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DIGITAL HEALTH VS. PATIENT PRIVACY (GENERAL DATA PROTECTION REGULATION): IS THE FUTURE HERE TO STAY?

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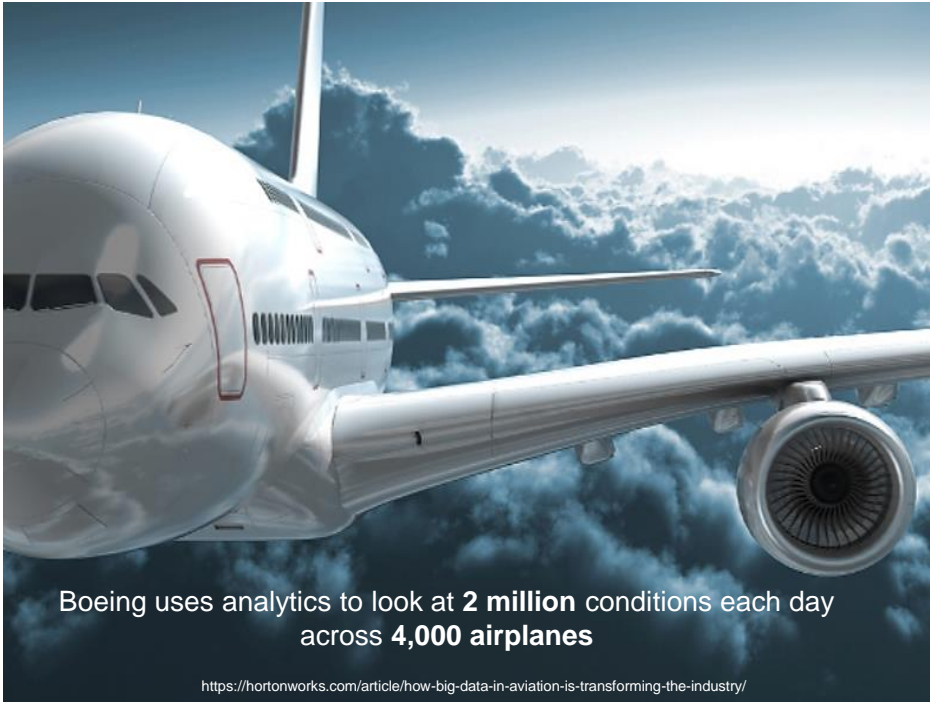
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ISPOR Europe 2018





Boeing uses analytics to look at **2 million** conditions each day across **4,000** airplanes

<https://hortonworks.com/article/how-big-data-in-aviation-is-transforming-the-industry/>



IBME The Institute of Biomedical Engineering

40 000 admissions to ICU each year



http://www.euro.who.int/__data/assets/pdf_file/0012/302331/From-innovation-to-implementation-eHealth-Report-EU.pdf?ua=1





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10% decrease in cardiac arrests in Oxford University Hospitals NHS Trust annually



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Scotland National Telecare Development Programme

Based on data from 44,000 people receiving telecare

- 93 % of patients/elderly felt safer
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Over a period of 6 years...

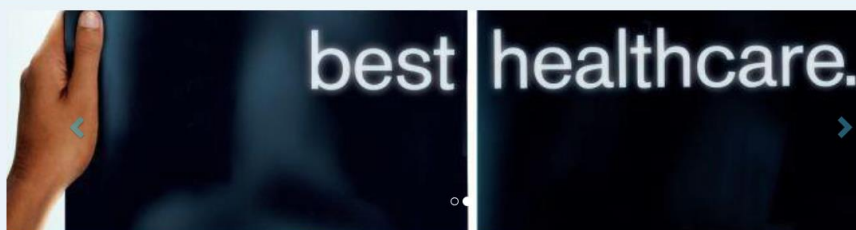
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<http://www.ehfg.org/intranet/app/webroot/uploads/presentations/files/uploads/591995778318c311171275084a957b.pdf>



ERN Collaborative Platform



About the European Reference Networks for Rare and Low Prevalence Complex Diseases

European Reference Networks are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. There are 24 ERNS involving 25 European countries including Norway, over 300 hospitals with over 800 healthcare units and covering all major disease groups.



https://ec.europa.eu/health/ern_en





British Airways faces possible £500m fine for data breach

Under new Data Protection Act, which includes new GDPR provisions, a company hit with a data breach faces fine of £10m or 4% of global turnover, whichever is greater

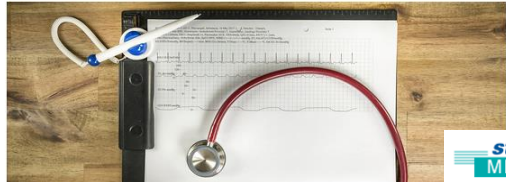


Facebook faces \$1.6bn fine and formal investigation over massive data breach

Irish data regulator could penalize the social network after hack of nearly 50m accounts



Over £1 million spent by NHS trusts on GDPR preparation, FOI reveals



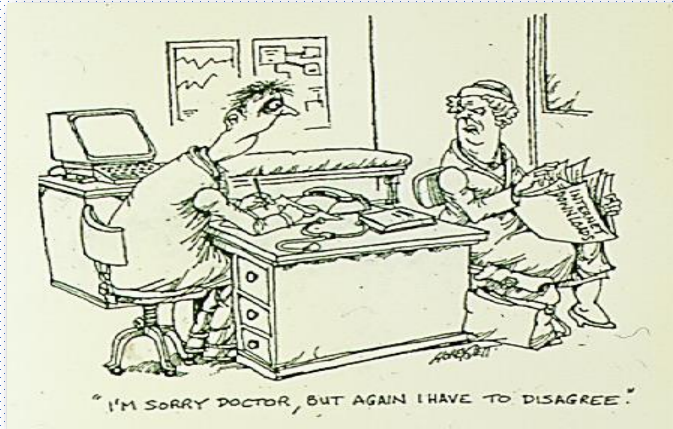
General Data Protection Regulation 2016/679

Why?

- protection (against breaches of privacy)
- harmonization (one set of rules applicable throughout the European Union)
- new mindset (from „business-to- business“ to „business-to-consumer“)
- actualization (replaces Directive 95/46/EC)



It's about... Patient Empowerment



GDPR is about...



CONSENT



INCREASED
TERRITORIAL SCOPE
(EXTRATERRITORIAL
APPLICABILITY)



RIGHT TO ACCESS



RIGHT TO BE
FORGOTTEN



DATA PORTABILITY



BREACH
NOTIFICATION/
PENALTIES



Welcome GDPR!



As many as 80% (n=41/51) of anonymised healthcare professionals at UHL (University Hospital Limerick (UHL), confirmed that WhatsApp was used as a mode of communication with other colleagues



- A group of 15 volunteers recruited in 2007 to help dementia sufferers and their families or carers seek NHS healthcare funding.
- Between them, and over a seven-year period, they handled 1,920 cases.
- Volunteers were using personal email addresses to receive and share information storing unencrypted data on their home computers...



<https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2016/01/ico-criticises-disappointing-attitude-of-dementia-charity/>
<https://innovations.bmj.com/content/3/4/238>



GDPR unlocks the power of data



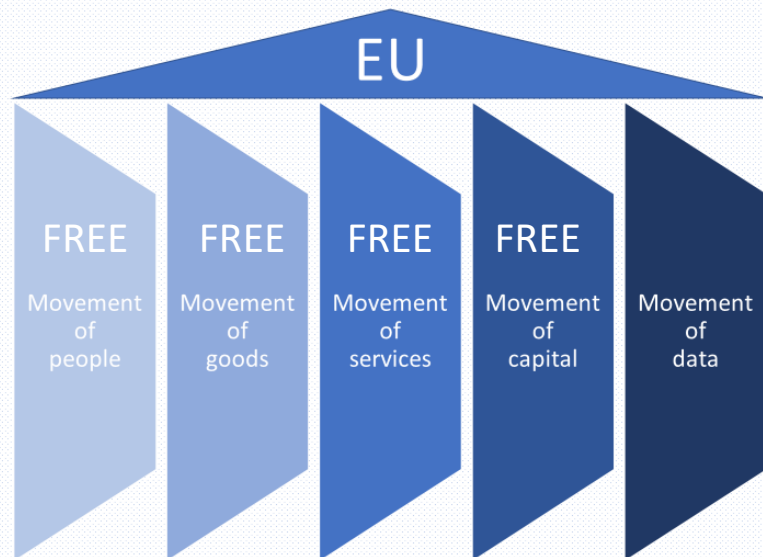
GDPR's introduces pseudonymization

Pseudonymization reduces the linkability of a dataset with the original identity of a data subject

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



Welcome Digital Single Market...



Brussels, 13.9.2017
COM(2017) 495 final
2017/0228 (COD)

Proposal for a

REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

on a framework for the free flow of non-personal data in the European Union

{SWD(2017) 304 final}
{SWD(2017) 305 final}

Together with the GDPR, it will ensure a comprehensive and coherent approach to the free movement and portability of data in the EU



http://europa.eu/rapid/press-release_MEMO-18-4249_en.htm



...more than 690,000 data users in the EU28



http://datalandscape.eu/sites/default/files/report/EDM_D2.2_First_Report_on_Policy_Conclusions_20.04.2018.pdf



This app is only available on the App Store for iOS devices.

Health Data Importer

Import Your Health Data

Lionheart Software LLC

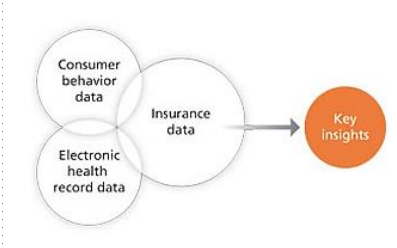
4.5/5, 244 Ratings

\$4.99 - Offers In-App Purchases

318,000 health apps



It's the highest time to connect data about not just the patient encounter but also the preferences and social circumstances shaping everyday health and healthcare-related purchasing decisions.



Diversity of healthcare ecosystem – NO single stakeholder has access to all available data

Type of data	Drug and device companies	Health systems	Clinicians	Insurers	Community organizations	Patient advocacy groups	Consumer health technology companies	Retail pharmacies
Clinical and family history			●					
Benefits/medical and Rx claims				●				
Call center		●		●				
Appeals, grievances, complaints				●				
Cost of care		●		●				
Real-time monitoring	●						●	
Clinical trials and reported incidents	●							
Preferences, expectations						●	●	●
Motivators, lifestyle, personality, behavior and habits						●	●	●
Caregiver data					●			
Social determinants					●			
Patient-reported outcomes					●			
Social media		●		●		●	●	●
Drug adherence								●

