Legislation and Compliance: Turning GDPR To Your Advantage Christine Overgaard Rasmussen Head of Data Science, Computerome

04/10/2022



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computerome

The Danish National Life Science Supercomputing Centre

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Danish National Life Science Supercomputing Centre

A world-class national supercomputing and data infrastructure for all clinical, academic, and industry users in Denmark

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What we do

We are **neutral infrastructure prodvider** supporting research groups from academia, research consortiums, industry, and the public health sector



Our Expertise

Large computing and storage facilities for sensitive data

Security and compliance for the processing and storing of sensitive data

Technical, data science, and compliance consultancy

Our Vision

Our vision is to be **a neutral and independent** HPC and cloud computing service provider, **truly dedicated to life science, healthcare and industry**.

We want to **enable data providers and data users** to connect, analyse and combine any kind of data no matter where they are stored, **securely and compliant**.

We aim to be a **strong contributor** in realising the national and international strategies for **life science**, for the better use of health data and for **personalised medicine**.



The Key Advantages Of GDPR

The GDPR Legal Framework can act as an enabler for research and sensitive data e-infrastructures



Citizens can **take back control** of their data and are assured that **breaches have consequences**

Transparancy builds trust, enabling data donation and research participation

Better Infrastructure



Common legislation and security requirements aligns infrastructures



Citizens can donate and withdraw their data

GDPR empowers the citizens to **donate their data**, ensuring that the citizens consent to the use and re-use of their personal data. The **digital consent** eases the use of data in research.



Share health records and other data

For **better treatment and research**, citizens can share their data with relatives and researchers. Standardization offers better access to own data cross borders.

Empowers Citizens

Builds Trust



Citizens are generally positive towards research

In Denmark, the citizens are generally very **eager to participate in and donate data to research**. This offers a unique position that is enhanced with GDPR, as citizens now can follow where their data is processed and stored.



Legislation offers transparancy

With GDPR, authorities are enabled to **fine and sanction** breaches and misuses of data. We must protect the public's trust in the purposeful and valueable processing performed by researchers and authorities.



Common requirements offers better services

Standardisation and common legislation **aligns international e-infrastructures** offering better crossborder services as trust between providers is established with transparency and security measures provided with GDPR



Standard procedures and processes

The requirements of international security and compliance standards demands for standard operating procedures, **simplifying the day-to-day operational and maintenance tasks**. Further, troubleshooting and incident management is eased as risks and risk management are analysed, planned, and maintained regularly

Better Infrastructure

The EU Sensitive Health Landscape





450 Million EU Citizens



181 Zettabytes By 2025*

€11 Billion Saved By EHDS**

66

A truly connected, interoperable and sustainable EHDS is a precondition to unlocking the potential of health data in the EU, and solving these issues is central to breaking any remaining barriers to data sharing between Member States.

Digital Europe

"Making the most of the GDPR to advance health research", June 2021

*Statista, Worldwide Data Created, June 2021 https://www.statista.com/statistics/871513/worldwide-data-created/

GDPR Is Both An Enabler And Barrier

The GDPR Legal Framework is the foundation for the common legal and scientific basis needed for the EHDS

GDPR was seen as an enabler:

• to user rights over their data,

- pre-existing laws regarding data privacy and data sharing,
- sharing anonymized statistics,
- developing new data analysis approaches,
- patients' trust towards dealing with their health data and transparency

GDPR was seen as a barrier:



- to identifiable and individual-level data sharing
- time needed to complete the process
- workload increase
- differences with local legal legislations
- different (and stricter) interpretations and access to data

What You Can Do

How do we change the narrative that GDPR is a barrier in research?



Improve skillsets and knowledge with GDPR and compliance Use established research frameworks, federated models, and regulatory guidelines It is often not the legislation itself, but the different interpretations that creates the barriers

Computerome Compliance & Security Model

Compliance is a target in Computerome, acting as the key driver for technical development



Compliance Model

ISAE-3000 GDPR framework PwC audit on ISAE-3000 framework, November 2020 PwC audit on ISAE-3000 implementation, January 2022 Follow ISO 27001 standard, roadmap for certification



ISAE-3000 ensures a high standard of security



Security Model

Organisational measures Technical procedures Logging and user behaviour analysis User authentication (2FA) and authorisation Computerome and cloud firewalls





Data sharing platform in Computerome: DELPHI



Citizen-generated data in Computerome





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Thank you!