

Health Data

*Balancing individual and societal interests through GDPR
and EHDS*

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May 2025



Data Protection and Data Sharing: From GDPR to EHDS



- GDPR - focussed on protecting the interests of the data subject, protecting privacy.
- Creates rules for sharing data can on the basis of informed and withdrawable consent or other legitimate legal bases (contract, providing care, research ...)



- DGA - the potential of data for European citizens is not being fully realised - more data must be made available.
- Creates the concept of data altruism and data altruism bodies that can support trusted sharing of personal data



- EHDS – recognises the special needs of releasing data for care and research and the need for trust in handling sensitive data
- Creates mechanisms for data holders to make data available in a trusted but routine manner.

What do patients want for and from health data ?



Concepts of Ownership Ia

Legal Ownership

My house...

My car...

My music, my
book, my
film...

My
chickens...



- *Right to sell*
- *Duty to maintain*
- *Right to make financial profit*
- *Duty to report/pay taxes*

Concepts of Ownership I**b**

Legal Ownership

My house...



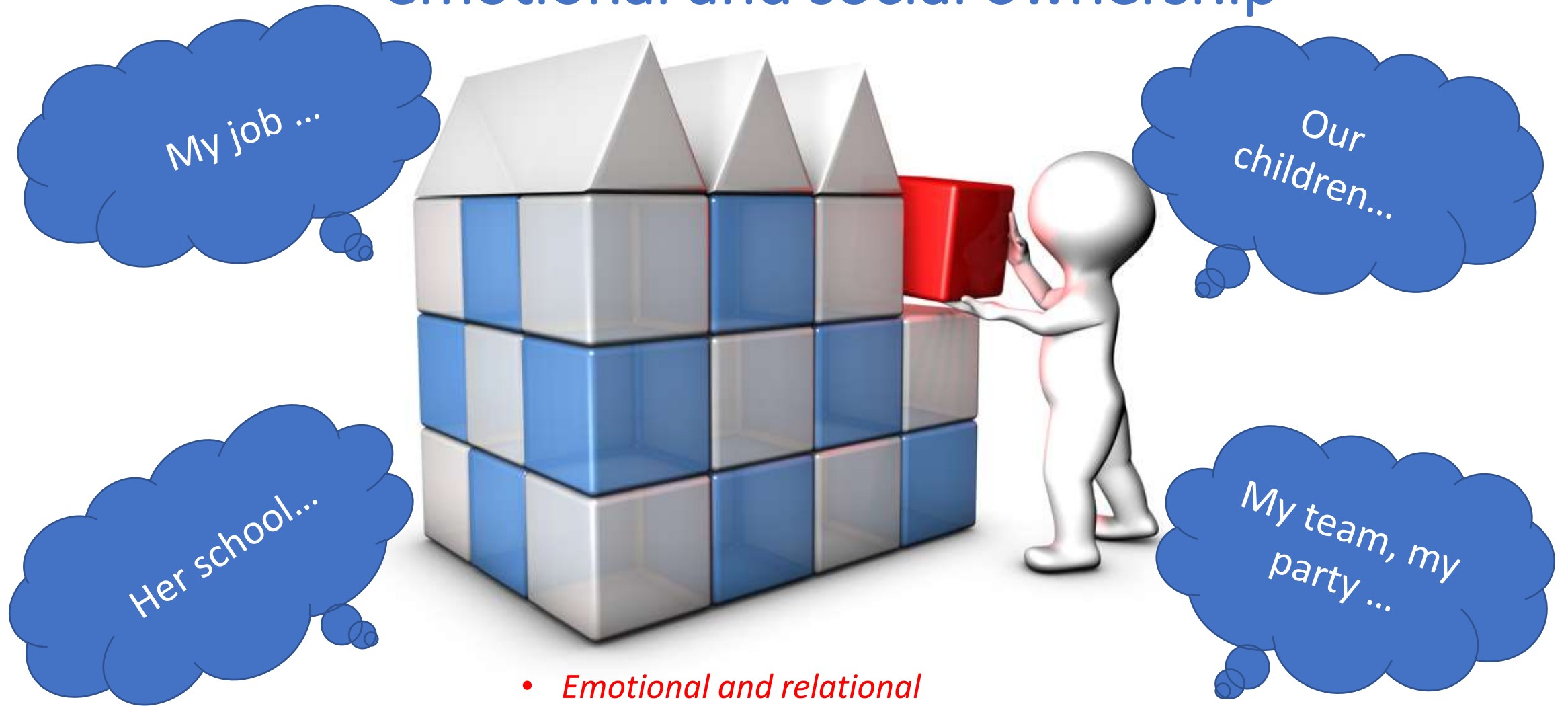
My car...

My music, my
book, my
film...

- ~~Right to sell~~ — ~~Right to reside~~
- ~~Duty to maintain~~ — ~~Duty to take care~~
- ~~Right to make financial profit~~ — ~~Right to enjoy~~
- ~~Duty to report/pay taxes~~ — ~~Duty to pay fees~~

My
chickens...

Concepts of Ownership II - emotional and social ownership



- *Emotional and relational*
- *Belonging and membership*
- *Responsibility and rights*

Concepts of (Data) Ownership III - GDPR

RIGHT TO
RENOVATE /
MAKE
ADJUSTMENTS

Right to rectification
(Art 16 of GDPR)

RIGHT TO CONTROL
ENTRY

Right to access
(Art 15 of GDPR)

INVITE OTHERS
TO ENTER

Right to data
portability
(Art 20 of
GDPR)

RIGHT TO SELL
/ MOVE OUT

Right to erasure
(Art 17 of GDPR)

LIVE
UNDISTURBED

Right to object
(Art 21 of GDPR)

RIGHT TO CHOOSE
PURCHASER/
PROTECTED FROM
UNFAIR ENVICION

Right to restrict
Processing
(Art 18 of
GDPR)

CHALLENGE
EXCESSIVELY
HIGH CHARGES

Right not to be
subject to a
decision based
solely on
automated
processing
(Art 22 of
GDPR)



GDPR

Patients' and researchers' rights

Right to be given a legal base for data processing

- Consent
 - Contract
 - Legal Obligation
 - Care provision
 - Public interest
 - Vital interest
- (Art. 6(1) and 9 (2))

Right to data portability

.... When processed on basis of consent and automatic processing
(Art 20)



Right to access and rectification
(Art 16)

Right to object
(Art 21)

Right to restrict Processing
(Art 18)

Right to erasure (to be forgotten)
(Art 17)

Right not to be subject to a decision based solely on automated processing
(Art 22 of GDPR)

Legal base for data re-use (Research)

- Explicit consent
- Public interest in public health or research
- National frameworks

(Art. 9 (2) and Art 89)

EHDS

Patients' rights and researchers' interests

Primary use

Legal base for processing

- *Legal base for primary use*

Enhanced data access

- *Immediate, free of charge*
- *Access for proxy*
- *Access service*

Opt-out

- MS may provide opt-out for sharing EHRs with other care providers

Data Addition

- Apps
- Personal notes



Transparency

- Access Log
- Annual report

Secondary use

A legal base for data re-use

- Legal base for secondary use,
- Health Data Access Bodies
- Data access Permits

Opt-out

- Right to opt-out of secondary use

Data Quality Assurance

- Data catalogues
- Quality and utility labeling
- Enhanced data returned to HDAB

Transparency

- Access Log
- Annual report secondary use

A change in rights, a change in perspective

From national focus to EU wide integration and interoperability

From data subject protection to active engagement

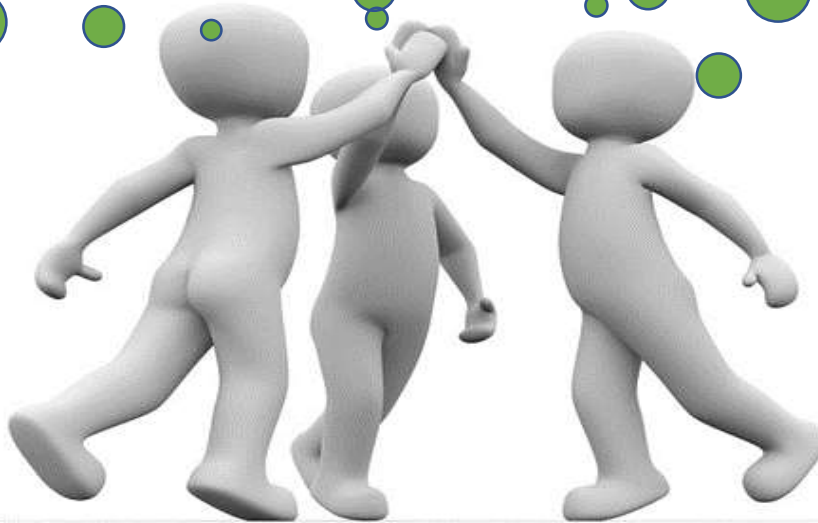
Introducing data altruism

From data protection to data usage

From data re-use as the exception to the norm

From DSAR to easy transparency on use, re-use and impact of re-use

From generic data controller to focused healthcare data controller and holder support



Thank you!

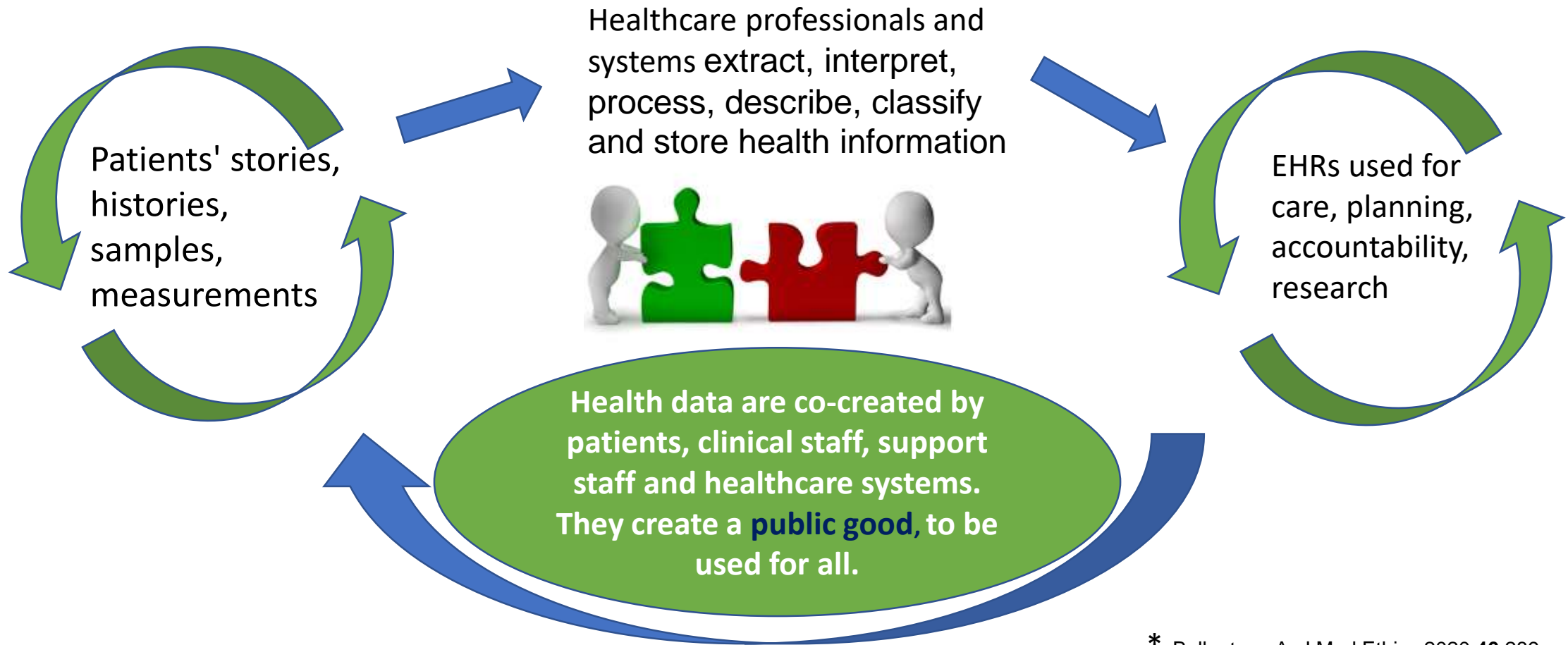
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Healthcare needs new concepts of data as a public good, in which investment in its use is rewarded.

“The patient contributes the ‘raw material’ which is transformed into clinical data by the actions of medical staff”*



* Ballantyne A. J Med Ethics 2020;**46**:289–