



**Healthdata.be**

**Minimalisation of registration burden,  
Maximalisation of Return on Information**

**Johan Van Bussel  
Herman Van Oyen**

**EGHI, Luxembourg, 2015 Nov 12th**

**ISP  
WIV**

WETenschappelijk INSTITUUT  
VOLKSGEZONDHEID  
INSTITUT SCIENTIFIQUE  
DE SANTÉ PUBLIQUE

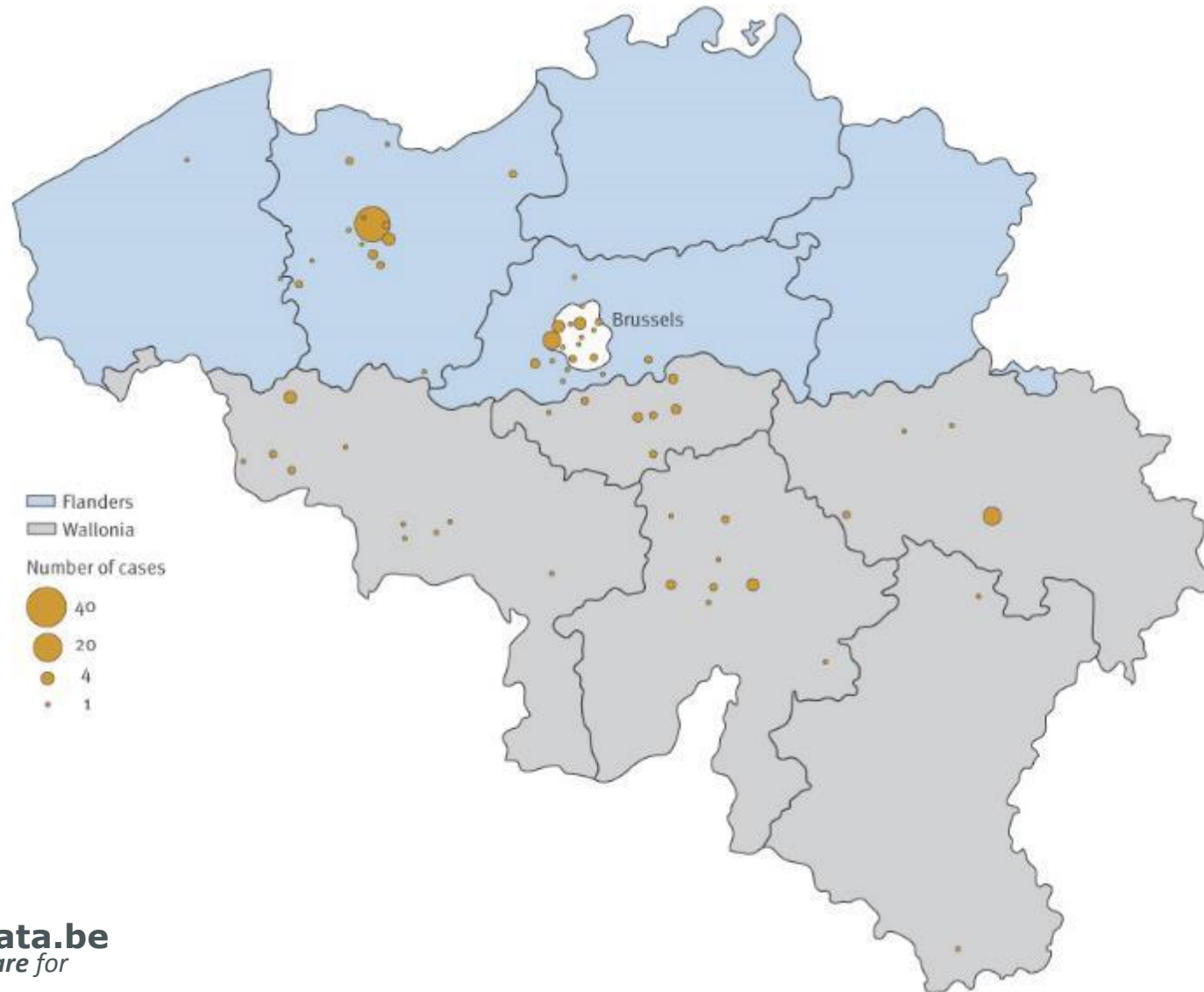


Handwritten text on lined paper, possibly a signature or name, written in brown ink. The text is partially obscured by a pencil tip.



# Epidemiological surveillances are necessary !

Sabbe et al., (2012) Measles resurgence in Belgium, Eurosurveillance



# Clinical registries are necessary !

**Unknown effectiveness**

**50%**

Effectiveness of 3000  
common therapeutic  
interventions

*BMJ Clinical Evidence (2014)*

Beneficial (11%)

Likely to be  
beneficial (24%)

Trade-off between  
benefits and harms (7%)

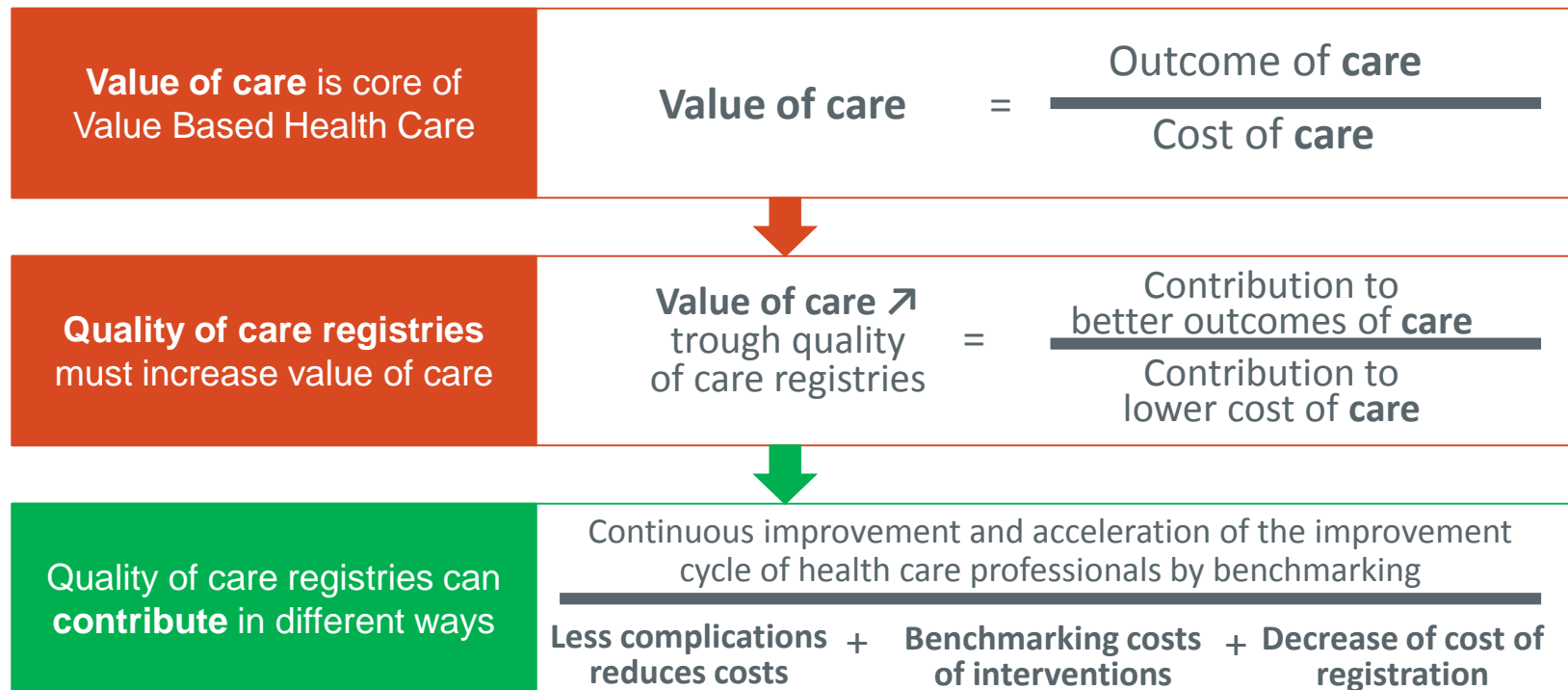
Unlikely to be beneficial (6%)

Likely to be ineffective or harmful (3%)



# Registries as a pillar of « Value Based Health Care »

ZorgInstituut.NL, based on Michael Porter





# Collection of health (care) related data in Belgium (n > 160 projects): “AS-IS”



Stage 7

Stage 6

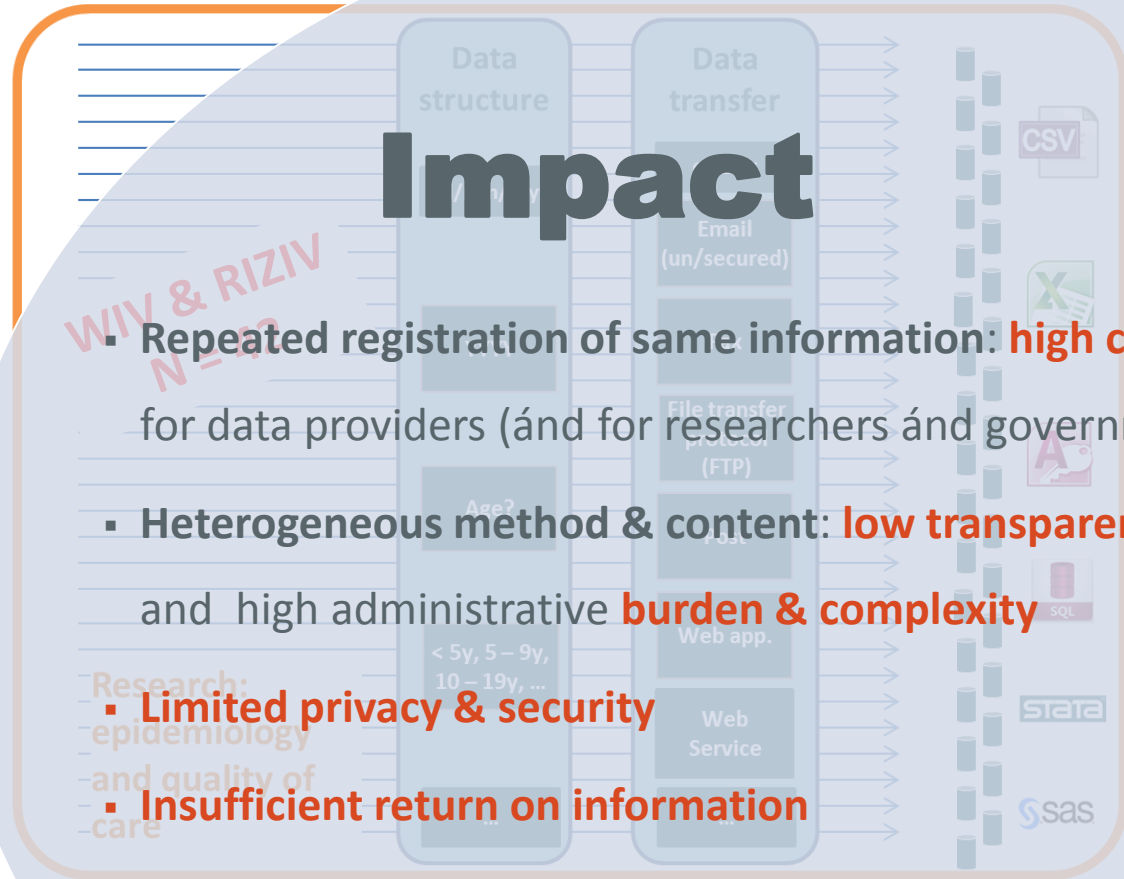
Stage 5

Stage 4

Stage 3

Stage 2

Stage 1



## Registratielast stroomlijnen vermindert administratie

BELGIË

10/09/2015 - 09h59

Over de meeste thema's in de enquête over ziekenhuisfinanciering blijken noord en zuid opvallend eensgezind te zijn. Als er al meningsverschillen zijn dan blijven ze beperkt. Zo slaat bijvoorbeeld het idee van ziekenhuisnetwerken in Franstalig België minder aan dan in Vlaanderen.



stelling dat de regels vereenvoudigen door in deze clusters stapsgewijs en financieel mogelijk te integreren –bijvoorbeeld voor geneesmiddelen. Een groot deel van de artsen (Zweden) en de specialisten- spreekt zich hier niet over uit. Ongeveer twee op vijf artsen gaan akkoord. Bij de directies en leden van de raden van bestuur zijn er meer aanhangers (66,7%) er achter staan.

Unanimiteit bestaat er onder de leidinggevenden in de ziekenhuizen niet. Het zou de administratieve last ook verminderen. De artsen gaan hiermee akkoord maar minder dan de directies.

### Communautaire verschillen

Uit deze enquête komen weinig communautaire verschillen naar voren. Een uitzondering op die regel vormt het voorstel van De Block om pathologiegroepen te concentreren. Drie kwart van de Nederlandstaligen is hiervoor gewonnen, bij de Franstaligen is dat niet eens de helft (49,9%). Vooral huisartsen (72,1%) en mensen met een ziekenhuisfunctie (72,7%) zijn pro concentratie, ziekenhuisartsen zijn hierin minder

# Growing Awareness

< Vorige artikel > Volgende artikel >

- Van de Sande, et al. (2006) **Inventory of databases health care**, KCE Reports 30A;
- Belgian Court of Audit (2010) **Scientific support of federal health policy**, BCA Reports;
- Coussée (2010) **Charter High-quality recording of data from the healthcare sector**, Brussels; Zorgnet Vlaanderen;
- Actionplan eHealth 2013-2018: **Action point 18 “Inventory and consolidation registers”**;
- Law 5 May 2014: **principle of “only once”** data collection in activities **gov. services & institutes**;
- Federal (9.10.2014) and Flemish (23.07.2014) **coalition agreement** prioritizes reduction of administrative burden of health care professionals: **“Only once”!**
- Federal Minister Maggie De Block (25.04.2015) : Reform plan **financing of hospitals**.

Meest gelezen

Werkgroep ziekenhuisfinanciering uit de startblokken

Integratie UZ Gent in UGent goedgekeurd

UZ Gent veroordeeld voor fouten bij bestelling

UZA behaalt ICU-kwaliteitsnorm voor veilige en

In deze editie

Magazine

De 'look' in de gezondheidszorg: van

zoek naar het volgende

Volg ons op

Klik hier

healthcare



# healthdata.be

- Law of 10 April 2014 various provisions related to health: Section 9: **initiative RIZIV-INAMI and WIV-ISP: healthdata.be;**
- A new service within the **legal body** of the Institute of Public Health (**WIV-ISP**), funded by **RIZIV-INAMI** (20/04/2015, contract of open-end duration)
- **Facilitate data exchange** between healthcare professionals and researchers according to only once principle and re-use of data, in order to **increase public health knowledge** and to **adjust health care policy**, with **respect for privacy of patient, healthcare professional and medical confidentiality.**
- **Intergovernmental services** for both federal and community/regional governments responsible for health and healthcare, and **private legal bodies** (indirectly);
- 2014-2017: **focus on uniformisation of 42 existing** registers managed by WIV-ISP and RIZIV.



# Simplification

Healthdata.be will focus on the *simplification*, *standardization* and *automatization* of the:

- Business **processes**
- **Data collection** architecture
- **Information** architecture (terminology)
- **Data management**
- Feedback **reporting**



Belastingdienst.nl/aangifte

Leuker kunnen we't niet maken. Wel makkelijker.

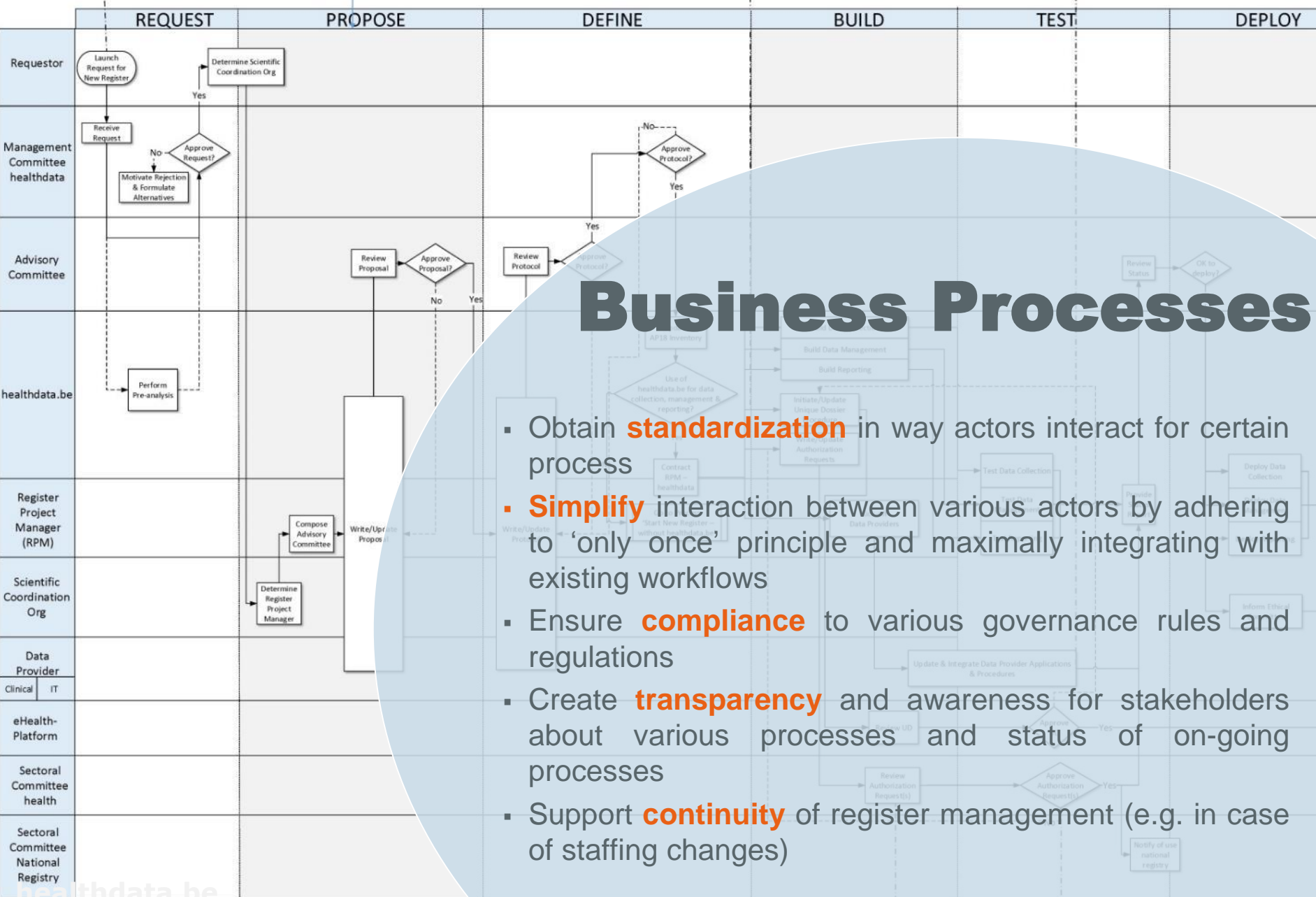
TaxOffice.nl/declaration

We can't make it enjoyable, we can make it easier

6 months

2 months

9 months

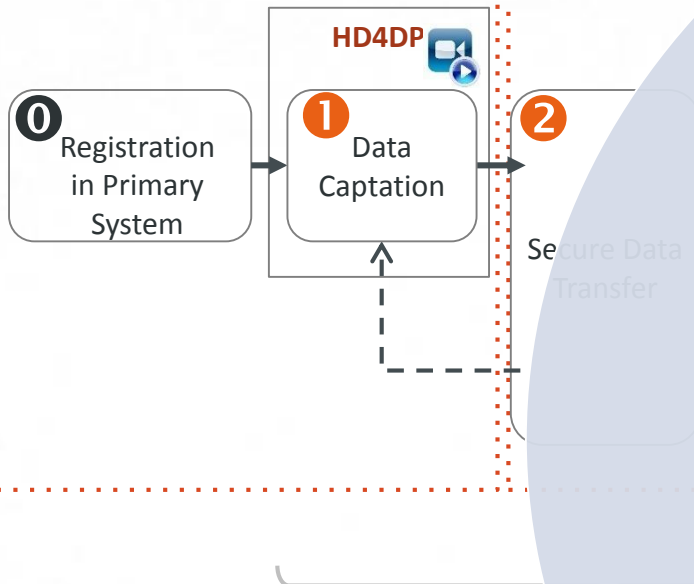


# Business Processes

- Obtain **standardization** in way actors interact for certain process
- **Simplify** interaction between various actors by adhering to 'only once' principle and maximally integrating with existing workflows
- Ensure **compliance** to various governance rules and regulations
- Create **transparency** and awareness for stakeholders about various processes and status of on-going processes
- Support **continuity** of register management (e.g. in case of staffing changes)

2 months

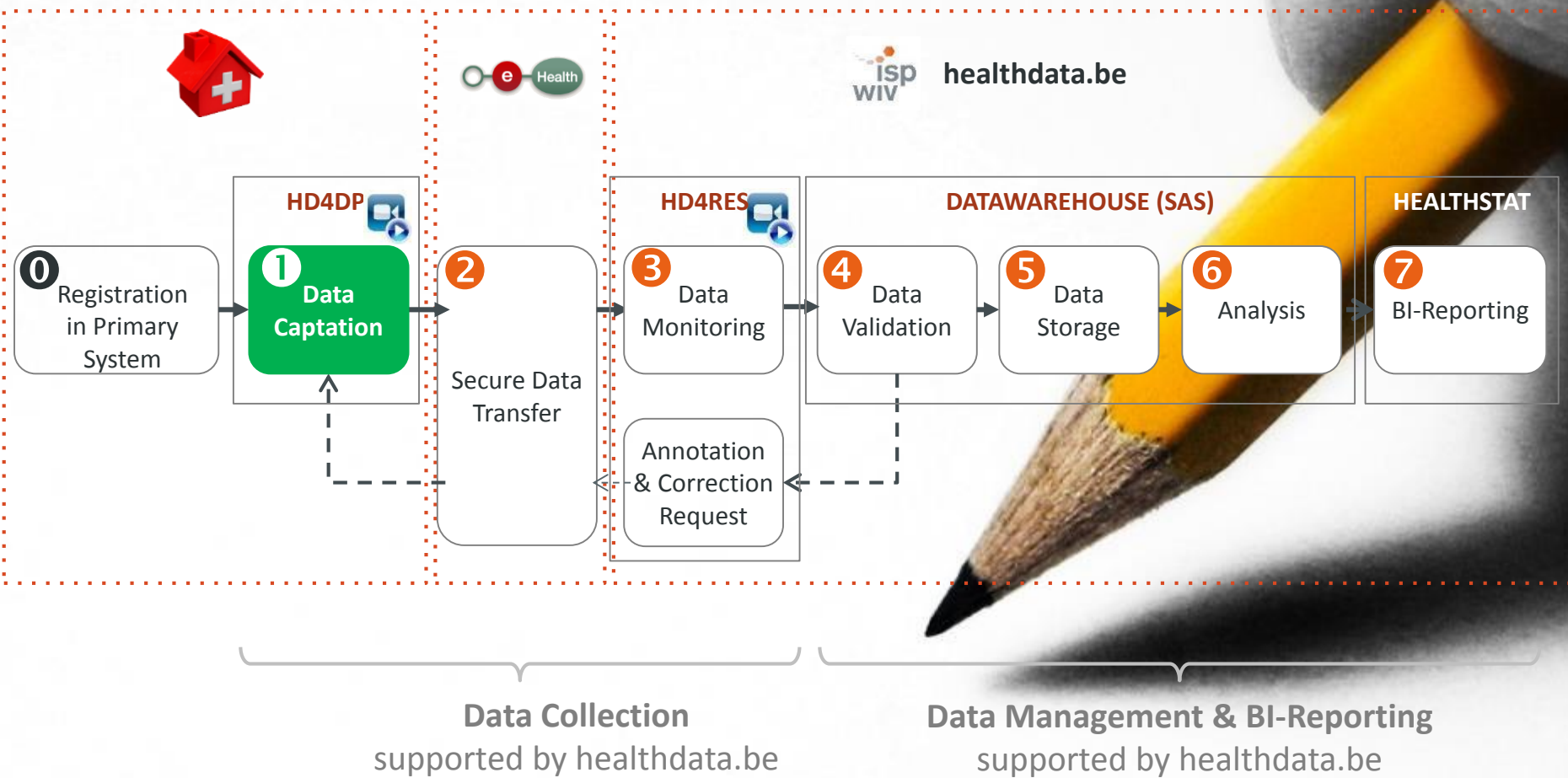
# healthdata.be: the end-to-end process



## Architecture

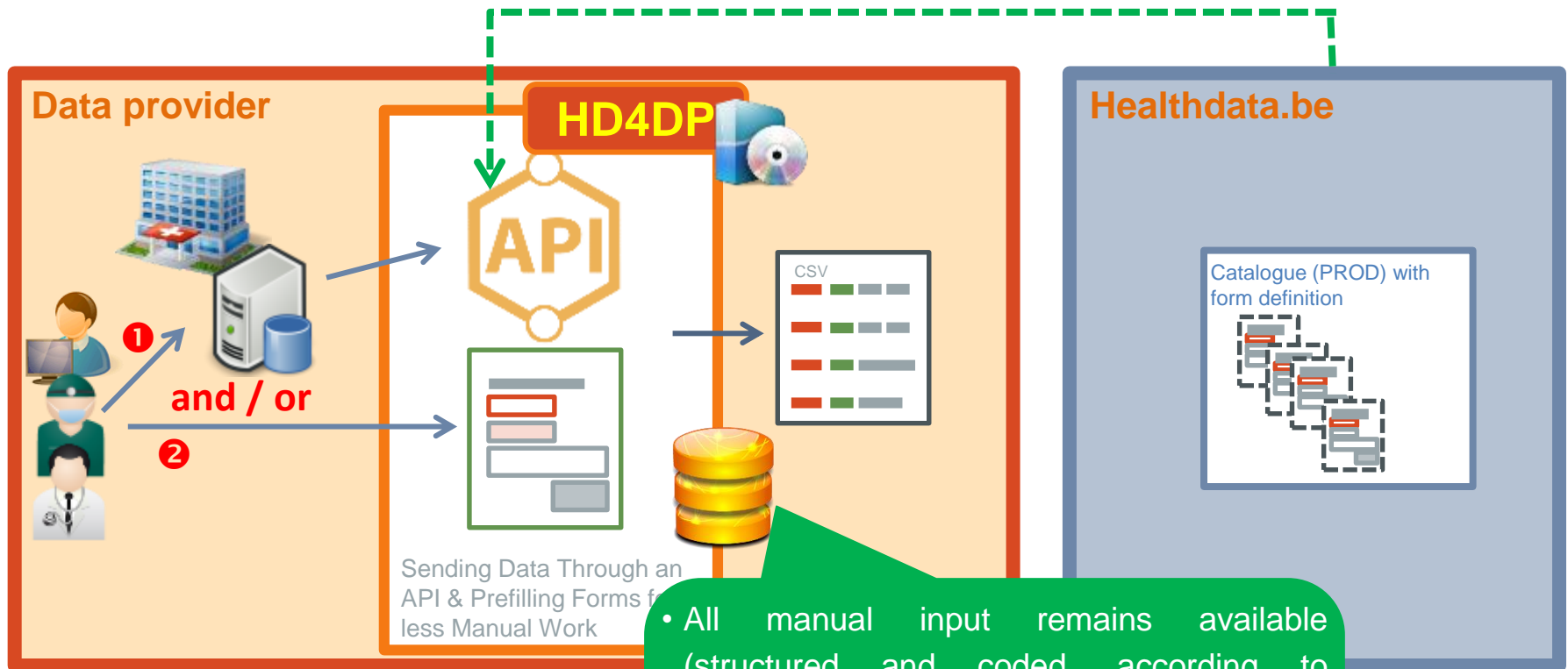
- **HD4DP:** Free and open (Apache License 2.0) local client software (API\* based with eForms) managed by HD Catalogue;
- **“Open” architecture approved by:**
  - **WG Architecture:** Positive advise (12/12/2014 & 06/03/2015) generic healthdata architecture;
  - **Sectorial Committee health (Privacy commission):** Authorization (21/04/2015) generic healthdata architecture;
  - **eHealth-platform :** Authorization (22/04/2015) generic healthdata architecture;
- **Successful test installations:** UZLeuven, UZAntwerpen, UZBrussels; ZNA, UZGent, CHU Erasme, CHU Charleroi, Inkendaal;
- **Industry:** integration HD4DP in their messaging software

# healthdata.be: the end-to-end process



# HD4DP : Healthdata for Data Providers

24/7



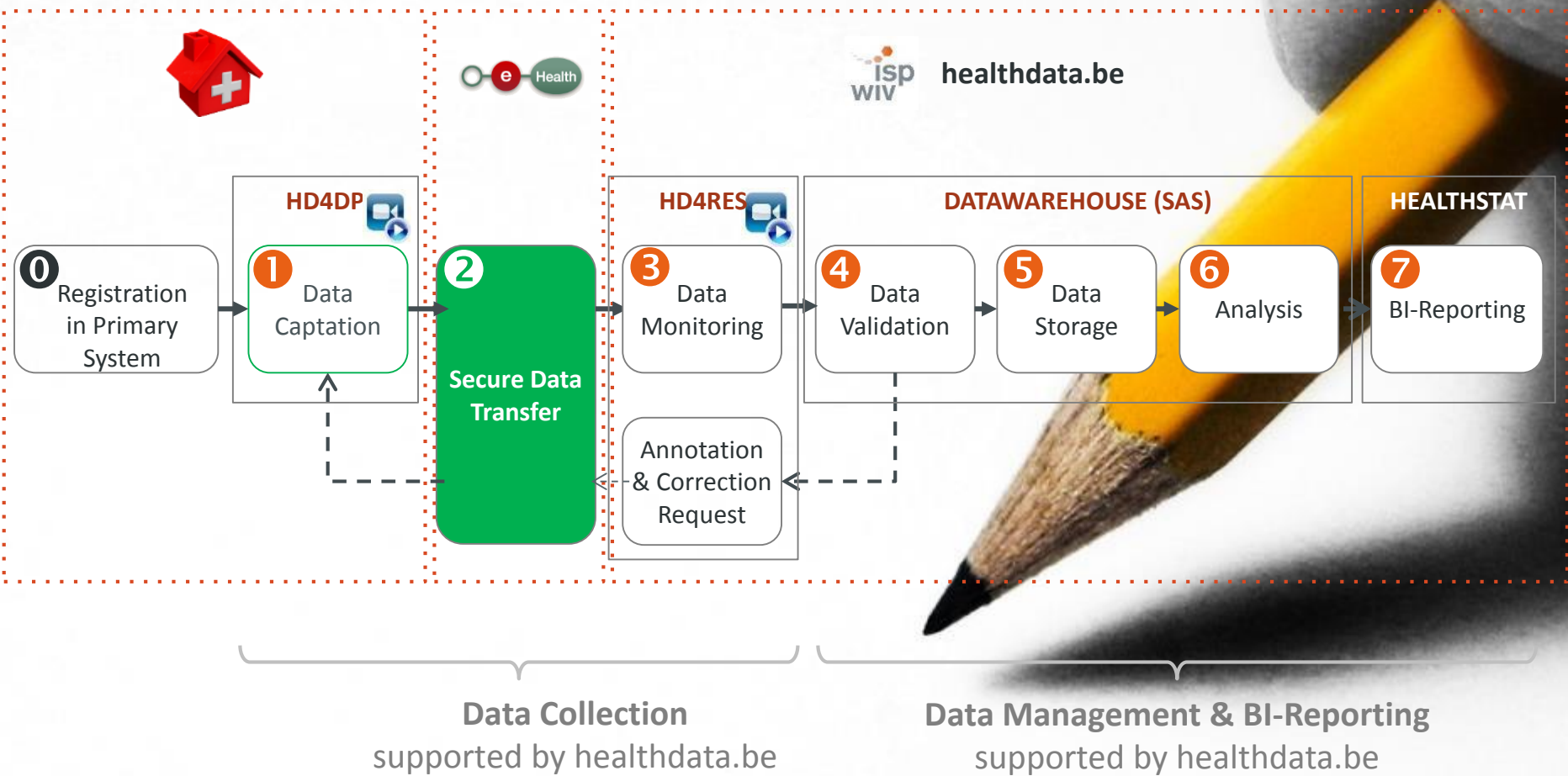
Sending Data Through an API & Prefilling Forms for less Manual Work

- All manual input remains available (structured and coded, according to [inter]national standard) in local database of DP:
  - Import in future upgrade of EPD/LIMS;
  - Re-Use for internal BI & QI

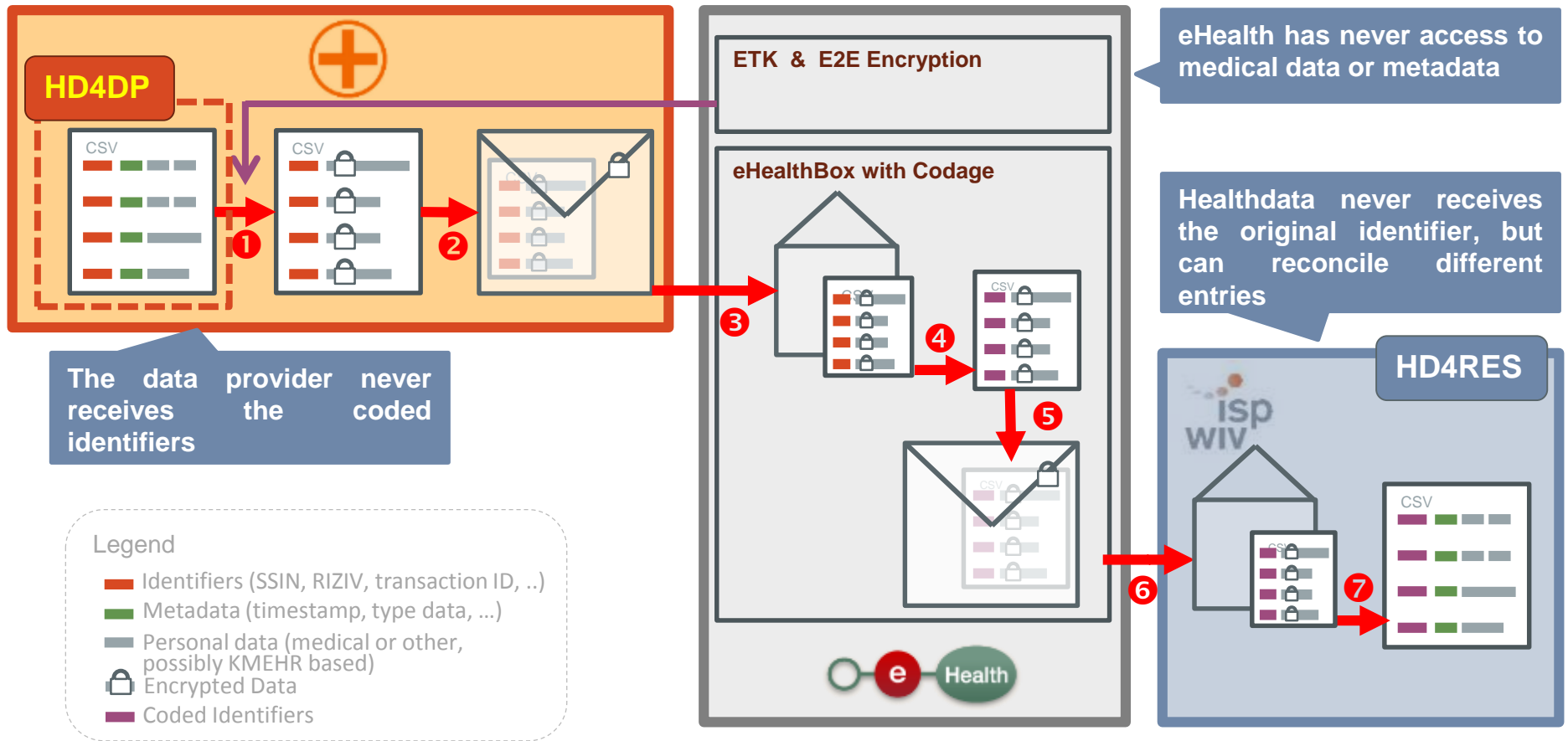
**Legend**

- Identifiers (SSIN, RIZIV, ...)
- Metadata (internal ID, type data, ...)
- Medical data

# healthdata.be: the end-to-end process

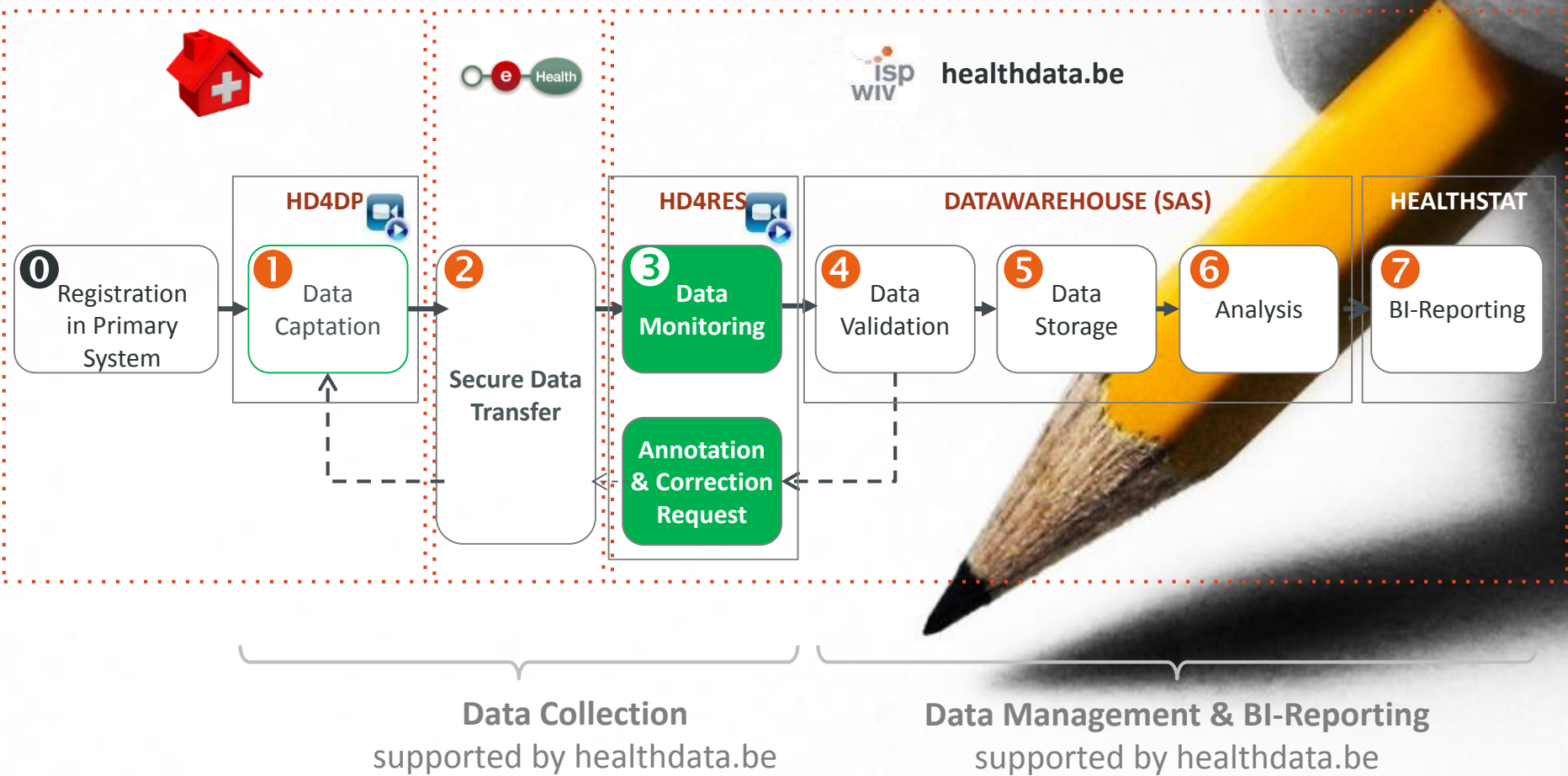


# Secure transfer of data and encoding of identifiers

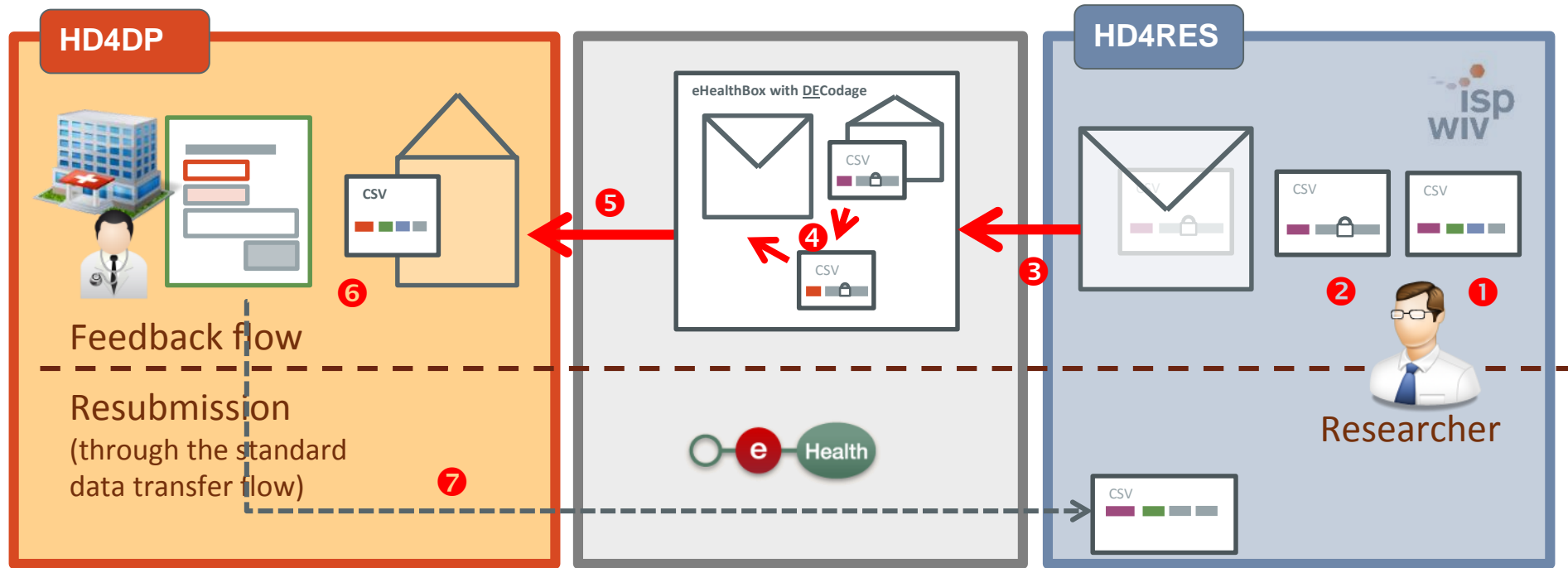




# healthdata.be: the end-to-end process



# Verify data and feedback to data provider (HD4RES)

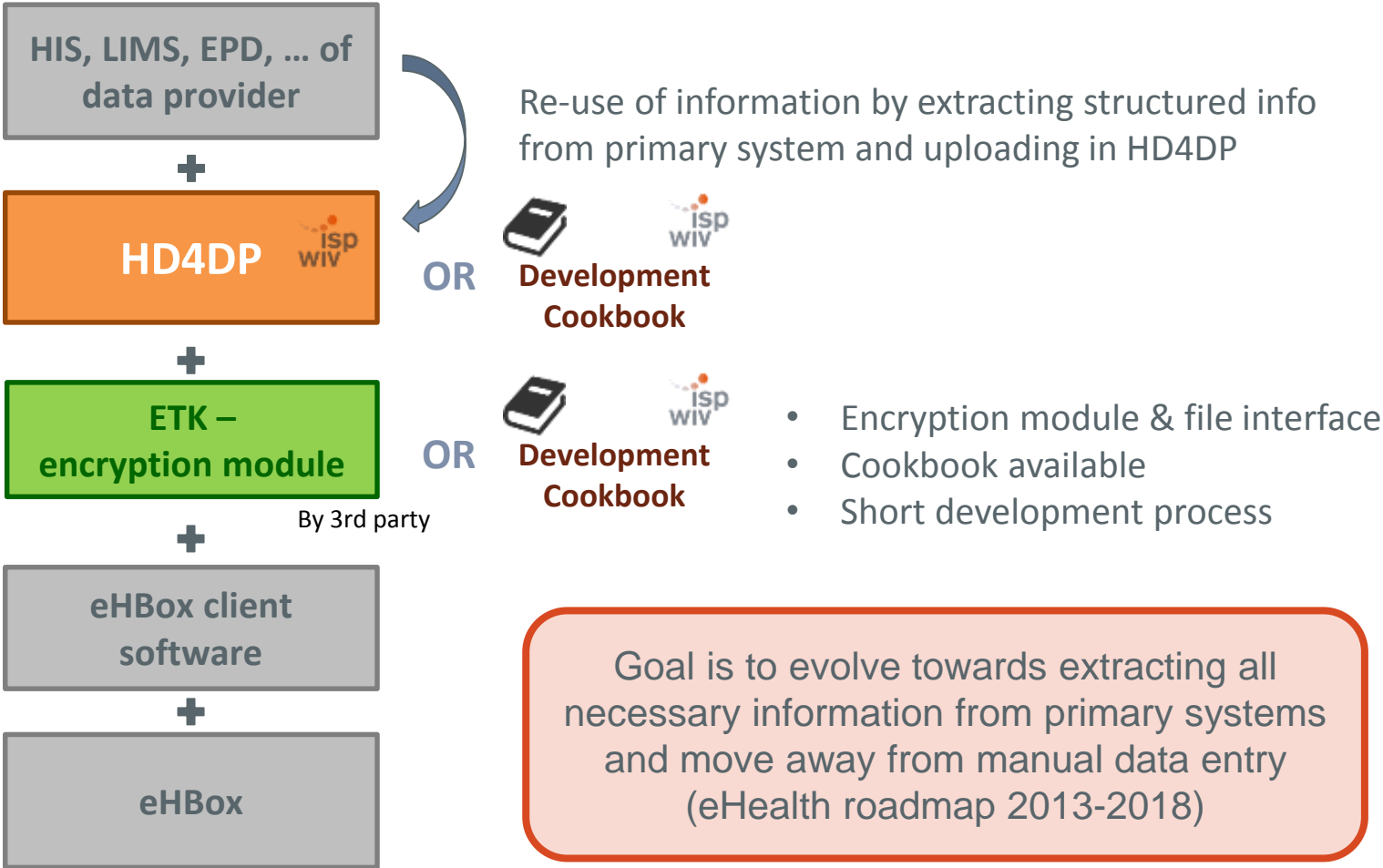


## Legend

- Identifiers (SSIN, RIZIV, transaction ID, ..)
- Metadata (timestamp, type of data, ...)
- Feedback
- Personal Data (medical or other)
- Field to correct

No impact on eHealth, existing services are used

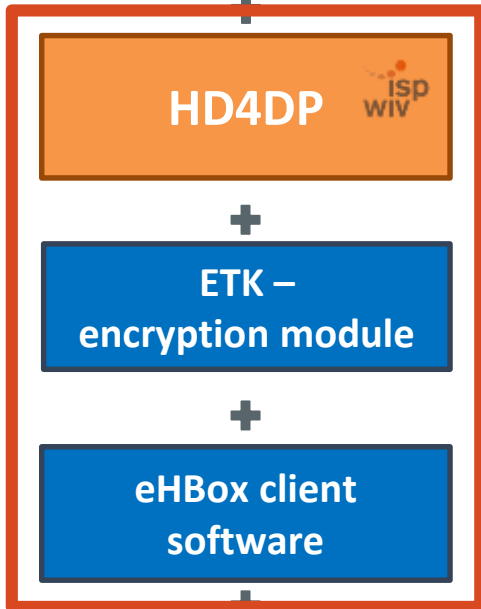
# Technical building blocks @ data provider



# Integration in existing software (in progress)

## ACTH (RSW/FRATEM)

HIS, LIMS, EPD, ... of  
data provider

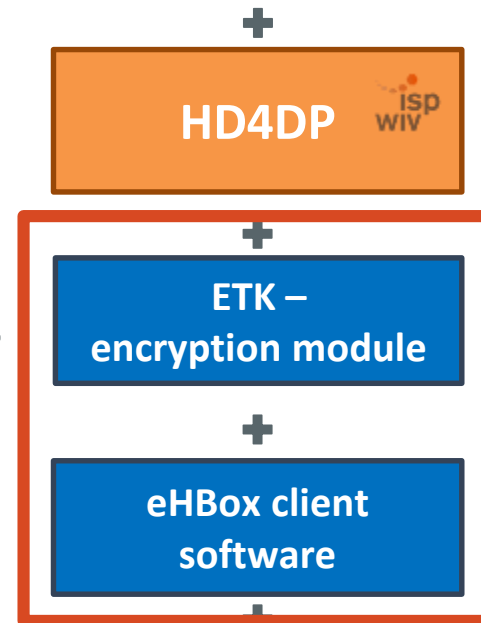


X-connect

eHBox

## Medibridge, HealthConnect

HIS, LIMS, EPD, ... of  
data provider



Medimail,  
UM, Hector

eHBox

# Development Roadmap HD4DP\* & HD4RES



**CURRENT VERSION 1.3.0. – 1.4.0. (dec2015)**

**PLANNED DEVELOPMENT**

## Re-use of data in primary systems:

CSV-upload functionality to upload data that is extracted from primary systems (e.g. EPD, LIMS).

## Built-in validation:

Inter- and intrafield validations are performed while the form is being filled out.

## Secure data transfer:

Data is transferred between data providers and healthdata via the secure eHealthBox channel

## Pseudonimization via eHealth:

The eHealth-platform acts as Trusted Third Party to pseudonimize patient identifiers before they are sent to healthdata.

## Correction request handling:

Registry PM can annotate records and send them back to the data providers for review.

## Application integration:

HIMS and LIMS can send the data through a standards based programmatic interface (API)

## CSV upload improvements:

Various improvements of the prefill functionality via CSV-upload, including supporting the upload of different CSV's for one record & support repeated upload of the same CSV.

## Desktop version of HD4DP:

Allow HD4DP to be installed on a desktop instead of a local server. Necessary for use by general practitioners.

## Multi-center HD4DP:

Allow one HD4DP-installation to be used by different organisations

## Origin of data:

Indicate for each record which data was pre-filled, manually provided or manually modified after initial prefilling.

## Integration with primary systems:

Allow users to open a pre-filled healthdata form in their primary systems (e.g. EPD, LIMS).

## Images in forms:

Allow data providers to indicate specific locations/zones on an image

## Registry PM self-service:

Allow registry PMs to maintain their own data collection definitions & reference lists

## Process reporting:

Display metrics about the data collection process (e.g. # corrections, process time, # sessions, ...)

## PDF/Print View:

Provide a printer-friendly version of the data collection form to support data collection on paper

## Bulk request corrections:

Allow the registry PM to select multiple records for correction with one action

## Improved search functionality:

Allow registry PMs to more easily search their records

## Email notifications:

Allow the registry PM to send email reminders to data providers

## Legend:



HD4DP – for data providers

HD4RES – for researchers

**\*4 planned major releases HD4DP each year**

# DEPARTURES

| DESTINATION    | FLIGHT | GATE | REMARKS   |
|----------------|--------|------|-----------|
| NEW YORK       | AA343  | A12  | BOARDING  |
| LOS ANGELES    | UA882  | A34  |           |
| LAS VEGAS      | RF453  | B45  | DELAY     |
| MIAMI          | KL722  | C23  |           |
| PARIS          | A1513  | A78  | CANCELLED |
| ROMA           | BA211  | B89  |           |
| LONDON         | LH231  | B37  |           |
| HONULULU       | QA313  | C52  | NEW TIME  |
| SYDNEY         | JA251  | C38  |           |
| TOKIO          | TO123  | C85  |           |
| BANGKOK        | TO123  | C85  |           |
| RIO DE JANEIRO | FP893  | B72  |           |

## Onboarding

**Technical onboarding:** “Only Once” for every data provider

- Step-by-step checklist to prep. install HD4DP, remote installation by HD
- People involved: IT data provider + HD (lead) + project owners (support)

**Thematical onboarding:** “Only Once” for every registry at every data provider

- Step-by-step checklist to make people & HD4DP ready for registration
- People involved: Data provider (IT, Medical, Admin) + project owners (lead) + HD (support)

isp healthdata.be  
 @healthdatabe

TWEETS 35 VOLGEND 248 VOLGERS 64 FAVORIETEN 3

healthdata.be @healthdatabe · 14 sep.  
 For more information about #BCFR : [healthstat.be/web/register.x...](http://healthstat.be/web/register.x...)  
 Gesprek weergeven

healthdata.be @healthdatabe · 14 sep.  
**MILESTONE: @healthdatabe** received 1st records from UZ Gent & UZA for 1st register "in production": Belgian Cystic Fibrosis Register (**#BCFR**)

| Type of Data provider              | Target  |
|------------------------------------|---------|
| All General and academic hospitals | 06/2016 |
| All Medical Laboratories           | 12/2016 |
| All Psychiatric hospitals          | 06/2017 |
| All General Practitioners          | 12/2017 |

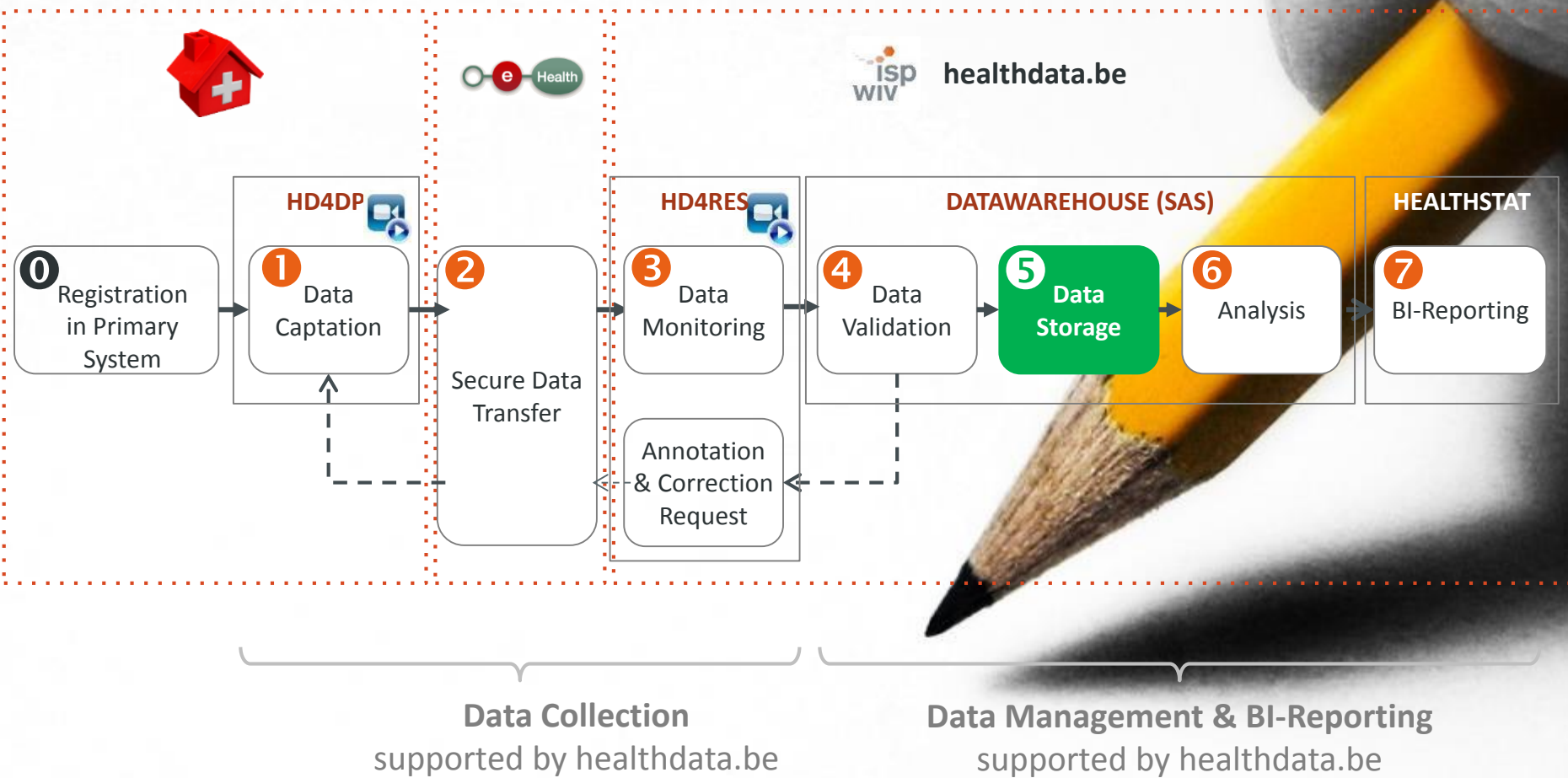
# Technical onboarding : status (07.10.2015)



| Organisation         | HD4DP                             |
|----------------------|-----------------------------------|
| UZ Antwerpen         | 12-05-2015                        |
| UZ Gent              | 23-06-2015                        |
| GZA                  | 15-07-2015                        |
| Erasme               | 22-06-2015                        |
| ZNA                  | 18-06-2015                        |
| IPG                  | 17-06-2015                        |
| Inkendaal            | 27-05-2015                        |
| Hopital Andre Vesale | 02-07-2015                        |
| UZ Brussel           | 15-04-2015                        |
| UZ Leuven            | 22-06-2015**                      |
| HUDERF               | 08-07-2015                        |
| CHU Liege            | 07-10-2015*                       |
| CHC St-Joseph        | 07-10-2015*                       |
| CHR Citadelle        | 07-10-2015*                       |
| CHU St-Luc           | Ongoing                           |
| WIV-ISP Labo's       | Finalizing                        |
| NEXUZ group          | **Multi center version in dev.    |
| RSW group            | *Integration in X-connect in test |



# healthdata.be: the end-to-end process

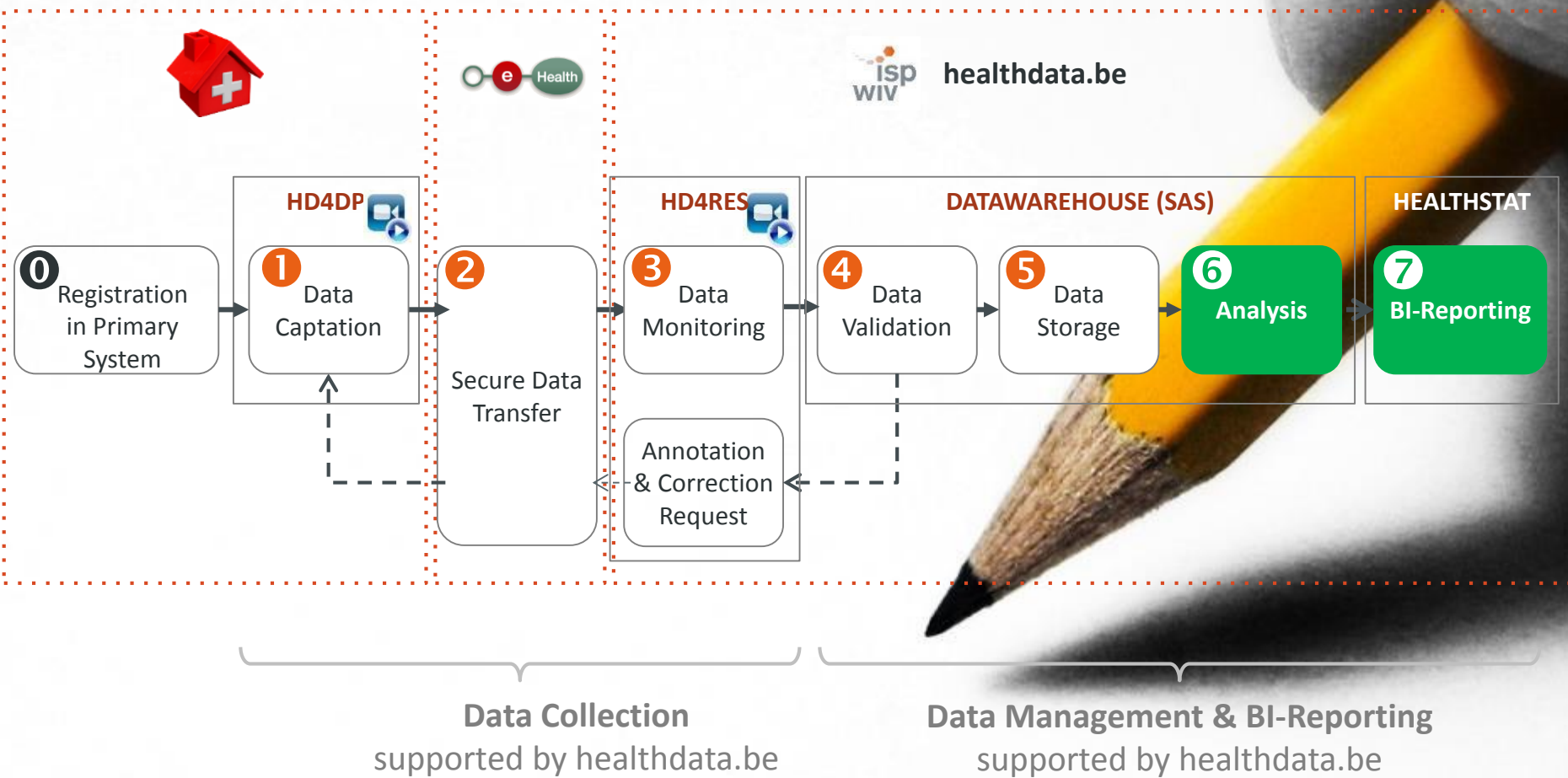


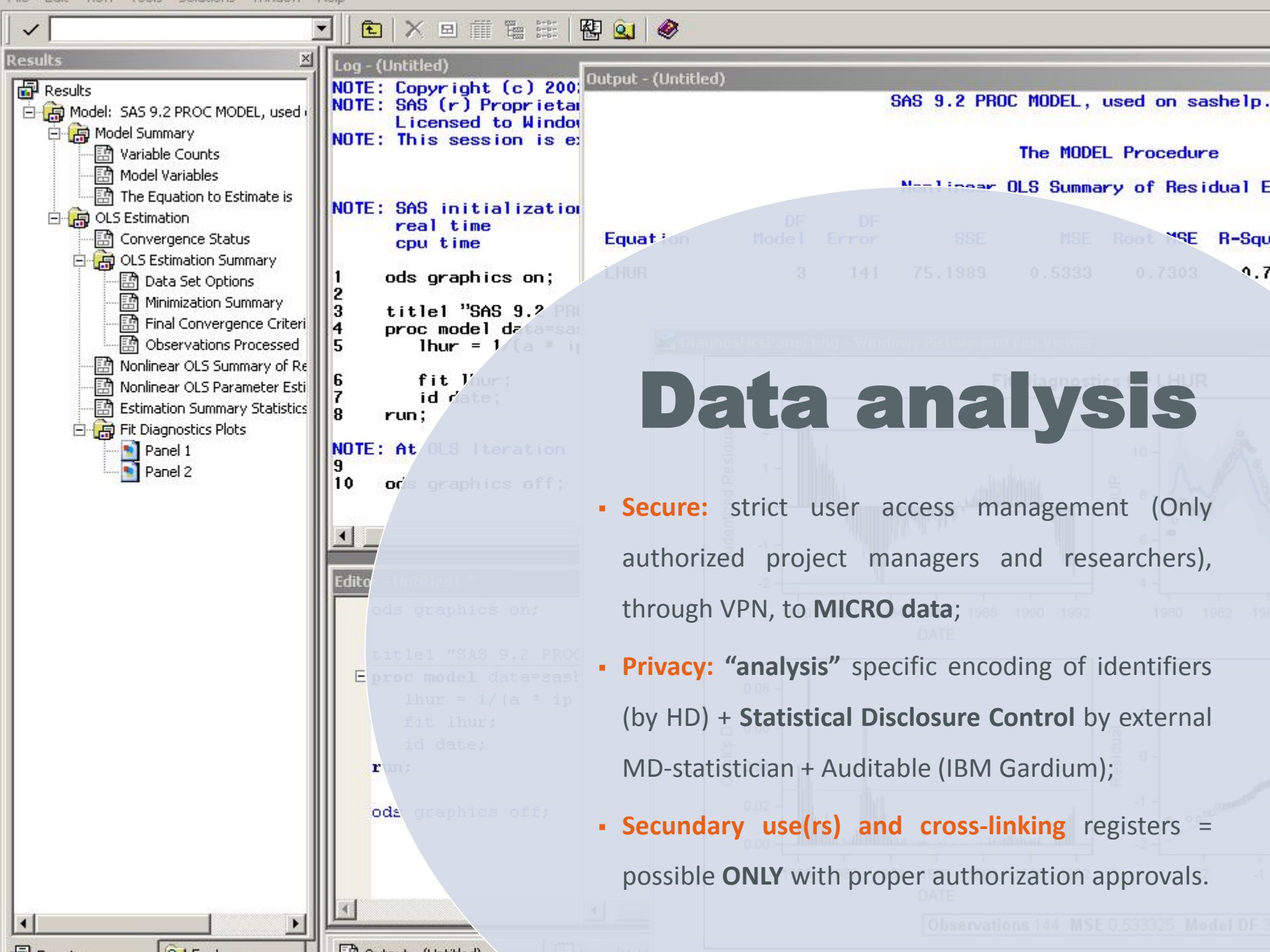


# Data storage

- **Secure:** strict user & access management (Only HD staff);
- **Privacy:** “register” specific encoding of identifiers (by HD);
- **Auditable:** logs of who has seen what, how and when (IBM Guardium);
- **Standardized:** common technology (DB2, SAS BI) and standards across registers;
- HD **Security officer** (Ir. Nand Staes);
- **Location:** Data center of Directorate General Statistics and Economic Information (FOD ECO-DGSEI): Contract and SLA available.

# healthdata.be: the end-to-end process





# Data analysis

- **Secure:** strict user access management (Only authorized project managers and researchers), through VPN, to **MICRO data**;
- **Privacy:** “analysis” specific encoding of identifiers (by HD) + **Statistical Disclosure Control** by external MD-statistician + Auditable (IBM Gardium);
- **Secondary use(rs) and cross-linking** registers = possible **ONLY** with proper authorization approvals.



# BI-Reporting

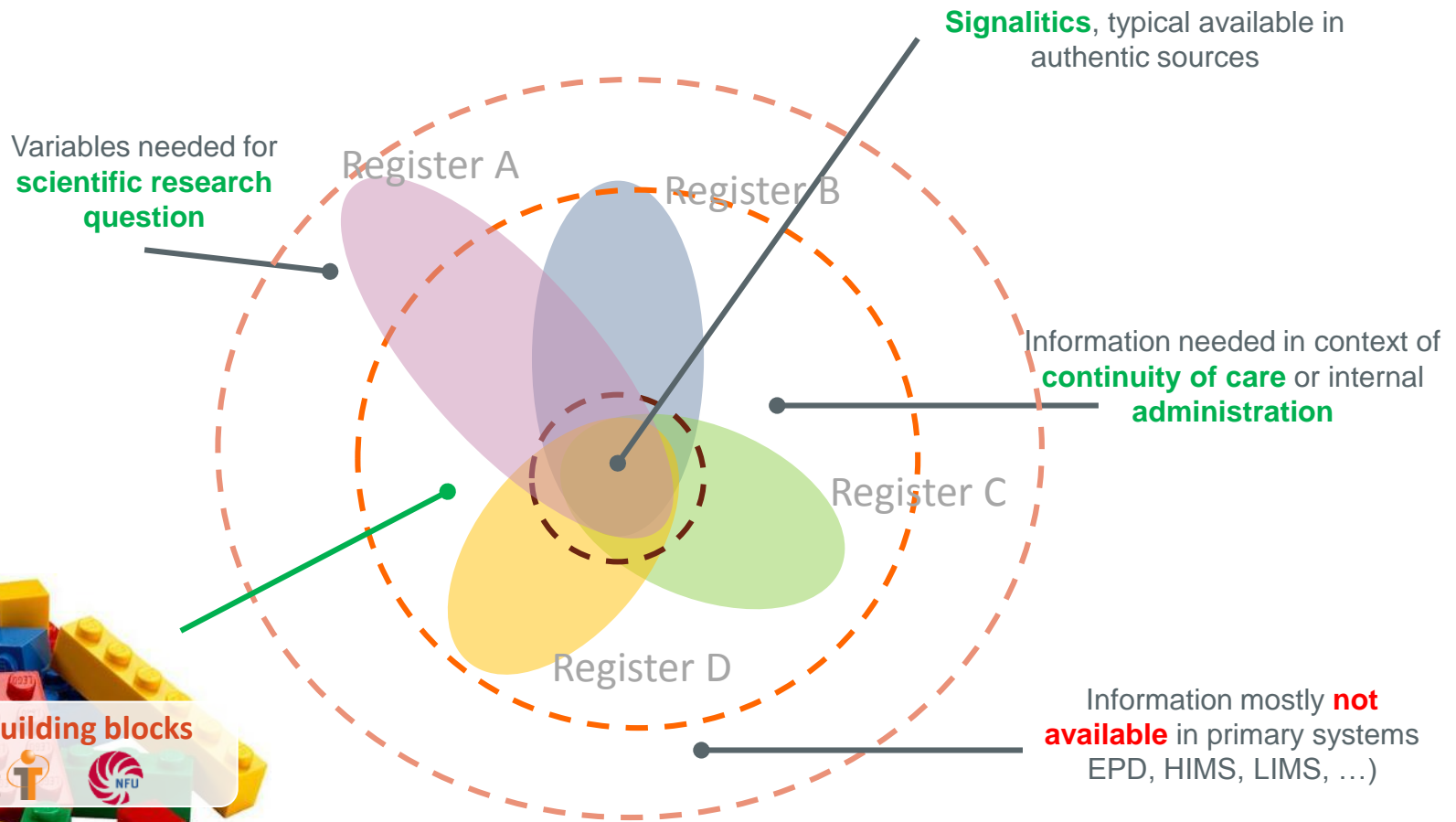
- **Healthstat.be** (website; live 11/2015) as a secure reporting platform, with only aggregated data;
- **Objective:** to give **Return on Information** (ROI) to data providers (reports designed by data providers), and **up-to-date reporting** for governments and stakeholders;
- 2 sections: **Authorized section for register stakeholders** (data providers, government, register project managers, ...), with reporting tailored for each user profile (UAM by eHealth);
- **Public section** available for everyone.



# Terminology

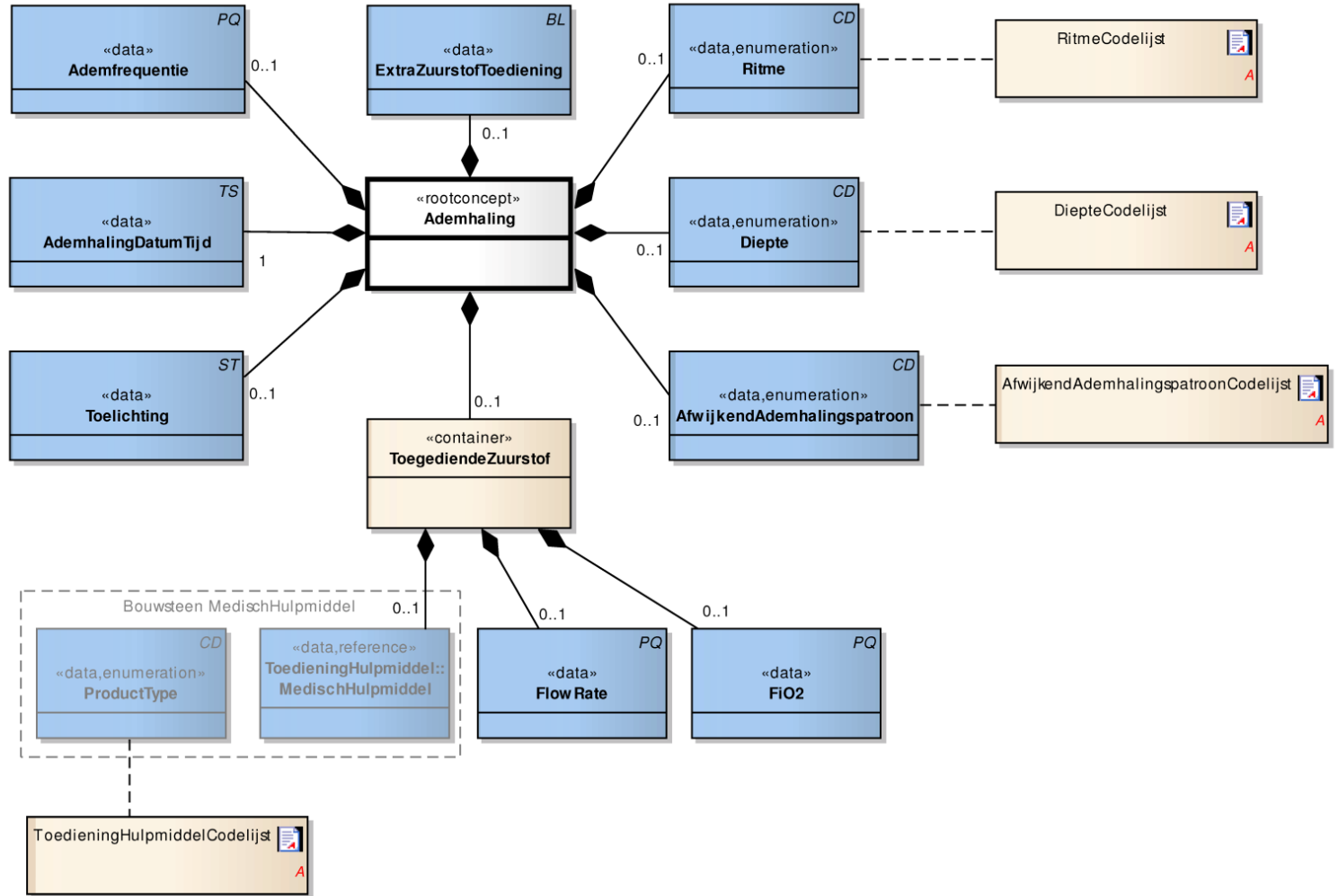
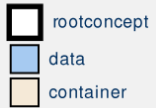
- 80 registers = > 8000 variables: **need for standards!**
- **Clinical Building Blocks:** introduction of a national minimal set of stable, structured, specialism independent, technical neutral, and reusable data specifications for (hospital) EPD. Collaboration with NICTIZ & NFU.
- **SNOMED-CT:** Prioritized standard for Lists of Values (LOV's) in Clinical Building Blocks.

# The challenge for scientific data collection



class Information Model

Legend





# Evaluation Action Plan eHealth 2013-2018:

## Revision Action Point 18: “Inventory & Consolidation of Registries

Official proclamation dd. 14.10.2015 by IMC public health

|       | WAT  | TIMING   | WIE  |
|-------|--|--|--|
| 18.11 | “Een <b>Belgische adaptatie</b> wordt uitgevoerd voor elke beschikbare specialisme overstijgende en technisch neutrale NFU-NICTIZ <b>Clinical Building Block</b> , en wordt na validatie in een publiek toegankelijke centrale digitale catalogus gepubliceerd ( <a href="http://www.healthdata.be/cbb">http://www.healthdata.be/cbb</a> ) (Zie ook AP2.7 en AP13).” | ▪ vóór einde 2016_Q1   | <ul style="list-style-type: none"><li>▪ <b>Coördinatie:</b> WIV, via het HD-platform;</li><li>▪ <b>Uitvoering:</b> Nederlandstalige en Franstalige clinici;</li><li>▪ <b>Begeleiding en validatie:</b> WG AP2, Terminologie Centrum (WG AP13), en Werkgroep Structurering van Elementen;</li><li>▪ <b>Beheer catalogoog:</b> WIV, via HD-platform.</li></ul> |
| 18.12 | “ <b>Alle</b> (a) nieuwe en (b) bestaande recurrente beleidsondersteunende wetenschappelijke <b>gegevensverzamelingen</b> worden inhoudelijk <b>samengesteld</b> doormiddel van de voor België beschikbare <b>gevalideerde Clinical Building Blocks</b> (Zie ook AP2.7).”  | <ul style="list-style-type: none"><li>▪ vanaf 2016_Q1 (a);</li><li>▪ vanaf 2016_Q1 gefaseerd volgens kalender (b: voor allen);</li><li>▪ uitgevoerd vóór einde 2017_Q4 (b: voor 42 projecten van WIV en RIZIV).</li></ul>  | <ul style="list-style-type: none"><li>▪ <b>Coördinatie:</b> WIV, via het HD-platform;</li><li>▪ <b>Uitvoering:</b> verantwoordelijken van wetenschappelijke gegevensverzamelingen.</li></ul>   |
| 18.13 | “De <b>waardenlijsten</b> van Clinical Building Blocks in alle (a) nieuwe en (b) bestaande recurrente beleidsondersteunende wetenschappelijke gegevensverzamelingen in domein van gezondheid en gezondheidszorg, worden prioritair met <b>SNOMED-CT concepten</b> opgemaakt (Zie ook AP2.7 en AP13). “   | <ul style="list-style-type: none"><li>▪ vanaf 2016_Q1 (a) ;</li><li>▪ vanaf 2016_Q1 gefaseerd volgens kalender (b: voor allen);</li><li>▪ uitgevoerd vóór einde 2017_Q4 (b: voor 42 projecten van WIV en RIZIV).</li></ul> | <ul style="list-style-type: none"><li>▪ <b>Coördinatie:</b> WIV, via het HD-platform;</li><li>▪ <b>Uitvoering:</b> wetenschappelijk verantwoordelijken van de gegevensverzamelingen;</li><li>▪ <b>Begeleiding</b> en validatie: Terminologie-Centrum;</li></ul>  |



# Planning

- 2014-2017: focus on **redesign of 42 existing registers** managed by WIV-ISP and RIZIV;
- **Examples:** Rare diseases, HIV-AIDS, Diabetes, Influenza, Common childhood vaccine-preventable infectious diseases, Nosocomial infections, Medical devices (pacemakers, stents, hip & knee, ...), Rheumatoid arthritis ...
- **3 'Waves':** 2014-2015(Q2); 2015-2016(Q2); 2016-2017(Q) (see [www.healthdata.be](http://www.healthdata.be)); Based on objective complexity criteria and policy priorities
- **Actualization** of planning possible because of new priorities and urgencies. ==> **NEW: Anatomic Pathologists towards Belgian Cancer Register**

JUNE 16, 2012

## Salad

Spring Mix Salad  
with strawberries, crushed nuts,  
feta cheese and a citrus vinaigrette

## Entrée

Duet of Filet Mignon  
and Jumbo Lump Crab Cake  
Sauce Bordelaise

Yukon Gold Potatoes  
smashed with Gorgonzola, apple,  
and rosemary

Grilled Asparagus

## Dessert

Wedding Cake

# What's next?

- **HD4Patients:** web portal supporting patient participation in registries (Patient Reported Outcomes & Patient Reported Experiences);
- **HD4Security\_Officers:** web application based on API of IBM Gardium to provide external security officers access to logging on DWH;
- **HD4ALL:** web application based on API of IBM Gardium to provide all Belgian citizens following information: Is there data about me in a Registry? Who submitted my data? Who used my data?;
- **HD4NGS:** generic architecture to collect, store, and make available for scientific analysis of human Next Generation Sequencing Data.

# PACTE D'AVENIR

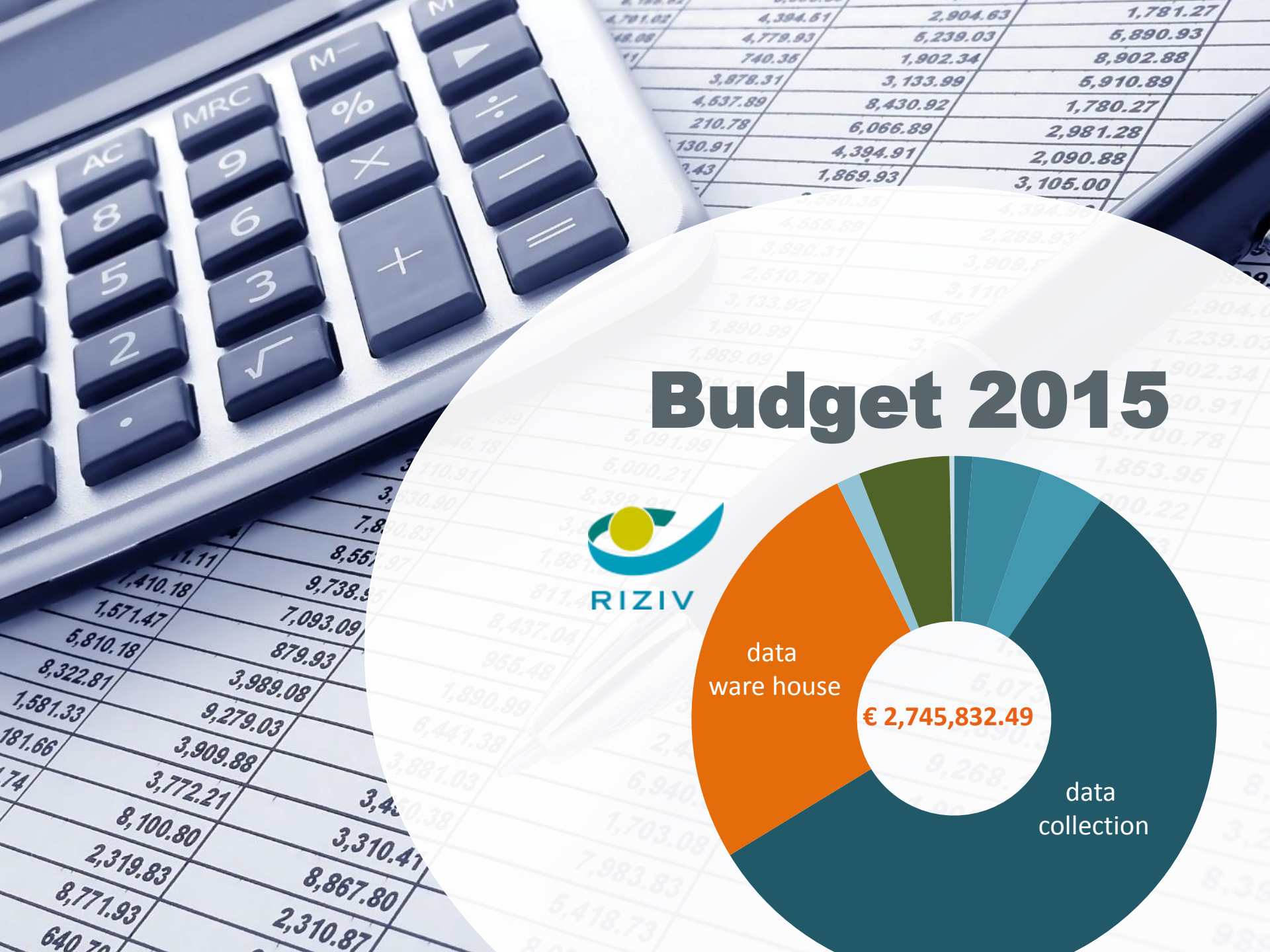
# HD4Industry

**Futur pact for patients with the pharmaceutical industry (2015)**

*"A knowledge system of patient registries which allows communication between registers analogous to the efficient collection of epidemiological data via healthdata.be, based on proposals from the European Medicines Agency and the European Member States in cooperation with our EU partners and with respect for privacy. "*

**Royal Decree (12/5/2014) "Unmet Medical Need"**

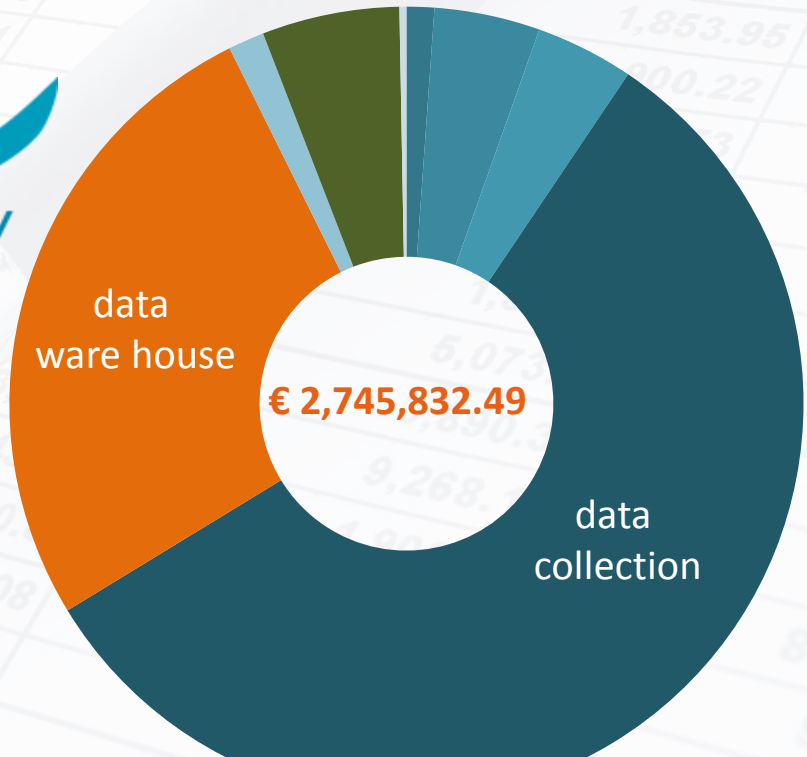
POUR LE PATIENT  
AVEC L'INDUSTRIE PHARMACEUTIQUE



# Budget 2015



RIZIV



# HD SteerCo

- **Alignment** with Action plan eHealth 2013-2018;
- Define **procedures and criteria** for start of new registers and the continuation of existing registers, with focus on reduction of registration burden;
- **Evaluation and prioritisation** new proposed projects;
- Follow-up of **Small Cell Risk Analyses** (Statistical Disclosure Control);
- **Service Level Objectives**;
- **Budget** control.

# Healthdata SteerCo: Composition

- **Chair, not entitled to vote:**
  - Chief civil servant (R De Ridder)
- **Members entitled to vote:**
  - **4 independent physicians** (J Kips, P De Plaen, G De Moor, H Vanpottelbergh, P Kelchtermans, P Vollemaere , H De Nutte, G Van Pottelbergh)
  - **2 physician –scientists** (P Cosyns , F Meunier, B Himpens, Y Englert)
  - **2 physicians from health insurance institutions** (P Berkein , M Callens)
  - **3 experts medical informatics** (E Bellon, A Vandenberghe, T Fiers)
  - **2 repr. of patients** (L De Bot, M Fierens, B Pirsoul, R Heijlen)
- **Members not entitled to vote:**
  - **1 repr. of NIDHI** (N Marly, P Meeus)
  - **1 repr. of FPS Health** (C Decoster, I Mertens)
  - **1 repr. of KCE** (S Devriese)
  - **1 repr. of eHealth-platform** (F Robben, T Duvillier)
  - **1 repr. of each regional and community government** (E Hendrickx, H De Kind)
  - Project leader **healthdata** (J van Bussel, J Kips)



# Summary

- 1 technical implementation for all registries;
  - 1 information architecture for all registries;
  - 1 service provider for all registries;
  - 1 set of business processes for all registries;
  - Max. re-use existing data (“only 1ce” registration);
  - Each DP can develop own strategy and priorities re. deep integration;
  - Each DP has the original set of submitted data in structured and coded format, in 1 local database;
  - Each DP receives timely feedback reports within 1 reporting environment;
- ==> Less administrative burden, higher efficiency, more time for patient, higher quality of care, more time for “research”, higher quality of research, lower costs**



# Q&A



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- visual attention
- auditory attention
- somatosensory attention

**Thank you for your attention!**

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on behalf of the healthdata team

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