The European Health Data Space and the Yellow Button:

Operationalising Citizen Rights for Integrated Long-Term Care

AUTHORS (EHTEL)

Sophia Schlette

Rachelle Kaye

Sara Canella

Marc Lange

Luc Nicolas

Funded by the European Union

Contents

Abbreviations

DMAT	Laurel Digital Maturity Assessment Toolkit
EEHR	European Electronic Health Record
EEHRxF	Electronic Health Records Exchange Format
EHDS	European Health Data Space
FHIR	Fast Healthcare Interoperability Resource
I-LTC	Integrated Long-Term Care
IPS	International Patient Summary
LTC	Long-term care

Executive Summary

The European Health Data Space (EHDS) establishes new rights for citizens to access, download and share their electronic health data across the European Union. These rights represent a transformative opportunity for Integrated Long-Term Care (I-LTC), where continuity of information across health, social and informal care settings is essential.

However, legal rights alone do not guarantee integration. Practical mechanisms, governance alignment, digital maturity and ecosystem incentives are required to translate EHDS principles into everyday care practice.

Building on existing initiatives, such as the Horizon Europe xShare project which provides a concrete operational example of how citizen-controlled data portability and Catalonia's Blue Button experience, this paper outlines:

- **How EHDS can strengthen integrated long-term care**
- **How the Yellow Button operationalises citizen rights**
- **The challenges that remain**
- **Policy recommendations structured along three pillars:**
    1. Effective national EHDS implementation
    2. Citizen and carer empowerment
    3. Ecosystem stimulation and organisational readiness

These recommendations would be an opportunity to provide additional inputs to the actionable policy in I-LTC developed in the forthcoming Laurel White Paper.

1 EHDS: A New Legal Foundation for Integrated Long-Term Care

Long-term care (LTC) is a range of services and support for individuals with chronic illnesses, disabilities, or cognitive impairments who cannot perform daily activities (ADLs) on their own, such as bathing, dressing, or eating. It focuses on managing long-term needs to maintain independence, rather than just medical treatment.[1]

Community-based long-term care (LTC) faces critical challenges centred on workforce shortages, financial sustainability, and the fragmentation between health and social services. Key issues include inadequate access to home-based services, the intense burden on informal caregivers, and the need for better coordination to prevent hospital backlogs and support aging-in-place. A fundamental requirement for meeting these challenges is the ability to share data among all the relevant stakeholders, a requirement addressed directly by the European Health Data Space concept and regulation.

The European Health Data Space (Regulation EU 2025/327) establishes a sector-specific European data space for health, introducing a common legal, technical and governance framework for exchanging electronic health data.

The EHDS introduces a patient-centric model. For the first time at EU level, citizens are granted:

- **The right to access their electronic health data**
- **The right to download it in interoperable formats**
- **The right to share it across providers and borders**
- **The right to control professional access**

These rights are particularly relevant for Integrated Long-Term Care. I-LTC depends indeed on:

- **Continuity between hospital, primary care, home care and social services**
- **Clear medication and care plan information**
- **Collaboration between health and social care professionals and informal carers**
- **Longitudinal understanding of complex, multi-morbid conditions**

Yet today, data remains fragmented across organisational silos. Informal carers frequently act as intermediaries. Transitions of care remain vulnerable moments.

EHDS provides the legal architecture to overcome fragmentation — but implementation choices will determine whether it strengthens or merely digitises existing silos.

1. https://www.nia.nih.gov/health/long-term-care/what-long-term-care

2 From Legal Right to Practical Tool: The Yellow Button Experience

Since the introduction of the first draft of the EHDS regulation, an increasing number of European funded projects have been focusing on various aspects of the regulation – among them the xShare project, which aims at enabling seamless, one-click sharing of health data in the European Electronic Health Record (EEHR) by focusing on making healthcare data accessible to all EU citizens. The xShare project intends to do this by developing a "yellow Button" specification that can be implemented by patient-facing Apps installed on mobile devices or patient portal and readily used.[2]

It enables citizens to:

- **Access structured summaries of their health data**
- **Download interoperable priority data categories aligned with Electronic Health Records Exchange Format (EEHRxF)**
- **Share them securely with professionals, carers, researchers or trusted digital patient facing applications**

The project draws on Catalonia's Blue Button[3] experience, integrated within the La Meva Salut portal, which has already demonstrated consolidated citizen access to personal health records and the use of the public sector 'Health Data for Sharing – Blue Button' to download a consolidated International Patient Summary (IPS) covering all public providers.

Lessons from these experiences show:

- **Citizen-controlled portability is technically feasible**
- **Interoperability standards (e.g. FHIR) and formats (e.g. IPS) support structured exchange**
- **Data sharing and download alone are insufficient — integration into workflows is key**
- **Governance alignment and ecosystem incentives are decisive**

The European Health Data Space (EHDS) reinforces this shift by granting citizens the right to access, download, and share their electronic health data. However, experience shows that patient portals alone do not automatically translate into citizens' empowerment. Especially in I-LTC, meaningful participation requires tools that are simple, trusted, and embedded in daily care practices, along with appropriate training materials to enhance digital literacy

2. https://hl7europe.eu/xshare-project

3. Through La Meva Salut, citizens can access their personal health record and, since 2022, use the public sector 'Health Data for Sharing – Blue Button' to download a consolidated International Patient Summary (IPS) covering all public providers. Key characteristics include a) a single access point for citizens across public healthcare; b) download of structured data (IPS in FHIR, CDA) and readable PDFs (e-Prescription, e-Dispensation); c) clear emphasis on continuity of care and citizen empowerment.

The Yellow Button concept addresses this gap by operationalising data portability and citizen control in a way that supports collaboration across sectors, domains and over time. In Integrated Long-Term Care settings, it enables four essential system functions:

Continuity

A portable, citizen-controlled care data supporting safe transitions (e.g. hospital to home).

Coordination

Up-to-date information sharing between professionals and informal carers, reducing duplication and errors.

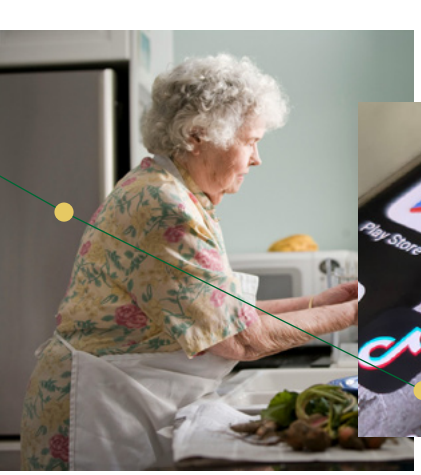
Empowerment and Co-Management

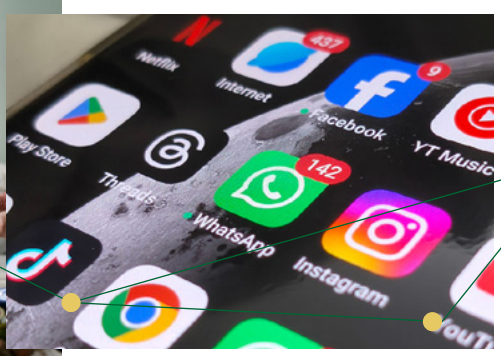
Improved patient and family engagement in everyday care decisions.

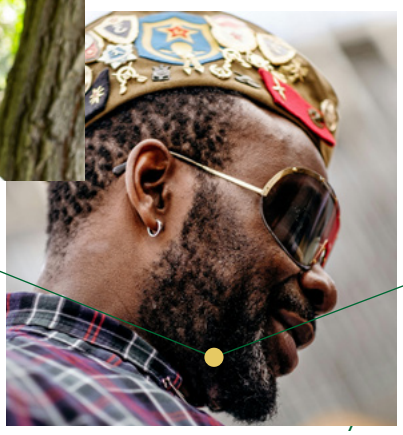
Ecosystem Interoperability

Integration with telehealth, remote monitoring, medication management apps and other digital supports.

The Yellow Button thus represents a practical bridge between EHDS rights and integrated care delivery.







3 What the Yellow Button Can Do for Integrated Long-Term Care

Several European countries and regions already benefit from mature national or regional systems that provide broad access to published health information. The value added by the Yellow Button extends beyond these existing infrastructures in two key ways: first, it guarantees data portability even in contexts where data sharing frameworks are not yet fully developed; second, it places a specific emphasis on interoperable data — not merely the exchange of messages — enabling information to be directly actionable within dedicated clinical or administrative workflows.

If embedded within care pathways and organisational workflows, citizen-controlled data portability can:

- **Reduce administrative burden for professionals**
- **Decrease avoidable hospital readmissions**
- **Improve safety at care transitions**
- **Strengthen informal carer involvement**
- **Enhance trust and transparency in care relationships**
- **Enable more proactive and preventive care models**

However, its impact depends on systemic alignment beyond technical deployment.

4 Remaining Challenges: Lessons from Catalonia and EU Pilots

Experience from Catalonia's Blue Button and Yellow Button pilots reveals critical challenges:

Health–Social Care Fragmentation

Data exchange remains primarily health focused and keep on relying on "messages" rather than data. Functional status, social care information and care planning data are not yet systematically integrated.

Organisational Digital Maturity

Portals do not automatically integrate workflows. Care organisations require governance, workflow redesign and workforce adaptation. Workflows are per definition dynamic and require continuous validated data updates with direct impact on individual and organisational roles and liability.

Incentive Structures

Providers may comply minimally with EHDS requirements without investing in meaningful interoperability.

Digital Literacy and Accessibility

Older adults and informal carers require targeted support to effectively exercise their data rights.

Governance and Trust

Clear accountability, consent management models and cross-sector coordination mechanisms are essential.

Unless these structural, organisational and governance challenges are actively addressed, EHDS implementation risks becoming a compliance exercise rather than a genuine enabler of integrated long-term care — reinforcing existing silos rather than dismantling them.

5 Policy Recommendations

To ensure EHDS contributes effectively to Integrated Long-Term Care, coordinated action is required across three strategic pillars.

Pillar 1 – Expanding Implementation of EHDS

- Explicitly link I-LTC requirements to the priority data categories and profiles selected under national EHDS transposition frameworks, ensuring that long-term care use cases are reflected in implementation choices from the outset
- Expand structured data categories to include new profiles with functional status, care plans and relevant social care information
- Ensure alignment between EHDS implementation and national integrated care reforms

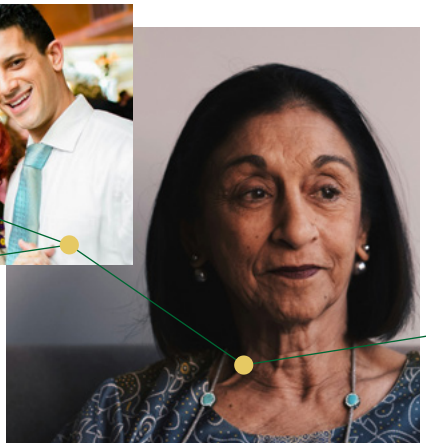
Pillar 2 – Citizen and Carer Empowerment

- Promote visible, user-friendly portability mechanisms (e.g. Yellow Button functionality).
- Reflect I-LTC requirements in EHDS priority data profiles and national compliance assurance mechanisms, building on existing integrated care pathway infrastructure where available.
- Leverage the Yellow Button's portal-independent design to integrate citizen-controlled data sharing directly into validated integrated care workflows, including in contexts with less mature digital infrastructures. Invest in digital literacy programmes targeting older adults and informal carers.
- Support multilingual, accessible and inclusive interface design.

Pillar 3 – Ecosystem Stimulation and Organisational Readiness

- Incentivise interoperability for digital integrated care workflows and additional profiles through certification and labelling schemes.
- Align funding and reimbursement mechanisms with coordination and data-sharing objectives.
- Support organisational readiness through structured digital maturity tools such as the Laurel Digital Maturity Assessment Toolkit (DMAT).
- Encourage public-private collaboration while safeguarding citizen rights.



Conclusion:
From Portal Feature to Care Infrastructure

EHDS establishes the legal right. The Yellow Button demonstrates operational feasibility. The Laurel project supports organisational transformation and ecosystem readiness.

Together, they form a coherent policy triangle:

- **Legal foundation**
- **Practical implementation mechanism**
- **Capacity-building and maturity support**

If aligned strategically, citizen-controlled data sharing can become a cornerstone of next-generation integrated long-term care systems — not merely a download function, but a catalyst for systemic integration.

Integrated Long-Term Care must be positioned at the centre of EHDS implementation, ensuring that digital rights translate into real improvements in coordination, safety and empowerment.

References

Busetto L, Luijkx K, Vrijhoef HJM. Development of the COMIC Model for the comprehensive evaluation of integrated care interventions. International Journal of Care Coordination. 2016;19(1-2):47-58.

Funded by
the European Union

This project (Project 101132643 - LAUREL - Actionable policies for adopting high-quality integrated long-term care) has received funding from the European Union's Horizon research and innovation programme. The content of this website reflects only the Laurel groups' views and the European Commission is not liable for any use that may be made of the information contained herein.