xShare
EHR Xchange Format

xShare: Expanding the European EHRxF to share and effectively use health data within the EHDS

<26-06-2025>

Better Connecting Primary And Secondary Use Of Data For Additional Societal Value

Lessons learnt from “Only Once” best practices

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« ONLY ONCE » BEST PRACTICE USE CASES

ONCE ONLY

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DENMARK

- Initial motivation: to provide healthcare providers with the **benchmarking** deemed useful for their practice and **build collaboratively the knowledge** which may improve quality of care in priority treatments (e.g. diabetes)
- Dataset discussed with each speciality
- Extending progressively to PH Databases and third-party applications with adapted privacy modalities.
- Limited semantic requirements (Diagnostics: ICD-10)
- Two systems: One public (specialists) and one private (GPs)
- Legal obligations came later (2024)

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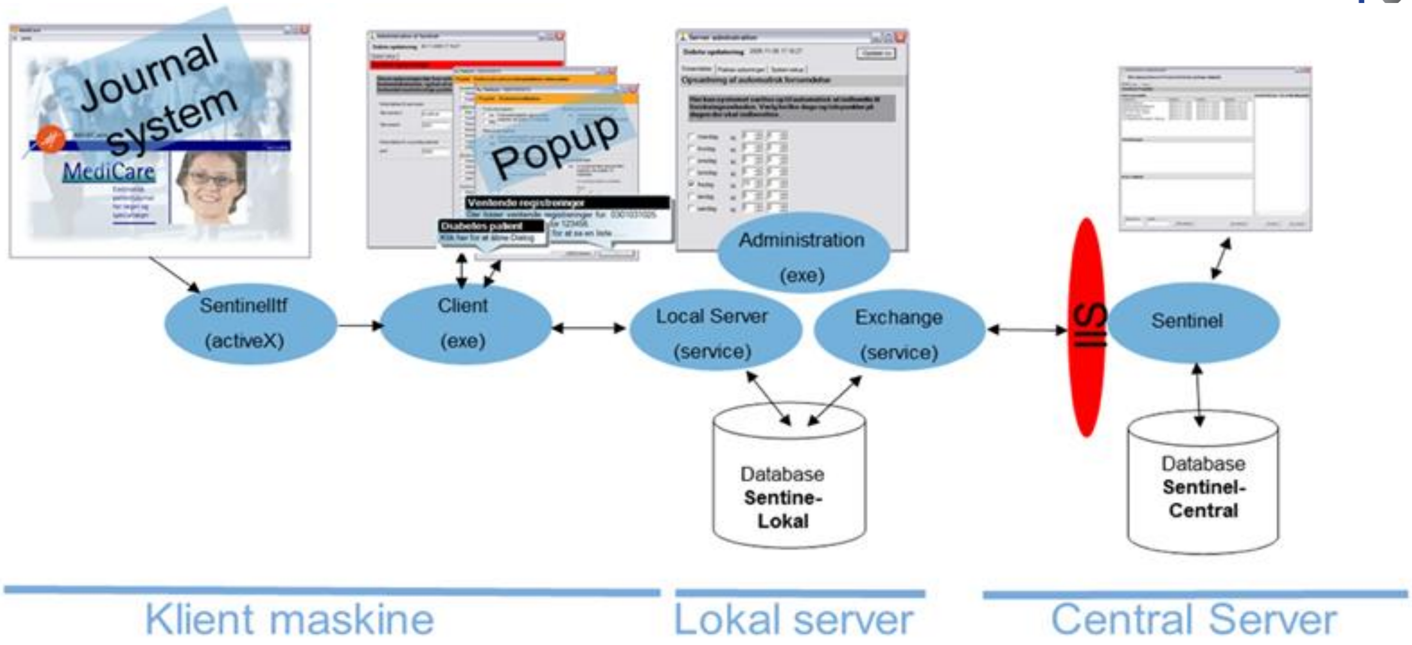

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Lessons Learnt

1. CALIBRATION and BALANCED ROI CO-CREATION and mix of DRIVERS
2. Other complementary co-created initiatives such as CAPRI and INCEPT (see annex) have been launched to support iterative research.
3. Industry can play a key role in providing adapted solutions for connecting primary and secondary use of data provided that their competitive advantage can be protected.
4. Although an eHealth European champion, Denmark has been slow to engage in discussions around interoperability challenges in Europe and beyond. **National legacies remain numerous and pervasive**. Both Public Competence Centre and Industry seem to have understood the necessity to make swift progress in this regard. The **EEHRxF specifications** are evidently considered with a lot of attention and expectation.

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Who are the data consumers? And what are the main data concerned?

- The Healthcare providers themselves
- The 28 national registers and the 85 quality registers
- The Regions

- Diagnostic codes
- Laboratory results/values
- Medication information
- Patient ID
- Practice identification information

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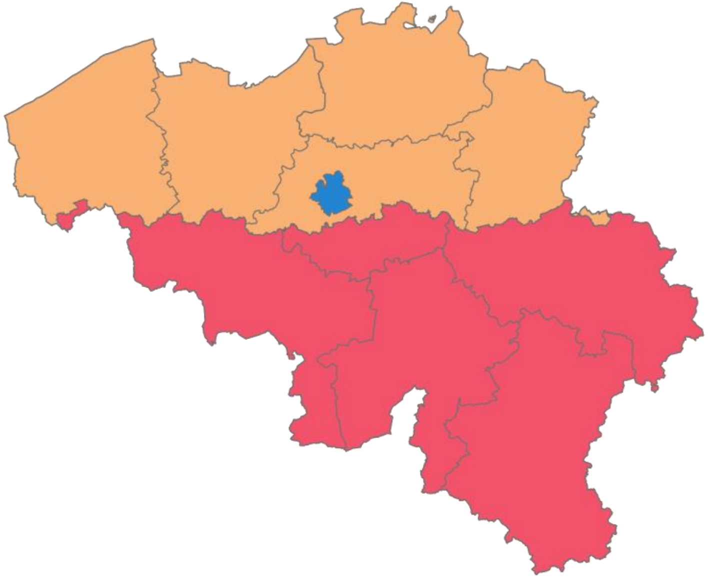
BELGIUM:

- Only Once Objective since 2013:
    - Full inventory of registers (with metadata)
    - systematic adoption of standardised system-to-system communication protocols and the gradual phasing out of dedicated data collection platforms tied to specific datasets in the mid-term
- Objective to cover progressively all registers (including reimbursement)
- Priorities on real time monitoring (e.g. infectious disease): Labos, GPs, nursing homes, Hospitals
- From “sentinel” to universal coverage
- HD4DP translates message standards into the standard required by the receiving system, including data formats and standards like HL7, DICOM, ANSI X12, ASCII, and XML. Main functionalities are filtering, transformation, extraction and routing.
- Public Investment in Care Sets and Belgian Integrated Health Record, using SNOMED CT and LOINC codes



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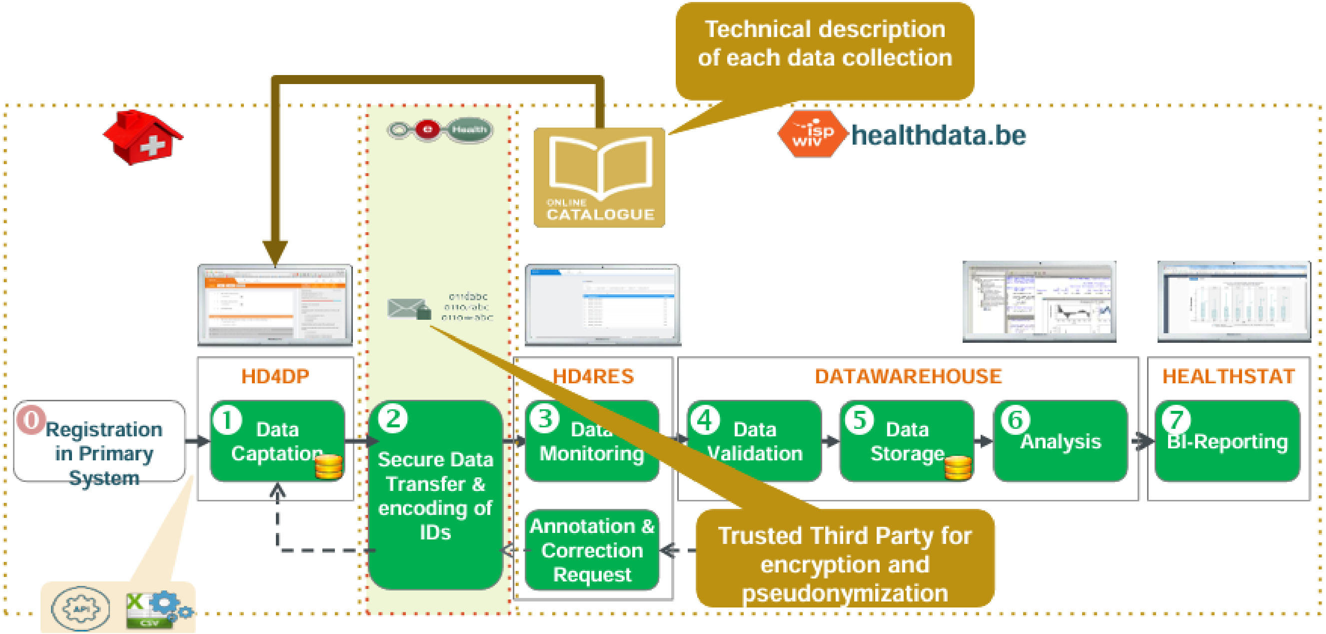
Health Data for Data Providers (HD4DP)



Technical description of each data collection

ONLINE CATALOGUE

healthdata.be

HD4DP

HD4RES

DATAWAREHOUSE

HEALTHSTAT

0 Registration in Primary System

1 Data Captation

2 Secure Data Transfer & encoding of IDs

3 Data Monitoring

4 Data Validation

5 Data Storage

6 Analysis

7 BI-Reporting

Annotation & Correction Request

Trusted Third Party for encryption and pseudonymization

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Lessons Learnt

- Support is needed to set up **official terminology servers** and improve human and technical resources within healthcare organisations → Community Support for Clinical terminologies (CSCT) in Belgium
- Importance of a **unified data entry system** that supports both primary and secondary data use cases
- Universal adoption and push for international standards can support interoperability and ease data production for care providers

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FINLAND

- Finland's healthcare system is constitutionally mandated and is based on the social welfare and healthcare services offered by the 21 counties
- In the last 20 years, legislation has strongly supported the digitalization and centralization of health data
- All healthcare providers must send their patients´data to the central Kanta archive
- Data from Kanta servers is also automatically available for secondary use through the centralized national entity, Findata

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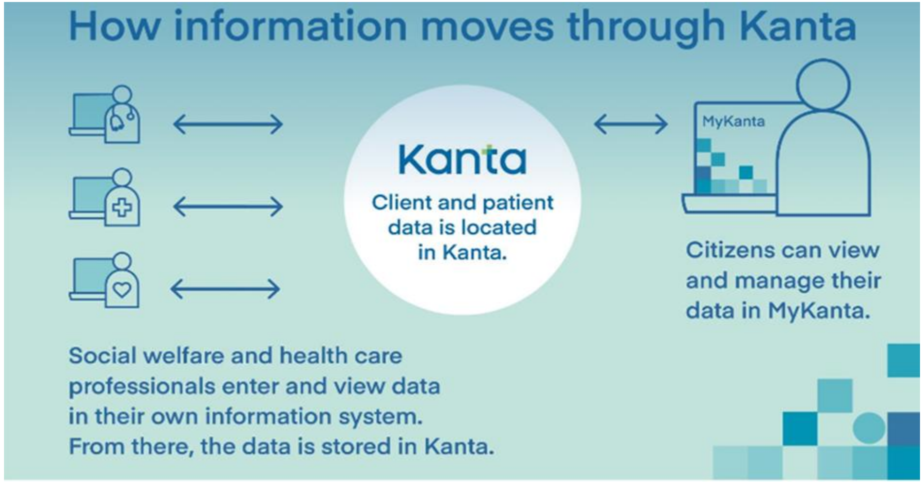
Kanta services


How information moves through Kanta

Kanta

Client and patient data is located in Kanta.

Citizens can view and manage their data in MyKanta.

Social welfare and health care professionals enter and view data in their own information system. From there, the data is stored in Kanta.

- Patient records (incl. discharge reports, laboratory results)
- Diagnostic images
- Prescriptions and dispensations
- Vaccinations
- Living wills and organ donation testaments
- Social services client data
- Medical certificates and statements
- Consents and denials of consent
- Pharmaceutical product data
- Appointment information
- Wellbeing data and measurement results (PHR)

Image source: www.kanta.fi

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Secondary use of data

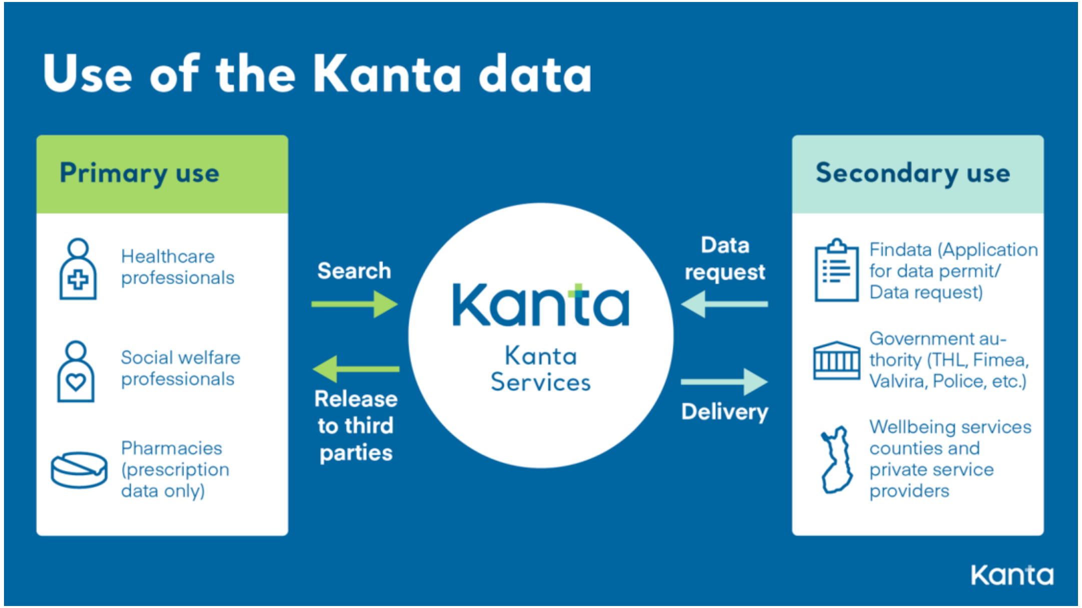

Image source: www.kanta.fi

FINDATA:

- grants permits for the secondary use of social and health care data
- includes secure user environments and interfaces for data provision, ensuring strong privacy protection and safe data usage
- Issues fee-based permits

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Lessons Learnt

- Despite the advanced legislation and underlying infrastructure, there is significant criticism from physicians and researchers regarding the **difficulty of using** the collected data.
- Criticism also concerns the difficulty of expressing thoughts within predefined structured data codes.
- Information **systems often lack usability and sufficient analysis and search capabilities** to fully leverage structured data, which diminishes physicians' motivation in providing the information.
- Requesting data permits is costly in both time and money

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Summary of lessons learnt across countries

- Multiple drivers is key for FAIRification of data
- Major investment in usability is still needed
- Only once should truly be only once
- The extra effort must lead to a RoI
- Legacies will still remain a burden for a while: EHDS specifications is a very powerful game changer.
- Public and Private initiatives might be competing

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Aligning standards

- **All models experience at some stage scalability issues.**
- No one approach can meet all requirements --> trending towards **hybrid approaches**. --> **all major models supported**, with data submitted in the model most suitable for the data producer. However, this demands greater effort in alignment, as e**ach domain must also consider the requirements of other domains.**
- Hybrid approaches require **adapted technology/tools and investment in advanced data management human competencies.**
- The metadata and data catalogue under discussion in TEHDAS2will create a first baseline but more efforts needed at **data level**.
- (Interconnected) terminology servers can play a role in reducing complexity and supporting alignment.

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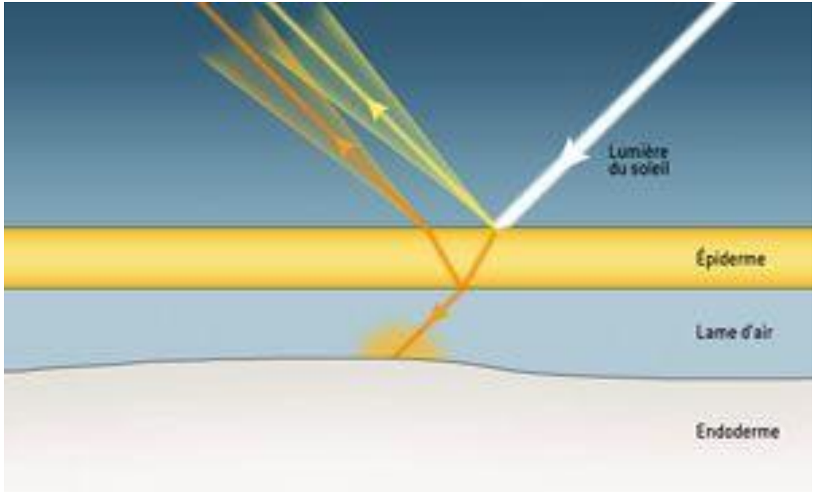
THANKS



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