Forced data altruism and informational autonomy under the European Health Data Space

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When did you last consent to your health data being used for research?

Under the EHDS — you already have. Unless you said no.

The EHDS Secondary Use Framework

Two Pillars of the EHDS

- **Primary use** — direct patient care, cross-border treatment
- **Secondary use** — research, policy, statistics, innovation

Key mechanics:

- Health Data Access Bodies (Art. 57)
- Purpose limitations (Art. 53)
- **Opt-out, not opt-in** (Art. 71)

The most ambitious health data infrastructure in EU history — but at what cost to individuals?

From Data Altruism to Forced Data Altruism

Data Governance Act — Data Altruism	**EHDS — Secondary Use**
Voluntary	Default participation
Purpose-driven	Broadly defined purposes
Revocable	Opt-out under pressure
Invitation to solidarity	Extraction of solidarity

Forced data altruism: collective benefit extracted, not offered.

The Opt-Out Illusion

Why Opt-Out Is Not Enough

❌ Assumes **awareness** — most patients are unaware of EHDS provisions
❌ Assumes **capacity** — patients engage health systems while ill or stressed
❌ Assumes **meaningful choice** — significant information asymmetry between patients and institutions

Opt-out in practice = silent consent

Where the EHDS Falls Short

Tension	EHDS Approach	What is missing
Autonomy vs. solidarity	Solidarity by default	Informational self-determination
Transparency vs. complexity	General notices	Granular, accessible information
Anonymisation as safeguard	Technical fix	Relational dimension of secrecy

Towards Genuine Informational Self-Determination

☐ **Granular opt-in** — by research type, data sensitivity, institutional context
☐ **Professional secrecy filters** — ethics reviewers within Health Data Access Bodies
☐ **Enhanced transparency** — plain-language, layered notices at point of care
☐ **Participatory governance** — patient representation in HDAB oversight
☐ **Privacy-by-design as mandatory standard** — federated learning, data minimisation

Conclusions

The EHDS will only succeed if it treats medical secrecy not as a relic of the pre-digital era — but as the functional condition that makes meaningful participation possible.

Can a framework that treats silence as consent ever earn the trust it needs?

Questions?

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