



The protection of health data at a crossroads

Data Privacy Day 2023

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Specific nature of health data

- Health data are particularly intimate and reveal private aspects of ourselves
- High expectations regarding healthcare and medical research
- Health data can lead to discrimination
- A great source of data in the digital era
- New possibilities offered by the analysis of large volumes of health data
 - 🔍 Better and faster detection and provision of healthcare
 - 📊 Epidemiology
 - 📈 Advance analytics
- The emergence of new health data markets



HEALTH TECHNOLOGIES IN LUXEMBOURG

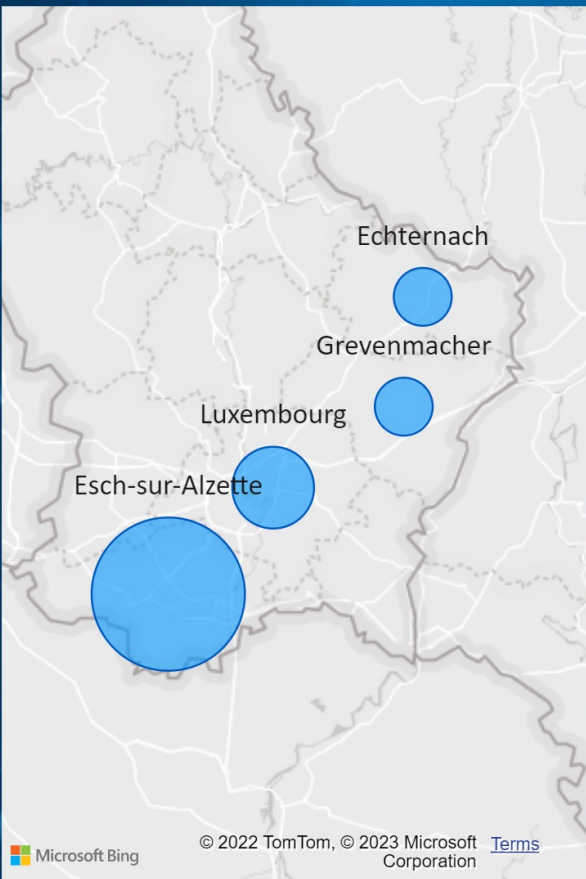
KEY FIGURES 2020 FROM THE PRIVATE SECTOR

FILTERS ARE ACTIVE

RESET ALL FILTERS



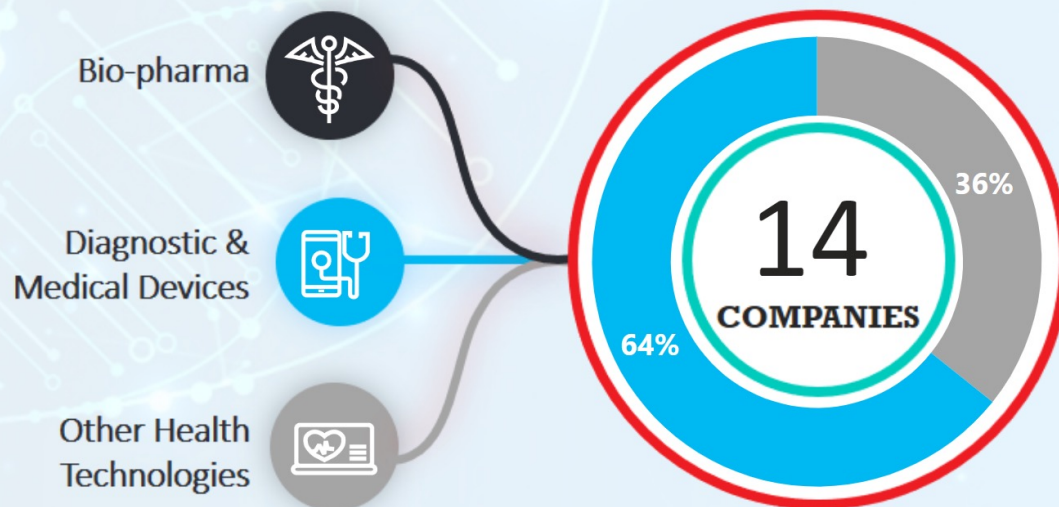
GEOLOCATION



79%

OF HEALTHTECH COMPANIES
ARE NOW LOCATED OUTSIDE
OF THE CANTON OF
LUXEMBOURG

SECTORISATION



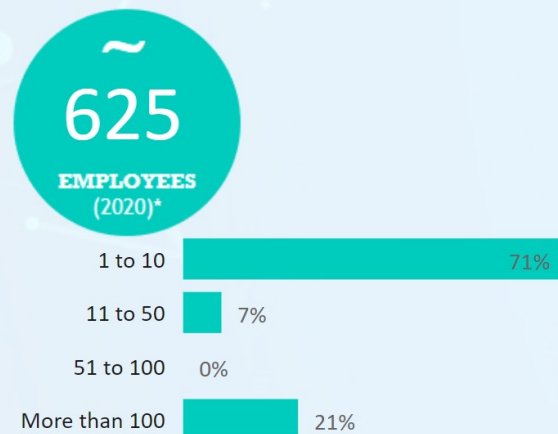
A YOUNG SECTOR

86%

OF TODAY'S COMPANIES
WERE INCORPORATED LESS
THAN 9 YEARS AGO

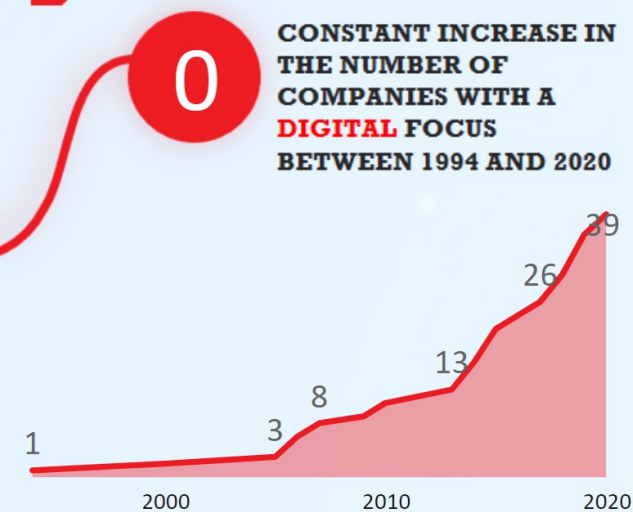


WORKFORCE

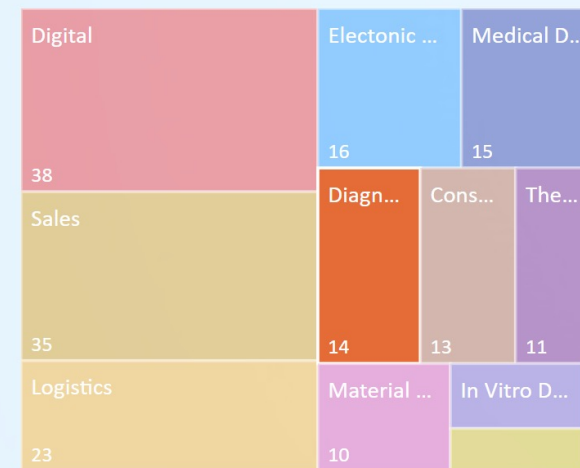


(*) Estimations based on latest available information from Editusdata

DIGITAL COMPANIES

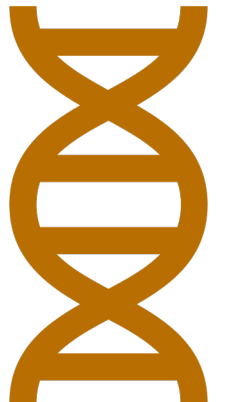


SPECIALISATION



Concerns with the use of health data (selection)

- Loyalty and transparency of algorithms
- Secondary use of health data and loss of control over personal data
- Ethical questions related to the interpretation of genomic data
 - 🔍 Evolution in the diagnostic approach: from diagnosing symptoms to detecting risks
 - ↔ Consequences in terms of ethics: explaining solutions proposed by AI, management of incidental findings, importance of genetic counselling



What does 'data concerning health' cover?

Art. 4(15) GDPR

'data concerning health' means personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status

Overlap with the definition of 'genetic data' (art 4(13) GDPR)

'genetic data' means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question

Broad interpretation of 'data concerning health'

Recital 35 GDPR

- Past, current or future health status
- Medical data
- Information derived from genetic data

CJEU, C-101/01, Lindqvist, 2003

- 'In the light of the purpose of the directive, the expression 'data concerning health' used in Article 8(1) thereof must be given a wide interpretation so as to include information concerning all aspect, both physical and mental, of the health of an individual'
- 'reference to the fact that an individual has injured her foot and is on half-time on medical grounds constitutes personal data concerning health'

How to recognise health data in practice

- The question is often one of context
- Interpretation issues may arise
- Illustration: data derived from well-being and lifestyle apps (quantified self)

Criteria (WP29, Annex Health Data in apps and devices, 2015)

1. The data are inherently/clearly medical data
2. The data can be used in itself or in combination with other data to draw conclusion about the actual health status or health risk of a person
3. Conclusions are drawn about a person's health status or health risk



Health data merit enhanced protection

- Health data are a special category of personal data
- ‘Data concerning in the list of sensitive data contained in art. 9 GDPR
- A stricter data processing regime applies to health data

ECHR, Z v Finland, 25 February 1997

‘the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention (art. 8). Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.’



Possibility for Member States to maintain or introduce of further conditions, including limitations, with regard to the processing of data concerning health (along with genetic data and biometric data)

A stricter data processing regime

Prohibition principle: processing health data is prohibited... (art. 9.1 GDPR)



... unless they are processed on the basis of exceptions/authorised legal grounds (art. 9.2 GDPR):

Employment,
social security and
social protection

Not-for-profit
bodies

Legal claims or
judicial acts

Vital interests

Explicit consent

Data made public
by the data
subject

Substantial public
interest

Health or social
care

Public health

Archiving,
research and
statistics

Further conditions under national law

Lux. DP Law

Law of 1 August 2018
(possible derogations to
some data subjects' rights,
appropriate safeguards
applicable to scientific
research)

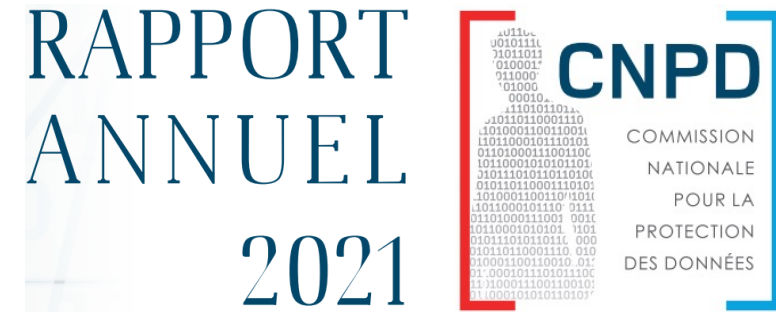
Other relevant laws (selection)

- Law on the Rights and Obligations of Patients
- Law on Hospitals and Hospital Planning
- Law on the National Health Laboratory
- Law of 3 December 2014 on public research centres
- Social Security Code
- Law on Medical Laboratories



Cyber threat

- Criticality of healthcare activities
- Vulnerability of health information systems
- Cyberattacks and risks for health data
 - 🔒 Confidentiality
 - 💎 Integrity
 - 📁 Availability
- State of the cyber threat
 - Ransomware
 - Data theft
 - Fraud
 - Industrial espionage



'The healthcare sector has experienced a significant number of security incidents, a state further accentuated by the COVID-19 pandemic and related computer processing. However, the CNPD notes the efforts of this sector to address and prevent these incidents.'

Conclusion

- The use of digital technologies in the health sector has undeniable and vital benefits
- By reducing privacy risks inherent to their use, such benefits can be increased



Thank you for your attention !

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