

- Consortium of European academies : networks EASAC, Euro-CASE, ALLEA, FEAM and Academia Europaea launched 13 december 2016
- Pull together expertise from > 100 European academies from 40 countries for highest policy level in Europe and for wider public
- Horizon 2020 project four years € 6 Million in EU funding
- scientific evidence to EU Commission Scientific Advice Mechanism
- Increasing transparency and public confidence in EU policy making.
- Two types of SAPEA's activities
 - bottom-up proposals made by the networks
 - top-down requests which the SAM High Level Group of Scientific Advisors receives from the various Directorate-Generals
- Interdisciplinary working groups
- Various output formats, e.g. scoping papers, evidence review reports, scientific statements, reports, and studies

PROGRAMME

14:15 *Can anonymous data exist in an era of massive information availability?* Chris Dibben, Chair in Geography, University of Edinburgh

14:45 *Social media users and their privacy concern: Do they know and do they care?* Karolien Poels, Young Academy

15:15 *Big Data - Why Big is Beautiful* Colin Mccowan (replacing Jill Pell), Institute of Health and Wellbeing, University of Glasgow

15:45 *Big data analysis in healthcare and the general data protection regulation (GDPR)* Frank Robben, CEO eHealth-platform Belgium, CBSS

16:15 *Debate with speakers & public*

16:50 *Conclusions & Recommendations* Marian Scott, Vice-president Royal Society of Edinburgh

17:00 *Reception*